What are the Lived Experiences of University Students with Autism During their Middle and High School Years?

By

Michael John Sullivan

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The dissertation is approved by the following members of the Final Oral Committee:
Michael W. Apple, John Bascom Professor Emeritus, Curriculum and Instruction and Educational Policy Studies
Mary Louise Gomez, Professor, Curriculum and Instruction
John Rudolph, Professor, Curriculum and Instruction
Simone Schweber, Professor, Curriculum and Instruction
Andy Garbacz, Associate Professor, Educational Psychology

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Dedicated to those
who were always there beside me
cheering on each small success,
it meant so much for me to know
you shared my happiness.
You were there beside me
whenever I felt sad,
helping me gain courage
from the quiet strength you had.
Through all my ups and downs
it’s been as special as can be,
to have felt your love and know
that you were always there for me.
- Anonymous

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Abstract

What are the lived Experiences of University Students with Autism
During their Middle and High School Years?

Michael John Sullivan
Under the supervision of John Bascom Professor Michael W. Apple
at the University of Wisconsin-Madison

A phenomenological study of twelve current students with autism studying in Mid-Western United States universities were interviewed about their time in middle and high school. The research question was “What were the lived experiences of university students with autism (ages eighteen to twenty-nine), during their middle and high school years?” Challenges and supports to the students are discussed. Chapter I, provides an introduction to the history and concept of Autism Spectrum Disorder and Asperger’s Syndrome also referred to as High Functioning Autism. Chapter II presents an academic literature review on the topic, including studies that have talked to students directly about their autism and time in middle school or high school. Chapter III discusses the data collection methodology, and introduces the researcher and the interviewees. Chapter IV provides the Theoretical Framework used to analyze the data in the study. Chapters V, VI, VII address the student’s own voices about the challenges they faced as students with autism in middle and high school, the supports they received, and their potential for the future. Included in each of these chapters is an analysis comparing and contrasting the student's voices to the academic literature on various topics. Chapter VIII applies the Theoretical Framework to the student's experience through an analysis. Chapter IX presents the conclusions. Challenges include late diagnosis of autism, the role of families in identification and support for obtaining resources, cultural issues that delay treatment, co-morbid conditions, academics, sensory issues, participation in class, executive function, lack of social skills training, bullying and loneliness. Successful supports and accommodations are discussed, including the concept of democratic schools, potential careers, and the issue of disclosure. Limitations and implications are noted, personal findings shared, and recommendations made for future research.

Prologue

"Know from whence you came.

If you know whence you came,

there are absolutely no limitations

to whence you can go."

- James Baldwin

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CHAPTER I

INTRODUCTION

In 1943, Dr. Leo Kanner, a child psychiatrist, while working at John Hopkins University, published an article (Ozonoff, Dawson, & McPartland, 2002), which he titled: *Autistic Disturbances of Affective Contact* (Kanner, 1943). In it he identified a group of eleven children, who shared certain traits: "governed by rigidity and consistently by the powerful desire for aloneness and sameness", (p. 249). "They showed little interest in other people, insisted on routines, and displayed unusual body movements. Many of them could talk . . . but rarely used their speech to communicate with others; they also had a variety of learning problems in addition to their unusual behaviors", (Ozonoff et al., 2002, p. 5).

About the same time (1944), unaware of Kanner's findings, Hans Asperger, published in German, a study of four boys, who showed: "a lack of empathy, little ability to form friendships, one-sided conversation, intense absorption in a special interest, and clumsy movements", which he called "a fundamental disturbance of contact", (Asperger, 1944/91, p. 37). The study described a higher functioning form of autism, with the same characteristics of conceptual thinking and difficulty with communication, as found earlier by Kanner; and he chose the Greek work *autos* (autism) to describe the phenomenon (p. 38). The work remained virtually unknown, until discovered by Dr. Lorna Wing, in 1981, (Ozonoff et al., 2002).

In the intervening years, the word autism, appeared for the first time in the New York Times in 1960, and before 1990, appeared only seventeen times. In 1994, the American Psychiatric Association (APA) recognized Asperger disorder as a specific entity, and published diagnostic criteria in the (DSM-IV), the Diagnostic and Statistical Manual of Mental Disorders. Then in 2008, the New York Times contained 169 articles, indicative of what was becoming a major part of the culture.

More recently, the APA recommended ‘subsuming’ Asperger’s Syndrome into Autism Spectrum Disorder (ASD), which it did in 2013. In DSM-IV-TR, the disorders were autistic disorder (autism), pervasive developmental disorder not otherwise specified, Asperger’s disorder, childhood disintegrative disorder and Rhett’s disorder. Dickel, (2014) writes that in DSM-IV-TR, Asperger’s disorder referred to high-functioning autism with intact verbal skills. Pervasive development disorder not otherwise specified referred to individuals who did not meet the full requirements of autistic disorder. “The changes in criteria in DSM-5 now subsume all of these diagnoses into ASD” (p. 114).

However, there is still controversy as to whether Asperger’s should be considered a separate entity. Many experts believe that people formally diagnosed with the label, do not always meet the diagnostic criteria for ASD, which requires a triad of deficits encompassing communication, social and behavioral skills; and that it should be preserved to represent a condition related to, but not the same as autism (NIMH, 2018, p. 2). Moreover, there is lament by many high functioning autistic persons, who have identified with, and still prefer the term Asperger’s.

The question might then be asked: What is the difference between autism and high functioning autism or Asperger's syndrome?

For the purpose of this chapter, autism will be used as a separate identity, while Asperger's and high functioning autism will be used interchangeably.

Persons with autism will score below average on intelligence tests, while those who are high functioning, or have Asperger's, score equal, or often higher than their neurotypical or typically developed peers.

While persons with autism will experience speech impairments, this is not the case with those who are high functioning. People with Asperger's can speak clearly, but may have trouble with "understanding the subtleties of speech (like idioms, jokes, or sarcasm)." (Otsimo, 2018, at p. 3).

Autism is generally identified in children before they reach school age, while persons who are high functioning, may be diagnosed when a child experiences problems in school, or even much later as an adult.

Persons with high functioning autism or Asperger's, may not correctly read body language, and may lack empathy. They may choose to be alone, because they do not fit in, and their peers may find them physically awkward, and socially rude.

Many writers however, choose to stress the particular gifts and positive aspects of high functioning autism or Asperger's syndrome, using the concept of neurodiversity, considering it to represent a different condition, an aspect of human variability, a way of being in the world, a culture, not the medical, stereotypical, deficit way of thinking.

According to the National Institute of Mental Health, positive characteristics of people with Asperger's Syndrome include: an increased ability to focus on details; the capacity to persevere; a special interest without being swayed by other's opinion; the ability to work independently; the recognition of patterns that may be missed by others; intensity; an original way of thinking; being strong visual and auditory learners, and excelling in math, science, music or art (NIMH, 2018, pp. 3-4).

These personality and cognitive traits are seen as beneficial, and many people with the syndrome believe it has helped advance their careers, including Temple Grandin, (1995) noted engineer, author and professor who affirms:

> If I could snap my fingers and be non-autistic, I would not – because then I wouldn't be me . . . As I have said . . . I realized the magnitude of the difference between me and other people . . . I have become fully aware that my visualization skills exceed those of most other people. I would never want to become so normal that I would lose those skills (pp. 60, 180).

During the past years, as a result of the many studies in the identification and treatment of autism, a growing number of young people are being made ready to enter college or university, (Van Bergeijk et al., 2008). However, Wei et al., (2013) note that despite the academic abilities of many autistic students, they are less likely to enroll in college or university than students with all other disabilities, except those with intellectual or multiple handicaps. Those who do enroll, have difficulty transitioning to a freer and more challenging environment, and face both academic and social challenges, (Adreon & Durocher, 2007, Kapp et al., 2011).

This phenomenological study will focus on the lived experiences of university students with high functioning autism, during their middle and high school years. It will shed light on what helped them in receiving a diagnosis and therapy, and entering a post-secondary education, and will provide suggestions on how the system could be improved.

Some of the students will contradict the prevailing assumptions about autism, and also reveal that deficit constructions can marginalize them and affect their self-esteem. It will also verify that they are knowers of their own lives, and can, and do, contribute to the knowledge of learning and identity. As a high functioning autistic person myself, born in 1968, I often wonder how I could have been better served in my middle and high school years, if only the public school system at the time had known about Asperger syndrome or autism.

That said, despite the enormous amount of research, which has surfaced in the ensuing years, there continues to be tremendous variably in the type and quality of education delivered across the spectrum. It appears that decisions and practices for persons with autism are often framed by the philosophical beliefs of an individual school district, the geographical location of the student's residence, administrative issues, and the skills or lack of skills of those involved, rather than on the educational needs of the individuals.

Students are educated in systems that are either designed for success, or that result in failure. The truth is that students on the autism spectrum face academic and social challenges even in the best of educational environments. The schools that are committed to core values, and open to exploring options recognizing the uniqueness of every student, including those with or without a disability, those are the schools that work in a collaborative endeavour, to see that every student receives the best efforts of all involved.

Surely, the purpose of an education in a democratic society is to instil in the hearts and minds of students the values of co-operation, fairness and justice. These values are essential to creating, maintaining, and improving a functioning democracy. To accomplish this, students should have a voice in the curriculum, as well as how they are assessed academically, and should be empowered to be critically democratic citizens.

> Apple & Beane, (2007) writing about 'democratic schools', emphasized an education where cooperation and collaboration rather than competition are the norm; where students and their families care more about the common good and helping others, than about grades, credits and credentials (p. 12). Schools would help young people to seek out a range of ideas, and to voice their own, rather than silencing the voices of those outside the dominant culture. The curriculum would prepare students to become 'critical readers', and would encourage questions like: Who said this? Why did they say it? Why should we believe it? Who benefits by it?

Such a curriculum would put knowledge to use in relation to real life issues:

> The focus on what is called "unmet community needs" . . . on social and environmental issues . . . or on finding answers to "serious questions," . . .

> is there because knowledge is thought about differently. Rather than being lists of concepts, facts, and skills that student's master for standardized achievement tests (and then go on to forget, by and large), knowledge is that which is intimately connected to the communities and biographies of real people. Students learn that knowledge can make a difference in people's lives, including their own (p. 151).

A democratic student with autism, would study their own experience and life histories as part of the curriculum, and would use one's competencies, not just to obtain good grades, or to focus on selfish goals, but be an agent to help others, who are also in need.

According to Coles & Knowles, (2001) the life history model, is individually and contextually shaped. Life history research across disciplines, is based on the fundamental assumption about the relationship of the general to the particular, and that the general can best be understood through analysis of the particular (p. 13). Lives interact with the influence of the cultural, political, familial, educational and religious spheres to name a few. The categories serve as a guide to help researchers uncover one's life to make broader cultural meaning (p. 20).

Such research could tell about the broader school context experienced by young people affected by autism. Examining significant life events could help uncover resiliency at different stages, across various developmental ages and events (Deegan, 2003) including both macro-history societal-level events and micro-history individual events, (Sosulski, Buchanan, & Donnell, et al., 2010).

They affirm, that life story techniques provide an opportunity, “to collect rich data textured by the respondents own interpretation of experiences, and the social circumstances in which their story has unfolded, and the ways in which they continue to be active agents”, (Roets & Goedgeluck, 1999, p. 5). Yet, in fact, little research has been conducted, about young people’s life histories of living with high functioning autism (Pelicano, Dismore & Charman, 2014).

What would be a good result for such students in the school system? According to Gillberg & Steffenburg, (1987), and McEachin, Smith, & Lovaas, (1993) this means: “having a normal social life and achieving independence.” Ivey, (2004) cites Rosen, Simon & McKinsey, (1995), who note that an important outcome for schooling is “a quality of life” as “the guiding framework for program and services”; and Ruble & Dalrymple, (1996) write that a good outcome “would be expressed in terms of the interaction between a person and his or her environment.” In other words, one might interpret these views as meaning that students with high functioning autism should be able to fully participate in school, following their passions, having successful lives regardless of their career choices, living independently as adults, and in contributing to democracy in some way.

Democracy is not for the faint of heart; it can be and is often messy, but it is something that must be protected by its citizens. Schools must be places where the voices of students are heard, and they must be able to take action on the issues they care about, if we are to have a democratic society in the future. The classroom should be an example of what the world could be.

The next chapter, will turn to the issue of what the academic literature says, about the experiences of students with autism in the school system, during their middle and high school years, and what outcomes they may be experiencing.

CHAPTER II

LITERATURE REVIEW

Studies estimate the worldwide population with autism between 0.6 and 1%, (Brugha et al., 2011, Davidovitch et al., 2013, Elsabbagh et al., 2012, Fombonne et al., 2011). According to the Center for Disease Control and Prevention (CDC), 1 out of every 59 children in the United States has autism, a significant increase in the last ten years, (CDC 2014, Schieve et al., 2012). The prevalence is thought to be due to increased awareness and improved diagnostic ability (Pinder-Amaker, 2014).

Students with autism are enrolling in higher education, most likely due to early treatment programs, and the introduction of disability legislation in education. Humphrey & Lewis, (2008) acknowledge that the limited research indicates that school is a stressful and anxiety provoking place for such students, (Carrington & Graham, 2001), with social isolation, loneliness and bullying being common, (Bauminger & Kasari, 2000, Ochs et al., 2001). Although many teachers are committed to inclusive education, some do not feel that they have the necessary training to provide for autistic students, (McGregor & Campbell 2001, Robertson et al., 2003). Current practices, may contribute to dissatisfaction and exclusion among such students, (Connor, 2000, Osler & Osler, 2002).

Humphrey & Lewis, (2008) reveal that students with autism are twenty times more likely to be excluded from school than their peers: one in five (21%)

are excluded at least once, compared with approximately 1.2 per cent of the total student population, (Barnard et al., 2000, NAS, 2003).

Kluth, (2003) lists six characteristics of successful inclusive schools for students with autism. They are: committed leadership, democratic classrooms, reflective educators, a supportive school culture, engaging and relevant curricula, and responsive instruction.

Research in the high school environment has found a number of effective teaching strategies to support students with autism, (Carrington & Holm, 2005), Osborne & Reed, 2011, Pearce & Forlin, 2005). Strategies such as providing support for social inclusion, behavioral issues, organizational skills, and less structured times, as well as teaching the hidden curriculum and facilitation of communication skills, are seen as helpful, (Carrington & Holm, 2005, Konza, 2005, Osborne & Reed, 2011, Pearce & Forlin, 2005). Professional learning for teachers, and the importance of building collaborative partnerships are also effective, (Carrington & Holm, 2005, Forlin & Bamford, 1995).

Davidson, (2010) notes that listening to students with autism, is one of the most valuable ways, to assess whether a student has been successfully included within a particular school environment. Fayette & Bond, (2017) conducted a systematic review of qualitative research methods, for eliciting the views of young people with autism, about their educational experiences. These studies focused on students' general experiences of mainstream secondary education, (Humphrey & Lewis 2008, Poon et al., 2014, Saggers, Hwang & Mercer, 2011). The researchers discovered in their Australian study, that six categories emerged from their interviews as having either a positive or negative effect on the participating and learning of students with autism. These categories are teacher characteristics (positive and negative); curriculum related issues (heavy workload, demand for handwriting, found to be physically demanding and exhausting); support mechanisms (attitudes to specialist' support, types of support, ways of receiving support); friendships (perceptions toward friends and friendships, attitudes toward socializing and solitude); environmental considerations; and teasing and bullying.

Only two American studies have surfaced, (Hedges et al., 2014), and (Myers, 2019), that solicited the views of young adults with autism in high school, and none were located involving middle school students. The Hedges et al., (2014) study, involved adults with autism currently in high school, one in college, one currently working and living independently, and one unemployed and living at home. The youth as well as school staff and parents were interviewed in separate focus groups. The questions looked at challenges faced by high school students with autism, as well as those that provide support and services. The study found that the focus group format did not capture significant information to "contribute substantially to our final themes" (p. 79). The authors thought that one on one interviews would have been a better format, because impairment in social interactions are a key characteristic of people with autism, as well as having difficulty describing feelings, (Hare, Wood, Wastell & Skirrow, 2014). One on one interviews, would have allowed the facilitator, according to Hedges et al., (2014), the necessary time to discuss with each participant more about his or her experiences.

Hedges et al., (2014) found however, three key challenges for students with autism: inconsistencies in the typical high school experience, difficulties with interpersonal connections, and knowledge breakdowns. Individuals with autism prefer consistency in their routine, (Lam et al., 2008). Inconsistencies include: changes in the daily schedule, different expectations across teachers, and different expectations across home to school environments.

Visual presentations have been effective, reducing the difficulty students with autism experience when juggling expectations across settings, (National Professional Development Center on Autism Spectrum Disorders, 2013). Applications for Apple iOS devices, such as Pictello and iPrompts, can be used to prepare students for different expectations. For an in-depth description of visual apps, see (Hume, Sreckovic, Snyder & Carnahan, 2014).

Another theme is the difficulty students have in making connections in high school. Difficulty with social interactions is a key feature of autism, APA, (2013). Carter et al., (2014) note that peer mediated and social skills group interventions can be used to support both the social skills development and enhance relationships with fellow students. Social skill interventions help students learn the skills necessary to interact with their peers.

A final theme by Hedges et al., (2014) concerns knowledge and process breakdowns. This involves a general lack of knowledge about autism across the school environment, as a major barrier to the success of students with autism.

Myers, (2019), on a yearlong inquiry group, with 12 autistic adolescents and one teacher, worked together weekly to develop multimedia autobiographical projects. The students used video production, photography, writing, drawing and speaking to examine their life experiences, and created projects that "demonstrated their understanding of themselves and others."

The writer regrets, that the dominant 'deficit model' of autism, places the disorder as something that "limits a person's ability to understand and relate to others" (Bilken, 2005, Smith, 1996), (p. ix).

Other research claims that children with autism are unable to develop narratives (Losh & Capps, 2006), and thus such children have "un-biographical lives" (Smith, 1996). As Myers, (2019) writes: "These assumptions about autism can be very damaging to the experience of autistic individuals, as teachers, clinicians, and even family and peers exposed to these assumptions, can view students with autism through this lens of limitation" (p. ix). She takes the position that "autistic adolescents are not represented in current research, because their experiences are not always valued" (p. ix).

In Myers', (2019) work with children and adolescents, the students and their creations contradict prevailing notions about autism. (Her book) *Autobiography on the Spectrum* elucidates how deficit constructions can marginalize individuals both in and out of school. Through the lenses of a "presumption of competence" Bilken, (2005), and taking a critical inquiry stance, this book explores how children and adolescents with autism can (and do) represent themselves to the world (p. x, xi).

Humphrey & Lewis', (2008) study, discovered that the autistic students they examined, were not having their needs fully met. According to Moore, (2007), there is often an assumption, that because a student with autism is able academically, he or she should be able to be adaptable in the mainstream school.

However, Humphrey & Lewis, (2008) found that difficulties in social communication and interaction experienced by students with autism, increased their exposure and vulnerability to bullying and social isolation, (NAS, 2006), Whitney et al., (1994). Autistic students' preference for routine, predictability and low sensory stimulation, conflicts with the noisy and often disordered environment of secondary mainstream schools, (Moore, 2007, Wing, 2007).

Humphrey & Lewis, (2008) further note, that the typical cognitive profile and preferred learning styles of such children, challenge professional assumptions about teaching and learning more than other groups of learners (Jordan, 2005), and that the lack of research and knowledge about supports for students with autism, means that many schools are not adequately able to meet their needs. Humphrey & Lewis, (2008) declare: "In light of this, it is unsurprising that parents' confidence in the effectiveness of inclusion diminishes, as pupils with ASD enter secondary school, Kasari et al., (1999), and it is during this period, that they are at an increased risk of developing mental health problems" (Barnhill & Myles, 2001), (p. 427).

Pelicano, Dinsmore & Charman, (2014) revealed that individuals with autism are still being excluded in decision-making, consultations and research. Fayette & Bond, (2017) note that "the absence of the views and perceptions of individuals with ASD (autism) within the literature is well documented, and as Milton, (2012) stated, this has created a knowledge base about ASD which is informed by non-autistic others, and imposed upon people with ASD" (p. 2).

Fayette & Bond, (2017) found that soliciting the views of young people with autism is still in its infancy. Only twelve studies met the inclusion criteria, and of those, the quality was weak, as only four studies were determined to have high "methodological quality", and only three studies had "high appropriateness of focus" (Gough, 2007), as cited in Fayette & Bond,` (2017), (p. 7).

Moreover, the review found that the available literature does not represent the heterogeneity of the autistic population, as it predominantly includes the views of young people with HFA (high functioning autism). According to McLaughlin & Rafferty, (2014), there is a great deal of literature about the experiences of young children with ASD, but not so with adolescents and young adults. How do young people with high functioning autism feel about themselves? Do they have positive or negative identities? One thing is certain; there is stigma, associated with autism.

Stigma as a mark

Link et al., (1997) conceptualize the stigma process as starting with the definition of stigma as a "mark" (Jones et al., 1984), which sets a person apart from others, and links the marked person to undesirable characteristics. Link and colleagues, (1989) note three components of the stigmatization process: culturally induced expectations of rejection, experiences of rejection, and efforts at coping with stigma. They write: "If one believes that others will devalue and reject . . .

one will fear that this rejection applies personally.“ For example, the newly labeled person may wonder: ‘Will others think less of me; reject me, because I am a person identified as having a mental illness?’ (p. 179).

They continue, that labelling causes “powerful expectations of rejection, which reduces confidence, interferes with social interaction, and disrupts social and occupational functioning. When a person becomes negatively labeled, not only do they expect rejection, but they experience it as well” (p. 179). These experiences of rejection, the second component of the conceptualization, range from ‘exclusions’ to ‘put downs’ and ‘slights’. Two coping mechanisms persons may experience are secrecy, where persons hide their treatment history from employers, family, or potential lovers to avoid rejection, (Link, Mirontznik, & Cullen, 1991). And the second mechanism used is withdrawal, where they limit interaction, to avoid the possibility of rejection.

Staniland & Byrne, (2013), note (Campbell et al., 2004) and (Harrower & Dunlap, 2001), who found that neurotypical peers may hold negative opinions of their peers with disabilities, despite the fact that they all learn together in the same classroom. They also cite that (Gray, 1992, 1993) has postulated that stigma related to high functioning autism, may be worse than that related to other mental conditions, “since odd or disruptive behavior coupled with a lack of any physical abnormalities, can result in peers attributing personal blame to either the children or their parents”, (Staniland & Byrne, 2013, p. 2816).

Gillespie-Lynch et al., (2015) caution, that while some anti-stigma programs, (Campbell et al., 2004), (Silton & Gogel, 2012), (Ranson & Byrne, 2014) were associated with decreases in stigma, findings suggest that stigma associated with autism may be fairly resistant to change e.g. (Campbell, 2007), (Staniland & Byrne, 2013), (Swayne & Morgan, 2001). As schools become more involved and take on responsibility for the identification and treatment of students, more students will become labeled as a group of symptoms, instead of being treated as individuals.

Michael Apple, (2004) writes about labeling students, such as those with disabilities and "slow learners", that the repercussions are often negative:

> I would like to argue that this linguistic system (labeling) as school people commonly apply it, does not serve as a psychological or scientific function as much as they would like to suppose. To put it bluntly, it often serves to abase and degrade those individuals and classes of people, to whom the designations are so quickly given. Labels are massively applied to children of the poor and ethnic minorities more than the children of the affluent and politically powerful (p. 129).

Welterlin & LaRue, (2007) write that immigrants experience social, cultural and economic barriers, which may inhibit their access to health services. They write that recent immigrants, who show what would be considered cultural norms in their home country, may be mislabelled as having autism or not labelled at all. They state, that in many Asian countries, "lack of eye contact, certain non-verbal gestures, and indirect models of interacting and communicating are socialized behaviors, and may be misinterpreted as manifestations of autism" (p. 751).

Disruptive behavior, and lack of emotional expressiveness are also characteristics of children receiving services under the Individuals with Disabilities Education Act Amendments of 1991 (20 U.S.C., 1400-1485). Welterin & LaRue, (2007) found: different rates of autism diagnosis across different races. In the U.S., of all the children identified, the percentage of Black students (0.13%) and Asian Pacific (0.13%) were "disproportionately high". Welterlin & LaRue, (2007) write:

> Although the reason for these discrepancies across racial groups is unclear, the data raises a number of important possibilities. One possible explanation for these differences is that professionals are mislabelling the behavior of multicultural students, indicating that their cultural characteristics, may lead to misrepresentations of behavior, as indicative of abnormality (p. 752).

What knowledge counts in our schools?

Who is to say that having autism is an abnormality? The late Steve Jobs, founder of Apple Computers, and Bill Gates, founder of Microsoft display traits of autism (Applied Behaviour Analysis Program Guide (2019). Why can't schools help students with autism develop positive identities? Michael Apple, (2014) writes:

> Schools are a site of conflict, about whose knowledge is official. Whose knowledge is it? Who selected it? Why is it organized and taught in this way? We need to examine critically not just how a student acquires more knowledge (the dominant question is our efficiency minded field) but why and how particular aspects of the collective culture are presented in school as objective, factual knowledge? How concretely, may official knowledge

> represent ideological configurations of the dominant interests in a society? How do schools legitimate these limited and partial standards of knowing as unquestioned truths? (p. 12).

In regard to access to school autistic services and public education, Michael Apple is saying that these matters should count as "official knowledge" to young people with autism, as it fits a need of a significant group, and meets the requirements for a democratic education. Texts are not simply "delivery systems" of "facts", but the results of "political, economic and cultural activities, battles and compromises." They are designed by people with real interests, and published within the "political and economic constraints of markets, resources, and power" (p. 47).

What texts mean, and how they are used are disputed within communities with different values, and also by teachers and students. What counts, as "legitimate knowledge is the result of complex power relations and struggles among identifiable class, race, gender, and religious groups." These groups struggle to have their "history and knowledge" included in the curriculum (p. 47). Apple states:

> Texts indicate particular constructions of reality, particular ways of selecting and organizing that vast universe of possible knowledge. They embody what Raymond Williams, (1961) called the selective tradition, someone's vision of legitimate knowledge and culture, one that in the process of enfranchising one group's cultural capital, disenfranchises another's (p. 49).

Including texts and information in school about autism, is part of obtaining democratic citizenship for such youth. Being able to see themselves in the curriculum helps create positive identities. To know they are included in society and not part of the fringes, to learn that others have coped with and managed their autism is part of democracy by being included in the curriculum.

Apple & Beane, (2007) write that a democratic school manifests itself in structures and processes including the curriculum. Democratic structures and processes mean that there is a genuine attempt to have stakeholders – students, parents, and teachers, participate in making decisions that affect their lives.

An example is the Byrd Academy in Chicago, Illinois, that had been promised a new school building, but nothing had materialized. The school building was inadequate. There wasn't a lunchroom, and students had to eat in the hallways, which distracted students learning in the classrooms. The students worked on a project to lobby for a new school. People were excited about the project, because it was connected to their lives. Projects like these could involve students in activist activities related to their condition as persons on the spectrum.

Similarly, Porto Allegre, Brazil, focused on democratic education for its citizens. It is a city of 1.3 million people, situated in the southern region of Brazil. From 1989 to 2005, it was run by a coalition of left wing parties under the general leadership of the Worker's Party (Partido dos Trabalhadores (PT). Transforming curricular knowledge was a goal of democratizing access to education, by having students learn about themselves. Gandin & Apple, (2013) write:

> The starting point for the construction of curricular knowledge is the culture of the communities themselves, not only in terms of content, but also in

> perspective as well. The whole educational process is aimed at inventing previous priorities, and instead serving historically oppressed and excluded groups, (see Apple, (2000), Freire, (1993), (p. 110).

The Citizen school adopted the idea of "thematic complexes". It involves teachers, students, parents and the community in action research. Main themes emerge from the interests and concerns of the community. They are then made into a thematic complex. The work is carried out in an inter-disciplinary manner during a specified period of time.

Gandin & Apple, (2013) give an example of a thematic complex addressing the community's standard of living. Three sub-themes were included: rural exodus, social organization and property. In the rural exodus sub-theme, the issues reflected the origin of the community living in a low-income ghetto, but originally in other parts of Brazil. This is a common story where people who had nothing, come to the city and face greater exclusion. The issues discussed in this sub-theme were migration movements, overpopulation of the cities, and "unqualified" work force and marginalization. Discussing this example, they write:

> Through the thematic complexes, the students learned history by beginning with the historical experiences of their families. They studied important social and cultural content by focusing on and categorizing their own cultural experiences. Yet it is important to note that these students will ultimately still learn the history of Brazil and the world, "high" culture, etc., but all of this will be seen through different lenses. Their culture was not to be

> forgotten in order for them to learn “high status culture”. Rather by understanding their situation and their culture and valuating it, students are able to simultaneously learn and have the opportunity to transform their situation of exclusion (p. 111).

The Citizen school thus respected the cultures and knowledge that the communities brought with them to the classroom. Similarly, this approach could be used to address the concerns of students with autism and other disabilities based on their life experiences. As Apple & Beane, (2007) state: the learning was connected to something “serious” (p. 151). The idea of the thematic curriculum was used, to put knowledge to work, in real life problems and issues of the students. It was a curriculum, as the literature says, that has “an ability to make a difference in how we understand and act powerfully, on the social world in which we live” (p. 151). As noted, the curriculum was not limited to “official” or “high status knowledge”, but included the voices of those who might otherwise be excluded.

Again, Apple & Beane, (2007) write: “A democratic school, includes not only what adults think is important, but also the questions and concerns that young people have about themselves and their world” (p. 17). Similarly, learning about autism, helps students learn about their identities and communities, and reflects a democratic education that could be provided to young people, to give them the information they need to know about themselves.

There is much more to be learned about the lived experiences of university students with autism in middle and high school. What success factors in school helped students with autism enter post-secondary education? Learning about the lived experiences of students with autism, who have succeeded in obtaining treatment and entering post-secondary education, will help inform what is working in schools, and what still needs to be done.

In conclusion, this chapter discussed the high number of young people who are being diagnosed as having autism. Generally, they don't feel included in school. Listening to their views is important, as there is a lack of knowledge about autism across the school system, and this presents barriers to the success of such students. Cultural characteristics of students may result in mislabelling, while students with autism seeing themselves reflected in the curriculum, may not only help them feel a sense of belonging in the school system, but also help them identify and understand their identities.

CHAPTER III

DATA COLLECTION METHODOLOGY

Research question

What were the lived experiences of university students with autism, during their middle and high school years?

Sub questions

How have these lived experiences impacted students in pursuing post-secondary education? And what can we learn from the experiences of students with autism, which helped or hindered their education in middle and high school?

A qualitative phenomenological study

The type of study utilized in this research is known as a qualitative phenomenological study. Such a study examines the meaning for several individuals of their lived experiences of a phenomenon (Creswell, 2007). According to Polkinghorne, (1989) (as cited in Creswell, 2007), the number of students involved in the data collection in such studies should be from five to twenty five participants. In this instance, it is the lived experiences of twelve autistic university students during their middle and high school years that will be examined.

To answer the sub questions, semi-structured interviews were used to learn about the students' experiences: what facilitated their success, and what more could be done to help students in middle and high schools to cope with ASD.

Research site and population

A large university in the mid-western United States with 43,820 students has a Disabilities Accommodation Centre, which serves approximately 2300 students. It is the organization on the campus that provides academic accommodations and supports for students with disabilities. An autism spectrum support group on this campus was used to recruit students for the study. Six students from the group agreed to participate.

The researcher wrote to the Disability Services of a college in the same city, and another university in the area, seeking assistance with finding participants, but no response was received from both of these schools.

The Autism Society, of a geographical location of the state where the research was conducted, placed on its Facebook page a description of the study, and a call for participants, but no one answered the ad to participate.

The researcher wrote to two other campuses of the university system, and recruited two students from one campus, and three students from the other.

Two more students were recruited, who live in a residence for students with autism and other disabilities, which provides academic and social supports. Both of these students attend a mid-western college.

Another student was recruited for the study through word of mouth by one of the participants, but was generally un-cooperative, and would only agree to participate through a technology application. The interview was discontinued after thirty minutes, but the student was paid $25.00 for the time.

One student dropped out of the study after one interview. After numerous attempts to contact the student with no response, the researcher chose not to use the data in the study, because he did not get this student's signed consent, and as a result was not able to pay the agreed upon $50.00 for one interview.

The other students signed consent forms to participate in the interviews, and received either $100.00 in cash, check, or a Visa Gift Card worth the same amount. The interviews took place in the university's library or the teacher education building. Three interviews occurred in a restaurant. The interviews were all audio-recorded and transcribed.

The researcher and the Interviewees

The researcher

I am fifty years old, and a high functioning autistic person with four degrees: a bachelor's in political science and in law; a master's in social work and in business administration. For fourteen years I worked as a policy advisor with the Government of Ontario, in Toronto, Canada, in the area of people with disabilities. I was diagnosed with obsessive-compulsive disorder when I was seventeen, and autism when I was forty-four. I have suffered with anxiety and depression.

My parents are university graduates. My mother has a bachelor's degree in education, taught school, and was a library assistant until her retirement. My father has four degrees: a bachelor's in English literature, a masters in divinity, another in theology, and a doctorate in ministry. For fifty-five years he was a minister in the United Church of Canada, serving mainly in the Toronto area.

I have a sister, six years older than I am, who has two degrees: a bachelor's in studio art and art history, another in education, and a diploma in post secondary art and art history. She taught junior kindergarten to grade eight in the public school system until her retirement.

I will share more about myself at the end of the dissertation, in the Personal Reflections in the Appendix.

The interviewees

Twelve students were interviewed. They included five women and seven men. Three self-disclosed as being persons of color, the others were of Caucasian descent. They have been given pseudonyms to protect their privacy. Here are my impressions of them, on meeting them and getting to know them. As you will note, they are all unique and likeable individuals.

Amelia comes from a middle class military family. Her parents are divorced. Both have university degrees, her mother is a nurse, and her father is a chemist. As a young child, she was diagnosed as having obsessive-compulsive disorder; and at eighteen, with autism. Of the women students in the study, she seems to be the most articulate.

Andy is confident, high achieving in his work and studies. He enjoys being outdoors, and helping others in the local community. Originally from India, both parents are engineers, and the family is upper middle class. He has a sister in college, younger than he, and knows no one else in the family other than a cousin who may be on the spectrum. He was diagnosed with autism in the sixth grade.

Audrey is athletic in appearance and personality, and was an articulate interviewee. Her life has been centered on a variety of sports. Neither of her parents graduated from college, but her sister has. Her parents work in the service industry. She was diagnosed when she was twelve, and is unaware of any other family member who may be autistic. She hopes to become a PE and health teacher, educating others on the importance of activity, diving deeper into health topics, giving kids more skills to use in their daily lives.

Bill was an excellent student in high school, but is struggling in university. He describes his family as being middle class. He has no memory of his biological father, as his parents were divorced when he was a baby. His mother remarried when he was four, and he has a twin brother and two stepsisters. His parents are technicians. He was diagnosed when he was two, and at eight with anxiety and depression. He is sensitive to touch and sound.

Dave is the oldest of three children. He is confident and friendly, more sociable than any of the other students. He is a graduate student in a master's degree program, and is also a Teaching assistant. He comes from a family heavily involved in activism. His mother has a PhD and is a professor, poet and writer; his father is an occupational therapist. He was diagnosed with autism and ADHD when four or five, had epilepsy until he was thirteen, and has struggled with anxiety and a lack of empathy. He knows who he is and where he is going.

Jason is a PhD candidate, and has one sister. He appears to be normal, is quiet, serious, smart and articulate. He is entirely focused on his personal goals.

His parents have PhD degrees and are in academia. The family is not super rich, but never he says, wanting for money. Having suffered for a long time with anxiety, and seeking help to cope, he watched a video by Tony Attwood on Asperger's, and as a result, was recently diagnosed as being on the spectrum. His hobbies are reading, and video and board games.

Judy is well aware of her identity, having received lots of support for her autism. She has a younger sister. Her father has degrees in chemistry and law; her mother a bachelor's degree in English, and a master's in marketing. The family is upper class. She describes herself as having been a difficult child. She was diagnosed in the sixth grade with ADHD, autism, anxiety and depression. She has a cousin who is lower functioning and is non-verbal.

Kent was diagnosed when he was two. He is serious, introverted, compassionate, and physically awkward. He has a twin brother, also on the spectrum, but more severely impacted than he is. His dad has an MBA, is a software developer; his mom has a BA, and is a stay at home mom. He describes his family's social economic status as being middle class; and is not aware of any other family members on the spectrum.

Nan describes her background as being African American and Hispanic. Her family consists of her mother, brother, and grandparents. Her father, who had both a B.A. and an M.A., is deceased. Her mother is a single parent and a school secretary. She says the family is totally poor, and she feels a personal responsibility for their economic future. She went to a private school; her teachers noticed that she was never able to complete her tests, but made any effort to find the reason. When she was seventeen, she was diagnosed with ADD and autism. She has trouble communicating, but knows that she can when she needs to, no more or less. It did not seem to be a problem during the interviews. Her brother is also autistic, but more severely impacted. She hopes to become a nurse.

Paul is a pleasant man, but of few words. He describes himself as tending to be introverted, so . . . not seeking out socializing. His family is pretty wealthy, but not super wealthy. His parents have bachelor degrees from the same university. He has four siblings, and he is in the middle. He has struggled with reading because of his ADHD, has recently been diagnosed with autism, but hasn't told anyone, and is presently receiving therapy.

Tony says that he is whimsical. He is Chinese, five foot two inches tall and an only child. He is personable, totally honest, and unhappily dependent. His mother thinks they are rich, but he doesn't think they are. His parents live in separate domiciles. His mother is frugal; his father spends his money on himself. When he was eighteen he was diagnosed with ADHD and ASD. He struggles with processing things the first time around, and has sensory problems with food. He is very centered on his goals, he wants to develop his own computer company, and he hopes to make a lot of money, because he thinks that would be the only reason a woman would want to marry him.

Trudy describes herself as being creative, analytic, artistic and totally disorganized. Her mother was a math major; her father has a master's degree in clinical psychology. She describes her family as middle class and living in suburbia. She was diagnosed with PDD when she was nine, and autism when she was thirteen. Of all the students, her autism is the most evident in her gestures and behaviour. A cousin may be on the spectrum.

Research techniques

While there are many ways to proceed with the numbers of interviews, Seidman, (1998), as cited in McCue, (2016), endorses three interviews per person to be conducted. As McCue, (2016) states, using this approach, each interview has a particular purpose. One interview allows for learning the participant's life stories, a second to listen to their experiences, in this case, their experiences in middle and high school, while another is a "reflective and sense-making interview" McCue, (2016), (p. 59). This allows for follow-up questions, after reflecting and reviewing the answers of the participants. For this study, two interviews were conducted combining the context of McCue's, (2016) three interviews.

Methodology

Following the model of McCue, (2016), the researcher read through the transcribed interviews. Notes were taken as the issues emerged. It was apparent that two of the students were the most articulate and dominated the conversation. One student offered only a sentence to each of the questions; another provided pages of material not all of it relevant or appropriate, while another shared information too personal to include. One stuttered in answering the questions, while another would say the same word repetitively. Most of the interviewees punctuated their responses with ‘uh’s, ‘um’s, likes, and ‘I don't knows'. The question arose, whether to include every utterance; or enough to be authentic, while making the dissertation as readable as possible. It was decided to go with the latter.

A file was set up for each of the students, and the edited material without the extra words was typed, keeping everything, which might prove useful. The next course of action was to identify the themes that were the common experience in all the transcripts. Each individual’s comments on each of the themes was then typed up and placed in separate files. The themes were then sorted into three possible chapters: challenges the students encountered, hurdles and hurts they experienced, and their hopes and dreams for the future.

With that in place, the theme files were placed in different folders for the three possible chapters. There was soon evidence that some important material remained. It was then decided that a better division would be challenges, supports (a positive approach, rather than the previous negative hurdles and hurts) and finally the third chapter, potentialities. Once more there was a required editing because some of the responses were too long, and if left in their original state, would result in the more articulate students appearing to dominate the discussion. Every voice needed to be heard as equally as possible.

When that process was completed, the literature research, which had previously been collected, was then sorted into a separate filing system for the three chapters, and for each of the relative themes. Space was provided for future research literature, which might be needed to respond to some of the material.

Finally, everything seemed to be together for writing. Looking back, it seemed that the preparation had required an enormous amount of time, but it proved to be a valuable asset in the writing, since everything was available at hand when needed, and returned to many times during the formatting.

Data analysis

Cresswell, (2007), (p. 610), notes that in a phenomenological study one would highlight “significant statements”, sentences, or quotes that provide an understanding of how the participants experienced the phenomenon. Moustakas, (1994) as (cited by Creswell, 2007) calls this step horizontalization. Next “clusters of meaning” are developed from these significant elements, and then used to write a description of the context that influenced how the participants experienced the phenomenon, called “imaginative variation or structural descriptions” (p. 61).

Moustakas, (1994) adds another step (p. 62). Researchers also write about their own experiences and the context and situations that have influenced their experiences. From the structural and textural descriptions the researchers then write a composite description that presents the “essence” of the phenomenon, called the “essential, variant structure (or “essence”). This focuses primarily on the common experiences of the participants. The reader should then be able to have a better understanding of what it is like for someone to experience the phenomena.

Ethical approval for the study from the University’s Ethical Review Board

Approval was granted and the study received an exemption under campus policy:

> The research is not federally supported, does not fall under VA regulations, and is not FDA regulated. In addition, the research falls within the following category (ies) of exempt research outlined under campus policy: Category 2: Research involving the use of educational tests, surveys interviews (NOTE: If children are involved in the research it can only be determined to be exempt under this if the research is limited to educational tests or observations of public behaviour, the investigator(s) cannot participate in the activities been observed, and the identification of the subjects either cannot be ascertained or the disclosure of the subjects' responses would not put them at risk.) This study underwent limited IRB review to ensure adequate provisions are in place to protect the privacy of subjects and to maintain their confidentiality (IRB, 2019).

Protection of Privacy Rights of Human Subjects

Humphrey & Lewis, (2008) note that students with autism are a vulnerable group. Having students talk about their lived experiences with autism in middle and high school may bring up harmful memories. To minimize potential harm and ensure their safety, the interview process might be easier for the participants, knowing a fellow student who has autism is interviewing them.

Pseudonyms were used in reporting the names of the people in the study. Collection of sensitive information was necessary for the research objectives. All communications and storage data utilized was secured, encrypted and online cloud storage systems provided for by the UW Madison. No subject data was maintained outside of cloud systems. All personal information by e-mail was conducted through secure and encrypted e-mail servers such as Wisc E-mail or Gmail. Audio recordings and transcriptions of one-on-one interviews were collected by a personal computer with password protection, and data was stored in cloud storage (UWBox) provided and secured by UW Madison. Transcripts were stored in a locked drawer as well as original signed consent forms.

Validity, Reliability, Limitations, Reflexivity

Cresswell & Miller, (2000) (as cited in Creswell, 2007) chose to focus on eight strategies that are used by qualitative researchers to ensure validity of the research. One is called prolonged engagement and persistent observation in the field, building trust with participants, learning the culture, and "checking for misinformation that stems from distortions introduced by the researcher or informants" (Ely, et al., 1991, Erlandson, Harris, Skipper & Allen, 1993, Glesene & Peshkin, 1992, Lincoln & Guba, 1985, Merriam, 1988) (as cited by Creswell, (p. 207).

Clarifying researcher bias from the outset is important, so that the reader understands the researcher's position, and any biases or assumptions that impact the study Merriam, (1988) (as cited in Cresswell, 1997). The researcher comments on past experiences, biases, prejudices and orientations that have likely shaped the researcher's approach to the study.

Cresswell, (2007) recommends qualitative researchers engage in at least two validation strategies in any study. In this study I have noted three validation strategies: reliability, limitations and reflexivity.

Reliability

The researcher followed Cresswell's, (2007) advice that reliability can be improved if the researcher develops detailed footnotes by having a good quality tape for recording and by transcribing the tape. The tape was transcribed to indicate the trivial, but important pauses and overlaps.

Limitations

Limitations to the research include the small sample size, self-selected participation and generalizability, as it is difficult to generalize the findings based on twelve participants.

Reflexivity

Reflexivity is defined as "the researcher's active consideration of his or her place in the research" (Bailey, 2007, p. 119). Similar to the research participants, the researcher has ASD. The researcher disclosed this information to the participants, in order to identify as someone who had gone through middle and high school experiences and also entered post-secondary education. It may make the researcher biased about the school systems' responses and non-responses based on his experience, since he was diagnosed much later than any of the participants.

CHAPTER IV

THEORETICAL FRAMEWORK

This dissertation adopts a post-structuralist approach to examining the lived experiences of current university students with ASD, during their time in middle and high school years.

Kellner, (2003) argues that a critical theory of education "has a normative and even utopian dimension, attempting to theorize how education and life, construct alternatives to what is." He notes that poststructuralist theories focus on the importance of "difference, marginality, heterogeneity and multiculturalism, calling attention to dimensions of experiences, groups and voices that have been suppressed in the modern tradition." He goes on to state: "They develop new critical theories of multicultural otherness . . . which includes engagement with class, gender, race, sexuality, and other important components of identity and life that many modern pedagogies neglect or ignore" (p. 6).

Using a post-structuralist approach, different perspectives about autism can be learned by asking students how their experiences impacted them in pursuing post-secondary education, and what we can learn that helped or hindered their educational experiences in middle school and high school. An introduction to the theories utilized will be presented, followed at the end of the student's perspectives, with an analysis applying the theories to the student's lived experiences.

Disability and the theory of complex embodiment

The late Tobin Seibers, (2013) contended that different perspectives including those of students with disabilities “stand outside of and offer valuable knowledge about the powerful ideologies that seem to enclose us” (p. 279). According to Althusser, (1971), “ideology represents the imaginary relationship of individuals to their real conditions of existence (p. 162). Tsai, (2008) states: “these imaginary relationships induce individuals to conform to social systems that constitute forms of oppression” (p. 21).

Seibers, (2013) challenged the ideology of ability, which he referred to as the “preference for able-bodiedness” (p. 279). He wrote that the ideology of ability is so powerful, that it is “a part of every action, thought, judgment, and intention, that its hold on us is difficult to root out.”

The literacy about disability on the other hand, is almost nonexistent. “Disability” he asserts, “creates theories of embodiment more complex than the ideology of ability allows, and these many embodiments are each crucial to the understanding of humanity and its variants, whether physical, mental, social, or historical” (p. 279).

> The sharp difference between disability and ability may be grasped superficially in the idea that disability is essentially a “medical manner”, while ability concerns natural gifts, talents, intelligence, creativity, physical prowess, imagination, dedication, the eagerness to strive, including the capacity and desire to strive – in brief the essence of the human spirit.

> It is easy to write a short list about disability, but the list concerning ability goes on and on, almost without end, revealing the fact that we are always dreaming about it, but rarely thinking critically, about why and how we are dreaming (p. 280).

In essence, Siebers, (2013) was writing that the prevalent medical model of disability and ability are two different concepts. Disability is viewed as a deficit, and ability is seen as an asset, and the two shall never meet. He provides examples of ability as an ideology as follows:

> Ability is the ideological baseline by which humanness is determined: the lesser the ability, the lesser the human being. Ability is the supreme indicator of value when judging human actions, conditions, thoughts, goals, intentions and desires. The able body has a great capacity for self-transformation. It can be trained to do almost anything.
>
> The disabled body is limited in what it can do and what it can be trained to do. It experiences new situations as obstacles. Disabled people must try to be as able-bodied as possible all the time. Disabled people are worth less than nondisabled people, and the difference is counted in dollars and cents. Because people with disabilities cannot see beyond their own pain, they lose the ability to consider the feelings of other people. People who wish to identify as disabled are psychologically damaged. If they could think of themselves as able-bodied, they would be healthier and happier" (p. 280).

Seibers, (2013) cites (Linton, 1998) to claim that “the ideology of ability collapses”, once disability is asserted as a “positive identity” (p. 281). He argues that as with other minority groups, once persons identify positively with their disability, they lead more “productive and happier lives, with shared experiences and a community in which to prosper” (p. 281).

The “identity politics” which he refers to, is often criticized that it cannot be upheld, as it refers to suffering:

> The idea that suffering produces weak identities both enforces the ideology of ability, and demonstrates a profound misunderstanding of disability: disability is not a pathological condition, only analyzable via individual psychology, but a social location complexly embodied. Identities, narratives, and experiences based on disability have the status of theory, because they represent locations and forms of embodiment, from which the dominant ideologies of society become visible and open to criticism (p. 283). All knowledge according to feminist philosophers occurs in “social locations”, and those persons, in “marginal social positions enjoy an epistemological privilege, which allows them to theorize society differently from those in dominant social positions” (Harraway, 1991, pp. 183-391).

Embodiment is critical to the field of disability studies. Embodiment and location are the same. Siebers, (2013) gives the example of George Lane’s body that asserted a group of theoretical claims regarding architecture that the U.S. Supreme Court ruled in a case involving the State of Tennessee. The court found that Lane, being unable to enter the Polk County Courthouse, unveiled “a pattern of discrimination against people with disabilities, found throughout the American court system” (p. 289).

Siebers, (2013) continues: “The ultimate purpose of complex embodiment theory, is to give disabled people greater knowledge of, and control over their bodies, in situations where increased knowledge and control are possible” (p. 291). When mentioning the idea of social construction, he suggested that we should “map as many details about the construction as possible, and to track its epistemological, political, and real effects in the world of human beings.”

> To start, we should consider three “Methodological” principles: First, knowledge is socially situated – which means that knowledge has an objective and verifiable relation to its social location. Second, identities are socially constructed – which means that identities contain complex theories about social reality. Third, some bodies are excluded by dominant social ideologies – which means that these bodies display the workings of ideology and expose it to critique and the demand for political change (p. 295).

Affective equality, love, care, and solidarity

Lynch, Baker & Lyons, (2009) introduce the concept of Affective Equality through love, care, and solidarity. They assert:

> Love involves acting for those we love and care for, not just feeling for them. Solidarity involves active support for others, not just passive empathy. Because love, care and solidarity involve work, affective inequality also

> occurs when the burdens and benefits of these forms of work are unequally distributed, and when this unequal distribution deprives those who do the love, care and solidarity work of important human goods, including an adequate livelihood and care itself (p. 1).

As this dissertation examines the lives of university students with autism, it is important to ask as Lynch, Baker & Lyons, (2009), whether these students had access to, or were "denied relations of love, care and solidarity" (p. 218). They also assert "it is vital to ask whether these relations are reciprocal or asymmetrical, whether they are structured by gender, class, race and/or disability, whether they are power balanced or power imbalanced, and whether societies operate in ways that help to satisfy or frustrate this human need" (p. 217). Lynch, Baker & Lyons, (2009) note, that those persons that are denied love, care, and solidarity, from important social providers (such as parent`s, teachers and health workers), are deprived access to critical "social goods" (p. 219).

This dissertation, through this critical theoretical framework, will also answer the issue of how institutions and social norms address the needs for love, care and solidarity. Lynch, Baker & Lyons, (2009) ask how key institutions such as schools affect the distribution of income, wealth, and cultural capital, how they generate or mitigate inequalities of opportunity, how well they can accommodate cultural and other group differences, and the degree to which they can reduce inequalities of power. If love, care and solidarity matter, all of these questions have to be revisited (p. 232).

Redistribution and recognition

Nancy Fraser, (2004) writes that claims for social justice can be divided into two different types; claims for redistribution and for recognition. Redistribution claims involve a more equitable distribution of economic resources. The second involves recognition of the different claims of ethnic, sexual minorities, gender, and people with disabilities. She explains: “Here the goal in its most plausible form, is a difference-friendly world, where assimilation to majority or dominant cultural norms is no longer the price of equal respect” (p. 6).

As applied to students with autism, redistribution claims may involve receiving adequate accommodations for the students’ disability in school. It may involve recognition in the curriculum through an accurate description of persons with autism, and to develop positive identities of such students.

Fraser, (2004) argues that both claims are necessary, and can be integrated together into a single framework. She contends for the notion of a “parity of participation”, which requires all adults to engage with one another as “peers”.

Two conditions must be satisfied for “parity of participation” to occur. First, resources must be distributed to guarantee participants “independence and voice”. She refers to this requirement as the “objective condition of participatory parity”. It excludes “economic dependence and inequality” that prevent “parity of participation” (p. 36). The second is called the “inter-subjective condition of participatory parity” (p. 36). It requires that institutions express “equal respect for all participants and ensure equal opportunity for achieving social esteem”.

Precluded, therefore, are value patterns that deny some people the status of full partners in interaction – whether by burdening them with excessive ascribed "difference" or failing to acknowledge their distinctiveness:

> The objective condition brings into focus concerns traditionally associated with the theory of distributive justice; especially concerns pertaining to the economic structure of society and to economically defined class differentials. The inter-subjective condition brings into focus concerns recently highlighted in the philosophy of recognition, especially concerns pertaining to the status order of society and to culturally defined hierarchies of status. Thus, a two-dimensional conception of justice oriented to the norm of participatory parity encompasses both redistribution and recognition, without reducing either one to the other (p. 36).
>
> Redistribution claimants must show, that existing economic arrangements deny them the necessary objective conditions for participatory parity. Recognition claimants must show that the institutionalized patterns of cultural value deny them the necessary inter-subjective conditions. In both cases, therefore, the norm of participatory parity is the standard for warranting claims (p. 38), and the claims for participatory parity must show that they will not "unjustifiably" create or worsen other disparities (p. 39).

Fraser continues:

> What is required is only what is needed to participate as peers in social life. And there is no reason to assume that all need the same thing in every

> context. In some cases, they may need to be unburdened of excessive ascribed or constructed distinctiveness. In other cases, they may need to have previous under-acknowledged distinctiveness taken into account. In still other cases, they may need to shift the focus onto dominant or advantaged groups, outing the latter's distinctiveness, which has been falsely parading as universal. Alternatively, they may need to deconstruct the very terms in which attributed differences are currently elaborated. Finally, they may need all of the above, or several of the above with one another, in combination with redistribution (p. 47).

Enduring, resisting and reframing school experiences

Myers, (2019) examined twelve autistic adolescents as they worked together developing multi-media-autobiographical stories. Many of the youth experienced oppression during the course of the inquiry. How the youth responded contributes to the development of the theory of the experiences of youth with autism.

<u>Oppression</u>

Myers, (2019) interprets oppression to mean: "experiences of prolonged and institutionalized distress; also experiences in which the teens were rendered vulnerable or powerless by an external structure" (p. 45). The students addressed oppression by "endurance, resistance or reframing"; and collaboration with each other allowed the students to assert "agency". The university students interviewed for this thesis, by their writing and other acts of resistance, also addressed the following three concepts. This will be discussed later in the analysis section.

Asserting power through quiet opposition

Charlie, one of Myers' students, experienced bullying constantly. He writes:

> Never got any attention, though. I never stood up for myself. That's one thing I really try to stick to is not fighting back, cause my school has a strict policy. You'll instantly get detention and stuff. I've never hit anyone. I never got a detention. But . . . I've always been constantly bullied and stuff. I've got punched, I've been kicked, I've been pressure pointed, I've been called names.

Myers, (2019) writes about Charlie asserting agency through the use of his writing:

> I read Charlie as using his group project as a way to withstand the cruelty he suffered at school. He created pieces about bullying but always included some consideration of the rules that dictated his own behaviour. Charlie garnered support of the other teens throughout the year; some admired his strength to withstand, and others pushed him to act. Despite his threats to retaliate, Charlie continued to share stories of quiet opposition. He defined himself in his works by his ability to endure the ridicule he experienced at school, and I see his work as helping him to endure. I read the work he did in the group as a way for Charlie to assert agency over his experiences (p. 49).

It might also be said however, that Charlie lacked Fraser's "inter-subjective conditions of participatory parity" (p. 36). Charlie did not receive equal respect and social esteem from his peers. However, Charlie did exercise "independence and voice", through his journals. For true parity of participation, Charlie should have been treated as an equal by his peers and not bullied.

Affirming power by resisting and fighting back

Elizabeth, another student of Myers, fought back against the oppression she experienced. She reported constant teasing similar to Charlie. She wrote that frequently she was in the principal's office and in detention. On four different occasions she told the story of pouring milk over a classmate, but said: "that it was worth getting in trouble for" (p. 50). Myers, (2019) writes:

> Charlie told stories of endurance; Liz told stories of resistance. She may not have seen herself in a position of power at school, but she would not allow herself to silently withstand persecution. She kept up an almost constant defense, prepared to fight back in all cases. In these works that Liz created in the group, she portrayed herself as someone clamouring for agency. She spoke up loudly and often, and told stories of how she stood up for herself at school. She authored herself as a young woman fighting for strength and control over her own circumstances. Elizabeth's writing and creating and positioning and interpreting was an agentive act. She learned about herself through, and with the other teens, and drew power from those connections. Given the assumptions about students like Elizabeth, her story is critical. It shows the potential for the voices of marginalized students to be heard (pp. 53-54).

Elizabeth asserted "independence and voice", but unlike Charlie, she had Fraser's second condition required for "equitable redistribution and recognition": . . ."equal respect and social esteem". However, she should not have had to fight to achieve it.

Asserting power by reframing oppression

Another one of the students was Cody, whose stories frequently changed. He would write that his grandfather was sick; then he just came from his funeral, and shortly thereafter his grandfather would pick him up. Some of the stories were true; some were not; they were all inconsistent and difficult to believe (p. 56).

> Myers, (2019) states: Cody chose to represent himself through stories. He created portraits of himself particular to his audience, the space in which the story was told, and the story he wanted to tell. This is a sophisticated use of narrative, and one that might not be expected of a student like Cody. He was able to make keen assessments about himself, his audience, and particular situations, all the while maintaining a strong narrative voice. These changing narratives were one way that Cody claimed agency over his circumstances (p. 58). Hull & Katz, (2006) explain: "How we represent ourselves in storied worlds depends on who we are trying to be in relation to others in the present" (p. 45). In another story, Cody told about throwing a chair at a teacher, knocking her out and having to go to court. Here, he represented himself as someone who had the power to fight authority (p. 59). Stories for Cody became performance, as he created different versions of himself.

Like Charlie, Cody achieved a sense of "parity of participation" by creating his own fantasy world, where he had "independence and voice" and "equal respect." Yet only Elizabeth seemed to achieve Fraser's, (2004) "parity of participation", but perhaps not in a truly equal way, as the respect is achieved by fighting back.

Conclusion

Siebers, (2013), Lynch, Baker & Lynch, (2009), Fraser, (2004) and Myers, (2019), all present post-structuralist theories that involve participation, hearing, and adequately addressing the words and voices of students with autism. These theories represent what might be termed the Autistic ideal. The reality as told through the stories of the students interviewed in this dissertation and the academic literature paints a different picture. The students however, are all privileged, they know at a relatively young age who they are, or will soon learn about their abilities and possible limitations that need to be addressed. Later in this study these theories will be analyzed through the specific words and stories of the twelve students interviewed in this dissertation. The possible achievement of these theories in practice will also be analyzed.

CHAPTER V

CHALLENGES

This chapter about challenges is divided into six divisions: academic, social, transitional, physical, cultural and health. The students in this study will speak for themselves in their own words and idioms. They will share their failures and successes as they faced their challenges, the obstacles they met along their way, and the hurdles they overcame. In the analysis at the close of the chapter, the research literature will be revisited to reflect on the student's narratives, how they agree or differ from each other, and at the end draw some conclusions what the findings mean in general.

Academic challenges

Every school day, whether attending middle school or high school, young people with autism face academic challenges different from those of their peers. In some situations, they may have an advantage, particularly if they have been diagnosed with HFA, the high functioning form of autism. In that case, they often excel at math and science, art and music, not infrequently surpassing their peers. By the same token, their lack of organizational and social skills put them at a disadvantage, when these abilities are considered necessary for academic success. All of the students faced different challenges, and each of the issues are named one by one with their responses.

Memorization/reasoning/mathematics/reading

Audrey, a junior in college, and a PE major, admits: I am not good at science, or any link: biology, chemistry type of thing, it's so complex, like if you take a definition of something, or you're trying to learn something specific in science, there's so many different facts or things you have to know that are so concrete and that doesn't change. Um, it's just this overload of all these facts, and all this knowledge that you need to know, that I just had to memorize. It was almost overwhelming in a way. I worked hard so that I got good grades, but it took a lot more effort than I wanted it to be.

Jason, a PhD candidate, on the other hand, excels at memorization. He says: I was successful in anything that involved memorizing facts: so history and science classes. I was a bit more challenged by writing and English classes. Um, but I think, just the way my brain worked, it was very easy for me to understand facts, and I kind of had strong memory skills. That's because middle school typically centers on memorization. As a result, some students at higher grades are turned away from subjects like science that focus on application and reasoning. Through probably at least middle school it's learn all this information and regurgitate it. And some people who might be good at reasoning, sometimes never get into those subjects because of their earlier levels, they are terrible at memorizing things. But it took more effort to try and figure out how to code the rules of say, good essay writing. I was good at math, so my grades tended to be A's across the board. It was mostly a degree

> of how hard I tried to get them. Um, so in English classes I had to deploy an enormous amount of effort, I pretty much did. Well, another part of that, I found it very interesting. I would be the kind of person that would read ahead in the book before the teacher even talked about it.
>
> **Amelia** acknowledges: I was terrible in math, so science was always difficult for me. I remember I was really good at biology, but that's because that particular class we didn't really use a lot of math, it was more like memorize how this cell looks and then be able to draw it. I remember what all the parts were called because that was more creative thinking. I always excelled in anything that could use memorization or writing-reading comprehension.

Both **Andy** and **Paul** had trouble with reading.

> **Andy** said: I was sometimes challenged by reading, but was able to get past the issue. I was really a good reader, but it was just hard for me to excel my capabilities in terms of reading new books, exploring my dictionary and word choice. I ended up easing into it. But if it became hard, I mean sometimes I stutter when I read, and there are other times I have to use my finger to kind of point out where I have to read, where exactly I am on the page. I have to use those techniques that I used when I was in middle school, because sometimes it's difficult, because I really talk very, very, very fast. It's almost like my mouth is speaking fast, and my heart is beating.
>
> **Paul** comments: I struggled with reading in grade school and early in high school, but that got better with practice. I used to not do well with it because

I have ADHD, so it's hard for me to stay focused, and I also don't have the patience to read a long text, (but) just reading books throughout school, and just doing that year by year, it helped me to focus more you know, with annotating the book, and doing assignments and things like that, kind of forcing you to pay attention.

The feeling of being overwhelmed

Audrey talked previously about being overwhelmed.

Kent had the same experience. He concurs: I didn't need a lot of (academic support) until I got to high school. It was so much harder than what I was used to. I was signed up for several honors classes; they got to be really overwhelming. It was at that point when I realized, I needed a lot more academic and emotional support. So I had an IEP. I met with the case manager, um, and that would help, we would work on assignments, helping in extra time with tests, breaking down projects, and things like that.

Bill talks about being overwhelmed while writing a chemistry test: I don't focus as well as I should, and sometimes everything gets blurred together. The test was really long, and I tried to look over everything at once, while I still could remember the answers. I was nervous, and I wasn't prepared to take the test. I kept moving from question to question, instead of focusing on a single question, and the time limit was making me panic. I wasn't able to think clearly, and ended up doing poorly on the test. If I had been able to focus better at the time, I'm sure I could have performed better.

Audrey gives another reason for being overwhelmed, this time due to a large class of twenty-five to thirty people she experienced in high school:

> If I didn't understand anything right away, I was behind; the class kept moving, and I didn't have time to be like, stop! I don't understand this. And before I moved on, the class had moved on, it was like if I was stuck, and had to fend for myself, because the class was not going to stop because one person didn't understand something. So I think it was the class aspect of things, being part of a bigger group, and you just had to go with the flow.

Executive function

Students with autism can struggle with executive function, leading to greater difficulties with organization, following multiple step directions and the ability to self-initiate (Rosenthal et al., 2013). The following narratives give proof to the fact.

Nan is twenty years old. She admits that executive function is a struggle:

> I cannot plan. I cannot organize. I am terrible at multi-tasking. I think I feel like if I try to focus on more than one thing then I can't get it done, and I just go back to doing one thing at a time. Um, and as for planning, I'm always more for last minute on the spot. Um, for me the definition of planning is thinking about it . . . it never occurs to me that I plan beforehand. Yeah. And I'm okay, well that's what I'm doing today, you know. And then my mom says: 'you know, people need to plan beforehand'. Um, and then with organization: I'm not organized whatever; even binders don't help.

Tony responds: Planning, initiating, and being proactive? Oh, I suck at that.

Participation in class

> Many participants interviewed said that they actively participated in class.
>
> **Amelia** remarked: I'd often be told to let someone else have another turn. I was either going to be quiet the whole class, or I was going to talk the whole class. There was no middle ground.
>
> **Andy**, a junior in college, has this to say: I tried to ask questions, and understand it; it was all about comprehending and understanding everything, because that was the hardest thing for me, to understand what this means, or what that means, or how to do this, or how to do that. Sometimes I would just stare at the blackboard and think about what question would be a problem, or if somebody else had the same question as me. Sometimes I really could participate, but sometimes I couldn't. And sometimes being a really good participant, I'd get in conflict with the teachers, so they shoved a degree in my face. I figured to trump, but they would say like, 'Hey I have a bachelors, and you're telling me that I am wrong, then speak to that'. It's almost like . . . they're directly challenging me.
>
> **Bill**, who considers himself 'to be pretty smart' says: I always try to participate in class answering questions, reading and helping others when it is necessary, though it makes me sad now when practically nobody in the class participates, and I end up having to answer so much, that the teachers tell me to let other people answer instead.

The propensity among autistic students to participate often in class is not universal.

Nan who is very shy, found it very difficult in a class setting. She said: There were various occasions where we had to do presentations. I would be like they say: everybody has to say something, everyone has to participate. I would literally be a person, who would say one sentence to get it over with. And then, there were the ones where we had to present by ourselves, um, I found it really hard to meet a time requirement uh, yeah it was really bad.

Unhelpful teachers and pedagogy

Amelia stated there were things that teachers said about her which were not very nice. One teacher said: 'I don't think you're ever going to go to college, you just don't have the personality, you're not very resourceful.'

Jason commenting about schoolwork in class said: I always had an issue with doing my schoolwork in the classroom. It was kind of a too busy atmosphere and I couldn't focus. So I would do all my schoolwork at home where it was quiet, and I didn't have any distractions. Um, and so when teachers made doing things during class a high component, that was less useful, than when their classes were about presenting and teaching material.

Judy found teachers who couldn't control the other students frustrating. She states: People would break the class rules, like going on their phones to take selfies and stuff, and a lot of teachers were not able to manage their students and that was stressful. Some teachers were unhelpful and uncaring. I've always responded to people who seem like warm and friendly, and I had a few teachers, who did not seem like they cared.

> **Tony** commented that he didn't like the teachers who taught in a sink or swim kind of way, like: I'm just going to grade these papers and if I notice that you need help, I'm not going to say anything, um like their failure to notice that I was struggling, and not really doing anything about it.
>
> **Trudy** complained that her English teacher couldn't seem to get across the essay prompts in a way where she could follow the writing assignments: If anybody had sat down with me, it might've helped.

Of all the challenges facing students with high functioning autism, academics are probably the least difficult to contend with. Intellectually, the students are at least equal to their neurotypical peers, and possibly superior to many. They do not have trouble getting good grades, particularly if the courses are geared to their special interests, and if not, they are prepared to work harder to achieve their goals.

Because they may have superior academic skills they may be advised to take the more advanced courses, and end up being anxious and overwhelmed. The students are saying they may need extra support to manage their assignments, with either more time on tests, or tutoring to address the issue of being overwhelmed.

Part of the problem lies in the fact, that many students have difficulty coping with the lack of executive function. They have issues with planning ahead, dealing with time management and initiating things, and as a result are constantly trying to juggle everything expected of them. **Nan** and **Tony** are honest and frank enough to admit it. The school system, which serves them well academically, doesn't do anything to help them to become better organized, and the students wonder why.

There seems to be a dividing line drawn by the students who enjoy courses that require memorization such as the maths and sciences, and those that require reasoning and analytical skills such as history and literature. **Jason** makes this distinction and points to the fact, that most of the academic learning in middle school is memorization and the regurgitating of facts. Most persons with autism intuitively recognize this distinction, and plan their futures accordingly.

As for participating excessively in class this appears to be a given. It seems this is annoying to some of their teachers, and the students are often rebuked for participating too much. **Bill** feels sad when this happens, because the way he reads it, he always tries to be helpful with his peers, helping them with their studies, and assumes they do not know the answers to the teacher's questions, while he does. **Nan** is the only exception, but then she is an example of an autistic person, who has communication problems. The norm is to say too much.

With regard to their teachers, half the students have complaints. Ironically, the other half, who express their opinions later in the dissertation, are full of praise.

Social Challenges

Muller, Schuler & Yates, (2008) interviewed eighteen individuals with autism about their social challenges. The themes that emerged included: (1) being isolated throughout childhood, watching other children play and being unable to understand how to be playmates; (2) difficulty initiating social interactions with peers; (3) communication challenges such as not being able to understand other's body language or implicit messages; (4) and a longing for deeper friendships.

Additional themes that emerged from the students interviewed in this dissertation included bullying, discrimination and stigma, struggles with having empathy, the negative possible results of disclosing one's autism, experiences with masquerading (conscious of one's disability and acting contrary to it), and loneliness, alluded to in Muller, Schuler & Yates, (2008), is also addressed.

Bullying

A number of students faced bullying, but the experience was not universal.

Amelia said: The bullying was so bad that I begged my mom to let me switch to a different school. People would say the meanest things, shove me in the lockers, physically hurt me and call me annoying. There was another kid with autism in my school that was non-verbal. The kids in my class were praised when they were nice to him. That's what I thought autism was, and I also had it, but the same kids, who would help this kid, were bullying me for the same thing. It was just a spectrum between him and me, though I wasn't non-verbal, I was still on the spectrum.

Judy tells a similar story, how a person with a visible disability, is treated better than a person with an invisible disability. She observes: In middle school, we were on the playground on the swings. There was this argument, because a boy with Down's syndrome wanted to use the swing I was using. Um, everyone just kept telling me to get off the swing, and let him use it, and that kind of thing makes me dig in my heels. They kept saying 'he has Down's syndrome'. I understood that he had a disability, but my point was, that neither of us was more entitled to that swing. If they accepted that not every disability is visible like Down's syndrome, that would've been helpful.

> **Andy** who is South Asian said: I was bullied for what I looked like, for what I was, who I was, what they thought I was. It was almost like there was this dark cloud over me, and it's no matter where I would run or hide, it was always there in high school. It drove me to the point, where it was so bad, I thought of suicide, . . . so one day, when I was in my junior year, I even felt like I didn't want to be at school or at home, I just wanted to be in a grave in a box, and I had to be put on suicide watch at a hospital. So it was just some fears, or some ways of thinking that broke me, and broke me hard.
>
> **Dave** is twenty-nine. In his growing years, he also experienced bullying.
> He said: People teased me you know. I occasionally got beat up, or was in fights. They hurt me. People, who didn't try to engage with me because they thought I was weird, hurt me; maybe even more so than straight aggression, I can understand that, and I can work through that. And anytime that happens everyone gets in trouble; then you have to talk through it. It's very hard however, to spot passive aggression, where people are socially isolating each other, by not speaking to them, or engaging with them, when they have the option to bring those two people together, and have them talk it out, like you would with a fight or things like that.
>
> **Trudy** said: I was bullied like a ton in middle school, and, at the first two years of high school this guy sexually harassed me, and shit.

In contrast, other students received little bullying, and **Nan** was not bullied at all.

> **Jason** remarked that he was rarely bullied: I went to a school where, a lot of the students were scholastically focused, and because, uh, I was smart and did well, I was regarded in that way. Um, sometimes people would kind of mess with me but most of the time I shrugged it off, nothing pervasive.
>
> **Kent** agrees: I wasn't bullied too heavily. I don't think that was too much of a problem in my school, and it was just really ever since high school, when I've had a lot of challenges, and that's when I felt bad about myself, not bullying.
>
> And **Nan** said: I wasn't bullied, I was actually with the popular kids; everyone wanted to be my friend, and I didn't understand why, and it was like that in middle school and high school. I limited myself to being friends with people I came from in middle school; so, it was only five of us. In high school people were trying to invite me out and I would tell them no, but I was never bullied.
>
> **Tony** said about bullying: There was nothing before the day I was diagnosed. Oh yeah, nothing, because people, specifically white people, think that Asians can't be mentally ill, and if there's something wrong it's just because of the Asian culture, or because we're just inherently weird.

Discrimination and stigma

> **Amelia** said: It's not something to be ashamed of, so I shouldn't hide it; it's just that everyone has preconceived notions. They're condescending, like it's not that they think, oh, you're on the spectrum, and they're scared of me. It's more like; oh you're like a twelve year old, in a twenty-year-old body.

Audrey responded: Yes, I've had moments when we've touched on mental disorders in class, and I've felt, that everyone was looking at me.

Jason, who was recently diagnosed, said: I don't feel too much of a stigma, but I do feel a bit. And then you know I'm not willing to tell my friends, because I'm worried about what they'll think, because there's a lot of bad information about autism; the whole anti-vaccine movement, is just how poorly the general information is. So in terms of that you know, I guess you could call me a closet autistic, so to speak.

Kent said: It's not so much because I have autism; it's not obvious. A lot of people don't know that I have it; but it's still there, because of the things that make me feel a little bit ashamed sometimes, like the sort of my social and academic and personal challenges. I've had some experiences based on some of those things, that I think, had a negative impact on my sense of self.

Tony has a great deal to say: I feel there is a lot of stigma around autism, and people see it as a label. If I tell people I'm autistic like, 'Oh, well why do you need to tell me that? Do you think that makes you special'? No, I just want to tell you that I can't eat what's in those crackers, because it has a weird texture. I feel there's a stigma in the sense that people don't understand it. Um, so when someone says I have autism, um, they treat it as some kind of preference that I think is a big deal, it is not a big deal, but it is part of the reason why my interactions are a certain way, and if you know that about me, then you would maybe know, um, how you should be acting around me.

Um, I also feel there is a stigma around being autistic, in the sense that it's not actually hard to come across jokes, where, um autistic is being used as an insult; or um jokes are made implying that someone that's either doing something stupid, or being annoying is autistic. I hear a lot of those jokes being made, without any thought, like what about the implications of that are, for autistic people. Like maybe I want to laugh at the joke too, but I can't laugh at it, when I'm the butt of it. Right.

Disclosure – negative responses

Dave has come to some strong conclusions with regard to disclosure:

I kind of worked with disability advocates with recent jobs and I now have a strategy, don't ever open up about ADD or autism, in any job period. I'll say that I have a disability, only after I'm hired, because they will discriminate against you beforehand. I might say, I need, and I have more of those needs. I'm not going to say why; you don't have to, because of the stigma attached to it. I've experienced this in jobs, and with friends earlier in life, more jobs now, cause like friends accept me for who I am. I only open up to people if I think it necessary, if, um, you know, once I get a sense of them, and they get a sense of me, so they will not change how they act toward me. I'm a very open person by nature, were it up to me I would be able to be fully open, and there wouldn't be any stigma, and when I need to, I can be very public about it. I can stand up for myself, for others as well, because I'm willing to take a hit or two, if that means that it will be better for the next people, behind me.

> **Jason,** who was recently diagnosed said: I haven't told anyone. I've been thinking about whether I should, and if so how I should. That's something I'm still thinking about and trying to work through. I have no idea what their response is going to be, which is a large reason why I haven't told them.

Empathy

The academic literature indicates that it is difficult for persons with autism to display empathy. This is interpreted by many as an absence of empathy, with the implication that autistic persons do not recognize or care about the feelings of others. Three students spoke to the issue:

> **Dave** said: I am of the opinion that most everybody has the capacity for empathy; just because of the way our brains are. Um, so I think I always had it, but at the same time, I think because of the impulsivity of the ADD and the systemic thing of the other side of me, that's the Asperger's, I can also be selfish. So it took a hell of a lot of work for me to become empathetic. I'm sure there's a lot with the development of the brain. But at the same time I think when I was learning how to engage with people with eye contact and stuff, I was learning to be empathetic, and I'm sure my Para-educators increased my empathy without me realizing it. No matter how embarrassing a situation I created or found myself in, they saw to it that I had to go back into that classroom and engage with those people.
>
> **Amelia** responded when asked to describe her personality: I'm a very empathetic person. That's usually how my friends and family describe me.

Trudy said, commenting on the first time she was being diagnosed: The neuro-psychiatrist didn't consider autism, cause he based his diagnosis on stereotypes, when he said that I had empathy, therefore I didn't have autism.

Loneliness

The students' experiences with loneliness, demonstrates a lack of response by the school system, in helping students to develop social skills.

Audrey said: I was very much alone, and did a lot of things by myself. I didn't really get advice, nor reach out to anyone about it. But yeah, I tell people now if they ask, but even in my senior year in high school, I didn't even eat in the lunchroom. I would sit in the hallway by myself, cause I just didn't want to be by anyone. So there were times where I would mention how I was by myself or alone, or do this by myself or, um didn't really have people to talk to, friends to have. So I don't know why it was never addressed, as I would think it should be. I'm not sure. Maybe, I don't know if it was a lack of the school's part, they didn't really know what to say or what advice to give.

Judy comments: I had no friends from high school. I mean I had friends from outside of school, but when I stepped into that school I was alone. Um, I ate lunch in the halls on my own. Uh, I feel like they the school should have had more in place, probably people make friends and be less isolated. Um, there were other people I saw sitting alone, but none of us really knew how to approach each other, or maybe the other people weren't interested in friendship, but it was just really kind of miserable going through high school.

Nan had a similar experience. She said that she preferred to keep to herself: That actually was something that happened a lot in middle school and high school. Um, it would always be like group work, and I would always be the one working by myself, because I couldn't ask someone, like, I couldn't say, Hey can I join your group? Yeah, it was lots of working by myself.

Tony's experience was the same as the others, he said: There's something really degrading, about having all of your friends stay in touch with you exclusively on line, or whenever you see them outside of school, because then at school you have to watch all of your school, who do have school friends, socialize with each other, and all I need is a buddy. Well you have nobody.

Masquerading

A characteristic of students with autism may include masquerading. The students were asked, if they tried to masquerade, when interacting with others.

Andy said: Yes I do, because I had a really hard time accepting my identity as a person, who I was to somebody else. There were times when I felt like my parents didn't even know who I was. I did not know myself, who I am as a person, what were people going to see in me. So yeah, I did masquerade what people saw in me, because I didn't want them to change their opinion of me. I think it really depends on the situation, for me, I'm really interested in cars. I don't masquerade that, but I'm aware it's not me masquerading and hiding it, but it's more about controlling it, like when it is a good time to talk about, and when there's a bad time. And having that sense of awareness will help you dramatically, because if people bring up the conversation of like, let's say for example, like alternative energy, I bring to the conversation about electric cars. So it's like a way into something else, rather than hide it.

Jason remarked: Yes, depending on whom I'm around. Um, I usually don't feel like I can just be myself, that I need you know, to interact with other people, how they would want me to interact with them. Um, otherwise I would just end up rambling on about things that interest me.

Judy seems to adapt her autism well to social situations. She is reflective:

I feel like I've tried to be myself in situations, but that person is changing. I guess that's true of everyone. Um, in the psych class I'm in, we talked how people have different faces they put on depending on the circumstance, and everyone does that, like when you interact with your teachers, or your boss, or your parents, every person you interact with, with every group you're in, you act differently. Yeah so I think the answer is: Yes I do, everyone does. For example, my dad, he's into baseball. So though I know nothing about it, I'll talk to him about it, because it gives us something to talk about. I'll ask him how the Chicago Cubs are doing, cause he's a Cub fan. I'll ask if they won their last game, if they have a chance of winning the championship, because it gives us something to talk about, and because it makes him happy, Yeah.

Dave said: I used to. It was a mask I wore, and then gradually over time, I became less at masking. I realized, it was just a part of myself that I had been growing and cultivating, and so masking wasn't a good analogy anymore.

The students discussed misunderstanding social cues, which resulted in bullying and loneliness, as well as their peers not understanding what it means to have autism. Based on their experience, there was a gap in the school system in terms of teaching social skills to students with autism, and what the condition is about to those students who are neurotypical, and the larger society in general.

This reinforces the point that students are on a spectrum, and thus will have different experiences. **Amelia** and **Trudy** said that they did have empathy, contrary to the literature, while **Dave** mentioned that he could be self-centered and had to work at it. Masquerading for the students seemed to be a part of their identity.

Transitional challenges

Transitions of any kind present challenges to everyone, but even more so for persons on the autism spectrum, as they move from one school to another. There is the change of location, a new set of teachers, a change in routine, the loss of friends, difficulty in making new ones, and finding places where they are accepted.

Elementary to middle school

Andy and **Tony**, expressed their concerns, as they faced the challenges of moving from elementary to middle school. **Andy** speaks of his feelings as he sits in his classroom, viewing a video prepared by people from his middle school, the purpose of which was to acquaint the incoming students what they could expect:

> I was a little kid back then. I still remember the overall dimensions, of what those places were going to be like, awed me. So the transition from elementary school was really tough, because I was used to small spaces.

> **Tony** shares his experience of his first day at school: I was like, wait, we have more than one teacher. We have to switch classrooms. What is this? Like I didn't even pick up on it, until somebody told me, cause, I was bad at reading like my schedule, and I wasn't even reading it until the fourth week of school. Um, and also like the first day I actually cried, because I had one of those autistic moments, because I couldn't get my locker open. Um, and like, I had to have people open my locker for two weeks straight, all of the new stuff we weren't explicitly told about except a piece of paper with your schedule on it; a paper with instructions on how to open your locker, except they didn't include one detail or okay instructions. And I seemed to be unable to make new friends in this new environment. Um, it was really scary for me.
>
> **Jason**, on the other hand, had a different experience. He explains: I think it was a transition that was beneficial, because in elementary school there was less emphasis on school, and more on just being you know, friendly classmates or whatnot, which wasn't my strong suit. And so that's where you know, that the academic focus of mine, uh, kind of was able to do better in the more advanced school settings.

Middle school to high school

New challenges surface in the move from middle to high school. There is the loss of friends and the difficulty in making new ones, the social dynamics that happen, changes in one's body, people start dating, expectations to be more independent, all hurdles for those on the spectrum.

The following comments are some of the feelings experienced by the students as they moved in transition:

> **Andy** has matured from being a frightened little boy, into a different person. He said: It was really easy for me to transition, because I was making a lot of friends. You were definitely treated as low class freshmen, but I ended up learning fast, I really did; and with the fourth year, I was able to bounce back.

Audrey and **Bill** begin their transition stories with the same word: scary.

> **Audrey** said: It was scary at first. It threw me for a loop the first year. I was getting used to making a new routine at school. Once I did that, it was fine.
>
> **Bill** said: It was scary at first. I had to learn all new teachers; my advanced math classes put me in with students two years older than I was. I had some prior experience with high school students, so I was able to adapt quickly.
>
> **Dave** spent a lot of his time with adults in high school. He said: I really became close to the staff at the library, and would hang out there all day just watching videos on line. I even ended up working at the front desk and being a student assistant, so I found a lot of support there.
>
> **Andy** talks about hanging out with teachers: During the office hours, I would go over there, and they would give me a place to sit, or offer me food. They would make me feel comfortable, but it also helped me out in certain ways, I mean they were always looking out for me. And, I had, there was a group of social studies teachers who were really looking out for me. I'm still indebted to this day because of what they are, how they helped me. Yeah.

History was always my strong suit, and they saw that, and we would always talk about this history or that history, or like issues going on in the world, political issues. We would talk about how would you react to that? That was something I enjoyed.

Judy lamented the loss of friends, and the difficulty in making new ones:

I knew absolutely nobody at my new high school. Making new friends, it's very hard. The other problem I think, school gets harder the further you get into it; so for students who don't have the academic abilities, that's one thing that will be hard. I think it's just bigger, the lion amount of work you have to do with greater volume. The number of people you have to deal with, I think that basically would be the main difficulty.

Nan struggled with expectations that she become more independent: I was always used to having my mom and relying on her, doing things for me. She would take care of everything, and then I wouldn't have to worry about it. And in high school I remember that we had to go, it was like orientation, and you know I am always the type of person, wherever I go, I prefer to have my mom along with me. Okay, and they said that in orientation, that my mom couldn't go with me, and I had to do everything myself, and they wouldn't even let me have my mom go with me to pick up my books, and literally that frightened me so much. My mom, she's like my ears and eyes, I always feel like safer doing things with her, and she would speak for me. So I had to advocate for myself in high school, which was difficult.

> **Trudy** gives mixed messages. She says: moving from middle to high school was, I think it was actually better. I mean it didn't feel that much different, except that it was anonymous, and I wasn't being bullied as much. On the other hand, high school had more classes and homework though, so many classes, so much work; I couldn't keep track, track, track of all the long-term assignments too, so that was completely overwhelming.

In contrast, **Jason** and **Paul** found that their transition was fairly straightforward.

> **Jason** comments: I can't remember too many notable differences between middle school and high school, for me pretty much the same in my mind, very distinct from elementary school, but pretty much the same between middle school and high school. Anything I did, I did well. I did better in middle school and high school because the transition was less playing with others, and more towards complete these math questions, or write this essay, or things of that nature. I can't recall anything specific that was problematic.
>
> **Paul** framed his response as always in a few words. He said: I did fine, and I liked high school more than I liked middle school.

High school to college

Most of the students struggled with the transition from high school to college, and whether they had been prepared to face the challenges that it would present.

> **Amelia** said: I felt that I was prepared academically because I had taken the advanced classes. What I wasn't prepared for, which I don't think high school could have prepared me for was the total freedom.

Audrey's response was: I know it's not like my high school's fault, but the schedule that you follow in high school, is not what you do in college. There it's very much a couple of classes a day, and you have a lot more free time.

Bill comments: Having to be independent, making your own time for everything, instead of the time you get regimented from your parents, that change makes it much more difficult to allocate time. You don't get any reminders to do homework, clean your room, or eat right, like you did at home with your parents. You have to become self-sufficient.

Dave said: High school could have done a hell of a lot more like help with looking for grants and here's how you do this, and here's how you do that. But I was already having a lot of issues just organizing myself. I think it's too much to ask for most seventeen year olds frankly, you know, to do all these different applications and all these things. I left most of it up to my parents, except for filling out the applications and writing these long essays and stuff. Um, so it would have been nice to be better educated on the type of schools available that have the resources, and that do well with people with autism.

Jason reminisces: I did come from a very good high school. Um, and so even while the jump to college level academics was steep, it was not nearly so steep as what a lot of peers faced. I think most of my issues were kind of socially based, and life skills based, that I don't really see how high school could have better prepared me for college. If I knew I had autism, I might've known some of my social difficulties and uh, how to, how to approach that.

Judy regrets that she was not socially prepared for university: My high school would have been much better, had they offered me support with the social aspects of having autism. Um, they were just awful in that regard. So in terms of the social preparedness for college, I was not prepared.

Kent thinks high school could have better prepared him for college. He says: I went through so much stress academically, do this, take these classes, math, biology, etc. I think it could have been done better, that you'd be preparing for the real world setting. So much of it was academic. They could have provided guidance on what to do after high school. Like, what to pursue in college, how to succeed in the world, things like that, and social skills as well.

Nan said: Socially it has been difficult, but academically it has been fine. Socially it's been terrible; I'm kind of a recluse. I don't attend many social events or participate in any activities. Um, I recently decided I'm going to go to the autism support group on campus. I was excited about that. So I was like, hey, maybe I can make a friend. It's essentially like a bunch of people, who are finding they're on the same level you know, so it's just technically, like a judgment free zone, cause we have like uh, some issues with communication and socialization. I guess, I learned from high school, what not to do in college. Um, don't keep things to yourself if you have a question. If you're unsure, always ask for help. Yeah. Um, so I guess what I learned from that in high school academic wise it has been fine. Like there's nothing about my autism, that doesn't allow me to get a better grade.

Tony said: Academically, I feel like I was definitely under prepared for college and there was not enough emphasis placed on social areas.

There was no teaching about how to fit in socially, nothing about self-care, or how to live independently by yourself, nothing about how to manage your time efficiently. In high school, no one ever teaches you how to do that.

And that's really frustrating because you'll have kids, who are like up all night like until seven a.m. doing their homework, but that doesn't really teach anything about time management, because in college it's a lot harder to do that, when you have like a bunch of 8 a.m.'s, or you have assignments that are a lot heavier than just here's this five hundred words essay.

Trudy comments: High school didn't prepare me for college. It would have been helpful if high school had taught me some organizational skills instead of just telling me to get organized, as if that was supposed to help. It doesn't. Sit down with me every so often to teach me skills for how I can organize my stuff; that would have helped.

Socially, I wonder if there was some way I could have received some feedback on how I was doing so that I could then apply it. And they could have put more effort in dealing with sensory issues like: if they had like pep rallies heading out, it's like we always got notice ahead of time, and those were ridiculously loud, like they hurt and that wasn't good; similarly fire alarms and the like, I don't know, if anybody ever took notice or took the time to talk to me about every day sensory troubles with lunch rooms and stuff.

Physical challenges

Diagnosis

With the exception of **Trudy** and **Judy**, the school system played no role in identifying that the students had autism.

For **Trudy** it was a teacher in the second grade that had some knowledge about autism, since she had a nephew with ASD, and the teacher told Trudy's parents. Her parents had suspected issues earlier, but the teacher triggered the diagnosis. For **Judy**, it was her parents who first thought that there was a problem, but it was the teacher that was the reason her parents had her tested.

Many of the students received the diagnosis relatively later in life.

Amelia was diagnosed at eighteen. She said: I felt so out of my depth.

> I really wanted to have a friend group, like people who would always know where I was, because I was convinced I was going to go missing, and no one was going to notice, because we had free reign. And so in my attempts to become closer with these people I started trying to be like them and mimicking their behaviors. They would always have a dark sense of humour, so I started copying what they were saying, but I was doing it out of context. So what turned for me just trying to be their friend, turned into them thinking there was something wrong, and they called the police and there was a whole incident. And so it kept spiralling because I kept trying to explain myself, but doing it in a way where I was taking everything literally. That incident caused my mom to seek out a diagnosis.

Jason, who is twenty-four, relates how his diagnosis came about: In Grad school, I entered a period of being overwhelmed, and my anxiety manifested as a physical pain in my chest, which then created a short-term panic disorder, where I was thinking I was having a heart attack. And even though I wasn't, at that point I went and got treatment for anxiety. And because I was undergoing treatment, and seeing a lot of psychologists, I started looking into various psychological conditions. I came across a YouTube video of Tony Attwood talking about Asperger's, I thought to myself, well, that kind of seems like me, because I had always felt a bit different from everyone else. So this was about three or four months ago that I saw this video, and then I started talking to my therapist, and we found someone who did adult evaluations and got myself evaluated. The diagnosis came back as autism spectrum disorder.

Andy said: I was officially diagnosed when I was in the sixth grade, so I was diagnosed very late. I was very shy. I wasn't making a lot of eye contact. I was having a hard time being a social person, and my middle school had a hard time accepting who I was, and that I needed extra support.

Audrey notes: I was diagnosed for sure, when I was probably around twelve or so. I was in middle school. I remember my mom telling me that I was noticing things were off, or different, compared to other kids when I was like two, or three years old. She started noticing there was something a little different in me, and then didn't really do much about it. I don't know the name of the place, going to talk to someone about it . . . and through a couple of sessions, I was officially diagnosed as having autism.

Judy, after receiving her diagnosis as Asperger's said: My parents had to argue with the school district a bunch, because they had a specific set of accommodations that they could only offer to people with autism, and a lot of it wasn't what I needed, so they had to get the diagnosis changed. Now it doesn't matter, because it's all on a spectrum, but at the time they had to like do some legal stuff, to get the IEP (Individualized Education Plan) to cover what I needed. I'm guessing there were probably some obsessive behaviors; there was a depression diagnosis, something about anxiety; I don't know if it's official or not, but ADHD or ADD or something like that.

Nan shares that she was seventeen: None of my teachers saw a problem, they just saw that I never finished a test on time, but they didn't know why. I was having a problem with my eyes, and sought out a diagnosis, and it turned out that I had 'convergence access' with my eyes, which required therapy. The therapist said to my mother, 'your daughter might also have (autism)' and presented a list of accommodations, that's when my counsellor told me, that I should get a psychological evaluation, otherwise I would never have got one.

Then there is **Paul** who is nineteen, who was diagnosed for the first time a year ago. His parents helped him get his diagnosis, and his father recently made arrangements for him to receive therapy.

Tony said: I was diagnosed for autism when he was eighteen: My mom took me to a specialist, who had interactions with me when I was a child, because I was kind of a problem back then, and they wanted to know why.

At the time my mom was like: 'There's nothing wrong with him, he's just kind of special'; and that was exactly what she said the second time round.

I kept being really annoying with my little autism behaviors. And then she was like, 'we've got to stop this.' So she took me to a second specialist, who was actually an expert in autism, and I was diagnosed after seven tests.

Amelia said: Had I been diagnosed earlier, it would have helped with my social skills. It might have stopped the bullying. There would have been more understanding about why I was being bullied. Some kids, not that it's their fault, are targets of bullying, and usually they don't have the personality at a young age to stand up for themselves. And I think that was my issue too, but another fact was the lack of social skills.

Cultural challenges

Nan who is African American and Hispanic, and **Tony** who is Chinese, faced cultural challenges before, when getting diagnosed, and afterward.

Nan comments: My (Hispanic) grandparents would say: 'You're not autistic, this is something that you can control, this is something that you can change.' Um, yeah, and even my mom, she's halfway with it. She sometimes says, 'You are autistic', and other days she would say, 'you are not'. Hispanics don't like to believe there's such a thing as health problems or mental illness. Um, and I guess for a while that's how it was. Um, it would just be attributes of your personality . . . and it would always be something you can change.

Tony has a similar story: My whole family before I was diagnosed was like there's possibly nothing wrong with me, because as an Asian person, you get conditioned to think, yeah, there's nothing wrong with you. You're probably just imagining whatever problems you're going through. You don't have problems, so unless your arm is falling off, or you're dying or something, just assume there's nothing going on, so I didn't notice anything like that, I just assumed there was nothing wrong with me. I still kept the same hobbies, habits, uh, um all the annoying stuff about kids that people say, 'he's going to grow out of it'. I never grew out of it. I still make poop jokes. I still lose stuff willy-nilly. I still take things very literally, and I'm still one heck of a loner. Anyway, all the adults in my life noticed a 'typical-ness' and they talked to my mom about it, and they came to the conclusion, that I have Asperger's.

Health challenges

A number of students have been diagnosed with other mental health conditions.

Amelia has OCD: **Andy** has OCD and severe mood swings; **Audrey** has ADHD and anxiety and depression; **Dave** has ADHD; **Jason** has anxiety; **Nan** has ADD and has suffered with depression; and **Paul** has ADHD.

Dave comments: I had all supports dropped from under me when I got to the seventh grade. And because of that I suffered severe anxiety. That's the one time in my life I had to go on anxiety medication, which I absolutely needed.

Um, you know, I would still have IEP's ever so often, whatever those letters stand for. Um, but it caused me to go a lot more internal, and through the most of junior high and high school, I'd be kind of sunk into video games and other forms of escape. I didn't really put any energy into socializing, because not only were the supports gone, but also looking back on it . . . it makes me think of how those supports gave me resources. They pushed me to socialize and engage, even when I didn't want to engage. I needed that in order to get that, and I'm really grateful for that. And without those things pushing me, like I wonder if that was one of the reasons as well.

Nan says that in her freshman year: I did not go to school whatsoever. Um, just because I was depressed, or I did not want to go to school, but there were also some times when it was impossible for me to go, because I wouldn't have any transportation to get there. Then I was troubled. I liked doing things I wasn't supposed to be doing. I would just spend time doing things that I would like, like reading or going to the library.

Andy tells about having mood swings and anger problems, which resulted, he says: In me acting out in very violent and destructive ways. I get hyped up over a lot of little things, and that's as if my brain sees situations differently, and tells me to react in a certain way, which is not always appropriate. I also suffer from technology addiction. It's kind of like that obsessive nature of mine that developed from my autism that makes it a problem. There are lot of good things about technology, but if it makes one distracted it has to stop.

> It’s unbelievable what technology does. It really screwed up my life. I just can’t stop, and it’s kind of the same thing I have with other things. I’m very passionate, intense, so that when I’m into it, I just can’t stop.
>
> **Amelia** talks about her Obsessive Compulsive Disorder: One of the fears I had, was that I wouldn’t have access to a bathroom. I’d be out somewhere and the bathroom would have exploded, or they’d closed it, or locked it, and I wouldn’t have access; and sometimes I would be nervous in high school switching classes, and you only had so many minutes to get to the next class. If I can’t go to the bathroom before class, I really get anxious.
>
> Another thing was, if I touched something like a chair, like I tapped it accidentally, I had to tap it again at the same place, but I would never get the same place, so I ended up tapping it like five hundred times, or like doing like, tapping my feet five times, so it was odd behavior.
>
> I also had a fear, that if I didn’t say goodbye to my family the right way they would die, and so I did goodbyes. It got so bad, to the point where if I left the room to go to the bathroom in the kitchen, I would assume they were going to die in the kitchen, unless I said goodbye to them in a certain way.

Sensory issues

Some autistic students have difficulty processing sensory information, whether over or under sensitivity, or both at different times. These difficulties, which involve eye contact, taste, touch; light and sound, can have a profound effect on a person’s life.

Eye contact

Amelia said: When I had to give presentations, I would always get marked down: like 'you didn't scan the room with your eyes wide.' But when you scan the room with your eyes, you make eye contact with people. I never liked that. I feel like I can hear what they're thinking, and that distracts me. **Dave** comments: Even though I was diagnosed with the mild form of the spectrum, I still couldn't look people in the eyes.

Touch and taste

Bill was and is very sensitive to touch: My mom and the school therapist would run soft bristle brushes over my hands and arms to desensitize them. They would also do joint compressions, in order to make the feelings in my hands more easier to tolerate. **Trudy** reveals that she became very resistant if people tried to hug her. **Tony** alludes elsewhere that he has difficulty eating certain foods.

Light and sound

Nan says: I can't take bright lights: that's a no, no, no! And noise distracts me. It prevents me from functioning. If it's like repetitive noise, repetitive noise, repetitive, repetitive, it will cause me like a meltdown. I just can't take that. **Bill** says: I get a very high sensitivity to sound, especially when lots of people are talking at once, so I would wear a headset with soothing music playing overhead, in order to block out all the remaining noise to make it easier for me.

ANALYSIS OF CHALLENGES

Academic challenges

An analysis of the literature regarding lived experiences of students with autism in middle and high school, finds middle schools are usually organized in teams where teachers work together with a group of students, and there are fewer opportunities to interact regarding the shared needs of peers. High schools on the other hand, seem to be more detached, with higher academic standards, and a greater focus on grades, than that of middle schools (Corocan and Silander, 2009).

In one day, a typical high school student will have four to seven different classes with a different teacher and a group of students. High school students are pressured to be self-sufficient "with greater expectations for having planning and organizational skills" Hedges et al., (2014). Students with autism face challenges with "leading to greater difficulties with organization, following multiple step directions and the ability to self-initiate" (Rosenthal et al., 2013). "These abilities are considered necessary for success in high school" (p. 66).

The feeling of being overwhelmed

It is not surprising that the students in this study frequently used the word overwhelmed, to describe their experience transitioning from middle school to high school and also to university. The feeling was due to the extra workload, the distraction of a large number of students in the class, and the focus on facts and figures. The academic literature uses the same word, for students being overwhelmed in high school and university.

Saggers, Hwang & Mercer, (2011) write:

> The students found it hard to cope with a tight work schedule, such as having exams or assignments due too close together, and submitting assignments on time. The problem of a heavy workload was one of the areas that students worried about most in relation to their schooling. The students found their work 'overwhelming and stressful' (pp. 9-10).

Van Hees, et al., (2015) writing about students in Belgium said about their subjects:

> Day to day activities required a lot of time and energy. The newer the activity, and the more new activities needed to be taken into account and organized; the more students felt 'overwhelmed' and the more their management of activities failed (p. 1678).

Audrey and **Kent** felt 'overwhelmed' but eventually they adapted.

Reading and mathematics

Attwood, (2006) states that research has found that generally academic achievement with ASD in reading and mathematics is consistent with fellow students (Dickerson, Mayes & Calhoun, 2003, Griswold et al., 2002, Reitzel & Szatmari, 2003, Myles et al., 2002). Statistically, more students with ASD are at the extremes of school achievement in reading and numeracy. A review of 74 ASD clinical cases between 1950 and 1986 at Hans Asperger's Clinic in Vienna, found that 23 % excelled at mathematics, 12 % had exceptional artistic ability, while 17 % had problems with reading and writing (Hippler and Klicpera, 2004) (p. 295).

Attwood, (2006) writes that hyperlexia (an advanced ability in word recognition with poor comprehension of the words or story line) is more common than one would expect in children with ASD (Grigorenko et al., 2002; Tirosh & Canby 1993). One study found that one in five children with ASD, have problems with reading, and almost half have problems with mathematics (Reitzel & Szatmari, 2003).

This was the case with **<u>Amelia</u>**, who had trouble with math, and **<u>Paul</u>** and **<u>Andy</u>** struggled with reading.

Attwood, (2006) states:

> We are not sure why individual children with ASD achieve high scores on reading tests, but such children subsequently tend to achieve high grades in tests of school achievement, due to relatively advanced ability to learn from written material (Grigorenko et al., 2002).
>
> We are also not sure why some children with ASD have specific problems with reading. We do know that such children can have specific perceptual and language problems that will affect reading ability. For example, a child with ASD described how he could learn to read a specific word, but when the word was printed in a different font he perceived it as a new word (p. 23).

<u>Andy</u> talked about stuttering when he read, and having to use his finger to point out where to read, and to know exactly where he was on the page. This experience appears consistent with the academic literature on reading for students with ASD.

Executive function

Nan, **Trudy** and **Tony's** problems with executive function, coincides with the academic literature. The students had problems with planning and executing tasks.

Attwood, (2006) writes that the term executive function includes: organizational and planning abilities, working memory; inhibition and impulse control; self-reflection and self monitoring; time management and prioritizing; understanding complex or abstract concepts; and using new strategies (p. 234).

There is evidence to substantiate that adolescents and adults with ASD, have impaired executive function (Goldberg et al., 2005, Goldstein, Johnson & Minshew, 2001), (Hughes, Russell & Robbins, 1994), (Joseph, McGrath & Tager-Flusberg, 2005), (Kleinhans, Akshoomoff & Delis, 2005), (Landa & Goldberg 2005), Ozonoff et al., (2004), (Ozonoff, South & Provencal, 2005); (Prior & Hoffmann, 1990); (Rumsey & Hamburger, 1990), (Shu et al., 2001), (Szatmari et al., 1990).

> Attwood, (2006) says: Working memory is the ability to maintain information while solving a problem. The child with ASD may have an exceptional long-term memory, and perhaps be able to recite the credits or dialogue of his or her favorite film, but have difficulty with the mental recall of information and manipulation relevant to an academic task. Another problem is that he or she may also "have a tendency to forget a thought quickly" (p. 234). Research has demonstrated that children with ASD are "less likely to learn from their mistakes, even when they know their strategy is not working" (Shu et al., 2001), (p. 235).

Parents and teachers frequently comment that children with the syndrome do not learn from their mistakes. “We now recognize this characteristic as an example of impaired executive function that is due to a problem of neurology (the functioning of the frontal lobes), rather than being the child’s choice” (Attwood, 2006, p. 235). Attwood, (2006) continues:

> In the middle school years problems with executive function can become apparent as the school curriculum changes to become more complex and self-directed, and teachers and parents have age-appropriate expectations based on the maturing cognitive abilities of age peers. This is seen in the elementary years where students in history class for example, are required to recite facts and dates. In middle school the child must demonstrate that he or she can write essays: that have a clear organizational structure, and that he or she can recognize, compare and evaluate different perspectives and interpretations (p. 235).

Adolescents with impaired executive function have problems with the organizing and planning aspects of class work, assignments and homework. This was particularly true of **Trudy**, who had problems with organizing essays. “Hardest” she said, “was probably health class because of organization: I was having a scene, then I ended up dropping it, cause I was just having a hard time organizing.”

Attwood, (2006) cites (personal communication) with Stephen Shore, speaker, author, and autistic advocate, who says: “Without appropriate support, the child with ASD may feel he or she is drowning in a million different sub-tasks”.

Participation in class

According to their teachers, students with ASD are less likely to respond to questions in class, or work cooperatively with other students (Newman, 2007).

In referring to university, (Gobbo & Shumulsky, 2014) and (Madriaga & Goodley, 2010) make the same findings. Hill, (2014), Connor, (2000), write: that students in high school had a preference for practical subjects since they involved “little social interaction”. She noted in her study that high school students enjoyed her Design and Technology course (DT) due to its practical nature, and the lack of fear of students getting the answers wrong. She writes: “As students are actively engaged in learning, the pressure may be taken off the need for social interaction.” However she found that it was striking that within the shared themes there was a considerable variation. This was apparent at various levels including how different individuals experienced the same event, individual triggers for a shared feeling, individual requirements in terms of levels of desired social contact with typically developing peers and variety of participation wishes. The research has highlighted that, while it is important to look through an ASD lens, it is of greater importance to focus on the strengths, needs, and interests, of each individual young person (Hill, 2014, p. 87).

Dillon et al., (2016) studying the experience of students with autism in secondary schools in the United Kingdom, found variation from previous studies as well that showed that students were interested in participating in class. “Teachers offering opportunities for group work and instruction are viewed more favorably by their students, signifying the importance of peers for learning and engagement." As one student interviewed by the authors said, "I like it when the whole class are involved and you don't just get told what to do," (p. 225).

In Anderson et al.'s, (2018) study of the perspectives of university students with autism spectrum disorder, most participants (n=21); 51.2% agreed or were neutral (n=7); 17.1% towards (feeling) comfortable asking questions in class, although females (n=8; 42.1%, and (n=2) 10.5% respectively) less so than males (n=13) 59.1% and n=5, 22.7% respectively (p. 655).

Carrington & Graham, (2001) write about the students they researched in high school that: "repetitive questioning or lecturing on special interest topics needs to be monitored by the classroom teacher. Perhaps a certain period of the school day can be put aside solely for work or discussion on the special interest. Once this routine is established; the child may learn to stop asking questions or making inappropriate comments at other times" (Williams, 1995) (p. 46).

For this study the students were active participants in class discussions, sometimes verging on excess. The exception was **Nan**, who said as little as possible.

Teachers

Hastings, (2005) & Woolfson & Brady, (2009) note that teacher expectations can be challenging for students with ASD. In contrast teaching styles have been seen to make a difference for students with ASD (Hughes, Bullock & Coplan, 2013). Teachers who are viewed as genuine and interested in each student are seen to make a difference in helping students succeed (Rubie-Davis, 2007). Teachers, who contribute to an increased sense of self-worth, especially to those with ASD, contribute to students' self-esteem, (Sciutto et al., 2012)

Students with ASD in Saggers et al., (2011) study, indicated that teacher characteristics were critical to feeling included in the classroom. These features seemed connected to students' desire for fair treatment and understanding from their teachers. Successful teachers for students with ASD knew about their students' strengths and weaknesses and developed a "structured and flexible learning environment" (p. 7). This is consistent with what **Jason** said, that he appreciated the flexibility to do school work at home where it was quiet.

Students communicated that they had problems with teachers who expressed anger at them. As Saggers et al., (2011) write: by contrast, students related to teachers who related to them; that there was a situation of mutual understanding. Relatedness with their teachers was deemed important by the students, because it allowed them to be understood and their voices to be heard. This is likely consistent with all students, as it was with **Tony's** and **Judy's** experience, that they did not do well with teachers who were "cold", or "didn't seem to care, with a 'sink or swim' attitude".

As Saggers, (2015) states, students wanted support in a way that did not visibly point them as being students with special needs. They described the support as being received in 'subtle ways' in an integrated classroom: The majority of the students' wanted this support delivered in such a way that the teacher went around the classroom to help all the students, and not just the student with ASD.

They also found support for managing personal matters, and developing social skills, as well as support for academic work, beneficial (p. 41).

Diversity of interests and strengths

In Anderson et al.'s, (2018) study, students identified their strengths as "attention to detail (n=35,85.4%) an ability to use technology (n=32, 78.1%), original and creative thoughts, a strong memory (both n=25, 61%) and consistency (n=24, 58.6%)" (p. 654). Hastwell et al., (2012) note that: "in-depth interest, focus and motivation are conducive to academic success and associated with ASD" (p. 59).

The literature affirms the findings in this study that the students have a range of interests and strengths: Chemical Engineering (**Bill** and **Jason**); Computer Engineering (**Tony**); History (**Amelia**); Finance (**Andy**); Business (**Paul**); Physical Education (**Audrey**); Restoration Ecology (**Dave**); Psychology (**Judy** and **Trudy**); **Kent** is thinking about majoring in sociology, criminology, or possibly psychology, with a minor in French; and **Nan** is committed to Nursing, with a minor in Spanish.

In Anderson et al.'s, (2018) study of students in Australia, the academic majors were similarly diverse including Maths, Engineering, Science, IT Computing, Business, Finance, Commerce, Marketing, Law, Arts, Psychology, Education and Linguistics.

Van Hees et al., (2015), in a study from Belgium, had a sample of twenty-three students, whose majors were also as diverse in their fields of study: Health Care, Education, Business Services, Art and History, Politics and Sociology, Law and Criminology, Industry and Technology, and Human Sciences.

Social challenges

Bullying

Bullying is a common problem for children and teen-agers. Self-reported assessments from forty countries, estimate that bullying among children is perpetrated by 11% of children and 13% are victims (Craig et al., 2009). Of those with ASD, bullying in school settings with neurotypical students has been estimated to impact between 46% and 94% of children with ASD. Adams et al., (2013), Carter, (2009), Begeer et al., (2016), Heinrichs, (2003), Little, (2001), define bullying as:

> A subtype of aggressive behaviour in which an individual or group repeatedly and intentionally attacks, humiliates and or excludes someone who has relatively less power, (Olweus, 1993, Salmivalli, 2010). Bullying can either be physical (e.g. pushing), possession directed (e.g. damaging belongings of other children), verbal (e.g. calling names), direct relations (e.g. turning one's back on someone who wants to play). Indirect relational (e.g. gossiping or saying mean things about someone, (Olthof et al., 2011)
>
> or involve harm via electronic devices called web page cyber bullying.

(Kowalski et al., 2014, pp. 562-563), (Humphrey & Symes, 2010), Locke et al., (2010) state: "because of social skills deficits and difficulties in understanding the subtleties and nuances of social interaction, efforts to seek out social engagement with others are not always successful, and may make them easy targets for ridicule" (p. 74). Students may also exhibit repetitive behaviors: flapping, spinning, rocking, or as **Amelia** did tapping, because of her OCD. As a result, a negative response from students and teachers may ensue (Wilczynski, Menousek, Hunter & Mudgal, 2007). The literature confirms the experiences of **Tony**, **Amelia**, **Dave** and **Trudy**.

Disclosure

Similar to the stories of most of the students interviewed, hiding one's ASD is a common theme. Studies have found that students did not disclose their diagnosis in order to avoid discrimination by peers and teaching staff (Humphrey & Lewis, 2008), (McLaughlin & Rafferty, 2014). But like the diversity of being on the spectrum the academic literature is not consistent.

Clarke & Van Amerom, (2008) found that while the parents they interviewed believed ASD to be a neurological disorder that should be cured, the students with ASD were proud of themselves, and saw themselves as neurologically diverse, and not as someone with a disability. Some students accepted their ASD, either as something to celebrate, or as a key part of their identity (Humphrey & Lewis, 2008) or as simply not a problem (McLaughlin & Rafferty, 2014).

Van Hees et al., (2015) interviewed university students about disclosing their being on the autism spectrum. Many students only revealed their ASD when they believed they could not manage the stress, or when they felt safe in doing so, or needed a specific support. Students disclosed their ASD, to the Disability Support Office at a university, to apply for accommodations, but would not disclose to peers or academic staffs. The authors write that this was "mostly due to past negative perceptions and comments, the fear of stigmatization, prejudice, rejection or negative recommendations" (p. 1681). However, in some cases disclosure was found to be beneficial. Eric, age 27, had this to say:

> It was actually a mistake of mine to have difficulties talking about it in the beginning of my university career. Especially not telling professors about it was wrong, because from the moment I disclosed my autism to my supervisor he was able to understand me better. From that moment on he had the patience to allow me to work on my thesis in peace and quiet, at my own pace. I really recommend disclosure to people (p. 1681).

Leon, age 23, another student said: "When I finally made up my mind to stop pretending, an enormous weight fell off my shoulders, because you can stop being who you ought to be, instead you can be who you are" (p. 1681).

Peers

Adults with ASD have participated in a number of qualitative studies and have revealed some striking details about their lives. A large portion of ASD adults, state that their negative social relationships with their peers resulted in them believing they were 'different' (Bagatell, 2007), (Portway & Johnson, 2005), (Punshon et al., 2009). Williams et al., (2019) write that these authors "also identify a link between internalizing the negative attitudes and reactions of others, and the possession of a more negative self-identity exacerbating mental health issues" (p. 9).

In a study by McLaughlin & Rafferty, (2014) they found that some of the participants were not happy with having autism. Ruby said: "I really, don't like it. It's something that you can't change (p. 66). Charles' description of ASD was: "the best of the worst". He talked about how ASD had taken away friendships.

He was upset that he had been given a life that made him distant from his peers. He said: "The arrow pointing to the path you want to go suddenly points in a different way, so that it goes in a different direction" (p. 66).

Van Hees et al., (2015) say about students reluctant to make disclosure, "A lack of knowledge regarding ASD, an ignorance and many types of generalizations about what ASD really is, doubts concerning privacy, a lack of supportive policies and the wish to make a fresh start, were all reasons why students decided not to disclose their diagnosis to their social contacts" (p. 1680).

Empathy

Baron-Cohen (in press) has clarified that people with ASD generally struggle with "cognitive empathy (e.g. imagining other people's thoughts and feelings, including decoding complex facial, vocal, and bodily expressions)." Dziobek et al., (2008) attest, that persons with ASD can have "affective empathy (e.g. feeling concern for other people's suffering"). The literature is scant however, about how it must feel to be classified as someone lacking in empathy, (Hastwell et al., 2012).

Three of the students mentioned empathy as a quality they possessed. **Dave** said he was assisted through his Para-educators, and that developing empathy can be a challenge, due to ASD making someone self-centered. **Amelia** said her friends would describe her as being empathetic, and **Trudy** was originally misdiagnosed as not having ASD because the doctor thought she had empathy. This is obviously a complicated characteristic of people with ASD, but the interviews for this study demonstrate that it is possible to obtain a concern for other people's feelings.

Loneliness

Another characteristic is loneliness. Margalit, (1994) defined it as an unwanted emotion connected with a negative result, and may occur from a wish to have a friend or as Locke et al., (2010) state: “an understanding of the gap between an actual and desired social status, and a lack of affective bonding” (p. 74). (Asher, et al., 1990), (Bauminger & Kasari, 2000), (Peplau & Perlman, 1982).

According to Asher et al., (1990), typically developing (TD) children are motivated by loneliness to initiate social relationships with peers. Locke et al., (2010) write this may be true for young people with ASD, but because of “difficulties in understanding the subtleties and nuances of social interaction” (p. 74), their attempts to initiate connections with their peers may not be successful, resulting instead in bullying and more loneliness, (Bauminger et al., 2003).

Research has demonstrated that some people with ASD report having at least one friend: (Bauminger & Kasari, 2000), (Bauminger, Shulman & Agam, 2003), (Bauminger et al., 2008), (Koning & Magill-Evans, 2001), (Orsmond et al., 2004). There is no consistency however in the research that young people with ASD differ from (TD) students regarding social network affiliations to which a student belongs (Boutot & Bryant, 2005), (Farmer & Farer, 1996). Boutot & Bryant, (2005) found no differences between students with ASD, and those classed as TD.

Students with autism were considered to be members of a definite group, with the same frequency as students without disabilities, (Boutot & Bryant, 2005). Chamberlain et al., (2007) report: “students with autism are often on the periphery of their classroom social structure, and tend to associate with a small group of other students". Locke et al., (2010) (p. 76) write that this research suggests that students with ASD in classrooms are able to establish social relationships with their peers.

Locke et al., (2010) examined twenty adolescents, seven with autism and thirteen TD peers. All were students in a drama class at an integrated secondary school in the Los Angeles area. The research demonstrated that adolescents with ASD experienced significantly more loneliness than their TD peers, "had significantly poorer friendship quality in companionship and helpfulness, and had significantly lower social network status than their TD classmates" (p. 74). In addition, 92.4% of TD adolescents "had secondary or nuclear social network centrality, which means that those adolescents were significantly connected and recognized in their classroom social structure, although 71.4% of the adolescents with autism, were either isolated or peripheral in their classroom" (p. 74).

The authors write:

> These findings imply that although inclusion in regular classrooms may allow adolescents with autism to be involved in the social structure of their classroom, they experienced more loneliness, poorer friendship quality and social network status as compared with their classmates. These results suggest that, perhaps more intensive social skills interventions that focus on friendship development are needed in adolescents with autism (p. 74).

For **Judy** and **Tony**, interviewed for this study, they had friends, but none were at the school they attended. They were both capable of making friends, but it seemed not in the school setting. **Audrey**, like Locke et al., (2010), said that schools could do more to help students with ASD develop friendships at school.

Masquerading

Young people with autism can sacrifice their identity, by trying to build friendships and acceptance by their peers (Hill, 2014), (Humphrey & Lewis, 2008), (Carrington & Graham, 2001). Williams et al., (2019) write: that some students observe and copy the behavior of their peers to blend in and be accepted, which results in "considerable stress and anxiety".

Baines, (2012), Carrington et al., (2003), Humphrey & Lewis, (2008), McLaughlin & Rafferty, (2014) (p. 17) Williams et al., (2019) note: "The behavior is termed 'passing as normal' in the wider disability literature, where it refers to concealing social marks of impairment to avoid the stigma of disability, often with considerable psychological and emotional cost." (Brune & Wilson, 2013) (p.18).

Van Hees et al., (2015) found that students with autism articulated a clear need for friendships and relationships. By observing social situations they created an "array of scripts" (p. 1679) that allowed them to react appropriately in various interactions. As Leon age 23, an autistic student in their study said:

> I just keep thinking how to react in social situations. I taught myself the art of small talk; you see other people, you read books, you watch movies. You just look at what people do in a situation, and you adopt it, you act in the same way. But it was not really 'me' in the beginning, I felt as if I was just "doing anything". But after some time it became a thing of my own (p. 1679).

Hastwell et al., (2012) have noted “The convention of imitating neurotypical (NT) behavior in order to fit in is increasingly contested by people with ASD” (p. 59) (Beardon, et al., 2009). **Amelia** shared when explaining how her autism came to be diagnosed, about imitating her friends and how they talked.

The students, who commented about masquerading, seem to have come to terms with it as a form of developing social skills. **Judy** noted how everyone seems to masquerade in social situations, and not just persons with autism. She provided the example of talking with her father about the Chicago Cubs baseball team, because that is what interests him. One could argue that this is not a situation of persons with autism abandoning their identities, but simply becoming socially skilled. As **Dave** commented: “It was like a mask that I wore, and gradually over time, I became less at masking. I realized, it was just a part of myself that had been growing and cultivating, and so masking wasn’t a good analogy anymore”.

Diagnosis

For positive behavioral and cognitive outcomes, early diagnosis and intervention is seen as critical. The diagnosis of autism, increased dramatically during the 1990’s and early 2000’s, with children being diagnosed at an earlier age (Fountain, King & Bearman, 2011). The literature states that while in the recent past children may not have received a diagnosis until they entered school, they are now more likely to be diagnosed in the preschool years (Rutter, 2006). The increased knowledge about autism among parents, physicians and teachers, widespread screening, and the belief that early treatment is associated with better outcomes for children, all probably play a role in both increased and earlier diagnosis (Fountain, King & Bearman, 2011).

However, the age of diagnosis has not declined for all children, and previous research suggests that factors such as sex, race, access to health care and severity of symptoms are associated with the age of diagnosis (Shattuck, Durkin, Maenner et al., 2009), (Wiggins A. S., & Baio, R., 2006). A recent study of a larger sample of U. S. children born in 1994, found that being male, having a low IQ and developmental regressions were associated with earlier diagnosis (Shattuck, Durkin, Maenner et al., 2009). Many students, who meet the criteria for ASD, are never diagnosed, or not until years after first symptoms develop (Mandell et al., 2007). Hastwell et al., (2012), write: "it is well established that in the adult population, autism is often missed" (p. 57). Davidovitch et al., (2015) found in their study that late diagnosis, after an initial ASD negative comprehensive assessment, is very common. They suggest the following reasons for the diagnosis being missed:

> First, the presence of other developmental concerns or diagnoses may have masked or overshadowed an ASD diagnosis. Many children were diagnosed initially with developmental language disorders and motor difficulties, and almost half the sample was diagnosed with ADHD features and behavior problems. Second, the child's presentation changed or evolved, and the ASD criteria were truly met at a later age, after not having been present at an earlier age. This may reflect an evolving diagnostic picture in some children with later diagnoses of ASD, and possibly even a unique phenotype of ASD

> that arises because of developmental processes. It is feasible that as children age social demands increase, and social and pragmatic deficits become more obvious and lead to an ASD diagnosis, as is being proposed in DSM-5 criteria. Third, features of ASD could have been overlooked during evaluations, and the diagnosis missed at early ages. Late diagnoses may have been assigned to “borderline” or otherwise developmentally complex children, despite previous documentation refuting an ASD diagnosis. Put in another way, ASD is being over-diagnosed at later evaluations (p. 232).

This explanation is consistent with the findings, because for the majority of the cohort, no initial ASD suggested features were noted through the age of 6. One reason for the over-diagnosis could be the increased treatment benefits for children with ASD. The combination of increased benefits in addition to the increased awareness may cause providers to feel pressure from families to assign ASD to borderline cases.

A second possible reason for over-diagnosis is the lack of reliance on formal assessments, despite recommended guidelines (p. 232). The authors, note in their literature review, that the most consistent findings were that children with autism tended to be diagnosed at younger ages than those with high functioning autism, presumably because of lack of language delay and or milder features. Additionally, children with greater symptom severity tend to be diagnosed earlier, as did children from families of higher socioeconomic status.

Fountain et al., (2011) found that children with highly educated parents are diagnosed earlier, and this effect has strengthened over time. They write: "There is a persistent gap in the age of diagnosis between high and low socioeconomic status children (SES) that have shrunk but not disappeared over time". The authors call for routine screening for autism in early childhood for all children, particularly those of low SES, as they see this as being necessary to eliminate disparities in early intervention.

Despite the literature indicating that many students are diagnosed in pre-school, this was only the case for **Bill** and **Kent**, who were diagnosed at two. **Bill** was identified almost by luck. His brother was born prematurely with many health problems and watched closely by doctors. They noticed issues consistent with autism present in **Bill**, so he was diagnosed early. The other exception is **Dave**, who was diagnosed at four or five. The rest of the cohort were diagnosed at nine for **Trudy**, and then only as early as grade six, with many diagnosed after high school. Social economic status did not seem to be relevant in terms of being diagnosed earlier. **Kent** and **Bill** come from middle class families. **Jason** comes from a family of two university professors, who played no role in his identification of autism, as he diagnosed himself. Similarly, **Paul** comes from an upper middle class family but was recently diagnosed at age nineteen. **Amelia** comes from a middle class family but was diagnosed at eighteen. Many of the students had other disorders, which may have masked their autism such as Obsessive-Compulsive Disorder, Attention Deficit Disorder, Attention Deficit Hyperactive Disorder, depression and anxiety.

Transitional challenges

Transitioning from one activity to another is a challenge for children with autism, (Marks et al., 2003). These obstacles may be due to the unpredictability of a new situation, a wish to continue a previous activity or avoid new responsibilities, (Davis, Reichle & Southard, 2000), (Earles, Carlson & Bock, 1998), (Marks et al., 2003), (Volkmar, 1996). Transitions can result in aggressive behaviour, opposing teachers and crying, (Schreibman, Whalen & Stahemer, 2000). **Tony**, interviewed for this study, mentioned crying, when unable to cope with not being able to open his locker in the first week of middle school.

Elementary to middle school

Draper Rodriguez et al., (2017) surveyed teachers about current transition practices for developmentally delayed identified students (including students with autism) transitioning from elementary to middle school. Fifty-seven teachers responded to the on-line survey questions from three U. S. states. The majority of the teachers stressed the importance of students learning to communicate and develop "functional and personal skills, related independence, developing and maintaining friendships, and working co-operatively". (Draper Rodriguez et al., 2017, p. 16). They believed these competencies would be necessary in middle school where pupils have multiple teachers and interact more with fellow students than in primary school. For example, one teacher stated, "Since students have less contact with and support from a single teacher in middle school, they need to learn strategies for coping with increased academic demands from multiple teachers and the skills of how to work cooperatively with their peers" (p. 16). Five respondents mentioned self-advocacy. Activities involved having students attend the meetings for their Individualized Education Plans (IEP) learning how to advocate for their special needs. In the U. S. students with disabilities who require accommodations have these needs written out in their IEP.

Elementary schools helped the students by practicing middle school routines such as moving from classroom to classroom and other activities students are involved with, such as school visits, students meeting with middle school staff, peer mentoring and parent programs. One respondent viewed school visits as an important part of the process: planning is enhanced by class visits and a tour of new campuses in late May/first week in June for a maximum of one day; the transition meeting is held in April (Draper Rodriguez et al., 2017, p. 17).

While transition planning may be beneficial to students who have already been identified with ASD, **Andy** and **Tony** were not yet diagnosed when they entered middle school. **Andy** would soon learn about his ASD in the sixth grade, but for **Tony** it would take until after high school, being diagnosed at age eighteen. Their experiences were consistent with the literature that transitions are difficult for students with ASD. **Jason** on the other hand felt that the transition was fine. He was academically focused, so the emphasis on academic skills in middle school, rather than social skills of primary school was more accommodating to him.

Middle to high school

Hebron, (2018) writes that at the time of her publication only nine studies focused on the transition for students with ASD from middle school (primary referred to in her study) to secondary school. All of the studies were done in the United Kingdom, with the exception of the Tso and Strnadova study, from Australia.

Hebron, (2018) found a number of themes emerged. She discovered that the transition for ASD students appeared to be similar to their TD peers including: adapting to new organizational/structural demands; understanding the expectations of multiple subject staff (e.g. Coles, 2014); anxieties about forming relationships with a new peer group (Peters & Brooks, 2016).

Hebron, (2018) writes that what may be different about the experience of young people with autism, is that they may face these pressures at a greater level than their peers, requiring more training to prepare for the transition (Dann, 2011). A key theme from the research is the "social aspect of transition, including psychosocial adjustment" (Hebron, 2018, p. 399). Support of peers and friendship resulted in a more positive transition (Dillon & Underwood, 2012), while poor social relationships were correlated with a more negative experience.

Findings are inconsistent regarding the extent to which anxiety may be increased for students with ASD during transition. Hannah & Topping, (2012) found no such patterns of anxiety during transition, while Peters & Brooks, (2016) discovered the presence of anxiety during periods that were unstructured. Mandy, Baykner, Staunton, Hellriegel et al., (2016) found no significant change in difficulties of students across transition, "although they found high and frequently undiagnosed mental illness present at primary school that continued during the transition".

Hebron, (2018) hypothesised that if students with ASD experience more problems with transition than their TD peers then “promoting school connectedness during this period may have substantial benefits for the future education and well-being of this group of young people.” Goodenow, (1993) defined school connectedness as “the extent to which students feel personally accepted, respected, included and supported by others in the school social environment” (p. 80). Hebron, (2018) discovered that: students with ASD reported positive levels of school connectedness across transition, although their scores remained lower than those of typically developing peers. The gap between the two groups narrowed significantly during the first year, with students in the ASD group reporting improving levels of school connectedness, although there were non-significant signs of a decline for both groups in the second year. She concluded that the transition from primary to secondary school could be positive for students with ASD (p. 396). However, she emphasized the need for ongoing monitoring and support for such students due to the lower level of school connectedness compared to TD students.

Neal & Frederickson, (2016) conducted a qualitative exploration of the perspectives of six children with ASD, who had recently transitioned successfully. The findings indicate that the transition can be a positive experience for children with ASD. Despite these commonalities, experiences varied and it was evident that children benefited from individualized support tailored to their specific needs.

The transition from middle school to high school for the students participating in this study is generally consistent with the academic literature.

Andy, **Jason** and **Paul** found the transition to be smooth. **Audrey** and **Bill** struggled at first; then adjusted. There were still challenges for **Judy**, **Trudy** and **Nan**, citing the need as Neal & Frederickson, (2016) noted, that support should be given to ASD students to accommodate to their individual needs. With particular reference to **Nan**, Draper Rodriguez et al., (2017) note that she would have benefitted from transition planning with the support of her mother. It is a widely recognized evidence-based practice; students with disabilities are not typically involved in this process (Shogren & Plotner, 2012). This is a troubling outcome, given that active involvement in the transition process allows for the development of self-determination and self-advocacy skills (Van Laarhoven-Myers, Van Laarhoven, Smith, Johnson & Olson, 2014) and is correlated with improved post-school outcomes, such as employment, community living, post-secondary education participation, and quality of life (Van Larrhoven-Myers et al., 2014) (pp. 3-4). Draper Rodriguez et al., (2017) add: There are a number, of transition planning curricula available, such as *Whose Future is it Anyway?* (Wehmeyer, Palmer, Lee, Williams-Diehm & Shogren, 2011), that support students in building self-determination skills and being involved in transition planning,

Family involvement in the transition process is equally important, and associated with positive post-school outcomes of students with disabilities (Smith, McDougall & Edelin-Smith, 2006) (p. 4). Again, the problem is that if such supports were only offered to students identified with ASD, people like **Nan**, diagnosed at seventeen, would not have received the needed supports.

Social skills

Dave and **Andy's** experience of spending time with adults such as those working in the library and history teachers is also consistent with the academic literature. A possible reason for this is to avoid conflict with other students due to a lack of social skills. This may be the reason why **Dave** spent much time in the library, yet **Andy**, who hung out with his history teachers, seemed to make friends in high school. Wainscot et al., (2008) found that students with ASD mostly spend break times in school classrooms or the library. Tobias, (2009) discovered that students chose to escape to quiet places to avoid noise and feel secure. Landor & Perepa, (2017) state that: "Both studies indicate that students prefer to spend unstructured times in a safe, quiet environment which can be considered by some as contrary to the aim of social inclusion" (p. 131).

Life skills

Chiang et al., (2017) examined the extent to which life skills were offered to middle and high school students with ASD. Life skills are "the skills required for daily life in the community" (Dever, 1988, p. 7). Chiang et. al., (2017) write that life skills include "self-care and domestic living, recreation and leisure, social interaction, employment and community participation" (Clark et al., 1994) (p. 113).

Chiang et al., (2017) conducted a second analysis of the National Longitudinal Training Study-2 (NLTS-2). They found that most of the middle and high school students with autism (77.4%) had received life skills training. It varied between students with ASD, with and without an intellectual disability ID.

ASD students who did not have an (ID), were less likely to receive life skills training. Yet Szatmari et al., (2009) found even if high functioning, the adaptive skills of people with ASD were generally below their cognitive abilities. Chiang et al., (2017) concluded that even high functioning persons were in need of life skills training.

High school to college

Kidwell, (2005) referred to the first year as often a struggle for students with ASD not due to a lack of intellect, but away from family and friends, and getting used to the routines of being a college student. Alverson et al., (2019) note that this transition can be incapacitating for persons with ASD, who struggle with communication and social skills, as well as sensory and organizational problems.

Roberts, (2010) writes that success in post-secondary education for students with autism may require substantial planning and ongoing support because of social challenges. Browning, Osborne, & Reed, (2009) state that the transition from high school to post secondary education leaves many students without adequate assistance, and that this might be because of the lack of a good transition plan.

Alverson et al., (2019) looked at the high school to college transitions of young adults diagnosed with ASD. They defined transition planning as including support for taking entrance exams, completing applications, applying for financial aid, assistance with social skills, communication and executive functioning. The researchers used a family questionnaire, review of special education records, and multiple individual interviews (N=27) with young adults, teachers, family members, and rehabilitation counsellors. The authors found that issues with social skills, communication, and executive functioning persisted into post-secondary education. Alverson et al., (2019) found that the four students, who were most successful in college, had an awareness of their disability beyond simply being able to describe it:

> Participants with the most awareness understood the influence of ASD on their academic and functional skills. They provided descriptions of challenging situations, and strategies they used to function effectively (e.g. keeping a daily schedule, using email to communicate with professors).

These traits are consistent with previous literature describing "highly successful" adults with physical and learning disabilities (Gerber, Ginsberg & Reiff, 1992, Noonan et al., 2004) who displayed the ability to accept their disabilities and work in environments that maximized their strengths (p. 61).

Doren, Gau & Lindstrom, (2012) noted a strong relationship between active parental involvement, and high parent expectations for educational attainment for youth with disabilities. Alverson et al., (2019), found different parental involvement during the transition to college for students with ASD. Of the five families in the study, two expected their children to make decisions on their own at the age of eighteen, including applications, registration and financial processes. Alverson et al., (2019) discovered that two families took a middle ground between expecting total independence and controlling each step of the process. They facilitated their sons' independence by encouraging them to complete tasks independently, thereby developing the skills and confidence to navigate the college achievement (p. 61). The two participants who took part in transition services through their secondary schools, had more focused post-school goals, and were more able in addressing the challenges of post-secondary education (p. 62). Although their programs differed, these high schools had a co-ordinated set of transition services designed to explore options and complete the process of entrance exams and systematic opportunity to explore and develop post-school goals aligned with their interests. Two students developed career goals and a plan for meeting these goals. In both cases the defined interests associated with ASD were perceived as strengths; and became a launching point for post-school planning and ultimately post-secondary education (p. 62).

None of the students interviewed for this study mentioned receiving any transition planning. Most said they could have benefitted from more assistance with social skills. For those students diagnosed from a younger age **Audrey**, **Bill**, **Dave**, **Judy**, **Kent** and **Trudy** this awareness did not make much of a difference in their transition, they all faced problems with social skills and executive function. **Dave** mentioned the role the school could have played in helping him prepare college applications, and being aware of schools that were good at accommodating students with ASD. He seems to have the greatest awareness of his identity, and was well prepared to cope with it. His ASD maturity likely comes from being older, and addressing the challenges he faced with autism. This awareness, it seems would make a difference for anyone with ASD, who takes steps to address their condition.

However, **Bill** and **Judy**, who probably received the most support, still face struggles, implying that high school could, and should have done more to prepare them for post-secondary education.

Cultural challenges

Mandell & Novak, (2005) discuss the role that culture plays in treatment decisions for children with autism. They write:

> The meaning parents attach to their children's symptoms and their beliefs about the symptoms' causes, prognosis, and most appropriate courses of care can be described within the context of culture. Culture is often defined as a group of people's way of life, consisting of predictable patterns of values, beliefs, attitudes, and behaviors. These patterns are learned and passed from generation to generation to generation (Kakai et al., 2003). Since cultural factors are intertwined with thoughts and behaviors, they may assume a major role in the way families address deviations in their children's development (Pachter & Harwood, 1996) (p. 110).

Lau et al., (2004) discovered that Asian/Pacific and African-American parents were more likely to disagree with teachers than white parents that their children's behavior represented some type of disorder. They in addition to Latino parents were less likely to recognize personality, family issues, or trauma as cause of children's problems (Yeh et al., 2004). Mandell & Novak, (2005) cite (Bussing et al., 1998) who postulated, that ethnic minorities, are less likely to "view symptoms as related to a health condition," and less likely to access medical care (p. 112).

Zuckerman et al., (2014) note that Latino children are diagnosed with autism at older ages and at the onset of more severe symptoms. The authors conducted five focus groups and four qualitative interviews with thirty-three parents of Latino children diagnosed with ASD. Participants described the perceptions and barriers they experienced during the diagnostic process. The authors concluded that:

> Perhaps the most important message for providers to understand is that many Latino parents operate in an environment poor in ASD information, high in messages that their child's behavior is normal, and high in feelings of embarrassment and shame about disability and mental health issues. If a Latino parent discloses a concern about ASD, providers should address this concern with seriousness and sensitivity, because it may have taken a great deal of effort for the parents to raise it. In addition, parents may not know even basic information about ASD, and may not be able to navigate the ASD diagnostic process without significant assistance from providers (p. 306).

These findings were consistent with the interviews with **Nan** whose background is Hispanic/African-American, and **Tony**, who is of Chinese descent. Their families found it difficult to believe that cognitive or mental health problems were really medical issues. Despite the potential barriers to treatment both **Nan** and **Tony** were diagnosed, and receive treatment from their university's disability services. **Nan** also sees a therapist for her mental health issues. When interviewed, **Tony** said he didn't have time to see a therapist. Knott & Taylor, (2014) found that many university students didn't access supports because of being too stressed.

Welterlin & LaRue, (2007) note that under the *Individuals with Disabilities Education Act* students with disabilities are entitled to free services to accommodate their disability. **Nan** believes she was not diagnosed sooner than her late teens because she was enrolled in a private school. Welterlin & LaRue, (2007) note that: "Some families may not be aware of these services and may not enrol their disabled child in the public education system" (p. 755). Late diagnosis is an issue with Latino children (Fountain et al., 2011) and (Valicenti-McDermott et al., 2012).

Health challenges

The students interviewed also experienced conditions such as:

OCD (**Amelia**), ADD (**Nan),** ADHD (**Audrey**, **Judy**, **Paul**, **Tony**), depression (**Audrey**, **Bill**, **Judy**, **Nan**), anxiety (**Audrey**, **Bill**, **Dave**, **Jason**, **Judy**, **Nan**), anger issues (**Andy)** and technology addiction (**Andy)** and (**Dave**).

Kohane et al., (2012), used electronic health records to compare the co-morbid conditions of children and young adults with ASD with the general population. Three general hospitals and one paediatric hospital participated. Over 14,000 individuals under the age of 35 were examined. The authors concluded:

> Through this study, across multiple health care systems with over 14,000 patients with ASD, we have been able to corroborate with a few notable exceptions, that the burden of co-morbidity is substantial across multiple health care systems, with over 10 percent of patients with ASD having bowel disorders or epilepsy, over 5% with CNS or cranial anomalies, and over 2% with schizophrenia. With regard to schizophrenia, although the 2% was high relative to the general hospital population study, there is a broader controversy of whether or not the population prevalence is 55 or lower.

With the exception of **Bill**, who suffered from Crohn's disease, and **Dave**, who coped with epilepsy until his teen years, the above co-morbid disorders are different from those experienced by the students interviewed. A likely reason is that the persons with ASD in the study were hospitalized, whereas the students in this study, except for **Andy**, who had been suicidal, did not require hospitalization.

Carrington & Graham, (2001) found that students faced depression and stress due to being unable to navigate social situations. A number of researchers have discussed ASD students having greater amounts of anxiety and stress than others (Green, Gilchrist, Burton & Cox, 2000, Humphrey & Lewis, 2008, Kim, Szatmari, Bryson, Steiner & Wilson, 2000 Sofronoff, Attwood & Hinton, 2005). In addition to issues of specific learning abilities, Humphrey & Lewis, (2008) found the school environment as a "considerable source of anxiety" (p. 37) (Saggers, 2011). Noisy classrooms can cause extreme levels of anxiety, which in comparison with TD students, can disable their ability to function (Wood & Gadow, 2010). Attwood, (2006) found that anxiety and depression are most common among students with ASD due to "ambiguity, unpredictable change, bullying, humiliation and loneliness" (Cambridge Study). Attwood, (2006) notes that about 25% of adults with ASD have clear signs of Obsessive Compulsive Disorder and about one in three children and adults have a clinical depression (p. 170).

These characteristics are all consistent with the research participants interviewed. In Dillon et al., (2016) the authors interviewed high school students in the United Kingdom who had anger issues similar to **Andy**, who was interviewed in this study. Some of the students in the Dillon study made the following comments:

"I'm getting more angry now than I was in year 6. An even now it could start to get worse. I'm concerned". Another student said, "I just argue back, I don't know why". Another said, "I try to count to ten, but people still annoy me, and that's when I start to throw things" (p. 225).

Andy admitted having a technology addiction; **Dave** spoke about spending excessive time on his computer. Dillon et al., (2016) interviewed students who escaped into playing on their computer; it served as a distraction from doing homework. One student remarked: "I don't like doing my homework at home cause I'm on my Xbox". Another said: "I don't do homework, I play computer!" (p. 227).

> Furthermore, Dillon et al., (2016) write: That playing computer games can offer students with autism a source of relaxation after a day working within the school environment, which can be unpredictable at times. This is also true for other students, and is supported by a comment from one of the students without autism: "I like playing on the computer to relax" (p. 227).

Dickel, (2014) notes that: some of the most challenging students are those who have ASD in the more moderate range of severity, but who also have multiple other psychiatric disorders such as depression, bipolar mood disorder, ADD, ADHD, Obsessive Compulsive Disorder, panic disorder and so on. If these students are in categorical special education programs, they may be placed in the Emotional disturbance category, rather than in the Autism Spectrum category. Given the dramatic symptoms of these other problems the ASD may not be obvious. However, it is important to recognize that this disorder has unique characteristics that can interfere with a student's educational progress and social-emotional functioning in ways that other mental health disorders do not (p. 115). This relates to the point in the section on late diagnosis, that many students with co-morbid disabilities may not be diagnosed with ASD, because it is masked by other health conditions.

Sensory issues

Taste and touch

In Hastwell et al.'s, (2012) study of Cambridge University students with ASD, the authors found one student to say: "Taste and smell sensitivity cause nutritional issues" (p. 60). This was the situation for **Tony** when he remarked what people should know about students with ASD. Another student said: "I don't like people touching me" (p. 60). **Judy** in this study said, she did not like people hugging her.

Noise

The noisy and chaotic environment of secondary school and university can cause "sensory overload for ASD students (Pinder-Amaker, 2014), (Anderson et al., 2018). This was the situation for **Bill**, as well as **Jason**, who had problems doing work at school, due to the noisy environment, and also **Audrey**, who found classes of 25-30 distracting.

Eye contact

Unusual eye contact is also found in the academic literature as an issue for students with ASD, (Beardon, et al., 2009). Attwood, (2006) writes:

> People who have ASD have two problems, in using information from the eyes to determine what someone is thinking and feeling. First, they tend not to

> look at the eyes as the dominant source of information regarding social/emotional communication, and second, they are not very good at reading the eyes they do look at (p. 115). In other words, if they do look at someone's eyes, they are not able to ascertain the emotions of the person.

Dave in the current study said: that even though he was diagnosed with HFA he still could not look people in the eyes. **Amelia** when making presentations found it hard to make eye contact with people because she "could hear what they were thinking".

Conclusion

Considering the academic, social, transitional, physical, cultural and health challenges that persons with high functioning autism face, in addition to the stigma, bullying, discrimination and lack of empathy they receive, it is no wonder that the word "overwhelming" is often on their minds and lips. It is one thing for the researchers to describe the hurdles they face, but a different thing to listen to the voices of those who live with it.

Dave, in this study, diagnosed with ADHD and autism when he was four or five, living with epilepsy until he was thirteen, suffering with severe anxiety with poor grades in high school, now a graduate student and a teaching assistant, planning a career in restorative ecology said: "I've been described as a success story by people who knew me as a child". It is no wonder. Yet, it is a wonder.

Andy, bullied so badly for the color of his skin, hospitalized at one time and put on watch for considering suicide, stuttering, says: You have to evolve, you have to adapt, it's like, it's like, and it's like the animal kingdom. If you put a species of an animal in a different environment, than what the animal is used to; it either grows or diminishes, adapts or dies. It’s kind of like that in a similar sense, it’s like you put us in a different environment, you give us different expectations, and we’re either going to adapt or grow, be challenged, or give up and not do anything. Right? Yeah!

CHAPTER VI

SUPPORTS

It is critical that students with ASD, high functioning not withstanding, have a good support system in place, whether family, caregivers, or other advocates. Part of the support will come from professionals, and it begins with a diagnosis.

In this chapter the students will tell their stories about when, and how they were diagnosed, and the therapy and accommodations they were granted. They will share how they received help from caring peers; and from teachers, who recognized their special interests, encouraging them to excel and get good grades.

The chapter continues with the need to raise awareness of what autism is, the difficulties attached to disclosure, and a discussion about sensory issues and environmental considerations. At the end of the chapter there will be an Analysis, which will relate what the students have said, with that in the research literature.

Early diagnosis

Bill said: I realize that the main reason I was able to succeed so well in school, was due to the fact that I was diagnosed at a very early age, and was able to get assistance for anything I required. If I hadn't been, I don't think I would have performed nearly as well socially and academically. If students have autism, it's important that people look for symptoms and get diagnosed early, and if not get help as soon as they can.

Therapy

Of the eight students who responded to the question about therapy, two were diagnosed when they were two, and began therapy; three were diagnosed in the sixth grade; one was diagnosed when she was seventeen, and two just recently. **Amelia** and **Kent** were diagnosed when they were two.

> **Amelia** says: I went to therapy for obsessive-compulsive disorder, and exposure response therapy, and that helped.
>
> **Kent** shares: I've been given occupational therapy, speech therapy, and was on medication for a few years, but stopped. It's sort of helped me to cope in different ways, but I haven't needed as much up to this point. I've just been getting school academic and other emotional support.

Andy, **Audrey** and **Judy** were diagnosed in the sixth grade.

> **Andy** who shared earlier about his anger and mood swings, says: In my second year of high school, I finally started seeing a life coach to help me understand my emotions, and it helped 90% of the time. I tried meditation, I tried living a healthy life style, I tried doing a lot of things that people say reduced stress, reduced anger, reduced anxiety; and I started implementing that in my life. Seeing a psychologist, trying to release all that excess emotion and stress helped me immensely: and I'm eternally grateful for those people.
>
> **Audrey** said she talked to therapists around the time she got diagnosed: Throughout high school, I tried to maintain talking with someone, just to get it out and explaining things. I've never had medication.

Judy's treatment was complex: I've seen probably over a dozen different people. They tried a lot of different things, like the standard talking therapy type of things. They tried DBT (Dialectical Behavioral Therapy) and they might have tried CBT (Cognitive Behavioral Therapy). Um, and I met with different people who specialized in autism. We met with someone who was prescribing me medication. It was working well enough and we didn't want to mess with it, because it might not work as well. I take medication for a number of things: there's an antidepressant, um, some kind of anxiety pills.

A lot of trouble I had been having, by seeing a therapist weekly, was that if something were to happen, there would be an incident that we needed to discuss. When I get upset, my memory doesn't work as well, so something would happen, and my parents would want me to talk to the therapist, and I just wouldn't remember enough of how I felt, or other people felt, and like what was said, to benefit from processing it that far into the future.

When I was a sophomore in high school, my parents sent me to a residential treatment center in Utah, which specializes in autism and similar disorders. I was there for about eleven months. I hated it, but it helped a lot. There were people who could be stopping things before they got really bad, because there were like trained people on site all the time. We had individual therapy once a week and biweekly group therapy sessions. I didn't understand the point of biweekly group therapy. I don't think those helped me at all.

> **Nan** was diagnosed when she was seventeen. She said: The only treatment I had was talking about the challenges and difficulties that I face, and then my therapist would tell me, Oh, you know, you should start doing this, or you can work on that. So just like, yeah, just to help me communicate and socialize. And then lately I finally saw a psychiatrist, and that was originally for ADD, but then as I told her that I had autism, she prescribed these medications for irritability and like socializing when it comes to autism.
>
> I haven't seen any changes, if anything they just make you gain weight.
>
> My therapist encourages me to get out of my comfort zone and speak up for myself, um, to socialize with friends, but like Nah. Um, yeah, okay.

Jason and **Paul** have recently been diagnosed.

> **Jason** says: I'm going to therapy sessions. And I still have medication to treat my anxiety. The therapy sessions are for autism. Well you know, they are generally for, how to cope with mental problems. And the therapist is aware that I have this condition, and frames things with that in mind, honestly, I don't know what it has to do about autism.
>
> And **Paul**: I haven't done much one on one therapy yet. The fact that I was diagnosed with autism explains things a little bit why I might not be that social of a person, but I just kind of accepted that as the kind of way that I am.

Accommodations

Myers, (2019), writes: Our culture puts labels on people, assigning them "numbers, goals and objectives". This is particularly true in the educational system, where students with disabilities are measured more than other students. They are reported on, and always listed as being deficient, or different in some way. It is done so that they can qualify for services, to satisfy some specific need (p. 87).

Amelia and **Bill** were given accommodations for health reasons.

Amelia says: One of my accommodations was that I could raise my hand and I could go to the bathroom, there wasn't as much pressure on me to have to go when the hallways were crowded and people were in the stalls. I would have all these tests. There was enough time that you could complete them, but if you took a bathroom break, you wouldn't have time, so having time and a half, allowed me, so that was all.

Bill who has Crohn's disease explains: I was able to use the bathroom multiple times if I had a flare up.

Judy mentioned earlier, that her parents had to argue with the school board, in order to get the help she needed, because she had been diagnosed with Asperger's when the laws only provided supports for those with autism.

Andy almost sounds defensive, for the reasons why he should have an IEP: You have to understand that what I call the normal people, are a lot different from people with special abilities. The words special abilities mean something: people who have enhanced memory skills, writing skills, and analytical skills, people who can do better. It takes longer for them to learn, but they can do it at a level that's unheard of; and it takes time, patience, and a lot of hard work. So in terms of a normal student receiving the same

> amount of attention as a person with an IEP, I would say a person with an IEP, should receive more attention, because you have somebody, who uses his or her special skills to the fullest advantage.

Then in gratitude he says:

> I had a case manager in high school that prepared me for college by being on top of assignments, showing up for meetings, getting involved, doing things a student should be doing. My IEP was giving me accommodations for testing, and extra time when I needed it.
>
> **Judy** says: I was in this sort of a study hall that was supposed to help me be a more effective student. It wasn't specifically for people with autism. I did get time and a half on tests, and I had the option to take them on my own. We had something in my IEP, that if I was getting really upset, I could just go for a walk around the school, and then come back, that was helpful.

Nan and **Audrey** had contrasting experiences. **Nan** had a negative experience, which may have been due to the fact that she was the most in need: there was never enough time to write the exams. **Audrey** reflecting on her more positive experience recognizes that she was much more proactive:

> I would sit in front of the class instead of in the back, and the teachers knew that I was paying attention. If I asked I would get a presentation or a Power Point or anything like that. I would get a note copy from the teacher instead of having to take my own notes, for tests I would get extra time, or if I did poorly they would allow me to retake it.

Advocates

All of the students recognized that having an advocate was advantageous to their success at each stage of their schooling. For **Nan** and **Tony** their mother was the primary advocate; for **Paul** it is his father, **Jason** is his own advocate, while **Audrey** was unable to articulate whether she had an advocate or not, and the other seven people indicated that both parents made for effective advocacy.

> **Andy** said: I struggled a lot, but my parents, if they know one thing, Asians value education, like there's nothing else there . . . they trained me to work hard for the things today that I love. So I, I, I credit my parent's help for being there when I needed them . . . and they, they know their stuff.
>
> **Bill** said: My family supported me and encouraged me to do my best. They taught me extra stuff whenever I needed it. I had good manners and they saw to it that I was socially acceptable to everyone, and I'm grateful to them.
>
> **Dave** says: My parents advocated for me. They helped to change the school board, and ensure that other students like me, got more resources. So it's one of the reasons why I want to be more like that kind of person, because I saw it modeled by my family.
>
> **Judy** shared: My parents' put a lot of time and money into doing everything they could for me. Um, they paid out of pocket ready to go to a program in Utah, which was extremely expensive. But they've always seen things like that, as investing in my future, and they're caring, which is great.
>
> **Amelia**, **Kent** and **Trudy** said it was their parents.

School advocates

> **Andy** credits his case manager: He was someone who helped me with a lot of problems, like navigating class, and how to talk to certain people.

Others were not so positive about their experiences with school advocates.

> **Dave** had this to say: It didn't feel to me like the special education people were advocates in any way. I felt really abandoned in junior high. In high school, I feel like the library staff, were advocates. They were very close at the time and probably still are to the LGBTQ community. And although I'm predominantly straight, I think they saw me as someone who also struggled, and they connected to me, cause the library was a real safe space for a lot of people, especially people who felt marginalized.
>
> **Judy** said: School districts were not very great for me. Um, I guess they didn't know what to do, so I wouldn't say school was helpful, but the therapy was.
>
> And **Trudy** said: The IEP in some ways tried to be helpful, but at the same time they can also be kind of obstructive and condescending and stuff.

Advocating for oneself

The majority of the students seemed comfortable advocating for themselves.

> **Amelia** felt that she had gotten much better at self-advocating.
>
> **Bill** said: I've learned to be better at building relationships. That way if I need to ask for accommodations that aren't explicitly in my letter, the teachers will be much more ready to grant them, than if they didn't know me.
>
> **Dave** comments that he has become good at reaching out, but wasn't always:

> It took a long time to get to that point. That wasn't because of my parents. It was because of that unspoken attitude and cultural norm you shouldn't ask for help, you should deal with that on your own, and I took that to heart. Luckily the wall to seeking help was much thinner and shorter than it could have been. The reason for that is, because I had the help earlier with the Para-educators for my autism. That made it easier, to break through those barriers. I still got a hell of a lot of bad grades before I did that, but I did it.

Judy, **Kent** and **Tony** found it quite easy to ask for help.

> **Judy** said: If I know what I need, I tell someone.
>
> **Kent** said: I have no difficulty seeking support when I need it.
>
> **Tony** said: If I have a certain difficulty, I talk to the teacher about it.

Nan and **Trudy** aren't so certain about advocating for themselves.

> **Nan** says: My therapist tells me I have to get out of my comfort zone, speak up, and advocate for myself, and express what I am feeling. Unfortunately it always backfires on me: people always jumping to the wrong conclusions. I'm very good at communicating other people's needs. But when it comes to my own, I don't know how to voice it. This is where I'm not good at advocating for myself, because if I were, I'd ask regardless of the outcome.
>
> **Trudy** tells a story about herself: I always had trouble asking for help. In middle school I got these pants that were way too tight, where it kind of hurt and it just like, I don't know, like I had a thing where like it just wouldn't occur to me to ask for help, or like I wouldn't remember to ask for help.

So yeah, like I pretty much like just kept wearing them forever, even though they weren't okay. I mean that's just one example, it just didn't occur to me.

Other support systems

Dave said: My parents knew the importance of good community. There were times when they were really busy, and couldn't devote much time to me. There was a wider community of people that were helping raise me. Um, and uh, for context my mom got her PhD when I was seven years old, so she was working through grad school, you know, with one, then two kids. I think she became pregnant with my brother around the time she graduated. Um, so this support system was like my grandparents, on my dad's side, they're both gone now, but they lived on our family's land. A year or so before my mom graduated from university, uh, we built a house and moved out there. My support system was my grandparents. They helped raise me, um, before that, and even more so afterwards, because I could literally walk across the hill and they would be there. And there was the Jewish community center, which also supported me.

Self help

Tony found support, through his writing skills: I kept a diary, and I guess talking to a notebook, while it doesn't talk back, it still allows you to express your feelings. Um, so I felt like that was a kind of companionship, cause I felt I was talking to my hypothetical readers, who would read my biography in 300 years, when I'm all famous and stuff. Like it was this world where I could be anybody I wanted to be. I could give myself superpowers if I wanted. Um, and I could have a significant other. I could have, um friends. Um, and I guess I gave myself the super cool life that I wanted for myself, but could never really have in real life. And that was what I spent most of my time doing, especially, um, when I was in school.

Peers who were helpful

Andy credits a woman in high school, helping him move beyond his shyness: I would see her, she would say 'hi' to me, but I wouldn't say 'hi' back to her, and she would always question me like, 'Hey you have five to ten seconds to say hi to me, it doesn't take a long time, and it doesn't take a lot of pressure, just do it'. And I started saying hi to people; like, Good morning, Hello, How are you? It's unbelievable what other people can teach you . . . they help you in a way that makes your whole life a whole lot better.

Bill said: My peers were always kind, and never treated me differently than they would anyone else. Also they didn't have autism, for which I'm grateful. I think they knew I did. I know the teachers explained it, when everyone was young; and I probably said it at some point or another, but I don't think to them it made much of a difference.

Dave said: My friends really accepted me, there are a few more like freaks and geeks anyway, in high school. So I think there were more people I could connect with. I was just like a person. That's how I perceived it.

Kent said: Students were able to work with me and talk to me and I was able to contribute to groups, them just being open to my ideas that helped, um, you know, if they weren't as open and willing to sort of include me, listen to me, that may have hindered my ability to do well in class activities.

Paul, who never goes into much detail, had this to say: My peers provided some occasional help with things I didn't understand, for example calculus.

Audrey said: There were people I knew from my classes, or just other people that I would ask, that would help me with homework, and we'd work together, um, type of thing, so that could help me understand things if I needed help on a problem or question. Um, but other than that, I didn't really talk about school struggles or things in school that I was going through.

Tony described a time when he made a group chat with people he knew, who were all in the same chemistry classes: We all hit it off really well, and we would get together to like work on problems and generally have fun; um, that was awesome. And I really love it when people, like make an effort to include me, and help me with my homework, in a non-judgmental environment.

Trudy also speaks about chemistry class: There was this one girl, who was also like my friend in chemistry. Like I had a hard time in chemistry with the material, and then when we were supposed to do the experiments I had a hard time with group work. They said, 'no, you're fine'. They just did it all. That wasn't working. So then after class hours, I did stuff with her, and actually liked doing the stuff. So that was good.

Amelia didn't understand the concept of having friends, she comments:

I was reading a lot about characters in children's books and they all had friends and they kept talking about friendships. I was like OK, what is this like? These friendships are so different than what I was having in real life. These friendships are supportive and caring, and they help each other. And so I decided that I would have friends, and I actively tried to make friends in high school and I did, the types that you know don't insult you and are nice to you. I was involved in cross-country, that's actually where I made friends.

Extra curricular activities

In addition to the studies that show that young people who participate in a music program do better academically, youth with autism who participate in extra-curricular activities like sports, cheerleading, mock trials, chess and health clubs, gay straight alliance, robotic and partner's clubs, hone their social skills by interaction with others and create friendships for themselves. All the youth in the study participated in one, or more, of these activities.

Music

Bill and **Jason** played in the school band. **Dave** played the piano, then switched to violin and played in the orchestra. **Nan** played the cello. **Trudy** sang in the choir.

Clubs

Andy belonged to a military history club; **Bill** and **Judy** joined a chess club; **Kent**, a mental health club for students with disabilities; **Tony** was involved in a robotics club; and **Trudy** in the gay straight alliance, the Chinese sign language club, and the circle of friends, which helped people with IEP who had social problems.

Drama

Amelia was the assistant director in a school play, and helped with the props. **Judy** joined the stage crew building sets for plays.

Sports

Amelia played soccer, was in cross-country and track and did the decathlon.

> **Andy** was that middle school athlete. He said: I was involved in track and field. I wanted to show off my strength and running ability. It gave me something to focus on, but it also gave me this: to never give up. I still remember this from that time: 'Pain, is temporary; pride is forever' and it's that pride that you have achieved something that nobody else could, and that nobody else can, and you're doing it, because you want to: that's the type of feeling I have when I do athletic events.

Audrey played volleyball, basketball, and softball for the school travel teams.

Bill participated in track and field.

Jason was part of the swim team.

Nan played volleyball, basketball, soccer, and was a cheerleader.

> **Tony** played tennis. He said: My aunt had this game called wee sports, and one of the sub games was like a tennis game, and I was really good at that. So I was like, oh, my gosh, like I'll probably be really good at real tennis. Nope, I really hate to say this, but I was the weak link on the team, and I just wasn't very good, even though I did try to do all this stuff my tennis coach was saying to do.

The winter court king

Dave tells this story: As a joke, someone nominated me in my senior year at high school to be winter court king. When the newspaper interviewed me, I was like, don't vote for me. I don't believe in this shit. And I remember when they asked if I could be anybody, who would I be? I said, Fred Phelps, so I could throw myself off a cliff, because Fred Phelps, with the Westboro Baptist church, protests at the high school and my synagogue, whenever they weren't engaging elsewhere in the country. So I think that pushed me over the edge. I had no campaign or anything. Uh, but I remember when I won, it made a lot of parents: mainstream, attractive, white, rich, with straight A kids, so angry, especially since I was in the orchestra too; it's usually band people. Um, so that was pretty funny. I hung out with some friends a little bit right there, but there would have been a million parties going on, and I didn't go to any, cause I didn't know how to ask. And so I went home afterwards. So it was this interesting paradox, and that support I think, prevented me from going into worse things, considering where I was socially at that period.

Special interests

All the students expressed an interest in a favorite topic or subject that has captivated their imagination above all else, and which they innately know is their greatest strength, and the key to maximizing their full potential.

Amelia, always articulate, puts it bluntly, clearly, yet amusingly: People on the spectrum were always the difficult but brainy ones, and the one's who

> weren't brainy, were caricature stereotypes, and they weren't as valuable. So I internalized that Asperger's was bad to have, and the only way you could be tolerable, is if you excelled in something specific. I had always liked writing, like I was a good storyteller. So I was like, maybe that's my special skill. And I tried to be the best at it, because I don't think many people could be the best at what they're meant to be right away. But another thing I wanted, I thought I needed a special skill. I once saw a movie where a kid had autism and was into music. And the parents were like, 'Oh, he goes up to the piano and Beethoven comes up and like whoa, he's amazing', like suddenly he has value. So I would go up to the piano sometimes, hit the key, and just expect intricate melodies, and it never happened. So I internalized that, and honestly it didn't even get better until our group that I started my junior year had a different perspective on it, and somehow Asperger's wasn't a bad thing anymore.

The others either excelled at math and science, or English and history. **Andy**, **Bill** and **Nan** excelled at math. **Dave**, **Judy**, **Kent** and **Tony** excelled at English and history. **Audrey**, **Tony** and **Kent** had more than one special interest. **Audrey** excelled at math, writing, history and sports. **Andy** in history and math, **Tony** biology and English, and for **Kent** it was French and English.

The following is what three students had to say about their special interests:

> **Audrey** said: Sports was my thing. Every morning before I went to school I'd watch the Sports Center and then I'd go and play sports all day. And then I don't know if it was because I played it so much that made me interested in it

or if I was just interested off the bat, but for as long as I can remember, I was either playing or watching sports, or talking about sports, or something like that, which is why I'm going through physical education.

Math was my strong suit. The teacher would put a problem in front of me and I would want to figure out how to get it. Cause if I don't, it bothers me. Um, so I think I worked harder at that subject than any.

As far as English, and the writing portion of it, I was always told that I was an excellent writer. I don't know why, but I would just sit down and write a paper, and the next thing you know, I would have my mom, or other relatives read it, and they'd tell me how great it was, and I was kind of shocked. I didn't think it was special, but I always got A's.

History worked for me because I wanted to dive deeper and know the answers to things and know why this happened or who was involved in what. And it's almost like me digging up facts and figuring things out, and I don't know, it kind of fascinated me to do that.

Bill said: I always loved math, as it is one of the things that made the most sense to me, because the numbers always add up to something. In middle school, I hadn't even heard what calculus was. We started learning about polynomials x squared plus x plus one. And I was looking at a good table of the values 1 4 9 16. And I looked at it and I saw that they tend to increase by a set amount but at 0 it's 0 at 1 it's 1, at 4 it's 5. And I looked at it and I started subtracting numbers 3 and 6 and 9 and 12.

So I did it again and I saw there was a pattern. And by looking at the pattern I was actually able to figure out the line before I ever knew what a derivative was. The teacher was impressed that I had found that, and I doubt that she was thinking that I was doing anything like that.

I also did it once, when I was going through in my chemistry homework. I was looking at a series of sequences of numbers and had to figure out the basis of the equation behind it, and I saw that the sequence jumped, and looked a lot similar to a polynomial jump. So I did what I did before, and I found out that it was correct, that I was able to figure out the equation from that.

I really enjoyed chemistry. I always wanted to be a chemical engineer ever since I was six years old, so when I was actually able to take chemistry proper, I was really happy, and I'm still happy. I'm in advanced chemistry right now. History classes I enjoy, but most of it, is a memorization issue.
<u>Tony</u> has always liked English: I've always been good at it, maybe because I had been writing it since day one. Um, and I was really good at biology, because um, my teachers were really encouraging, and they always paid special attention to me, and they were like, yeah, you're so talented or whatever, because I would like do the homework and get the questions correct. And since the teachers liked me so much, I went out of my way to study. Like even when we had free days in gym class, I would just go back to the locker room, get my homework and stuff, and just take notes on the book.

Helpful teachers

Earlier, the students voiced their discontent with teachers who were not helpful; here they sing praises for the teachers who helped them succeed.

Amelia says: Teachers in general are helpful people . . . pitching you a bunch of knowledge . . . I always liked them for different reasons, like one of my teachers who was also my cross country and track coach, always encouraged me in both academics and sports.

Bill was full of praise: They were the main contributors to my treatment since they taught me everything that was necessary. They were also able to help me find my friends, I got a lot of friends, once I was able to interact with them, which made me very happy, it kept me from being isolated as well.
I really believe that my gifted and talented teacher Ms. Brown was very important to me. She took me and my twin brother and another child, and taught us accelerated math, so that we were not stuck at the level of every student, that we were able to excel. That really made me feel special, like I was unique, and I was doing pretty well, and that made me really happy, and as well, it gave me the opportunity to continue being advanced. If I just stuck in the normal classes, I would be good at them, but my skills would have been lessened down to those of regular students, and because of the accelerated math, that didn't have to happen, for which I'm thankful. Because of that I was always one of the students at the top of my class, which continued throughout school. Our teachers were always very approachable.

Dave looking back on his earlier behavior, had this to say: When I would have an emotional breakdown in the middle of class or something you know, the teachers having to deal with that, had a negative effect on me in the moment, but in the long term, had a real positive effect. I was still accountable. Like I couldn't use my, um, ADHD or Asperger's as a shield: like I can do no wrong, it's all because of this. Um, I think I had some of that kind of attitude later, but it was never pronounced . . . so if I got in trouble I would still get, you know, punished by being, having to go to the principal's office, but the principal, and the staff, were really compassionate with me.

Nan who was always hesitant to ask said: It helped me when a teacher would say, 'You can come to me for help, I want to help you succeed'. I had this great math teacher, and she made me feel I could go talk to her.

Kent valued the fact that there was an open environment: If the teacher was able to support, listen, if I had things to say, that helped, and if they were able to give testing accommodations, like did I need more time, that helped.

Tony said the teachers that helped: Praised me for like being the best behaved, or doing the best work, or having really good skills. That helped a lot. Um, and the teachers like, specifically math, who really went out of their way to explain things, and go through examples so I could see how it works.

Trudy explained that her art teacher was like ridiculously flexible: I think part of it was I was really good at art, so like there'd be a lot of leeway there. Like I mean sometimes, I was just off and pursued my own projects and not really even doing the assignments. And at one point he was like, 'I'd like, if you'd at least do the assignments'. Sometimes I would do the assignments.

Grades

High grades raise self-esteem; low grades are detrimental

Amelia: I was in the top ten percent of the national honor society, and in the Department of Public Instruction: I think I got the highest GPA award.

Audrey: Um, I'd like to think I did very well. Um, GPA wise, I got a 4.0.

Judy: I got a 3.8 GPA in high school and about the same now in college.

Jason: Objectively, grades I did well. It was just a case of having to work hard and, putting a lot more effort, and you know for the first time I got some B's in university. After that, I kind of adjusted to the sort of academic standards.

Nan: I can be really smart when I want to be, as long as I dedicate myself, I can get A's. What helps in college is that you don't have to communicate to do well, cause everything that you need to know to succeed is on the syllabus.

Tony: I was a very good student, because everything was kind of easy, um, and as a result, I did well in my classes. So that was a source of self-esteem.

Dave: I got a lot of B's, C's and D's, never an F. I've occasionally had an F in the middle of the semester, and I was able to pull it back. I never did really well in school, and I think that's because of just the way things are taught. We were taught in a more traditional way, and that's not good for teaching in general, as, as I found out now that I've taught as a TA for some years.

Trudy: It was tricky in high school . . . like the top part of the bottom third.

Raising awareness of autism through the curriculum

The students were asked if they were to design a program to raise middle and secondary students' awareness of autism, what would such a program involve?

> **Amelia** explained: Autism is not a spectrum, but more like a buffet. So you're going down the aisle with your tray. The track to train the mac and cheese is non-verbal; the sprinkles mean you're sensitive to sound. And so it's not a spectrum, where everyone has so much of each, it's like a buffet: some people have some thing or some things, and not everyone has the same things. So that would work well with middle school and high school students: the buffet, if you're on the spectrum, you maybe have some of this, but you don't have it all. You might have nothing to do with cognitive disabilities, or you might have nothing to do with moving when you're nervous, or you might have nothing to do with being sensitive to noise, but you might also. So I think that example would have helped . . . when I was younger, because I would have known it sooner, but . . . I thought well, because I was not like that kid in the class, and I wasn't like any autistic people I saw on the media, I didn't recognize it; but if they told me it was a buffet, maybe I'd be like 'why I have that. Maybe I should get diagnosed'.

It's true that autism is more like a restaurant buffet spread than a spectrum, but **Amelia's** analogy breaks down, when one considers that unlike a buffet, the autistic person is not a consumer, who chooses and pays for what one takes to the table, but someone who accepts what is put on his or her plate, just like neurotypicals do.

Audrey offers these suggestions based on her experience in health classes: We didn't learn much, in the little bit of health class we were required to take, it was maybe touched on. It was never discussed in detail, never went further than just the name of it. People would bring up examples of people they knew that had it, and that's how they knew about it. They don't know what it is, or how to deal with it, or how to go about one's daily life, or that there are likely students in every class, and some people don't realize it, cause a lot of people I was in school with, they didn't know. They still don't know, because they're high functioning. Yeah, they have no idea.

Dave thinks that teaching about autism should be a living part of the curriculum: In the same way that progressive schools teach students about racial bias and sexism, without making anyone on the spectrum or with disabilities in the classroom feel like they are representatives of that group: integration, not separation, but equal type of things.

Jason thinks it's a challenging thing: Kids with autism have different issues. Some are sensitive to sound, whereas others are sensitive to other things. So I don't think one size fits all. When I think of autism, I think of someone who is intellectually impaired, which is true of some, but not for the people who don't get diagnosed until later in age. So I think if there are some ways to put into the education system that autism is not necessarily something that is super debilitating, um, and then be able to get the people, who aren't aware that they have autism, enough information to realize that they might have it.

You know, I didn't have any information on what was previously known as Asperger's syndrome. Um, and it's that one, it's just the highest functioning mode of autism spectrum disorder. I didn't have any information on that, until I looked it up for myself a couple of months ago.

Nan said: I think if people were aware, they would get evaluations a lot sooner, and therefore prepare on how to succeed with the condition they have, because you can only take steps to help, if you know what's wrong.

Tony says: I don't want to single autism out. It's not something to be taken lightly. I guess I'm talking about what autistic kids need to hear from their peers in order to feel supported and happy, how to be respectful, not to diagnose them, because that's going to make everybody look at the autistic kid in the room. Um, but like, I guess teaching people how to interact with us.

And I guess debunking common myths about autism, so that people don't walk around with negative stereotypes of us. And then bring in, uh, adults with autism to talk to the kids, so they can see what an autistic person looks like, we come in a lot of different forms, we're diverse, we don't act or look one specific way. Maybe they could show videotapes of different types of autistic people speaking about themselves, so that people can see, yeah, autism doesn't come in just one form, and its very normal to be autistic.

Disclosure – positive responses

'To disclose or not to disclose, that is the question'

The majority of the students were fairly positive about disclosure.

Amelia says: I think sometimes, having friends and family know that I wasn't purposely being rude, or different, to like annoy them, has helped.

Andy thinks it's a great idea to be open: I would ask friends, do you know that I have autism? And they (would say) 'No', they act surprised. I'm like a very open individual that's easy to talk to. Some of them want to hang out with me: somebody they want, they can depend on. And yeah, I'm somebody who suffers from mental illness, and yet they don't see it as a bad thing. They see it as a special thing. And you know sometimes their love for me grows even more because of that. So I would say it affects my friends in a very good way. At first it surprises them, and sometimes it's hard for them in transition. But they end up, liking me more.

Audrey says that she did not tell anyone specifically: There were people on softball teams, or could have been basketball too . . . they knew about it, because it was made known to the coaches, and I don't remember how they found out, it could have been from them, but it was in some way made known to the whole team: (there was someone, that had something, that needed to be treated differently, without saying the name.) And then I would tell them.

Judy says: A friend I had in middle school, we got in a huge fight one day. And when I get into an argument with someone, I tend to just like dig in my heels and can't make myself stop pressing my point. Whether or not I'm right, it doesn't even matter. And so after the fight, I sat down with her and explained and I apologized. I explained that I had autism, and that it has made it harder for me, to have conversations and disagreements in a way that is a beneficial. We're still friends now; it cleared things up for her a lot.

Kent says that he didn't talk about it with a lot of people: Some people knew that my brother was on the spectrum. There was one friend who I told him about it, and he was very understanding and accepting: he's also on the spectrum. So we're kind of able to talk and sort of understand each of our respective spaces, but it's not something that a ton of people know about, and it has not strongly influenced how I socialize.

Tony says that he used to tell people: Then people kept telling me, 'Oh, why does that matter? I don't care about labels'. And so I started tracing my requests more like, if there was something specific that bothered me. Um, I would be like, 'Hey, um I struggle with processing stuff people say the first time around, so can you maybe not complain so much when, uh, when I ask you to repeat it, because it's not like I'm not trying to hear you. I just need to hear it a couple of more times, because I didn't really get what you said the first time'.

Architecture and environmental considerations

According to the National Center for Educational Statistics, (2011), the average high school in the United States has 854 students, approximately 50% larger than the average middle school. The physical size of the school buildings, the long and wide corridors, the sheer number of students, teachers and assistants, the noise in the hallways, can overwhelm almost anyone, until they become acclimatized to the new environment. This is even more the case with students with autism in the process of transitioning from middle school to high school.

The following remarks reflect some of the concerns and preferences by the students in this study, about the buildings and the classroom environment.

Windows

Amelia said: I've been in a lot of different buildings and they're so diverse. I like the ones where the fluorescent lights aren't so bright. When they have windows, the natural light lowers the sensitivity to those lights, because you're in that area . . . for eight hours.

Two Doors

Amelia likes two doors for two different exits. She says: With OCD, I just feel safer; yeah, not just shooting, but also, sometimes it's like the door is where the teacher's talking, and you have to get up to go to the bathroom, and you have to walk by all those students. If there were a door near the back, it would be helpful, you could walk out before anyone sees that you've gone.

Desks

Amelia comments: I never liked the desks about the size of your hand. That's how much space you get for writing. Those are so uncomfortable if you're a fidget. So having those desks to have chairs wide enough, and then the desk portion attached to the chairs also helps. I know I always like the schoolrooms where the desks were big enough for four chairs around a table.

Paul disagrees with **Amelia**. He said: Maybe individual desks would be good, since ASD is a disorder characterized by a lack of socializing and stuff, you know, like group tables might not be, as you know, preferred.

Preferred Seating

Judy favors preferred seating: I prefer where you can sit where it would help you best. I think that might be beneficial, because with assigned seating they frequently rotate, and it doesn't give you the chance to try and form a connection with the people sitting around you

Noise cancelling and dim lights

Nan says: Noise distracts me. It's an analyst artistic component. I know when the bell rings, that can cause a person to have her trigger, have a shutdown or have a meltdown. Um, something that would be more friendly and more like a melody. Um, yeah, and I can't stand bright lights!

Warm and inviting classrooms

Bill says: Well I know that I personally did much better with the warm classrooms that looked like they had a lot of use in them. And everyone was always nice enough to each other, and the teachers were enthusiastic. I think it's just in general, that if the students feel like they've been accepted, then they'll lean more into learning.

Judy comments: Sometimes classroom settings seem really cold, like not temperature wise, but like they don't seem very inviting: that could benefit from being changed; making them seem less institutional could be helpful.

Modular classrooms

Dave says: I think I like classrooms that are modular: where you can move things around and stuff and easily switch up the students, so that everybody gets to know each other. I think that it should be designed with students, um, learning by engaging, instead of learning by listening . . . and you have more of a facilitator person instead of a traditional teacher and lecturer type of person. Um, and I think if at all possible, connecting something to the real world, including doing projects and assignments where you have to do that.

Sanctuary

Dave expresses the desire for a place: Someplace, where if somebody is freaking out he or she can be taken to relax, and then re-engage. It has privacy, without feeling cut off, and loneliness is actually for the good. That's something I wish I could have changed, that feeling of loneliness when I was cut off, put into the hall or things like that. It's going to make them, I think more angry with the people that did it with authority, and you know, in the moment it might calm them down, but . . . that can cause long term issues.

Andy says: God didn't make us all the same. You can't make a classroom fit the need of all autistics, because every person is different.

Jason admits that he's never really thought about whether a building was helpful or not: Of course I went to the same building for, you know . . . four straight years. So it's not like I have a counter building, they say, oh, this building is much better. I think I'm not really qualified, you know.

Early diagnosis

Of the twelve research participants only **Kent** (at 2), **Bill** (at 2) and **Dave** at (4 or 5) were diagnosed at a young age with autism. They said that an early diagnosis and treatment was important for their success. DosReis et al., (2006) state, that though the large majority of developmental paediatricians screen for general developmental delays, very few patients are screened for autism spectrum disorder (ASD). The reasons for not screening include a lack of familiarity with screening instruments and insufficient time to do what is required (Rutter, 2006). The problem with accurate and early assessment of ASD, despite knowledge of the condition is that "clinical diagnosis is reliant on the developmental behavioral presentation" (Charman & Gotham, 2013, p. 2).

The students who participated in this study who were diagnosed at a young age, showed those recognizable signs, while students like **Amelia**, **Jason**, and **Paul** did not. **Amelia's** ASD may have been masked by attention given to her Obsessive Compulsive Disorder. **Nan** and **Tony** may have faced cultural issues that delayed their diagnosis. **Nan** also talks about going to a private school where the services for students with autism and awareness may not have been as prevalent as in a public school. Today, many children are first identified with autism in their toddler years, yet those with average or above average intelligence are often not diagnosed until school age or older (Charman & Baird, 2002, Mandell, Novak & Zubritsky, 2005, Manning et al., 2011).

Writing about screening instruments, Charman & Gotham, (2013) note: "Screening and diagnostic instruments help clinicians least in the cases where they are most in want of direction, since their accuracy will always be lower for marginal cases" (p. 1). Hence, the difficulty remains in accurately assessing high functioning young people with autism, such as the majority of those students who participated in this study. However, two studies indicate, that assessments can, and have been made (Wilkinson, 2010, So et al., 2012).

A study, (Kim et al., 2011), in a large sample, comparing seven to twelve year old children (N=55, 266) in South Korea, found an estimated prevalence of ASD of 1.9% in a general population sample in regular classrooms. Kim et al., (2011) identified the students with ASD using the Autism Spectrum Screening Questionnaire (ASSQ), (Ehlers et al., 1999). So et al., (2012) write:

> One of the important findings of the Kim et al., (2011) study is that most of the children identified with ASD in the mainstream school population had not been previously diagnosed. That is, they had not been identified with ASD as toddlers or preschoolers, the time period in which many children with ASD are diagnosed and placed in intervention programs. This finding suggests that higher functioning children with ASD may not be identified when they are preschoolers, and also will not be identified once they are in elementary school, unless they participate in a large-scale screening program, such as that conducted in the Kim et al., research study, (p. 596).

So et al., (2012) state that the diagnostic assessment of ASD is a time-consuming process. This is particularly true when children are less impaired (Howlan & Asgharian, 1999) and the diagnosis is not evident after a brief assessment. Overlap in symptoms can make it difficult to pinpoint children with ASD and children with other psychiatric disorders. The current diagnostic assessment procedures for ASD involve the use of standardized instruments, including the Autism Diagnostic Observation Scale-Generic (ADOS-G: Lord et al., 2001) and the Autism Diagnostic Interview-Revised (ADI-R: Rutter et al., 2003). So et al., (2012) write that the "high costs, time and specialized training required for such assessment of ASD, warrant the use of less expensive and easier-to-use instruments" (p. 597). They note as mentioned by Charman & Gotham, (2013), that there are no medical tests that can determine whether ASD exists in a child, if "observable behavior is the primary means of identifying ASD" (p. 597), (American Psychiatric Association (APA), 2000).

Specific ASD screening instruments have been developed, such as the Social Responsiveness Scale (SRS); Constantine & Gruber, 2005). So et al., (2012) state: such instruments are usually not implemented in schools or clinical environments. In contrast, the Child Behavior Checklist and the Teacher's Report Form are often used since they are broad scales and can identify different kinds of problems.

The purpose of the So et al., (2012) study was to determine whether the Child Behavior Checklist and the Teacher's Report Form were useful in identifying the children with increased risk of ASD, who would benefit from further diagnostic assessment. The study found that both the Child Behavior Checklist and the Teacher Report Form scales were able to identify children in all comparison groups.

According to this study, the Child Behavior Checklist and Teacher's Report Form can help to correctly identify children who need to be referred to psychiatric outpatient departments and/or undergo more extensive ASD specific diagnostic criteria.

Wilkinson, (2010) examined five screening instruments for identifying school age children in need of a more in-depth diagnostic assessment for ASD. The instruments are the Autism Spectrum Screening Questionnaire, the Childhood Autism Spectrum Test, the Children's Communication Checklist-Second Edition, the Social Communication Questionnaire, and the Social Responsiveness Scale. Wilkinson made the following conclusions:

> The screening instruments reviewed demonstrated utility for identifying children across the broad autism spectrum that are in need of further diagnostic assessment. School-based professionals might consider the following algorithm for screening students who demonstrate risk factors, and/or warning signs of atypical development, or where caregiver concerns strongly suggest the presence of ASD symptoms (p. 354). School personnel can play a vital role by participating in case finding and screening activities to ensure children with ASD are being identified and provided with appropriate programs and services (Rogers & Vismara, 2008) (p. 356).

It was noted earlier in this study, that teachers had a significant role in identifying only **Judy** and **Trudy** that they had autism. The studies referenced suggest that teachers can play a bigger role in identifying students with ASD.

Regarding implementing successful interventions for students with autism by teachers, Alexander et al., (2015) reviewed twenty-three studies where researchers experimentally evaluated training for teachers of students with Autism Spectrum Disorder (ASD). Alexander et al., (2015) note that the use of evidence-based practices (EBP's) can make significant improvements in the lives of individuals with ASD and their families (Simpson, McKee, Teeter & Beythem, (2007). Under the Individuals with Disabilities Education Improvement Act (IDEIA, 2004) and No Child Left Behind Act (NCLB, 2001) teachers are required to use EBPs when educating children with disabilities. School districts are required to deliver staff training on EBP's, to employee-educating persons. Litigation has occurred to require school districts to implement evidence-based practises for students with ASD. Thirty-nine percent of all special legal cases from 2005 to 2008 involved students with ASD (Zirkel, 2011).

Recommendations from authors reviewing ASD litigation continue to conclude that school districts should pay specific attention to students with ASD, ensuring they are educated by teachers using EBP's (Yell, Dragow & Lowery, 2005, Zirkel, 2011). Alexander et al., (2015) note that there are resources available to assist educators on EBP's for persons with ASD. Alexander et al., (2015) also state that though there is a wealth of available resources, teachers do not readily use EBP's when educating individuals with ASD (Hess, Morrier, Heflin & Ivey, 2008, National Research Council, 2001, Stahmer, Collings & Palinkas, 2005).

The students who participated in this study noted good qualities of teachers that they had encountered during their middle and high school years but generally the teachers did not offer any specific assistance regarding students with ASD. The exceptions were accommodations on exams and knowing how to address problems that **Dave** had when he had an emotional breakdown in class.

Therapy, interventions, and peers

Eight of the twelve students said they received therapy for their autism. Dickel, (2014) writes that for high functioning individuals with autism, cognitive-behavioral treatments can help patients understand the nature of their disorder, and to achieve "clearly defined goals" (p. 118). Group work can also be beneficial, to develop social skills on how to behave in social situations (Attwood, 2006). **Nan** noted this kind of therapy, when she stated that her counsellor helps her by talking about challenges and difficulties posed by her autism. Cognitive therapy was also useful for students who had mood disorders, such as **Judy** and **Amelia**, (Attwood, 2006). Murray, (2015) writes that in high school, therapists work with ASD pupils on things like recognizing facial expressions, and appropriate responses when asked a direct question. These therapists, he says, meet regularly with teachers and intervene if the child has an outburst in class.

Bond et al., (2016) conducted a review of ASD intervention studies published between 2008 and 2013. The focus of the review was 'what works best in the provision of education for persons with autism'. Three interventions were identified as having the most evidence for school-aged children. Many of these interventions focused on the role of peers in assisting students with autism.

Peer mediated interventions and multi-component social skills interventions to develop social skills, and behavioral interventions to decrease challenging/interfering behavior were some of the therapies.

Nine peer-mediated interventions were included in the review. All the studies in this group focused on children aged 5 to 14 years attending mainstream schools. These included naturalistic proximity based lunchtime clubs where peers and pupils with ASD interacted around shared interests, or discrete group interventions which involved meeting for one to two short sessions for about six weeks, with some direct teaching to enable peers to interact more successfully with children with ASD.

Outcomes for children receiving these interventions included: increased peer interaction, improvements in social skills, and the potential for increased social inclusion. Researchers delivered most of the interventions; so further work needs to be done to trial delivery by school staff (Bond et al., 2016).

Six studies in the review provided evidence for multi-component social skill interventions with 5 to 17 year olds. The studies included several elements, such as social skill training or peer support, or they involved parents in addition to a child-focused program. Studies in this group included manualized researcher delivered after-school social skills groups for pupils, with concurrent parent groups. These were often delivered weekly in clinics for about three months, and tended to measure a wide range of social outcomes. Other studies involved training teaching staff to deliver manualized social skills groups, parent training and emotional recognition intervention over ten months. They provide evidence, but changes reported were not consistent across all measures/respondents, perhaps reflecting the wide range of skills measured and respondents sampled. Further independent replication in school contexts is also needed.

Research shows that having positive peer relationships assists ASD students to succeed in school through acceptance of other students, having a sense of belonging and well-being (Wentzel et. al., 2012), and young people have noted that having friends is the most important factor in creating a positive quality of life (Helseth & Misvaeer, 2010). High school students with ASD however, have limited positive social interaction with their fellow students (Wagner et al., 2004).

Despite students with ASD learning in integrated classrooms this has not resulted in more social contact with other students, (Sreckovic, Hume & Able, 2017, Bauminger et al., 2003, Humphrey & Symes, 2010, Wainscott et al., 2008). Sreckovic, Hume & Able, (2017) note: that "in a recent systematic review of the nature of friendships in youth with ASD, the reviewed studies demonstrated that youth with ASD have fewer friends, lower frequency of contact with peers outside of school, shorter duration of friendships, and lower levels of reciprocity in friendships"(p. 2556), (Petrina et al., 2014).

When students without disabilities form a social network around students with disabilities outside of the classroom (e.g. lunch, between classes, extra-curricular activities, etc.,), these peer-to-peer networks become very effective in breaking down barriers. Carter et al., (2012) and Streckovic et al., (2017) found that peer networks are effective at increasing social interactions of secondary students with ASD, and provide preliminary support for the use of peer networks to reduce rates of bullying victimization.

Most of the students interviewed in this study indicated that they could have benefited by school focusing on helping them develop their social skills. However, they indicated that they had peers that were helpful for them, indicating that peer interventions are likely a helpful tool for young people with ASD.

Advocates

Teaching assistants and/or Para educators

Symes & Humphrey, (2011) noted that an increasing number of teaching assistants are being utilized in classrooms. TA's are learning-support staff: that work supporting an individual or a group of individuals, as well as the teacher, (Teacher Development Agency (TDA) 2010), (p. 1). The authors conducted a study, where they looked at developing an understanding of the aspects of school culture, that teaching assistants (TA's) feel contribute to the development of inclusion, and identify aspects of policies and practices that facilitate or hinder their ability to support people with ASD. Fifteen TA's in four mainstream secondary schools were interviewed. The study identified positive attitudes towards pupils with special needs, school leadership support for inclusion, and collaboration and respect as components of an inclusive school culture. The factors perceived as facilitating or hindering the ability of TA's to effectively include pupils with ASD, included access to expertise, communication within school, and teaching staff awareness of ASD.

Symes & Humphrey, (2011) write that:

> Inclusion can refer to the promotion of pupil's presence (e.g. without the use of withdrawal from classes), participation (e.g. the quality of pupil's educational experience), acceptance (e.g. by teachers and peers) and achievement (e.g. greater academic progress, better social and educational skills) in mainstream schools where possible (Humphrey, 2008) (p. 153).

Some studies have shown that TA's have little impact on the success of students with ASD in terms of overall achievement scores (Howes, 2003), and the more support they receive the less success they achieve (Blatchford, Basset & Brown et al., 2009, Farell, Alborz & Howes et al., 2010). However, TA's have been found to provide consistency when students move from one teacher to another (Alston & Kilham, 2004). This is important according to Symes & Humphrey, (2011), because autistic students prefer routine and predictability. The authors also state that the failure of TA's to increase participation, presence, acceptance and achievement may be due to other issues. They argue for a system wide school approach to inclusion, to making a difference for students with ASD. They write:

> The shift to a whole school inclusive culture requires all staff to have a clear understanding of the aims and expectations of inclusion within their school (Eldara, Talmora & Wolf-Zukerman, 2010, Huang & Wheeler, 2007), and these must be supported by senior management (Horrocks, White & Roberts, 2008). A high level of collaboration and information sharing among teachers, senior management (Huang & Wheeler, 2007), educational

> professionals (Simpson, de Boer-Ott & Smith-Myles, 2003), support staff (Abbott, 2007) and parents (Leach & Duffy, 2009) are essential. Mutual respect between staff and pupils are also fundamental (Centre for Studies on Inclusion Education, 2002). It is imperative, that this inclusive culture is backed with inclusive policies and practices (Dybvik, 2004) (p. 159).

Due to the uniqueness of each student with ASD being on a spectrum, flexibility is an important component of good practice. As Humphrey & Symes, (2011) note: "schools and teachers for example, should be aware of the individual needs of each pupil and adjust their curriculum and pedagogy accordingly (Jordan, 2008), particularly so for pupils with ASD", (Horrocks et al., 2008, Whittaker, 2007).

Bill and **Dave** were examples where supports needed to be specifically tailored to their needs. **Dave** found the work of Para educators in elementary school to be very effective in helping him in engaging in social interaction. He had support at every single level until he went to junior high and lost the support of Para educators. Until then he had a social life and active friends group. After losing a lot of that, he never regained it again until college.

> **Bill** said: In my special education classes I would be taught the correct ways to interact with others like playing or talking with others and that continued until I was about ten years old in fourth grade. When with my mom I decided that I had learned enough from my classes that I could function well from that point onwards, so I was taken out of the class. I developed anxiety and depression, which was most likely due to feeling isolated from other

> students, since I couldn't interact with them very well because of that. I was prescribed with anti-depressants, which I still take overall.

Committed leadership

Kluth, (2003) explained that committed leadership is evident, when staff in leadership positions such as principals and case managers play a critical role: "in articulating a vision for inclusive schooling, build support for the vision, and work with the school community to implement strategies and principles to make the school successful" (p. 24).

Subsequently for the next few sections, the research will turn to a different kind of literature than that provided by the academic community. Instead, parents will share their personal experiences, in delivering supports to students with autism. First of all, we will hear from Kymberley Gross, (2012), a parent, who at the time of writing had a child with autism in middle school. She writes about the important role that the principal can play, in maintaining a culture that supports students with autism.

The principal

> When a principal gets autism, the results can be amazing, and culture change follows: teachers follow IEP's, children with special needs are not just included but welcome in every activity and sports, and leadership takes a proactive role in helping your child succeed (p. 2).

Case managers

Grosso, (2012), also writes about the important role a case manager can play.

She says: That many kids with (IEP's), Individualized Education Plans, have a case manager, with the job of making sure the IEP is executed and coordinated with regular teachers. It is essential that the person assigned have a good understanding of autism, as it can make a difference in successful implementation of the IEP.

> For example, my son's case manager attends the regular education team meetings, and often helps regular education teachers understand autism, how it affects the children, how to implement adaptations. While many regular education teachers have some knowledge about autism, having a case manager who is a specialist in autism, helps both the students and the teachers come up with quick, reasonable solutions to issues kids may be having, and help them succeed in the regular classroom (p. 3).

Andy credits his case manager for helping him navigate through his autism, and for helping him improve his social skills.

Role of families

Grosso's, (2012) experience signifies the important role that families play in ensuring success for their children. With the exception of **Jason**, all the students noted the critical role their parents played in getting treatment, and in soliciting academic support and accommodations. Grosso, (2012) offers the following advice:

> Frequently autistic kids have splinter skills; so levelling can actually be a great way to best meet their needs. I would encourage parents to analyze every subject and then select the level your child can best learn. Do not make a broad stroke of the brush and assume a child should be on one level for all

> subjects. For example, my son is in high math and science levels, but still has learning support for reading. Yet when we made the jump from 5th to 6th grade the 5th grade teacher wanted to put my son in a lower level because she did not want to 'stress him out.' Eventually in 7th grade we were able to bump him up a level to high math.
>
> Looking back on it, this was the wrong move. As parents we should have insisted they put him in the correct level from the beginning (p. 2). Our children should be encouraged to excel in the subjects they are good at, supported with accommodations/services in order to help them grow. Now that my son is in 8th grade, he is still excelling in math and science. He tolerates English but it is not his interest area (p. 2).

In her article, Grosso, (2012) offers an array of advice for parents of children with autism, from ensuring that Specially Designed Instructions (SDI) are placed in the IEP such as: whether or not a child requires a study guide three days prior to tests? Whether he or she needs testing in a quiet, alternative environment? Whether the child requires their homework to be adapted so that the work is more manageable? (p. 4). She writes: "these are just a few examples of SDI's, that could mean the difference between a child melting down in frustration, and a child successfully learning in an inclusive environment. Also having the right SDIs can allow a child to succeed and learn in a higher level class" (p. 4).

One more example is her suggestion that parents write an email to their child's teachers, that "sums up your child's strengths and weaknesses." "Parents certainly hope that all teachers read the IEP, but it is good to create a quick summary letter in the beginning of the year in case it does not happen" (p. 4).

Dave when talking about advocates noted the important role both his parents and the larger community played, in advocating for more resources for students with autism. He grew up in a college town where an educated community/families, can make a difference in supporting students with ASD.

Self-advocacy

Noel Murray, (2015), as a parent of a child with autism, and autism researcher, writes that while the processes in middle and secondary school may be effective for students with autism, they do not prepare students for entry to college. Dr. Gerald Hoefling, who works with the Autism Support Program at Drexel University, says: "We make the erroneous assumption that high schools are getting ASD students ready for college, and they're not really ready. That's not their primary task. High schools do a wonderful job of getting students ready to graduate from high school" (p. 2).

Murray, (2015) says: There are steps that can be taken, to help students like his son, become independent self-advocates – "the same goal most parents have for their neurotypical kids."

Jane Brown, co-director of the organization College Autism Syndrome, described how students on the autism spectrum transition from high school to college: "Up through high school, parents are advocates and CEO's of their children's education" (p. 3). Yet once students attend university, the role as an advocate ends.

Murray, (2015) writes that under the *Family Educational Rights and Privacy Act,* once students turn eighteen, they are responsible for their own paper work from grades to accommodations they might request. While high schools are required to ensure that all children get an appropriate education, colleges have no such requirements. They provide accommodations, only if students ask for them.

Murray, (2015) quotes Dr. Susan White, co-director of Virginia Tech's Autism Clinic for suggestions on how to bridge the gap between what happens in secondary school and college. White says that parents of neurotypical kids usually start thinking seriously about college when their children enter their junior year of high school; it would help if parents of children on the spectrum started much sooner, asking the questions, "What are the life skills they're going to need, and how can they start developing more independence?" (p. 3-4).

The biggest issue according to Murray, (2015) is self-advocacy. Many of the ASD students never knew what was requested on their behalf in high school, and don't know what accommodations to seek in college. The most important advice he offers is that the student with ASD should attend the IEP meetings in high school:

> If more kids on the spectrum were aware of how much special leeway they were being given in elementary and secondary school, they'd know what they needed to work on. It's especially important that parents talk with their children about the nature of their disorder and how they can manage it (p. 4).

Despite what Murray, (2015) says about high school not preparing students, most of those interviewed in this study, were comfortable advocating on their own behalf.

The exceptions were **Judy** who had the most supports to help her with autism, still had problems advocating for her self. **Nan** is still struggling with self-advocacy, but sees a therapist who encourages her. **Dave** noted that he had trouble advocating for himself, not because of the support of his parents, but because of the cultural hegemonic belief, that you should not ask for help, but solve problems on your own. He said the assistance he received from the Para educators made asking for help much thinner and shorter than it could have been, but that he still had to go through a period of getting poor grades before he became a self-advocate.

Extra curricular activities

The students interviewed in this study participated in a variety of activities from music, drama, clubs and sports, to even being the Winter Court King. This is in contrast to the National Longitudinal Transition Study-2 data where Wagner et al., (2004) reported that only 33% of students with intellectual and developmental disabilities participated in any extracurricular activities. Simeonsson, Carlson, Huntingdon, McMillen & Brent, (2001), indicated that students with intellectual and developmental disabilities, when compared to students with other disabilities, participated less in these activities. The discrepancy may be due to the fact that the students in this study are high functioning, with many not being recognized as having autism, until they completed high school.

Agran et al., (2017) write that:

> Participation in activities, allow students with intellectual and developmental disabilities to explore and identify personal interests and preferences.

> to practice academic, functional, and social skills learned during the day, to develop and refine social relationships, to respond to opportunities to develop and apply self-determination and self-advocacy skills, and most importantly, to feel like a valued member of the school community (Kleinert et al., 2007, Pence & Dymond, 2015).

Section 504, of the *U. S. Rehabilitation Act*, states that school districts are required to offer equal access to students with disabilities to extra-curricular activities at school and provide the necessary accommodations to facilitate this participation. However, Powers et al., (2005) reported that only 11% of IEP's in a sample included any reference to extra curricular activities. Agran et al., (2017) note that research about students with intellectual and developmental disabilities involvement in extra-curricular activities remains limited. They conducted a survey of 146 special education teachers across five states working in a mix of rural, suburban and urban school settings. The authors found that teachers believed it was not part of their job to facilitate access to extra-curricular activities, despite the requirement to ensure equal access in law. The authors were concerned that if teachers don't believe they have a responsibility to facilitate access to extra-curricular activities, it is likely that participation in such activities is not discussed during the IEP meetings.

The views of teachers about participation in extra-curricular activities of students with developmental disabilities, raises the important role that families play in ensuring full participation for students on the autism spectrum. In providing advice to parents of students with autism, Grosso, (2012) states the following:

> Chess Club? Science Club? Video-Game Club? Art Club? Why is this important? At the end of the day, our kids need a place where they can do something they enjoy. It gives them the opportunity to create friendships and relationships based on a shared interest. For example, my son may have trouble initiating a conversation, but put him in a video club, and he can talk about video games until the sun goes down. The important thing about after school activities is that he gets to do something fun, creating a positive experience where he has the opportunity to interact with peers (p. 7).

Despite the importance of extra curricular activities in facilitating social connections many of the students interviewed in this study still experienced loneliness and had few friends. Most of the students said they could have benefitted from the middle and high school facilitating help with social skills. **Dave** made the point when even after being "The Winter Court King", he didn't attend any of the parties afterward, as he didn't know how to ask anyone how to attend.

In a (2004) study by Wagner, Cadwallader, Garza, & Cameto, the authors found from parent interviews that 32% of the children with autism had never visited with friends outside of school during the previous year, and 81% of children with autism never or very infrequently received telephone calls from friends. This study was done when Asperger Syndrome and autism were recognized as two distinct disabilities. As students with Asperger Syndrome are high functioning like the students in this study, these findings may not be accurate, but they are consistent with what was found in interviewing some of the study participants.

Special interests

Special interests are topics that persons with ASD follow with "intensity and focus" (Boyd, Conroy & Mancil, 2007, p. 5). According to South, Ozonoff, & McMahon, (2005) these interests increase over the life span of the individual with Autism Spectrum Disorder.

The focus on these interests may damage relationships with peers because the ASD person is only interested in talking about his/her interest (Attwood, 1998). Special interest is believed to be more present in individuals with higher functioning autism (HFA) (Epstein, Taubman & Lovass, 1985, Turner, 1999).

Characteristics of special interests include: accumulation of a mass amount of information or facts (Attwood, 1998, South et al., 2005); difficulty redirecting the individual from physically interacting with or conversing about the interests (Adams, 1998); the duration of fascination with the interests (Adams, 1998); and the intensity of focus, the individual spends a great deal of free time engaging with the interest (Adams, 1998, Mancil & Pearl, 2008, (p. 3).

Mancil & Pearl, (2008) write that using students' with ASD special interests in the curriculum, can assist such pupils to be engaged in activities which otherwise can be a problem. This is not surprising since it is consistent with the statistic that almost 75% of children with ASD, have behaviors of children diagnosed with ADHD (Heflin & Alaimo, 2006). Including these interests into math, science, history, and other applicable lessons, help increase academic engagement and improve outcomes (Boyd et al., 2007).

Mancil & Pearl, (2008) reveal how special interests can be incorporated into the curriculum for students with ASD in middle school. An example is Zeb, who was interested in hurricanes and when this topic was inserted into lessons, his teachers observed great improvement in math, science, reading and history. His math teacher developed a curriculum where Zeb had to calculate the wind speed of the hurricane. Based on the wind speed he had to determine the time it would take to make landfall. This activity required Zeb to practice several of his math skills. Mancil & Pearl, (2008) write:

> First, he had to use a ruler to measure distance from the plotted hurricane to the landmass. Then he had to convert the ruler measurement to rules using the scale provided on the map. After completing this, he calculated the time it would take to reach land given the current speed of the hurricane. Although several of these tasks were difficult for Zeb, he did not give up immediately as he had in the past. He still did not breeze through the assignments, but was able to focus more and work through difficult problems, possibly because of his intense interest in hurricanes (p. 7).

Zeb had similar problems in his English class. He didn't read books, would just stare at a page for an hour, throw the book on the floor or simply go to sleep in class. The process repeated itself when he was asked to write something. He would write a few sentences and then quit. His teacher's strategies for learning only worked when she realized Zeb had an interest in hurricanes. When reading books about hurricanes, Zeb no longer withdrew as he had with material that was of little interest to him.

He began to identify the main idea and key points. His teacher encouraged him to do a report about hurricanes, which he did successfully. According to Mancil & Pearl, (2008) great improvements in Zeb's motivation to read and write occurred.

A similar phenomenon occurred in high school. Jeffrey was considered an underachiever. His special interest was electronic gadgets. Jeffrey's history teacher found ways to incorporate electronic gadgets into the curriculum. She recognized that many inventors were involved in making history with electronic gadgets. Jeffrey researched inventors throughout history. He learned that the Civil War was the first conflict in which the train and the telegraph were used.

Mancil & Pearl, (2008) write: "In the past, Jeffrey never remembered dates or the effects one event had on other events. The focus on the gadgets improved this deficit, and his new skills generalized to other topics in his history class" (p. 9).

Jeffrey's history teacher couldn't include the electronic gadgets in all lessons about the Civil War. Instead, the teacher used the Premack principle for this topic. (An example of this principle would be: when your grandmother says that if you eat your vegetables first, then you can have some cake or pie after).

The teacher created a work chart for Jeffrey. The chart stated what information, and how much of the material Jeffrey had to read and write about, before he could work on his special interest. When Jeffrey completed each section of required work, he was allowed to access electronic gadgets for special amounts of time e.g. fifteen to thirty minutes, depending on the amount of work required. The teacher found that this approach worked. Jeffrey completed his assignments.

Most of the students interviewed for this study expressed as a special interest a subject in school such as math or chemistry or English. **Andy** expressed a special interest in cars, while **Audrey** was interested in sports. Their special interest was not incorporated in the curriculum specifically for them. However, if a teacher recognizes that a student has a particular interest that is all encompassing, this can be a sign that a student is on the spectrum. Improved teacher pre-service and in-service training could assist with identifying such students.

Raising awareness of autism through the curriculum

One of the key research questions asked in this study was, what is it that students with ASD need to know about themselves, and what do their peers need to know about them? **Nan** who was diagnosed with ASD at seventeen said: I did not know my identity. If students were provided information in school what to look for, that it's not necessarily shyness or being timid, or being quiet. It could be autism. I think if people were aware, they would get evaluations a lot sooner, and then prepare on how to succeed with the condition that they have. **Amelia** diagnosed at eighteen and **Jason** diagnosed in graduate school, note that their understanding of autism was that it meant that people were severely intellectually impaired. **Audrey** said: There are people still that don't know they have it after high school because they are high functioning. **Bill** said: Awareness should be incorporated into history or English classes and that once students know that many students with autism have similar capabilities, their perception of ASD may change.

The academic literature seemed to be lacking in how to educate students on what autism is, to help diagnosis, or seek evaluations. Since families play an important role in identifying ASD in their children, **Amelia** noted that awareness would help students once they become parents to identify ASD in their children.

Gavigan & Kurtts, (2011), note that bibliotherapy is a method of using literature, to help students with disabilities understand themselves, and cope with their developmental needs (Herbert and Kent, 2000). Bibliotherapy involves facilitating students' understanding and acceptance of individual disabilities through children's and young adult literature.

Gavigan & Kurtts, (2011) write: "Teaching future educators how to implement bibliotherapy sessions effectively, can help them develop an empathy and understanding of disabilities, as they prepare to meet the individual needs of children in their libraries and classrooms" (p.11).

Teacher candidates at the University of North Carolina, Greensboro, are required to learn about teaching bibliotherapy. From a selection of titles the education students choose a children's or young adult book that has as its subject matter persons with disabilities. The teacher candidates write a reflection paper on the book, an assignment that helps them address competencies in teaching about issues of diversity. Gavigan & Kurtts, (2011) note:

> When teachers and librarians implement bibliotherapy strategies in schools, they can help disabled students understand that they are not alone. It can also help other students develop an understanding of the issues faced by their classmates with disabilities (p. 14).

Curwood, (2013) writes that taking a critical look at reading young adult literature on persons with disabilities, helps both teachers and students to actively engage in "reflection, transformation, and action" (Gomez et al., 2010, McLaughlin & DeVoogd, 2004). Curwood, (2013) continues:

> Since people with disabilities are frequently depicted as having significant 'abnormalities' (Barnes & Mercer, 2001, p. 517), teachers may need to reframe students' understanding of disability identity, and equality. At its core, critical pedagogy provides a space to question, analyze, and transform cultural ideologies and social practices (p. 16).

In other words, all students should have a realistic perception of what it means to have ASD. Bibliotherapy is one example of a tool to promote that social change.

Architecture and environmental considerations

Architecture can play a vital role in particularly supporting those students who have sensory problems.

Martin, (2016) writes that classroom environments have been designed based on "heuristic decision making" (p. 281) by classroom teachers and other caregivers. 'Local knowledge' (p. 281), consulting with stakeholders with ASD, can be the best evidence available. However, "it is anecdotal and empirically untested for the most part and therefore possibly unreliable" (p. 281). Many of these designers have little empirical evidence upon which to design solutions. Martin, (2016) notes that little is agreed upon on how to design a supportive educational environment for students with ASD (Sanchez & Serrano, 2011).

The Ziggurat Model is an intervention planning reference used by special education teachers to utilize strengths and abilities of students with ASD to help address their challenges and deficits (Autism Project, 2014). Authors of the Ziggurat Model state that modifying the environment to ensure physical health, comfort, and optimal sensory arousal level, may be critical to the success of an ASD intervention program (Aspy & Grossman, 2008).

In a review of articles by Martin, (2016) covering the years 2000-2012, only thirteen articles addressed issues related to the design of the physical class environment for students with ASD. The literature found was mostly from the United States and the United Kingdom.

Design criteria (i.e. interventions) identified by researchers were organized within seven themes: space, visual sensory aspects, lighting (daylight and artificial), auditory sensory aspects, FF & E furnishings, fixtures and equipment, flexibility, design process (p. 291).

In describing the research, Martin, (2016) writes:

> Space and visual sensory aspects were the two themes most commonly identified in terms of Design Criteria categories, with recommendations for implementation in the classroom. In the space theme, definition and organization were comprised of issues of volume, mass and boundaries, circulation space and movement, safety; especially relative to adjacencies and visual sightlines for teachers and caregivers to all students at all times, an inclusion of an escape space or quiet area (p. 291).

Martin, (2016) continues:

> The visual sensory aspects comprised of: visual simplicity and view to the outside in combination with the lighting (day light and artificial) theme comprised of quality, and quantity Design Criteria were also identified. In general, sensory aspects (i.e. visual and auditory) comprised the majority of the Design Criteria identified by the researchers (p. 291).

Dave noted the importance, as the literature states, of a 'sanctuary' where a student with ASD can go to calm down if they are "freaking out". Sensory issues were noted by **Nan** such as noise that can irritate people with autism and the importance of dim lighting. **Amelia** agrees with the literature regarding lighting where there are windows with natural light, which lowers the sensitivity to lights.

Martin, (2016) concludes that design decisions continue to be based on what has been done before on anecdotal evidence (West, Toplak & Stanovich, 2008), (p. 930) instead of evidence-based knowledge (Hamilton & Watkins, 2009). Martin, (2016) recommends consulting with stakeholders in the ASD community about what they would like in the classroom but Mesibov & Shea, (2011) note the challenges of the "numerous, inter-related, pervasive defects of individuals with autism who are extraordinary heterogeneous in multiple dimensions" (p. 121).

Scott, (2009) states that the key British document in relation to published auditory guidance is Building Bulletin (BB) 77, *Designing for People with Special Educational Needs and Disabilities in Schools* (updated 2005). It contains the following points in relation to designing educational spaces for children with ASD:

(1) The building should have a simple layout, which reflects order, calm, clarity and has good signage. (2) Pupils may show different sensitivities to spaces: some will be frightened by large spaces and wish to withdraw to smaller spaces, whilst others will not like enclosed space. Providing a mix of larger spaces with smaller ones to withdraw to when anxious can help. (3) Low sensory-stimulus environments reduce sensory overload, stress and anxiety. (4) The provision of pleasant, well-proportioned space, with plain, bare walls decorated in muted soft colors will allow teachers to introduce stimulus, (such as wall displays of work or information), (5) Classes can be arranged so that teachers may employ different teaching methods, with spaces for individual work or screened personal workspaces. (6) Use of indirect lighting and the avoidance of noise or other distractions.

(7) Containment in the class base for reasons of supervision, safety or security by the use of two door handles, at high and low level, must neither compromise, escape procedures, nor violate human rights. (8) Robust materials should be used where there are pupils with severe disabilities and safety precautions for doors, windows, glass, plaster and piped or wired services will be required. (9) There is a need to balance security and independence and to find the right mix between tough materials and equipment on the one hand, and ordinary everyday items on the other, while at the same time eliminating risks. (10) Simple or reduced detailing and changes of plane may reduce the opportunity for obsessiveness.

Conclusion

An early diagnosis makes for earlier treatment and results. Therapy, interventions, advocates such as one's parents, grandparents, helpful teachers, Para educators, case managers and positive peer relationships, can provide a supportive role; but students eventually have to become self advocates. Knowing one's special interest is the key to present happiness and future success. Extra curricular activities can increase social interaction: the one area where the students were unanimous, that the school system did not do enough to help them. Finally, the chapter dealt with architecture and the environment, how it can play a positive or detrimental role for students with sensory issues. When it all adds up, a community of people is required to provide support, while keeping in mind that the ultimate goal, is to assist students with autism to become competent and independent.

CHAPTER VII

POTENTIALITIES

What does it mean to be persons with high functioning autism, in one's late teens or early twenties? What does the future hold? How does it affect one's identity? How does one manage one's autism to succeed in a career and family life? What roles do middle and high schools play, in answering these questions?

Once again the students will address the questions with their answers, while the researcher will utilize a different kind of scholarship to relate their narratives to the concept of democratic schools, an issue previously raised by **Dave.**

The analysis will critique the neoliberal policies and practices that limit the effectiveness of teachers, who strive to incorporate a democratic curriculum by example and teaching, and provides a case study of a team of teachers, who were able to accomplish this, while still satisfying the mandated standards based curriculum required by their school board. The chapter will conclude with how the discussion ties in with the politics of recognition, what it argues for, and means.

Effects of autism

Researcher: How do you see your autism affecting you?

Andy: I don't feel I'm not worthy. I think that goes back to the idea that you need to accept who you are. You're not going to change anything, but it doesn't mean that you're not worthy; you might be incompetent.

Are you competent or incompetent? I think that's more of the feeling that people should have, and if you're incompetent how can I get competencies?

Audrey: I want to say if affects me negatively, because it makes me have to go about things in a much different way than some people and then it makes it almost more difficult at times to get the same result. Normal people can just walk up to someone and start talking to them, whereas it's just a lot harder for me to be able to do those things.

Positively, I would say it almost makes me stronger, because of the fact that I have to go on a more different path, and it makes me work harder at things. And when you work harder and you get the result that you were wanting, whether it's out of class, or you getting a good grade on something that you really worked hard for; like it makes it all worth it. And it makes me have a work ethic, and more drive and motivation to get things done. And it transforms and transpires, and not only school work, but in your regular life, as I don't give up on things at all. Um, and I don't stop until I get the result that I want on a thing, cause I know I can, I just have to work a lot harder at it.

Dave: I think there's a danger in making autism a label in the first place. For me, what's been much more helpful, is seeing it as something that makes me special, that makes me different, and I'm happy with that. I also see that it has limited me in social ways. I think it has forced me to excel more socially than other people around me, cause that's because I've learned how to manage, I've had enough resources where I've got to the point of learning how to read body language, and being comfortable with socializing and stuff. In fact socializing gives me energy. I'm more extroverted. I love socializing with people. Um, so it's given me a perspective that I'm really grateful for. At the same time, I think that earlier in my life I made it like this: I'm the kid with Asperger's. If I could change anything, it would be that kind of attitude, because I wasn't the kid with Asperger's, I was Dave, a person that was really complex, and so is every kid, and I don't think they should be taught that. That's like only a part of their selves.

I don't really see it as a big part of my identity anymore. At the same time I think I can give it a lot more power than it needs to have. I used to make it a central part of my identity. You know, this is who I am. And in reality, I was a lot more of a complex kid, than just like a kid on the spectrum. So is any kid, I think it's a part of myself, and it should not make anyone feel separate. It's an aspect of oneself. Just like, oh, I've got this kind of personality. So, that scenario, that's what made progress, I can always continue growing.

It also means I'm going to learn things, or do things better and these types of ways, so how can I alter you know, what's going on with my life so that it's easier, so I don't have to struggle so much in that sense of things. I accept who I am. I feel very comfortable with who I am, and I'm happy with who I am, and at the same time when it keeps improving, at the same time I can hold those two things in my mind.

Kent: It affects who I am, because a lot of it is socially: so, being shy and introverted, and having a lot of social awkwardness and struggling to connect, that's the biggest piece. And that's something that impacts me constantly, kind of on a day-to-day basis. So it makes me question who I am, and where I'm going. So it's that and the academic piece, and still a lot of factors play into it, that kind of makes me who I am that I struggle with.

Nan: It impacts me just in the way that I'm not able to do as much as everyone else. But it's something that's a part of me, and I'm completely okay with that. I wouldn't change it, and I just accept it, to be a part of who I am.

Apparent progress

Researcher: Has your autism become more apparent as you've progressed through your education?

Amelia: No, I think it's become less apparent as I've moved along. For me, I never had anyone teach me social skills. I had to learn through trial and error and observation. And um, I think part of it is that I do ask a lot of questions. Um, in fact, some of my teachers had a bet, that I couldn't go a day without asking a question, and it was this big competition thing. I think a lot of times people thought my questions were stupid, because I'd be like: 'Why is she sad when this happened'? And they'd be like, 'What do you mean, why is she sad?' I was fascinated by the phenomenon of people experiencing similar situations but reacting differently. People who are sad, I didn't cry. People who will cry, but what's sad, or who are angry at the room cry, and I wondered why certain people don't get certain things, and to other people it's obvious. But like the things I learned were that if someone's tired at the end of the day, they're more likely to snap then if they've just eaten, and you don't understand why are they mean now. But they weren't mean earlier, and people didn't get with the questions, but you know what I'm saying.

Andy: Yes, it has become more apparent, because the demand is higher; the expectations too have grown.

Judy: While my autism may have become more apparent as I progressed through my education, I've also learned how to cope better. So it sort of evens out. So I can't really tell, um, because like when I was first diagnosed, I had no idea how to handle it. In my senior year of high school, we had me tested again for some reason, and the person who did the test said that I still had autism, but I knew how to manage it. Um, cause like she gave specific examples about things that had happened during like our conversation. Like she was trying to write things down to what I was saying, and I asked her like am I going too fast? Do you need me to stop for a second so that you can catch up? And people I guess without autism, they just like know that's what's happening; I had to ask, but like I knew that I should ask.

I think there are a lot of social things that neurotypicals just know. It's like instinctive I guess. But if you have autism, the social rules are a lot less upbeat, like the rules don't make sense. But it's sort of like everyone else just automatically knows how to use the program, or play a game, and you have to refer to the rules all the time, whereas everyone else says to memorize that, you know what I mean? Say you're playing a board game with a group of friends. The neurotypical people have the rules memorized, and it just comes naturally to them. People with autism, have to flick back and check, and you're like, so is that what I'm supposed to be doing, or is there a different way to play that I'm supposed to be?

Kent: I think it has become apparent just in my academic struggles that I've had since high school. And um, I mean I feel more socially awkward. I didn't think of myself as being socially awkward when I was a kid. I was more outgoing, you know, maybe I was kind of different, awkward, but I felt comfortable, it didn't matter to me as much, just being able to, you know, connect to people and all of that. So now it feels like its different, like I've matured, so I think about it a lot more. I think it has changed me in terms of just how I do school, and socially how I go about the world.

Tony: I would say so, because before I was diagnosed, I thought of myself as a super normal person. Um, and I always thought, that there was nothing wrong with me, other than I had OCD because of the intrusive thoughts, I was like, that's probably not normal. But like as for the rest of me, like, my leg wasn't broken, my eye wasn't shot out. So I thought, there's probably nothing wrong with me. I'm a pretty normal person. But then as I got older, I started to be like, wait a second, other people don't have difficulty with these things, and I guess I started to notice more difficulties I had with socializing, or the, um, and the difficulties that I had with eating different foods, like for example, if you ask me to drink some soda, it would hurt bad. What are you drinking there? Oh, this is tea, and I guess I noticed that a lot, a lot more.

Oh yeah. And also, um, sensory stuff that I don't know: there are certain noises that I'm just, uh, and um, and I have a lot of difficulty recognizing faces. I mean I have specific features about people that helped me to recognize them. And if they were to get a haircut, or shaved their eyebrows off, or shaped their eyebrows, if their eyebrows was that feature, I would look at them, and be like, wait, who is that?

Trudy: You get socially behind. I think it's a lot easier to have a conversation when you are a kid, than when you are an adult. The organizational issues give you a lot more trouble as an adult than as a kid. A kid's like, oh boohoo you got like, like B's and A's and stuff, like it's not going to affect your life, while later on it's more important to be organized. Well, that was not working. I'm not a person who gets everything done on time. Like organization affects all my life, missing appointments, being late for things

Managing autism

Managing the twelve year old self

Researcher: If you were to tell your twelve-year-old self anything about managing autism, what would you want yourself, or your group to know?

Amelia: I responded well to books, so I would write a book for my twelve-year-old self, and have the main character be on the spectrum, and have them deal with certain things that I was going to deal with because I didn't. I don't think I responded well to my future self, and I'd have them going through things and solving them and like getting to that place. And then I would give that book to myself, I was a big reader, so I would read it, if the font was small enough. I'm really big on font. Um, and then I, that would've helped me.

Andy: Accept the fact that you're autistic and its okay. You may be socially or academically challenged; it doesn't mean you can't do something about it. One of my biggest problems is my follow through, my execution. So I mean I would tell my twelve year old self do something, you may be socially awkward, it might be difficult for you to understand certain things, but that's not going to stop you from defining your own destiny.

Bill: I'd tell myself that it's okay to be how you are as long as you try to have control over yourself, and just don't blurt out everything that comes to mind, because that's one of the problems I used to have, a problem with self control over my actions and words. And I'd also try to see the positives in life, rather than focusing on the negative, because I used to be very pessimistic; and I'd try to tell my friends how much they mean to me. I would tell them that having autism doesn't make me any different emotionally than anyone else. I still care for everyone, and they meet me in both worlds, and I want them to know that I would never take them for granted.

Dave: I would say I do not like the way I'm wired, the way you're wired. You're going to want to jump onto things to distract yourself from your frustration and pain and don't do that. Lean into that and learn. The more you lean into it, the less painful it will be, the more you become used to it instead of trying to avoid it. And you know, otherwise, it'll be a lot easier for you to get addicted to like video games. Additionally you need to start, you know, you think you might have like dealt with your ADHD, you really haven't, you've just focused more on your ASD, and that will get better as you work on that. I would really start working on your ADHD now, as well, and work with them hand in hand, don't work on them separately. Um, you start like seeing a psychologist regularly. That would be a big thing, If I had seen a psychologist once a week as a teenager that would have made a huge difference. And remember, a psychologist, all of this stuff may sound big to you, but you know, these psychologists will make it a lot less hard because they'll take care of part of the work for you. They'll help you build up strength to be able to do more and more work, which is really exciting.

Jason: Some things are hard for you and you don't need to be perfect at everything. Basically, uh, I always put a lot of pressure on myself to kind of succeed in everything, and you know, when it comes to things that were social, or, you know, just coping with life, I you know, I struggled a lot, and uh, it was very hard on myself for struggling because of that.

Nan: My advice would be um, blend in a little. Don't necessarily speak what you are thinking, or say things even if it's the truth because people won't like it, and they won't want you to be their friend.

Judy: Um, there will come a point where I can figure out how to interact with people in an acceptable normal way, and that everyone has their challenges. It helps to know your identity, because then you can do something about it. Yeah. You can, uh; you can seek your dreams, and not be held back.

Kent: It's going to be really hard. I'm going to face a lot more pressure and a lot more social challenges, but just connecting and with kind of finding my place, and there's going to be some academic challenges. You know, I want to be prepared, just know that even if things are okay now, it's going to be difficult and just being able to know that support is out there, you know, I should try to make friends and it's going to be tough, but that they'll be able to get is something that I would want myself to know at that age.

Trudy: You can forgive yourself if you like to procrastinate on things like having a hard time getting things done. The grades you want won't kill you as like middle school, this is just like preparatory stuff; I know you'll be okay. Just try and do your best, but you're still okay, even if you don't manage.

It may be also like you know a coping mechanism, but be careful about your sense of humor. They think it's just weird, or an excuse to make fun of you.

Managing the sixteen year old self

Researcher: If you could tell your sixteen your old self anything about managing autism, what would you want yourself or your group to know?

Amelia: I think when I first entered school I had not no social skills, but limited social skills, and I learned by trial and error. And eventually I got to the point where I could, from observing, I could understand some things, but kids don’t really forget. So if you’re a pain, if you are really annoying to them in second grade or third grade, and suddenly you’re not annoying in seventh grade, but you still harm yourself, so they still kind of associate you with being annoying, they’re still going to be mean.

In seventh grade, I begged my mom to switch schools, because it was a kindergarten through eighth grade school, and so on eighth grade she sent me to a middle school. I was so worried about being bullied that I was a mute. I didn’t talk, and one of the girls on my bus line sometimes exchanged a few words, I think she thought I needed a friend. She was one of those kids that parents want to have, like the ones who’ve taken on a loner or kid; um, and so she let me sit with her big group of friends at lunch, and I wouldn’t say anything. I would observe them. Like how did they talk, how did they get into a conversation? And I just observed all of eighth grade.

My school district is really large, so the kindergarten through eighth school feeds into this high school. The middle school I went to, which was on my bus line, feeds into another high school. I went to a different high school that had the advanced college classes. So it was a new group of people. It wasn’t that middle school people I observed, who knew me as a mute; it was a whole new group of people. And I took what I learned from social skills from kindergarten through eighth, and I took my lunch at home, so I was probably still weird, but I wasn’t annoying, or maybe people were just more mature. Oh, and this group of people weren't mean to me. Um, but my mom had pushed me to go into sports. So in August before high school started, I joined the cross-country team. And from that I knew people.

Andy: In high school I had the programs needed in defining who I can become, because I had a lot of social skills and career classes, and understand what I can become as a good individual and contributor to society. I don't know if they addressed the fact that I had autism, but they addressed the fact that I had skills other people do not have. Your skills are rare, because you're the only one who has them, and your skills are in great demand, and if you can communicate that to an employer that's huge. And what was my skill? My ability not to give up: not say no to a challenge, but to say yes.

Bill: I'd tell my friends, I'd also tell myself to be considerate, and not to think that I'm better or smarter than them, because my autism gave me accelerated knowledge in math. I'd say try to take part in things, and get out of your comfort zone in social circles, since they'll turn out to be fun, and they'll make you happy, and I'd still tell my friends that they all mean a lot to me, no matter if they're close to me, or just acquaintances, they mean everything. From my high school years, I learned that having good teachers and good friends could make a lot of difference, between enjoying school and hating it. I love school, and to learn things with my friends, and just have fun.

Dave: I know that your last few years were like really non-social for you, and you thought you were becoming more social at age twelve. A lot of that was your environment. But a lot of that is also you too. And you know what? You can change that, and you can start working on that now. Don't wait till college; don't wait for a friend group to take care of you. You will probably find more friend groups. But don't wait for that certain learning how to do it. And a great way to do that is join an existing friend group, by making a difficult call of 'Hey, I can I hang out with you guys after school? Focus on listening, and start reading books on body language, and how to read it. Um, stop making everything about yourself. I know you are a teenager, but you know, there are bigger things than yourself. And uh, and don't believe me, convince yourself, because I would probably not believe me, if I told you an older version of me told me that, you know.

Kent: I didn't have a lot of friends at that age. I had one really good friend, and I've changed since then. There's been some stress, and I've had a lot more feelings of just being a bit depressed since then, just kind of struggling with how it fits into the world. So I would want my friends to know that, you know, things are going to change. I'm going to be different, but I'm still going to be me, I'm still going to want to be friends with you, and I'm still going to be willing to check to connect with you, even if things get tough and uh, things change, there's still a connection between us. Yeah.

Tony: Learn it now. I don't care if you have to see a specialist for one hundred dollars a week, learn it now, because you're going to be in for a hell of a ride later on if you don't. Uh, I guess, the ability to stand alone, and like still get everything done on time, and still be functioning, and happy and healthy, and not be lonely by yourself, and like not be sad and feel hopeless. I am not sure if this is like common with autistic people but um, I noticed that for me, um, when I have to be by myself a lot, um I notice myself getting really lonely. It becomes harder for me to do my homework because of that.

Um, and then, and then the other thing is I don't really know how to actually make friends. So I ended up, uh, either trying unconventional things, or getting in contact with people that I used to talk to, and being like 'Hey, you want me to hang out again, or something'? I never got any kind of support or therapy or social skills. No I didn't. I'm so busy at school, and it's hard to go to appointments, and try and get your work done.

Um, I think another one would be, um our parents. I feel like that's an obstacle for me anyways, because like, my mom is just so freaking extra about like trying to get me to do, I guess fit in and not be weird, because every time she drives me to a friend's house or something, she's like: 'Make sure you don't say that or the other thing and just be normal. Don't be weird. Don't tell them all your baggage'. And I'm just like 'okay mom, what do you think? This is a friendship; it's not a job interview. You can relax'.

Um, and, uh, another thing I would say is like probably self-care. My first year of college I had to live by myself, and like even though I didn't think it was hard per se, I forget, I'd have stuff happen to me. Like I would forget to eat, or I wouldn't complete my homework on time, or I wouldn't go to class because it was like, they'll probably make fun of me if I'm late. So I just slept in and skipped class or, um, I wouldn't shower for a week, which I know is kind of gross. I'm sorry, it wasn't just because I didn't want to shower, I just forgot to shower. And I guess I didn't have the motivation to actually do it.

Success

Researcher: What does success mean to you in college?

Amelia: When I first came to college I wanted a 4.0. I thought that was the epitome of success. Now I view it a little differently: a successful semester is one that I got through where I didn't feel overwhelmed, or like stressed out to the point, where like I feel sick. It's more of like, I've gotten a lot better. That's like last year, I was stressed out with the finals. This time I wasn't stressed out. I was just like oh, I got to study this much, and I will do it these days. And they felt a little stressed but it wasn't to the point, where I'm like, I can't do this, like there's a difference between good stress and bad stress; and a successful semester for me is I get good grades, not necessarily all A's, but I just feel content most days.

Andy: I like the way Bill Gates puts it: "Success seduces people into thinking that they cannot fail". I'm thinking, he's actually got a good point, because people tell you how can you be successful? I think it's just trying to keep a level head. I think more people should start: What can you do better? You don't need to be the most successful, and you just need to stay stable. I think that's what people should be communicating to other people in terms of being successful in school. For me to be stable in college is to be getting good grades, making new friends, communicating with other people, that I have problems and they're being addressed, and I'm going to therapy for it, and doing well in school.

I think academics has a lot to do with what it means to be a success, because most of the time, its either social or academic skills that people on the autism spectrum are having difficulties with. But if you could put some of the energy that you have in the social aspect, you can do so much better; I mean that's what people are telling me; you have so much passion, so much energy, and so much curiosity, and the things that you'd like to do. But if you don't put some of that energy in academics, then what's the use of your going to college. So that's something that I really try to define myself as being stable, or trying to improve myself in some way.

Audrey: Outside of like after college, just solidifying a good job, I mean to me, I had succeeded, when I've used the four years here, wisely. It's just not about grades, if you get all A's it doesn't mean you're necessarily successful afterwards, if you don't use the knowledge you had. So even now using my knowledge outside of class, I know that I'm getting something out of it, but for sure I would judge it on whether or not I got a job, and which job I have got.

Bill: Success I think means that I've earned good grades and I've learned enough, that I can be hired somewhere. I want to develop a water filter, which can be produced cheaply and effectively, so that it can be used around the world, and give people access to clean water.

Dave: I think I succeeded socially. And in that sense, if you still have serious social hang ups, that they're preventing you from activity, like seeking out friend groups, and creating a friend group, or joining them at least, then that is I think one of the most important things. And I'm very happy that despite my own mistakes, um, I was able to do that, because of all the support that was given, at least from my family and friends that I made academically.

Jason: I think you were successful in college if you come away, with the tools and skills necessary to build a life for yourself, so if your degree let's you get a good job, and if you feel you can live independently.

Judy: Success means that I pass my classes, have friends, um, be able to figure out a plan for after college, like career wise, for things to stop being hard. I am going to major in psychology, and from there I have no idea.

Nan: Success means to do as well as any normal student would do without difficulties. If I'm performing at the same level as them, I'm like successful.

Tony: I would say first and foremost, getting good grades. Um, and probably liking what I'm studying, because I mean no one fully likes what he or she is studying especially if you're still taking general education classes. You might have to take stuff like painting, or humanities, or history, even though you're not majoring in that, just so you have a required course. Right, exactly. And I would definitely also add like learning how to become an adult, before you actually have to be an adult. And I mean by that, learning how to take care of yourself, how to do your taxes, drive a car, all of which I'm really behind on. So, but like I guess, college is the start of your adult life for many. But like I feel like it’s probably better to learn how to be an adult in college, than after college, which is kind of unfortunate, because there are people like me, who are going to have to learn after college, because I still live with my freaking mother.

Um, and also another thing I would say is, um, important to succeeding in college, I guess having a life outside of school, because um, there’s this saying that my friend told me: ‘all work and no play makes Jack a dull boy’. And I think that especially applies to people on the autism spectrum, because, um, if we, if we’re only doing schoolwork, and we don’t really talk to people, or do fun things for ourselves, then we’ll probably end up really like unhappy.

Trudy: For me, it means setting myself up to be competitive, and like the next steps I take like, graduate school. Like I get a bunch of different experiences that let me put like into play, what I want to do, and this is what I’m going to do. I mean I want to have these research and work experiences, in this and that, to be competitive. I mean that’s kind of prior, for making friends and stuff. I mean I think that’s important for life. At the same time, I guess I kind of like treat it as like secondary to the other stuff.

Dreams for the future

Researcher: What are your dreams for the future?

Audrey: Career wise it would be a Physical Education and Health teacher at a school somewhere. Educating others and the PE side, just the importance of activity and all of that. But on the health side, diving deeper into health topics like autism, or just giving kids more skills to use in their life. Because when you take health classes, especially in middle and high school, they don't touch on things, and it's very, don't do this, don't do that, this is bad for you. So I would like to go more in depth with those and actually teach kids why, whatever drugs, whatever is bad for you, or it's the mental health disorders, what they actually are, how it affects people, how they feel, how um, I don't say deal with them, but how to interact with them, and how they interact with others, and get them more comfortable I guess. Because they have the knowledge about them, that they're not spooked out by someone that has autism specifically, or some other type, or has depression or whatever it may be. They understand it, and they are comfortable talking to them about it, because it's not unknown to them, for say like they just know depression is a thing, or autism is a thing. They know more about it, to where they can actually have conversations with those people.

Bill: My dream for the future is to live independently, to not let technology ruin my life, and to live an active lifestyle, have a family and be successful, but help the world and the people around it.

Kent: My dream is to have a good career and to work in the social setting helping people. It could be psychology; it could be through sociology, something that helps people develop a strong personal identity.

Nan: When I learned I was autistic, I thought about all the challenges that I will have to face. And I thought how does that work, when I have a job, you know, how am I supposed to communicate? But it didn't necessarily influence my career choice. I was embarrassed; you have to communicate, like that's a big thing. I think what it did, I guess is that I didn't see it as a problem, because when it comes to communication, I knew that I was capable of communicating just what needs to be communicated, nothing more, nothing less. So it didn't impact what kind of career l was going to choose, cause it's just on a need to do basis, you know. And I guess I was okay with that, because I wanted to be, still want to be a nurse so bad, there's nothing more that appeals to me. So if it comes to like yeah, just communicate I know it's a must. Yeah, I want my bachelor's in nursing, doing my Spanish minor right now, and I have been doing two certificates. Uh, I might want to do Grad school, to become a clinical nurse leader.

Tony: If everything works out the way I want to, get grades in my classes and finish my degree, and then after what I learned, to start my own computer company, uh, which would make computers that have the gaming compatibility of Windows and the easy to use beautiful software of Mac, because those are two things that I would like to have. But since my dad pretty much raised me on apple computers, I've always been excluded from games that my friends all play, uh, which tend to be PC, um, and also like having a common computer. But in general, I want to start my own computer company so that I can be very rich, so that eventually some girl can marry me for my money, because I really don't see any other way that, that a girl would be attracted to me.

Trudy: My dream for the future is, if somehow I could balance both art and trying to do research stuff. Maybe if I found out it's what I want to do, I'm still unsure about that, and like tried to do art. I don't know how realistic that is, but that would be ideal like, kind of a foot in both worlds. And then like maybe also write a graphic novel, or something like Aka Comic book, like not super hero comic though, like something along the line of science fiction or fantasy.

Democratic schools

Researcher: How do you see the school system providing programs and curriculum that would level the playing field, and encourage academic and social interaction between students with ASD and their peers?

Audrey: I would want there to be events, at least once in a while, where the students would be involved in some sort of social interaction, because I feel it would benefit them just getting the experience of being in an environment like that, and working on the social aspect of things, and talking to people, and having conversations and stuff like that. But I think if I had the social aspect where I worked on that, I would have been a lot more successful than I already was, because just being social and outgoing and talking to a person helps you, not only mentally, but I think it would kind of transpire into other parts of their life. And I think that would be just as important as the schooling that they would get in different subjects.

Dave: Uh, more group work, less lecturing, more activities, um, less testing, uh, less graded assignments and as few grades as possible. Honestly, I'm a big fan of eliminating all grades. I think that it's a relic of the industrial age, and that it's very harmful for growing minds. Um, uh, I think I did well in spite of it. Um, also I think because I grew up in a very radical liberal community that was different from a lot of other kids, I naturally would have struggled I think, in a system like the system I was in.

For anyone on the spectrum, making sure they have the infrastructure there to have Para educators, um, maybe differing types than like elementary school. But I would say that Para educators might have been more crucial during the teenage years, because there are a lot more volatiles in certain ways because of the emotional, sexual and physical, all the other changes you're going through. Um, so I think Para educators, and then also the style of teaching, would have benefitted everybody if that were changed.

Tony: Well, I definitely think that one thing schools could do in order to make it more democratic for us is, I mean it's the easiest solution in the book. Go up to us and talk to us about this in a very private way, and ask us: 'what can we do to help you with your academic experience more?

And also like, I guess fill us in early on what college is like, and maybe have us talk to autistic college students, so that we know what it's like for someone who either is doing it, or attempted it, and definitely have more pre-college programs for like autistic students, um, where we can experience college life, and I guess to have a test period so that we can get used to things before college happens: like self care and stuff, um, and like living without your parents, because a lot of us might not be able to function without a caregiver, and so that would be new to us.

POTENTIALITIES ANALYSIS

The previous chapter examined what it means to be a person with autism in their late teens and early twenties, and what does it mean to succeed in life with such a condition. Is there a role for middle and high schools in helping students prepare for what the future holds?

Apple, (2014) writes: "One of the things a serious education should do, is not only to provide the necessary tools to do something decent with our lives, but to 'destabilize' our ordinary understandings, of our own places in the larger society." (p. xxx).

E. H. Erickson, (1968) talks about having "the courage to be independent individuals, who can choose and guide one's own future" (p.114). As **Judy**, one of the interviewees in this study says: While ASD presents challenges; it helps to know your identity, because then you can do something about it. You can seek out your dreams, and not be held back.

"Destabilizing our ordinary understandings" means: not allowing oneself to view autism as a 'deficit'. Myers, (2019) writes that: "the deficit model of autism positions it as a disorder that limits a person's ability to understand and relate to others" (p. ix) (Bilken, 2005, Smith, 1996). And **Andy**, another interviewee says: Having ASD is not a question of being unworthy, it is about being competent, and if you are incompetent in certain areas, ask and seek out ways to develop competencies. **Dave** cautioned that there is a danger in making autism a label. For him, it has been more helpful seeing it as something that makes him special, makes him different, and he is happy with that.

Most of the students seemed comfortable and accepting of their ASD.

The researcher asked **Paul**, who only learned about his ASD, months before an interview, whether he was planning his career to accommodate his disability. He didn't seem to be cognizant of the challenges that might lie ahead, but he was determined that he was not going to let his disability get in the way of becoming an entrepreneur.

The question remains, how does one create an educational environment, which would prepare and support autistic students to meet the challenges of the real world, and at the same time service the neurotypical students and the expectations of their parents? Competencies in math, science, language and English are the subjects that parents commonly believe will help their neurotypical children succeed in university and the economy. Time taken away from learning and developing competency in those subjects, may be resented and opposed. How then do schools challenge existing inequities in providing a balanced approach? How do concerned parents and autistic students address the dominant forces and values of schools that are already imposed on children?

Democratic Schools

A 'democratic school' aims to create knowledgeable citizens, and include everyone regardless of class, race, gender, sexuality and disability. Such schools would be difficult to achieve, because teachers and administrators have to deal with "dominant economic forces, relations, ideologies, and identities" (Apple, 2018, p.11).

> He writes: Capitalism in the form of neo-liberalism, acts as a set of too often taken for granted classed, race, and gendered structures, that reorganize our societies in truly pervasive ways (Harvey, 2007, Leys 2003, Lynch et al., 2009, Root, 2007). This makes the prospects of creating the egalitarian conditions for

> thick democracy and human flourishing difficult (p.11). When undertaking an effort to establish democratic schools it is important to observe how the "ordinary" nature of such relations can get caught up under its "prevailing logic and ethos" (p.11).

According to Diniz-Pereira, (2012), neoliberal ideology believes that in order for corporations to maximize profit, and compete in the global market place, an economy must be regulated by the market. As Apple, (2008) puts it, "For neoliberals, the world in essence is a vast supermarket" (p. 39). The role of the market can be described as minimum intervention from the state and deregulation. It relates to schools, because it destroys "collective and solidarity" (Bourdieu, 1998), (p. 98). An example would be the issue of school choice, where parents act to choose the school that is best for their child, without reference to the common good; competing for academic achievement to gain admittance to prestigious universities. Real estate values are based on where the schools that perform best on standardized tests are located. It also tries to impose such concepts as "democracy" and "citizenship" and make its definitions the only ones possible and acceptable (Diniz-Pereira, 2012, p. 159).

"Democracy" for neoliberals is conceived of what Chomsky, (1997, 2000) calls "market democracy", which is a "top-down form of democracy" that attends to the interests of the market "with the public kept to a 'spectator' role, not participating in the decision making" (2000, p. 142). In essence, neoliberalism pretends to be in favor of democracy, but it results in a competitive structure that favors already established interests such as persons who are male, white and middle class.

What then does it mean to be a democratic school? The most comprehensive examination of the definition comes from Apple & Beane, (2007). A democratic school manifests itself in structures and processes by which, school life is implemented in the curriculum. Structures and processes mean that there is an attempt to have stakeholders – students, parents, teachers and school boards participate in making decisions that affect their lives. Apple & Beane, (2007) write that such schools are marked by an emphasis on cooperation and collaboration rather than competition, . . . and the curriculum has "an ability to make a difference in how we understand and act powerfully on the social world in which we live" (Apple & Beane, 2007, p. 151).

John Dewey, theorist and professor wrote about democracy education as far back as 1916, and implemented it in his school in Chicago in 1894. He believed that democracy in education points to a mode of living, of interaction between the individuals who constitute a community. He saw democracy as not just advocating for one's rights, but working together in the community for the common good (Dewey, 1916).

Similarly, the Mission Hill School in Boston, Massachusetts is an example of a school where like Dewey's vision its purpose is "to help students become affective citizens" in a community setting (Knoester, 2012, p. 12). The school's mission statement describes democracy as a form of deliberation requiring citizens with the capacity to step into the shoes of others, even those we most dislike, to sift and weigh alternatives, to listen respectively to other viewpoints with the possibility in mind that we each have something to learn from others (Knoester, 2012, p. 12).

Unlike Dewey, where students are working in harmony, deliberate democracy can be messy, with stakeholders disagreeing and arguing with one another. Yet it also involves a process of mutual respect. Young people are to see each other as political equals, and consider how their views and behaviors affect others. Students need to discuss and deliberate on questions where there are multiple and competing views.

A democratic curriculum

Apple & Beane, (2007) agree that since democracy involves the "informed consent" of people (p. 14), a democratic curriculum emphasizes access to a wide range of information and the right of these other voices to be heard including those of the students. However, knowledge shared in schools is limited to "official" or high status knowledge that is produced and endorsed by the dominant culture. Other voices are silenced such as those of women, people of color and the young. This can be observed by a review of textbooks, reading lists, and curriculum guides by noticing what is not included. Often this knowledge is presented as the "truth" (Apple & Beane, 2007, p. 15).

A democratic school is committed to a participatory curriculum that understands that knowledge is socially constructed, and produced by people who have particular values, interests and biases. Apple & Beane, (2007) state: "In a democratic society, no individual or group can claim sole ownership or possible knowledge and meaning. A democratic curriculum includes not only what adults think is important, but also the questions and concerns that young people have about themselves and their world" (p. 17).

Related to being critical readers, and having access to multiple perspectives, is whether students, if their culture is not dominant, are acquiring an accurate positive identity about themselves. This was a concern of W. E. Du Bois. For him, a democratic education was something that can change society, as Apple & Beane, (2007) attest, and also be personally liberating. He wrote that: education needs to "give to our youth a training designed above all, to make them (people) of power." (Du Bois quoted in Watkins, 2006, p. 223). *In the Souls of White Folk,* he argued for the broadest public education, for the expansion of the canon of general culture to include the lives and works of the excluded and oppressed. For Du Bois, the key goal of education was to identify talent, allow curiosity to grow, and create conditions that promised social democracy (Apple, 2013, p.77). Discussing Du Bois, Michael Apple, (2013) asserts:

> Becoming conscious of one's condition as a collectivity of the oppressor's consciousness, that had influenced the oppressed, was crucial. Knowledge of one's collective self and of one's history and current realities, and a knowledge that extends outwards to encompass powerful traditions, is to be a key instrument in defining the conditions of freedom (p. 78).

This curriculum was needed because African Americans faced racism with discrimination in employment and housing, segregation, and barriers to higher education. Similarly, students with ASD need to know that their needs are addressed in school, and are taught how to live with ASD in a way they can succeed and follow their dreams. As **Judy** says: When I was first diagnosed, I had no idea how to handle it. In my senior year of high school, we had me tested again for some reason, and the person who did the test said that I still had autism, but I knew how to manage it.

In contrast to deliberative democracy where all voices are heard, Du Bois and Woodson contended: that we need to put oppressed people at the center of the discussion, in order to have personal and social liberation. **Dave** contends: For a democracy that ensures that there are not only Para educators to help autistic students in middle school, but that the program be extended to secondary school, because the teen years are more volatile because of emotional, sexual, and physical changes that adolescents experience.

A culturally relevant curriculum

The type of curriculum for which W. E. Du Bois and Carter Woodson advocated, could be called what Gloria Ladson-Billings refers to as a culturally relevant pedagogy. Ladson-Billings, (2009) studied eight teachers who placed "a strong focus on student learning, developing cultural competence, and cultivating a socio-political awareness in their students" (p. xi). Student learning was multi-faceted and not demonstrated as simply a score on a standardized test. Students demonstrated what they knew in writing, speaking and a variety of exhibitions. Cultural competence meant for the teachers that students were well versed in their own culture as a requirement to become versed in mainstream culture. African American history, literature, art, music, dance, and perspectives played a major role in the curriculum. These perspectives were viewed along with others, so students could see the various ways different groups interpreted the world. An ideal characteristic of the culturally relevant notion of knowledge is that it is something that each student brings to the classroom. Students are not blank slates ready to be filled with knowledge from teachers, but instead what they know is acknowledged, valued, and incorporated into the classroom. In other words, democratic schools involve students in shaping the content they are studying and building on each other's ideas instead of just deliberating where people argue over ideas.

A case study

Dr. Barbara Brodhagen, (2007) a middle school teacher, describes how she and her colleague developed a democratic curriculum that was created in collaboration with students. The students asked questions they had about themselves and the world. The curriculum along with democratic governance of the class, co-operative learning, and student conferences, were all key characteristics. A democratic approach was still possible while mandatory standardized testing and curriculum guidelines were in place.

> Brodhagen, (2007) writes: I have been teaching for a long time. For many years, I worked with children identified as having a learning disability. This work gave me the opportunity to get into many classrooms in several school districts in two different states. Rarely did I see students in any of those classrooms practice in determining what they were to learn or how they would learn it (p. 85).

The students were invited to provide input on how they might get to know each other and develop a sense of community. For the first two weeks, a theme chosen by the teachers was “Who are we? Who am I?” The questions were answered by measuring heights, collecting family health and education histories, and writing brief autobiographies. Brodhagen, (2007) commented that the teachers changed the makeup of the groups across the school year so students had more chances to work with all their classmates. Students said that in other classes they only knew a few classmates, but in Brodhagen’s class they knew everyone. **Audrey**, interviewed for this research, agrees that such an approach would be helpful: “Even though I know that people with autism don’t really like social interaction, I think if I had worked more on that, I would have been more successful”.

Students in Brodhagen’s class were asked to select questions they had about themselves and the world. They developed the questions on their own, but then worked in groups to develop a consensus on which questions to use. Themes developed include Isms, Outer Space, Time: Past and Present, Mind Bogglers, Environment, Death, War, Violence and Conflict. Brodhagen, (2007) observed that the students:

> Are curious about almost everything and are trying hard to make sense of life in all its complexities and to find out who they are, and what they want to become. Their serious questions reflect a need to see themselves as members of a variety of groups within numerous cultures, including the dominant culture (p. 9).

Questions usually addressed matters such as Why does it have to be that way? Or who says so? Or who makes the decisions? Or why don’t we just change it? Brodhagen, (2007) noted that the teachers wanted students to study subjects critically, and consider as many different perspectives as possible. Students reviewed textbooks and discussed how certain groups of people and their accomplishments were omitted from the publications, and figure out how things got to be the way they are. Brodhagen, (2007) asserts:

> There have been times however, when we’ve stared at the long lists of questions suggested by the students, and wondered how we would ever find the strength to teach about some of those overwhelming, real-life issues. During those moments, we remind ourselves of students’ intense desire to know why things are, and then reaffirm our commitment to helping kids find the answers (p. 92).

One way these answers were addressed was by bringing in people from the community to answer questions that the students had raised.

External expectations and mandates

As noted, the ideology of neoliberalism can negatively impede the development of a democratic curriculum. Brodhagen, (2007) tells about how a number of school districts including the one she worked in, mandated specific standards based curriculum materials to be implemented in the way determined by the publishing company. This often stops a democratic curriculum from occurring. She says:

> If teachers want to continue integrative practices, they have to spend a lot of time getting to know what is in the new programs. And in many cases, teachers simply do not have the confidence to do anything but teach the mandated programs. High stakes state achievement tests have "scared" many teachers into moving away from doing what they believe is right and abandoning best practice. Instead they resort to using more conventional teaching technique, often times only teaching to the test so they can "guarantee" that all students have been taught what is needed to pass the test. Listening to and including student voice is left behind. Teaching decisions are made through the lens of "teaching to the text" (p. 105).

Neoliberalism and the influence of a capitalist market economy also present barriers from parents to facilitating democratic classrooms. With cooperative learning some middle class parents were concerned that their children were not going to continue to be the "best." The parents of poor and colored children were worried their children would not be successful in academics since the teaching practices were so different than conventional forms of practice. Despite these challenges, Brodhagen, (2007) writes:

> Soon a reputation was established, and what we were trying to do became desirable. Many parents began requesting that their children be on our team because we would be able to challenge them in ways conventional classrooms could not and because more students seemed to have more access to more knowledge. I believe this was because the young adolescents and parents who had participated in the kind of "situation" we were trying to create told others about the relationships between teachers and students, the in-depth projects, high quality content, problem-centered themes, and so on (p. 105).

Brodhagen provides the reader with an example of what a creative team of middle school teachers can accomplish, when committed to the concept of a democratic classroom. However, when it comes to high schools, most democratic classrooms are found in alternative schools, with few examples in the public school system. Exceptions might be individual classrooms where there is an open, critical dialogue between teachers and students, as experienced by **Andy** and his lunchroom history teachers. The dominant focus is on preparing students for graduation; or post-secondary education and a career.

Dreams for the future

The students interviewed all have different career ambitions. **Bill** wants to become a chemical engineer and make cheap and effective water filters to give access to clean water in developing countries. **Audrey** plans to be a Physical and Health Education Teacher to help change the way health classes and information is provided, teaching more knowledge on topics like autism and mental health disorders. **Kent** is still deciding a major, but wants a career where he can help people. **Nan** wants to be a nurse.

These dreams are consistent with the employment characteristics of people with ASD that Attwood, (2006) describes as having "a sense of social justice and integrity" (p. 295) and being "naturally kind and considerate" (p. 297).

Andy wants to work in finance and real estate; **Amelia** to be a writer; **Dave** an expert in Restoration Ecology; **Jason** a chemical engineer; **Judy** to study psychology; **Paul** an entrepreneur; **Tony** to own a computer company; **Trudy** to be a psychology researcher.

Potential careers

Attwood, (2006) says that a person's special interest can become a career as is the case with **Audrey**, and that people can pursue careers in academia focusing on their interest as with **Trudy**. He states that there is no career that is impossible, while at the same time acknowledging that people with Asperger's can face specific challenges and may not achieve employment appropriate to their abilities. He says that high schools can play a role in helping ASD students plan for their future and suggests a guidance plan:

> The first stage is to conduct an assessment of the person's vocational abilities and experiences. This will include cognitive abilities, personality, motivation, interests and interpersonal skills. There is a workbook specifically designed for adolescents and adults with ASD, which determines the person's employment strengths and weaknesses and helps resolve issues identified from previous work experiences. A vocational assessment should be conducted improving cooperative skills in teamwork, the art of conversation and interaction during work breaks, and how to cope with changing job expectations (pp. 296-297).

Attwood, (2006) cautions that careful consideration should be given to what career path to choose, and advice should be sought on whether the ambition is realistic. Work experience programs that expose students with ASD to various career options is one way to assist such students in making appropriate career choices.

Disclosure

Some students interviewed were reluctant, **Dave** in particular, to reveal that they have ASD. Attwood, (2006) recommends disclosure because it can help in providing specific accommodations:

> Once employed there are specific issues that will need to be addressed. The person with Asperger's syndrome may need initial and continuing support and guidance from his or her employer regarding job expectations especially if there are any unexpected changes, the interpersonal skills necessary to work effectively and cooperatively in a team, and the organizational skills required, especially work priorities and time management (p. 298).

Attwood, (2006) found that a key problem with people with Asperger's Syndrome in the workplace is personal hygiene. Other issues include the importance of written instructions in addition to verbal requests to address problems with auditory memory and not to explain one task until another is completed. He also suggests that employees with ASD receive regular feedback praising successes and ways to improve.

Conclusion

The students have spoken. Much of what they said is in agreement with the research literature, but there are variations depending on where the person is standing.

Two people can look at the same thing, but depending on their line of vision, they can see and draw different conclusions. Only a person with autism can accurately describe how the condition affects them, or whether there has been progression or regression, or if, or how, they have learned or are learning to manage it.

The students have different concepts of success. Grades are important, they are proud of their academic achievements, but concerned whether or not their education has prepared them to live independently, interact socially, find a job and have a family. **Nan** feels she is successful, if she does as well as her neurotypical peers.

That is where the concept of democratic schools comes in. Schools should be truly inclusive with a curriculum, which would be responsive and relevant to the needs of all, not only to the able-bodied intellectually, socially and physically, but for those with autism and other disabilities. That would be a dream for the future, and then disclosure would no longer be a question. Is it too much to dream?

CHAPTER VIII

CONCLUSIONS AND FINDINGS

It is important for people with disabilities to speak for themselves, and to have their experiences validated. The best way to understand autism is to listen to people, who are directly affected by it. This dissertation, has examined the research literature, heard the voices of the students, the challenges they faced, the systems that supported them, and their potentialities for the future. The implications are that the students know what they are talking about, since their experiences are consistent with the literature. The present chapter deals with how the theoretical frameworks apply to the student's experiences and their common experience.

This study asked the question: "What were the lived experiences of university students with autism (e.g. ages eighteen to twenty-nine), during their middle and high school years?" The sub question was: "How have these lived experiences impacted students in pursuing post-secondary education? And what can we learn from the experiences of students with autism, which helped or hindered their education in middle and high school?"

As a phenomenological study, the research asks the question: What was the common experience of the phenomenon of current university students with autism, during their time in middle and high school? A post-structural approach was taken as a way of answering the question.

Post-structuralism

What is post-structuralism? It is an alternative perspective to the dominant reality, in this case, how persons with autism are perceived. As Hall, (1985) writes:

> A particular ideological struggle chain becomes a site of struggle, not only when people try to displace, rupture, or contest it, by supplanting it with some wholly new alternative set of terms, but also when they interrupt the ideological field and try to transform its meaning by re-articulating or changing associations, for example, from the negative to the positive.

The role of ideology: invisible vs. visual disabilities

Diagnosed with Obsessive Compulsive Disorder as a young child, **Amelia** shared her feelings about what it is like to have an invisible disability, vs. someone with a visible disability. One of the students in her class had a visible disability. He had trouble counting to ten. This student participated in the Special Olympics, and was paired with an able bodied child, and the pupils were fighting over who would be paired with him. The students, who were nice to him, bullied her. To **Amelia,** it was a problem of unequal treatment, and a lack of access to resources, since she would not be diagnosed with autism until she was eighteen.

Michael Apple, (2004) writing about hegemony, alludes to **Amelia's** concern:

> It gets to 'saturate' our very consciousness, so that the educational, economic and social world we see and interact with, and the commonplace interpretations we put on it, becomes the only world that counts. Hence, hegemony refers not to categories of meaning that reside at an abstract level

> somewhere on the 'roof of our brain'. Rather it refers to an organized assemblage of meanings and practices, the central, effective, and dominant system, of meanings, values and actions, which are lived (p. 5).

In other words, the idea that children with visible disabilities are not equal, but are special, and deserve to be treated differently, is ingrained in society, while people with invisible disabilities, remain unseen, unnoticed and unheard.

How did this differential treatment develop? Longmore, (2013) reveals how Tiny Tim from Charles Dickens' *A Christmas Carol* became the epitome of what it means to have a disability:

> Between 1901 and 2009, fifty-six live action and fifteen animated movie and television versions of a *Christmas Carol* were produced for television and the cinema. Many versions were run every December on television, and plays of the story were acted out in theaters at Christmas time.

"The poster child", is another example. Longmore, (2013) noted a March of Dimes spokesperson saying: "The poster child is our major ambassador to the public". Longmore, (2013) explains:

> That icon influenced business executives' attitudes about the millions of people they might have seen as customers, employees, or colleagues, instead of recipients of charity. It instructed lawmakers as they formulated policies that affected disabled citizens. It defined who Americans with disabilities were. Reinforcing the model, the charity images portrayed them as dependent objects of beneficence, whose needs were medical (p. 38).

In America, 'the poster child' was central to framing the cultural, social and political meaning of disability. The charities depicted the representative disabled person as a vulnerable child, one of the weak. Poster kids were "seen and listened to by millions of Americans" reported the Los Angeles Times (p. 37).

A review of the student's responses, with many being diagnosed in their late teens and early twenties, and the challenge of accurate assessments, especially for those with high functioning ASD, highlights the importance of sharing more information about ASD with the general public and in the curriculum. Such awareness as suggested by **Amelia**, might help reduce incidents of bullying. It might also help students like **Nan** and **Tony** from various cultures, raised to think that only physical, medical, and not mental conditions exist.

The role of a democratic curriculum

Apple, (2014) remarks that what is included in the curriculum, and whose interpretation of it, are "sites of intense conflict" (p. xvi):

> These conflicts cannot be wished away. They are constitutive to the very act of choosing the knowledge and values that we consider official and that we choose to pass on to students. Of course the word "we" here is also contentious. Who is that "we", academic experts at universities, teachers, government officials, textbook publishers, parents, communities of dispossessed people, social activists?
>
> Should students themselves have a significant voice? Thus the questions get complicated. Not only must we ask what and whose

> knowledge is to be selected as legitimate or official, but we also need to take a stand on who should be deeply involved in the entire process, of such selection and organization of knowledge (p. xvi).

For Paulo Freire, (1970), the answer was clear:

> Who are better prepared than the oppressed, to understand the terrible significance of an oppressive society? Who suffer the effects of oppression more than the oppressed?
>
> Who can better understand the necessity of liberation? In problem-posing education, people develop their power to perceive critically the way they exist in the world, with which and in which they find themselves; they come to see the world not as a static reality, but as a reality in process, in transformation (p. 45).

Freire is saying that by students understanding their true identity, they have, as **Judy,** one of the interviewees says, "the ability to change themselves and the world".

Four theoretical frameworks

In this study, four theoretical frameworks were presented, each different from the dominant view. They were: Redistribution and recognition; Disability and the theory of complex embodiment; Affective equality: love, care and solidarity; and Enduring, resisting and reframing.

1. Redistribution and recognition

Implementing a curriculum, that incorporates the life experiences of students with ASD into middle and high schools, fits with Fraser's, (2004) theory regarding the achievement of social justice, through claims for redistribution and recognition. Fraser, (2004) argues, that both claims are necessary and can be integrated into a single framework. As Fraser writes: Here the goal in its most plausible form is a difference-friendly world where assimilation to majority or dominant cultural norms is no longer the price of equal respect.

The students interviewed in this study, were not seeking to be treated with exceptional kindness, but were looking for equal respect. What most of them experienced was being treated as weird and different. **Trudy** said: Some people who thought they were being helpful, were being condescending and patronizing.

Equal respect would involve these young people receiving supports and economic resources that other students may not need. Fraser calls this "parity of participation". This concept requires teachers and students to engage with one another as "social peers".

> This is all that **Tony** was seeking when he said about his peers: They say what I want to say right before I get to say it. That's not fair. Another thing they do, they shut down my opinions when I am vocal about racism or other things I noticed are wrong with society. And when I say anything about what I'm going through, injustices that I notice, then I am just imagining it.

Two conditions must be met for parity to occur. Resources must be distributed to guarantee participants "independence and voice". Fraser refers to this requirement as "the objective condition of participatory parity". It excludes "economic independence and inequality" that prevent: "parity of participation" (p. 36).

The second condition for equitable distribution and recognition, is what Fraser, (2008) calls the “inter-subjective condition of participatory parity” (p. 36). It requires that institutions express: “equal respect for all participants and ensure equal opportunity for achieving self-esteem”.

This means that the students with visible and invisible disabilities, would not be labeled with “difference”, but would receive the resources they need to recognize their “distinctiveness” to participate fully in society. As Fraser, (2004) says, precluded therefore, are institutional value patterns that deny some people the status of full partners in interaction – whether by burdening them with excessive ascribed “difference”, or by failing to acknowledge their “distinctiveness”.

Consistent with this theory, would be recognizing the barriers to diagnosis for persons with ASD. The curriculum needs to address cultural barriers that only see physical health and not mental health disorders as illnesses. Schools and organizations may need to reach out to churches and other institutions focused on serving the needs of cultural minorities, to provide education about invisible disabilities, the signs to look for, and how to seek treatment. The curriculum might also help students who have never been diagnosed, to recognize ASD in themselves.

This theory might require the need to recognize the distinctiveness of students with ASD, who often have special interests that can be utilized in the curriculum; to engage such students in learning, and also to raise the question whether students with ASD need be required to take higher math, science or language courses, if they are not consistent with their skill set?

In both cases, claims for participatory parity must show that they will not "unjustifiably" create or worsen other disparities (Fraser, 2004) (p. 39). Parents may argue that resources earmarked for students with ASD, are taking money away from their children who also have unique needs, such as students of color. Fraser comments that what is required, is only what is needed to participate as "peers in social life". Her theory of participation involves guaranteeing "independence and voice, and an equal opportunity for achieving self-esteem" (p.36). In this regard, all the students have become their own advocates. Even **Nan**, who had totally depended on her mother, has made progress.

Some found it helpful to disclose their autism; while others found it resulted in confusion, as their friends were ignorant of their condition. Some like **Jason** haven't disclosed because they don't know what the reaction will be. **Dave** is concerned that disclosure hurts opportunities for employment. In this sense, the students lack the equal respect and opportunity for self-esteem that the theory requires.

2. Disability and the theory of complex embodiment

How do the experiences of the students interviewed conform to the theory of the late Tobin Siebers, (2013), who contended that different perspectives including those of students with disabilities, "who stand outside of, and offer valuable knowledge, about the powerful ideologies that seem to enclose us"? (p. 279). According to Althusser, (1971), "ideology represents the imaginary relationship of individuals to their real condition of existence" (p. 162). Tsai, (2008) writes: "these imaginary relationships induce individuals to conform to social systems that constitute forms of oppression” (p. 21).

Siebers, (2013) challenged the ideology of ability, which he referred to as “the preference for able-bodiedness” (p. 279). He wrote that the ideology of ability is so powerful that it has “its hold on us”. The literacy about ability on the other hand, is almost non-existent. “Disability” he asserts, “creates theories of embodiment more complex than the ideology of ability allows, and these many embodiments are each crucial to the understanding of humanity and its variants whether physical, mental, social, or historical” (p. 279).

Seibers, (2013) cites (Linton, 1998), to claim that, “the ideology of ability collapses” once disability is asserted as a “positive identity” (p. 281). He argues that as with other minority groups, once persons identify positively with their disability they lead more “productive and happier lives, shared experiences and a community in which to prosper” (p. 281). The students interviewed for this study agree:

> Autism makes me special, says **Dave**: It’s not the only thing that makes me what I am, but it is a thing that makes me who I am. **Bill** says: I keep telling myself that it’s okay to be me. **Nan** says: It’s something that’s a part of me. I wouldn’t change it. I just accept it as a part of who I am.

Weak identity?

The “identity politics” Seibers, (2013) refers to, is related to suffering. Those on the left and the right criticize that it cannot be upheld. However, Seibers, (2013) says: “The idea that suffering produces weak identities, enforces the ideology of ability, and demonstrates a profound misunderstanding of disability" (p. 283). **Audrey** claims that her disability makes her stronger: "It makes me have a work ethic, and more drive and motivation to get things done".

When asked if their autism had manifested itself more as they got older **Amelia** said, no, because she had improved her skills to deal with her disability. **Andy** said his skills had improved, but he faces greater challenges, as he grows older. None of them were defeated, and the majority have decided they want to engage their future in helping others, and making the world a better place.

Stigma

The students were asked if they experienced stigma for having autism. Some were clear that they did not want to share with others that they were on the spectrum, but most offered a different perspective than the deficit model.

> **Andy** sees his disability as an asset: "I have skills no one else has, my ability not to give up, not to say no to a challenge, but to think about it and say yes".
>
> **Tony** embraces the theory of Complex Embodiment: "If you want to see the world from something other than the dominant perspective, Go up to us and ask what more can we do to help you with your school experience"?

3. Affective equality: love, care and solidarity

Lynch, Baker & Lyons, (2009) introduce the concept of affective equality through love, care and solidarity, they state: "Love involves acting for those we love and care for, not just feeling for them. Solidarity involves support for others, not just passive empathy" (p. 1).

This study has shown the important role that families provide in ensuring that high functioning ASD children are identified, and play a significant role in their lives as advocates during their middle and high school years, when transitions between schools are problematic. Love, care and solidarity were in evidence when Para educators helped **Dave** with developing eye contact and social skills. His parents advocated for more resources for him and other ASD students. Teachers aided **Judy** and **Trudy** in receiving their diagnosis. Case managers helped **Andy** to develop social skills and find friends who assisted him in coming out of his shell. A special teacher provided love, care and solidarity for **Bill** and his twin brother and another child, helping them to succeed as advanced math students. **Tony's** mother persisted on his behalf, until she found the reason for his behaviour. Peers were helpful, and friends were made through extra curricular activities. These are examples of Affective Care in practice.

All of the students interviewed felt that they were well equipped academically but schools could have done much more to help them with their social skills. Those interviewed believed that such support might have prevented them from being bullied, and as a result having more friends.

4. Enduring, resisting and reframing

Myers, (2019) examined twelve adolescents as they worked together developing multi-media stories. Many of the youth experienced oppression during the course of the inquiry. How the youth responded contributes to the development of the experiences of youth with autism.

Enduring

Judy endured oppression: The group work thing we did, they (her peers) would push all the work on to me. It really hindered my success because it made me resent them. I would have been a lot more successful if they had been willing to see me as a person, as opposed to just another thing in the room. Uh, a lot of people just didn't interact with me, unless they had to, and that was really uncomfortable and unpleasant.

Andy, who is South Asian, said: I was bullied for what I looked like, for what I was, for who I was, what they thought I was. It was almost like a dark cloud over me, and it was no matter where I would run or hide, it was always there in high school. It drove me to the point, where I thought of suicide.

Resisting

Dave asserts his resistance: I grew up in a very radical liberal community that was different from a lot of other kids, so naturally I struggled in an educational system like the system I was in. The community stood up for me during times when I was being discriminated. I was kicked out of Sunday school because another kid who I was with did something wrong, and they assumed it was me, even though I had nothing to do with it. And my mom, and a bunch of people in the community were pissed off, and stood up for me. And what actually happened was a member of the board ended up resigning. And I guess that's been a kind of consistent theme wherever and whenever I was a catalyst for change.

Reframing

> **Nan** reframes the stigma related to being on the autism spectrum: Why is there stigma because we're different? Like I think it's unnecessary, as people should be seen as that we're all human beings. I like everyone being different. It's just like if you're autistic, or if you are neurotypical, everyone is unique. No one thinks the same way.

It may be argued that enduring, resisting and reframing are responses that are experienced by anyone dealing with oppression: you either accept it, fight it, or try to find some way to understand it, in a way that you can live with it. But the theory is helpful in understanding the phenomenological experience of students with autism, and therefore is useful for the purpose of this study.

Conclusions, Challenges and Hopes

How do we implement love, care and solidarity in our schools? How do we have an equitable distribution of resources for students with ASD to ensure parity of participation as Fraser, (2014) argues? How do we have democratic schools where the voices of ASD students are heard and acted upon as outlined by Seibers, (2013)? Can we implement more training of social skills in schools, despite the challenges of the ideology of neoliberalism?

Apple, (2014) reveals that in a number of U.S. states there were attempts made to have alternative democratic forms of assessment other than mandatory testing on core subjects. However, in state after state when it came down to funding these were more costly forms of assessment and were seen as too expensive.

Funding was given only to support standardized testing, and the wide support for newer kinds of evaluation was used by conservative forces, to put in place high-stakes testing that has differential effects on those students who are poor and culturally disenfranchised (p. xiii) (Smith, Heinecke and Noble, 1999).

Yet Apple, (2014) goes on to note: "the forms of curricula, teaching, and education in schools are always the result of compromises where dominant groups, in order to maintain their dominance, must take the concerns of the less powerful into account" (p. 9). Apple, (2014) gives the example of Central Park East Secondary School in New York City's East Harlem, a school largely comprised of Latino and Latino African American students. He writes:

> Based on a commitment to community involvement, CPES was organized around more personalized styles of teaching, an advisory system that assists students in decision-making, academic planning, and social relations, a lower teacher/pupil ratio, and a school community-service program. In my mind however, the most important political feature can be found within its core curriculum. The curriculum begins from the crucial political question, "From whose perspective are we seeing, or reading, or hearing." This re-politicizes what counts as official knowledge, making it a subject to critical scrutiny by students, teachers, and others (pp. 36-37).

Notice the school helped with planning for post-secondary education or work, provided students with support for social relations, and tried to have a democratic curriculum.

Apple, (2014) states that there have been movements across the United States to develop more democratic decision-making in schools. These changes can result, according to Apple, (2014) in more training of parents from lower income communities to advocate on behalf of their children's education.

We saw that this type of effort worked powerfully in **Dave's** community, which was liberal and well educated, and ensured at least for part of his education that he had access to proper resources.

Yet as Fraser, (2004) says parity of participation can only be achieved if it does not take away equitable resources from other disadvantaged groups. Fraser, (2004) in other words is saying resources cannot be removed unjustifiably. However, members of other groups may see such political action as taking money away from the needs of their children. Apple, (2004) says that such attempts can cause rifts and pit disadvantaged groups against each other unless groups are careful how they go about such change efforts. There is always the risk that if achievement scores on tests do not improve while implementing democratic reforms, there will be a backlash and a return to business as usual.

Apple, (2014) provides examples of successful community efforts such as the use of participatory budgeting in some of the poorest areas of Chicago and the successful Chicago teacher's strike. Apple, (2014) says that success came in these examples and other situations through "conscious building of coalitions between the school system and the communities being served" (p. 38). He tells us that we must continue to ask the tough questions to include students with ASD in the curriculum and other disadvantaged groups such as:

> Whose knowledge is taught? Why is it taught in this particular way to this particular group? How can we enable the histories and cultures of the majority of working people, of women, of people of color, again, these groups are obviously not mutually exclusive, to be taught in schools in responsible and responsive ways?

These questions are about addressing the theories of Siebers, (2013), Fraser, (2004), and Lynch, Baker & Lyons, (2009), of providing equitable resources for learning, parity of participation, love, care and solidarity, and the creation of democratic schools such as students with autism see themselves in the curriculum.

Common experience

All the students interviewed were high functioning on the Autism Spectrum. Since their disability is on a spectrum, it is challenging to say that there was a common experience. However, one could conclude there were some common characteristics. For example, they all faced to some degree, academic, social, transitional, physical, health and cultural challenges.

Academic challenges

Academically, they faced a dichotomy where they struggled in some subjects and excelled in others. Some were still able to do well in subjects they found challenging, they just had to work harder. Some felt overwhelmed with the course work and homework. **Audrey, Jason** and **Judy** found it difficult to focus on completing assignments in class because of the noisy atmosphere, they needed a quiet place to work. **Bill** and **Trudy** were particularly sensitive to sound, and **Nan** to bright lights. All of the students except **Nan,** participated too much in class. **Nan, Tony** and **Trudy** had problems with organizational skills, planning ahead, executing tasks, and initiating activities. Their experiences mirror what the research shows.

Transitioning challenges

Andy and **Tony** struggled with transitioning from elementary school to middle school, while others found the transition generally fine. All struggled with the transition from high school to college, being on one's own without the familiar supports of family, and believed they could have benefitted from career planning, which would have helped them choose their majors and subjects.

Physical challenges

With regard to physical challenges, only two of the students diagnosed, were identified by the school system, a third by a doctor, while a fourth, self-identified: all were confirmed by trained professionals. While economic status appeared to play no role in the age of identification, it did play a role whether they were identified or not, as almost all the students in the study were from middle or upper-middle income families. This meant that they had the financial means to confirm the identification. If their diagnosis occurred during K-12 it would be free.

Cultural challenges

Nan and **Tony's** diagnosis was delayed because of the culture of persons of Hispanic and Chinese descent, who are reluctant to see their children as having a disability unless it's a physical issue. Education among all parents about autism is needed, but specifically outreach may be needed to the parents of minority children.

Health challenges

The majority of students were identified with other health disorders such as Obsessive Compulsive Disorder (OCD), depression, and anxiety, Attention Deficit Disorder (ADD), Attention Deficit Hyperactive Disorder (ADHD), technology addiction and anger issues. These conditions may have masked the fact that some had ASD, and therefore were diagnosed later than they otherwise would be.

Limitations and considerations

The study looked at students and their transition from middle to secondary to post-secondary school. It revealed the kinds of supports that benefitted students with ASD. It used their own words to identify and explain what helped them to be successful at each stage of their educational experience. The eventual goal was to attend post-secondary education. Since many students didn't learn they had autism until after high school, perhaps it could be argued that it doesn't matter what supports were provided. The students were all middle class except for **Nan**. However, her deceased father was highly educated, which meant these students were going to go to university no matter what.

If the role of the school system is to prepare students for life, then supports are critical for students in middle and high school. The researcher has had the benefit of seeing into the future, of what life could entail for these students, if they are not fully aware of what it means to have autism, and what limitations they may face and how to address those limitations.

The study cannot be representative of all experiences of high functioning students with autism, since most of the students were white and middle class with the exception of **Nan** (African American and Hispanic), **Tony** (of Chinese descent) and **Andy** (of South Asian descent). Supports made a difference for **Dave** because they were both inside the school system and outside in the community. **Bill** received help from the teachers and the special education resources. **Kent** benefitted from his accommodations, as he felt that high school was overwhelming.

It has been said that the role of a good education is to help students know who they are, where they have come from, and where they are going. What schools can do to help students with autism answer these questions is an ongoing issue.

Seven of the students had been given a gift of being diagnosed on the Autism Spectrum early in their lives. The researcher on the other hand, being diagnosed at forty-four, lived all those years not knowing who he was, why he behaved the way he did, or why his potential was limited for the future.

Andy, **Audrey**, **Bill**, **Dave**, **Judy**, **Kent** and **Trudy** diagnosed between the ages of two and twelve have an understanding of who they are. **Amelia**, **Tony**, and **Nan**, though diagnosed in their teens also seem to have an understanding of their identities. **Paul**, and **Jason**, diagnosed within a year of this study, likely do not yet have an understanding of what it means, or will mean to be on the spectrum. However, they are learning by seeing therapists and attending the Autism Support Group at the University. **Andy**, of South Asian descent, **Tony**, of Chinese descent, and **Nan**, of African American and Hispanic descent, have an understanding of how their own unique culture, different from the dominant culture, has impacted their lives living with autism. For **Tony** and **Nan**, their culture presented barriers to being diagnosed. For **Andy**, it meant that his family greatly valued education, and he was extremely determined to do well in whatever he did, and overcome any and all the obstacles that his autism might present. All of the students with the exception of **Judy** and **Kent** have a clear direction and goal in mind for their lives. **Judy** knows she wants to study psychology and **Kent** is still figuring out what his career will be.

Did the middle school and high school education they received help them to answer these questions? **Bill** had the most positive outlook and experience. **Dave** considered himself a success story despite the challenges he faced at school.
All of the students with the exception of **Bill** could have benefitted from more social skills training. The middle and high school education system in the United States did nothing specific to help **Amelia**, **Nan**, **Paul** and **Tony,** as they were not diagnosed until after high school. However, that is not to say that they were not seen as special, or that a teacher did not take a keen interest in their wellbeing.

Personal findings

The experience of interviewing the twelve students gave me a deeper understanding of myself, and my identity as a person with autism. It provided new insights into why I behaved the way I did. It's not something to be ashamed of because that is how I was made. Autism has given me a passion for helping others and public policy, which made me very effective at my work at the Accessibility Directorate of Ontario. It also gave me a passion for social justice in my volunteer activities, and making me effective as an advocate for the less fortunate than myself.

I had been privileged to attend Leaside High School in Toronto, an excellent educational institution. Two of my history teachers were exceptional, and sparked my interest in ideas, and my special interest, was politics. As a result, I went on to become a lawyer, earn graduate degrees in social work and business administration, influence public policy and now earn a PhD. In my personal life I was married and have a beautiful son. Like all lives well lived there were great triumphs and happiness and great sadness and losses. However, understanding more clearly my identity helps me, as **Andy** said, to realize I have competencies and in-competencies and I will continue to work on improving myself.

What I cannot do, as I bring this dissertation to a close, is to posit cause and effect relations. The conclusions I have made in this chapter are based on the understanding that the students have about the experiences they had going through the school system in their middle and high school years. The reader may not agree with their understandings, the students may be wrong, they may not see the whole picture, but they are their perceptions and they are very real to them.

What does all this mean, what does it have to do with democratic schools, and how does it expose the need for continued and further research?

Democratic schools

The students felt that a democratic curriculum would help them understand themselves better, by providing an opportunity to discuss the issue of autism in their regular classroom. This would probably take place in a health class, and would include both high functioning students, and those unknowingly, who might be on the spectrum, along with informing their neurotypical peers what it means to be an autistic person with its challenges and potentialities.

Such a curriculum would have the possibility of increasing acceptance from their peers and limiting bullying. It might also play a role in helping the students when they become parents, to recognize the signs of autism, should it appear in one of their children. A democratic curriculum will be inclusive and supportive of all students, regardless of their abilities or disabilities, recognizing and affirming their differences, distinctions and identities, with a relevant curriculum, versed in their own culture as well as the dominant mainstream culture.

Future research

Future research may wish to consider the views of students who did not go to university or college, and the views of teachers, principals, Para educators and teaching assistants to learn more about what works for students with autism, and what is still needed. For example, can teachers play more of a role in identifying students with high functioning autism?

More qualitative studies are needed along with larger, randomized samples to inform public policy. Research on social skills and academic interventions are also needed.

Pellicano, Dinsmore & Charman, (2014) conducted interviews and focus groups with adults with autism, family members, practitioners and researchers to indicate priorities for future research on autism. The authors conducted 11 focus groups and 10 interviews with 72 people. They concluded that greater participation of the autism community is needed, in setting priorities for research.

The Interagency Autism Coordinating Committee (IACC), responsible for making recommendations to the U. S. government on autism related funding recommended six critical research questions in the areas of (1) diagnosis, (2) underlying biology, (3) genetic and environmental risk factors, (4) treatments and interventions (5) services and implementation science and (6) lifespan services and supports (IACC, 2009). A seventh question relating to surveillance and infrastructure was added in 2010 (IACC, 2010).

The study found that greater research needs to be conducted that assist with the day-to-day living with autism – for those who are autistic themselves, their family members and those who work with them. In particular, they prioritized research that will identify public services and evidence-based interventions, develop programmes to enhance individuals' life skills, determine how autistic people think and learn and understand the place of autistic people in society. Participants also called for more research on autistic adults across the lifespan, particularly research on girls and women with autism (Pellicano, Dinsmore & Charman, 2014, p.766).

The research is consistent with the views of the students who participated in this study, and as a result they would benefit from what to expect, across the life span of living with autism.

Epilogue

"We are convinced then, that autistic people
have their place in the organism of the social community.
They fulfill their role well, perhaps better than anyone else could,
and we are talking of people who as children, had the greatest difficulties
and caused untold worries to their caregivers."

Hans Asperger

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APPENDIX

Interview Questions

Protocol: (Note some of the questions are used from McCue's 2016 study on the lived experiences of law students with mental health disabilities).

1st Interview

Tell me about yourself, your family, social economic status, education level of your parents, religion, birth order, and other family members diagnosed on the spectrum.

How old were you when you were diagnosed as having autism, or when you might have realized that you might be on the spectrum? How was it diagnosed?

Did your parents or did you seek treatment? What did they or you do? Tell me about any "treatment" that you have received to help you? (i.e. from a paediatrician, psychologist, or psychiatrist). Based on your experience how would you describe the effectiveness of the treatment?

Who or what else aided you in your diagnosis, treatment and functioning? Was there anything beyond therapy and the medical profession that helped you?

What role did your school play if any in your diagnosis and treatment?

Were you involved in any extra curricular activities in or out of school?

What was it like to transition from middle school to high school?

What was it like to go through middle school and or high school with autism (the degree of academic success, involvement in school activities – sport teams, clubs, school trips and friendships)?

Were there specific subjects that you excelled in or found difficult? Why do you feel you were successful at some and challenged by others?

Did you have an advocate to help you? If so, in what ways did they help you?

What happened in the classroom that helped or hindered your success? Was there anything your teachers did specifically?

Was there anything that your peers did that helped or hindered your success?
If you were to design a program to raise middle and secondary student's autism awareness, what would such a program involve?

If you could design the ideal classroom or school building what would it look like so as to maximize the potential of students identified as autistic?

What did your friends understand about autism? Did you tell them that you were on the spectrum? What was their response?

Is there anything else you would like to share with me at this time?

2nd Interview

This interview will take the form of reflecting on the meaning. The questions will be generated after reviewing the responses from the first interview. McCue (2016) used this section for clarification and confirmation of his interpretation of the responses as well as providing participants the opportunity to make meaning of their experiences. In general, the questions take the format of:

After reading your transcript, I want to make sure what you said about . . .

In some interviews, specific questions were asked to clarify the meaning of the 2nd interview. Questions generated as follow-up to the first interviewees were used as questions for all of the second interviews. These questions are as follows:

Tell me about the transition to college? What was experience like academically and socially?

Do you think that high school could have better prepared you for college?

What strategies have you developed to better advocate for yourself?

What do you see as the three greatest challenges that students on the autism spectrum experience moving from middle to high school, and then also moving from high school to college?

What does it mean for you to be successful in college?

If you were able to tell your twelve-year old self anything about coping with and managing autism what would you want your twelve-year old self to know?

What would you want your sixteen year old yourself to know?
How do you see autism affecting your life/identity? Do you feel any stigma? Do you masquerade or change your identity to fit in?

Has your autism become more apparent as you progressed through your education?

PERSONAL REFLECTIONS

The first indication that I was somewhat different than my peers was when my first grade teacher noticed that I was having difficulty printing and copying things that required fine motor co-ordination. The therapy recommended was that I was to pick up small sticks and place them in a can. Whether that helped or not, I have no idea, but I can print notes and write my signature.

By the fourth grade I was showing a 'special interest'; mine was in politics. So it was, that at my request, my mother took me out of class, so that I could see Pierre Elliott Trudeau, the Canadian Prime Minister, who was visiting our town. Politics has remained my special interest, as my eight-year-old son says: 'Dad, you are always talking about politics'.

During the first few weeks of the fifth grade, the teacher told the class that we were to underline the title of any of our schoolwork twice, and the date once. This was a task that I somehow could not complete. Apparently this is not an uncommon characteristic of being on the spectrum, and it's a skill that requires short-term memory, resulting sadly, in not always learning from one's mistakes.

The teacher in an effort to instil in me the importance of remembering instructions, assigned as homework, that I was to write out a hundred times:
I will underline the title twice and the date once.

After school, at home, my father saw me at the kitchen table printing the same thing over and over again, and inquired what it was all about. Autistics are honest to a fault, and when I told him, he left immediately to see the principal, and requested that I be moved to another class. The principal honored his request, and the next day I found myself with a different teacher. Since then, my father has always been my best advocate.

The sixth grade was the only time I experienced being bullied, a rather common experience of being on the spectrum. It probably happened because one of the students thought that I was too smart, or a goody-goody. However, I didn't seem to have any trouble making friends at school.

All through that year, I had a messy desk, something that has followed me throughout my education, work experience, and every day life. I have trouble with organizing and planning. In other words, I am lacking that skill known as executive function. It is something that I am planning to work on to increase my competency. There are four recent publications about the issue sitting on my desk calling for my attention. They are: The CEO of Self by Jan Johnston-Tyler; The Smart but Scattered Guide to Success by Peg Dawson and Richard Guare; Brain Hacks by Lara Honos-Webb; and the Executive Functioning Workbook by Karen Fried and Melissa Mullin.

Co-morbidity, such as experiencing more than one disability is another common experience of people with ASD. When I was thirteen, I developed signs of Obsessive Compulsive Disorder (OCD). It took the form of repetitive, intrusive and disturbing thoughts. I didn't tell my parents, because I thought I should solve my problems on my own. Three years later, I told my parents that I had disturbing thoughts, and they sent me to see a therapist. The therapist did not recognize that I was experiencing OCD, and I received no treatment until a year later.

When I was seventeen, the time had come for me to learn to drive. On one of my driving lessons the instructor said that I had "gone around the corner on two wheels". He wondered if I was on drugs. He took me home, because I couldn't focus on the driving lesson. My father wondered why I was back home so early, and when I told him that I couldn't concentrate, he consulted a friend, who was a psychologist.

I was referred to the Toronto East Metro Services, where I met with a social worker that connected me with a psychiatrist at the Hincks Treatment Centre. The psychiatrist prescribed the drug Imipramine, and it drastically changed me for the better, as the intrusive thoughts disappeared. I eventually passed the driver's test, but after two accidents with the family car, one a total write off, it was mutually agreed that I would use my bike or the bus for local transportation.

Like the students in the study, I tended to participate too much in class, sometimes making unnecessary or silly comments. I excelled at certain subjects like history. In my sophomore year I received the highest mark on a test on government because it was my special interest. On the other hand, I struggled with other subjects such as math, science, and languages. Living in Ontario, I had the choice of exempting myself from the higher forms of math and science, and as a result I ended up with straight A's, achieving the Ontario Scholar Award.

In addition to the academics, I was involved in a number of extra curricular activities such as acting in school plays. I was also a sports reporter to the local newspaper, and a high school correspondent for a local TV station.

I found myself repetitively dialling the radio station because I knew the answer to the questions being raised, and as a result I received innumerable free tickets to music and sports events. I understand now that my actions were symptoms of both OCD and ASD.

I felt anxious transferring to university, and not having any friends, I was lonely in the new environment. For the first couple of months my OCD reoccurred as part of my anxiety. It took me a couple of years in university to learn how to obtain consistent A's, but in the end I graduated with a Specialized Honours B. A. degree in Political Science, which allowed me to go on to law school.

I was scared about my transition to law school, because it meant moving to a different city. My father was told about co-op housing situated in a former manse next to a church, in close walking distance to the law school. He knew the minister, and asked him to keep an eye on me. As soon as I settled in I discovered that I would be expected to take turns in the cooking and housekeeping. I did not know how to cook and not knowing how to cope, I frequently called my parents in tears. A psychiatrist put me on a different medication – Prozac – and it calmed me down during the rest of my time in law school. During the three years I was there, I was frequently invited to the minister's home for meals, and preached a number of times to the congregation. I was also engaged in extra curricular activities such as participating in the Community Legal Clinic, the Wilson Moot Court National Competition, and as a member of the student council. I graduated with a JD degree (Juris Doctor) in 1996.

I then went on to the School of Social-Work. I experienced no problems until the summer before my second year, when my recurring thoughts of OCD reoccurred. This would last for four more years until I saw a psychiatrist who placed me on the drug Paxil. After finishing the Masters degree in Social Work, I articled at a law office for a year (articling is a term used by the Canadian legal profession to describe the required year internship in a law office before writing the exams for admission to the bar and becoming a certified lawyer).

I had excelled at all the jobs I had done before, such as working as a Constituency Assistant for a Member of Parliament, working one summer at a labor relations law firm conducting research, and a number of summers working as a program director for a drop in center for street people. However, when I articled for a year at a law office, I ran into serious organizational problems. I had trouble multi-tasking and remembering to do something that was asked of me by my employer. The year working at the law office was the first time I experienced my disability as a deficit. It was a rude awakening, but I went on to write the bar admission exams, and received the highest mark in the Management and Professional Ethics exam out of 1200 students in the province.

After becoming a lawyer, I decided to go on to business school for the MBA program, a degree in those years highly favoured as a door into permanent employment. After I graduated I applied for a job at the Ontario Ministry of Labor as a policy advisor, a very competitive position to obtain. I became anxious at work, had problems with organization, and my contract was not renewed.

I soon found work at the Accessibility Directorate of Ontario, a government agency focusing on making the province of Ontario accessible for people with disabilities. I was asked to be part of the legislative team as a senior advisor to work on the new legislation, which would set out a framework for the development of accessibility standards for access to goods, services, housing, and employment for people with disabilities. When the time came to apply for a permanent senior policy advisor job I didn't get an interview. I was very good at compiling detailed research and information, but not at project management, which was necessary to be a senior policy advisor. The lack of this skill relates to the absence of executive functioning.

I was known for having a strange sense of humor at work, and blurting out whatever came to mind, without thinking first. I would also be in the middle of a conversation where one topic was being discussed, and I would change it usually to what I wanted to talk about which was politics. I would usually spend my weekends sleeping instead of socializing, preferring to keep to myself.

Since my special interest was politics, I ran three times for school trustee for the Toronto School Board losing each time, but on the third try by only fifty-six votes. I ran for trustee over the course of seven years since my goal was to be a politician, but in the meantime I did not spend time trying to develop my competencies to be a senior policy advisor.

Project management being a challenge, I thought something was the matter with me. At times I thought I was incompetent, at other times I thought it was the medication that caused me not to be able to focus on multiple tasks.

The other area I struggled with was in my relationship with women. They were not usually interested in me. My first girlfriend was not until I was thirty-one. A couple of woman I dated expressed some concern regarding the fact that I did not have a large repertoire of life skills. After my accidents with the car I did not feel comfortable driving, and found cleaning and cooking challenging, and required assistance from my father with the housekeeping.

I was married to a PhD student when I turned forty-one. Problems quickly arose between us as I found it challenging to follow her requests for assistance, as I did not always understand what was required in completing a job, and found it difficult to focus on what was wanted by my wife. Many of the responsibilities had to be solely completed by her because I could not do them properly, from cutting vegetables, to packing for moving. I also had personal hygiene problems, not looking after my appearance such as getting a haircut or not shaving every day.

I remember watching a movie with my wife. It was a true story about a young man who had autism. It was a sad movie because his first romantic relationship did not work out, and as I watched I had no idea at the time that this condition was a part of me. In fact it was first suggested that I might be on the spectrum during marital counselling sessions. Sometime later, I was diagnosed as being on the spectrum through a couple of sessions of psychological testing at the age of forty-four.

I saw a counsellor when my wife and I were living in Toronto in an effort to help me better understand my autism, but I don’t believe it helped me. However, I did come to better understand routines and I can do such chores as laundry, washing and drying dishes, and walking my son to and from school. I can also read him an appropriate bedtime story and go on social outings with him. However, it still remains hard for me to plan ahead and set long-term goals. In the future, I would like to learn to plan better and cook meals.

As strange as it may seem to others, I see my autism in some ways as an asset. It makes me an interesting person, as I can recall lines from movies and novels, and I have a vast knowledge that I can share with others. I also see my disability as a deficit. I would have hoped to achieve more in my career, but then I suppose, what I am most interested in, is conducting research and analysis.

A career as a lawyer may have been a better fit, where I could have worked by myself, but my special interest is in policy and politics. I feel that my disability was an impediment in my marriage. But at the same time, I believe what **<u>Andy</u>** said: It's not a question of being unworthy, but of being incompetent, and working on ways to become more competent. And as **<u>Judy</u>** said: Once you know your identity, you can deal with it, and address your disability.

The main characteristics that I have experienced by being on the spectrum are a lack of executive function; life skills such as being neat and tidy; looking after personal hygiene and appearance; being able to pack things properly; a short-term memory; feeling anxious in new situations and environments; being introverted. On the positive side, my special interest in politics has led to a career in public policy with a focus on social justice. Common characteristics related to ASD, which I do not have, are concerns about sensory issues such as light, sounds, taste, and touch.

At fifty, I still haven't learned to manage the shortcomings of my autism. In this way, I feel behind people like **Dave** and **Bill** and **Judy**, who have had years of experience to address it. What can I be expected to do? This remains an unanswered question. The answer likely lies in trying to develop as many competencies as possible. My greatest weakness that I seem to have trouble changing is my lack of executive function.

Postscript

Since last writing those words I have some good news. I have been hired to work as a Legislative Analyst at the British Columbia Ministry of Social Development and Poverty Reduction. One of my roles will be working on the new accessibility legislation for people with disabilities in British Columbia, which will be followed by standards in accessibility for people with disabilities in such areas as Education, Transportation, the Built Environment, and Service Delivery to name a few.

I worked on the first accessibility legislation in Canada in Ontario in 2004, followed by the development of accessibility standards. Since that time the Canadian provinces of Nova Scotia and Manitoba have adopted legislation and now British Columbia. I have an apartment that overlooks the harbour, the Royal British Columbia Museum and the Empress Hotel in downtown Victoria, a three block walk to the building I work in. My office overlooks the harbour and the British Columbia Legislature. Everything I need for daily living is within walking distance, there is no need to use public transportation.

My supervisor Dr. Apple said that I would either have an academic position, or be in a government agency where I was more respected that I was before. He was right, but most of 2018 left me extremely anxious about having quit my job and doing a PhD, and wondering if I would have any future at all. My new manager continually reminds me how happy everyone is that I am working there. As a person with autism I am able to utilize my research skills and vast knowledge of a special interest I have, accessibility for people with disabilities.

Twenty years ago, conducting research at the Canadian Mental Health Association for my MBA degree, I came across an interview with Dr. Clarence Hincks, the founder of the organization, which occurred near the end of his life. His legacy to the world was raising over a billion dollars for work in mental health, changing the way we look at mental health in Canada. He was asked what drove him to accomplish the work of ten people in one lifetime. He said it was his empathy for the mentally ill through his own experience of a mental illness. He remarked that his affliction of regular bouts of depression was the single greatest asset of his life.

Until reading that story, I had always wanted to be normal. I recall telling my eight-year old son about autism and referencing “normal” people, and he said: “Daddy, nobody is normal, everyone is different. Look at me, I was born with a different toe that had to be operated on.”

What we all have in common are our differences. A democratic school is one that allows each student to utilize what is unique about us, and to make our own individual contribution to the world.

ABBREVIATIONS

AS	Autism spectrum
ADD	Attention deficit disorder
ADHD	Attention deficit hyperactive disorder
ADI-R	Autism Diagnostic Interview-Revised
AD0S-G	Autism Diagnostic Observation Scale-Generic
APA	American Psychiatric Association
ASC	Autism spectrum condition
ASD	Autism spectrum disorder
ASSQ	Autism Spectrum Screening Questionnaire
CBT	Cognitive behavioral theory
CDC	Center for Disease Control and Prevention
CESSA	Center on Secondary Education for Students with ASD
CNS	Cranial anomalies
DBT	Dialectical behavioral theory
DSC	Disability Services Center
DSM	Diagnostic and Statistical Manual of Mental Disorders
DT	Developmentally typical
EBP	Evidence based practices
ERT	Exposed response therapy
GPA	Grade point average
HFA	High functioning autism

ID	Intellectual disability
IEP	Individualized education plan
LGBTQ	Lesbian, Gay, Bi-sexual, Trans, Queer community
NAS	National Autistic Society
NCES	National Center for Educational Statistics
NIMH	National Institute for Mental Health
NCLB	No Child Left Behind Act
NPDC	National Professional Development Center
NT	Neurotypical
OCD	Obsessive compulsive disorder
PDP nos.	Pervasive development disorder, not otherwise specified
SDI	Specially Designed Instructions
SES	Socioeconomic status
SRS	Social Responsiveness Scale
TA	Teaching assistant
TD	Typically developed
TDA	Teacher development agency

INTERVIEWEES PERSONAL DATA

NAME	AGE	DIAGNOSIS	PARENTS	EDUCATION	CLASS	SIBLINGS
Amelia	21	18	Divorced	Nurse/Chemist	Middle	
Andy	21	12	Married	Both Engineers	U/Middle	sister
Audrey	22	12	Married	Service Industry	Middle	sister
Bill	19	2 ½	D/Re-Married	Technicians	Middle	T/ brother 2 S/Sisters
Dave	29	4-5	Married	PhD/Therapist	U/Middle	two
Jason	24	24	Married	Both PhD's	U/Middle	sister
Judy	20	12	Married	PhD/Master	U/Middle	sister
Kent	19	2	Married	MBA/BA	Middle	T/brother
Nan	20	17	S/Parent	F/deceased BA/MA	L/Middle	brother
Paul	19	19	Married	Both BA's	U/Middle	four
Tony	22	18	Separated	F/Computer/Tech	Middle	
Trudy	22	13	Married	BA/MA	Middle	