

Autobiographical Accounts from the Autism Spectrum

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### Abstract

This investigation of the autism spectrum disorder (ASD), a complex neurodevelopmental disability, and autism spectrum used a thematic content analysis to identify the topics, ideas, and concerns in twelve full-length autism autobiographies published between 1994 and 2012, with an eye toward the feasibility of using the autobiographies as teaching tools for students in pre-service clinical fields. Portions of text that were coded into content categories were counted within each book and summed across the books. The investigators identified 1,989 instances of text described by 18 different content categories, organized into five broad themes, which were represented across the books. The autobiographies varied in the degree to which they emphasized particular content. The authors conclude that these personal accounts can enhance the education of pre-service students in various clinical fields and provides them with the inside perspective of life on the autism spectrum.

*Keywords:* autism, Asperger syndrome, autobiographies, themes

### Autobiographical Accounts from the Autism Spectrum

The research reported in this paper was sparked by a student's question in a graduate course, "Speech, Language, and Communication in Individuals with Autism," taught by the first author of this article as part of an accredited master's program in the applied clinical field of speech-language pathology. The student posed the following query: "What do people with autism think about being autistic?" Not knowing the answer to that question, the professor suggested that the student read some first person accounts from the growing body of autism autobiographies. These autobiographies could complement the information in the traditional clinical literature found in textbooks and journal articles, which often emphasize the characteristics of the disorder from a deficit perspective and focus on clinical educational issues. Autobiographies are useful for teaching students about autism because they reflect the voice of the only true "autism experts" (Kluth, 2004, p. 43) providing rich examples of some clinical phenomena such as savantism (Draaisma, 2009). These autobiographies enable the reader to better understand the autistic experience and empathize with those on the spectrum (Bates, 2010). Embracing these autism autobiographies could expand students' "ports of entry" (Stern, 1995) by providing a relationally oriented perspective to enable students to more deeply understand, appreciate, and explore the accomplishments, identities, and culture of the population.

#### **Medical and Social Models**

Autism spectrum disorder (ASD) is a complex neurodevelopmental disability, with a prevalence of 1 in 59 children in the United States (Baio et al., 2014). The medical model of disability, which is grounded in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders-fifth edition* (2013) and its earlier editions, emphasizes disorders and

deviations from the norm, framing the condition as a problem. Too often, this notion of impairment is the dominant discourse in clinical education. *A Practical Guide to Autism* (Volkmar & Wiesner, 2009) and the *Handbook of Autism and Other Developmental Disorders* (Volkmar, Rogers, Paul, & Pelphrey, 2014) are examples of textbooks with this dominant deficit orientation. The social model of disability, in contrast, views autism as a naturally occurring human variation, which represents differences but not necessarily deficits (Kern- Stähler & Thiemann, 2015). The differences are relative to the characteristics of the so-called “neurotypical” population, a term for non-autistic people that originated with the neurodiversity movement (Brownlow, 2010). The neurodiversity perspective “focuses on overall quality of life, recognizes positive aspects of autism, and acknowledges autism as a human experience” (Tomlinson & Newman, 2017, p. 93). *Autism: A New Introduction to Psychological Theory and Current Debate* (Fletcher-Watson, & Happé, 2019) is an example of a textbook that is more aligned with the social model of disability since it includes the voices of those on the spectrum and their families. This resource provides a contemporary understanding of autism for students and practitioners who work in educational and clinical settings. Scholars in various fields including cultural and literary studies (Van Goidsenhoven, 2017), geography (Davidson & Henderson, 2010), gender studies (Jack, 2012), phenomenology and philosophy (Costa & Grinker, 2018) and disability studies (Couser, 2011) have explored autism autobiographies. Embracing diverse fields of inquiry expands and enriches students’ perspectives on the condition.

### **Autism Autobiographies**

Personal narratives, including full-length autobiographies, describe the experiences of those who have written their stories “in the context of family, culture, environment, and community”

(Garden, 2010, p. 22) and attend to “the personal, the specific, and the particular” (Kramp, 2004, p. 72). The growing subset of published “autie-biographies” (Rose, 2005) reflects the voices of those on the spectrum. First among these was Temple Grandin’s *Emergence* (1986), co-written with Rosemary Scariano, which was instrumental in laying the groundwork for later autism autobiographies (Foss, 2009). This genre provides a form of “autistic textual self-representation” (Rose 2008, p. 45) for those on the spectrum.

Published autism autobiographies also serve a non-autistic audience, wherein “the authors seek to ‘explain’ the condition” (Murray, 2008, p. 5). Costa and Grinker (2018) note that autistic individuals not only wish to explain themselves to others, but also why they behave in ways that others might consider atypical. In this way, published autism autobiographies create pathways of communication between those who are on the spectrum and those who are “off the spectrum” (Davidson & Henderson, 2010, p. 464). Pre-service students in various clinical or educational fields, such as the student mentioned in the opening paragraph of this article, would be a prime example of those who would benefit pedagogically from these narratives by exposure to an alternative discourse about disability. For example, Shore, claims that he wrote his autism autobiography to promote “greater mutual understanding among society of life on and slightly to the right of the autism spectrum” (2003, p. 184). In reflecting on writing her life story, Prince-Hughes notes, “many high-functioning autistic people, unable to communicate with others about the ringing swirl, shout across canons of reality by writing” (2004, pp. 25-26). The preference for written over spoken communication has been expressed by other autism authors including Williams, Willey, and Lawson (Van Goidsenhoven & Masschelein, 2016). Hacking suggested that “stories about people with autism, told by the people themselves” (2009, p. 1467) benefit

those who might have limited direct interactions with persons on the spectrum such as the graduate student mentioned at the beginning of this article.

### **Thematic Analysis**

Thematic analysis is a qualitative methodology, which focuses on the content of the narrative rather than its form or structure. This method of inquiry is well suited to understanding how a disability impacts the “feelings, beliefs, and attitudes of the affected person” (Maxwell & Satake, 2006, p. 247). In discussing various traditions of inquiry in qualitative research, Damico and Simmons-Mackie (2003) note that biographical study provides insight into historical, sociological, and cultural context of a person’s life history. A number of researchers have conducted qualitative thematic content analyses of autism autobiographies. Foss investigated several autism narratives including Grandin & Scariano’s *Emergence*, (1986), Prince-Hughes’s (2004) *Songs of the Gorilla Nation*, and Robison’s (2008) *Look Me in the Eye* noting that “the diagnosis seems to open up rather than delimit” the full potential of the authors (Foss, 2009, p. 11). Foss identified topics related to the diagnosis and the subsequent self-identification as someone on the spectrum. In addition, the analysis indicated that the authors wrote about their unique challenges, differences, strengths, resilience, and accomplishments.

Vincent et al. (2017) conducted a thematic content analysis of the unpublished autobiographies of eight university students with ASD, which identified the students’ concerns about their higher education experience. The students wrote about their difficulties in establishing social interactions with their peers, “unease and apprehension” in social situations, “nervousness, loneliness, and social anxiety” (Vincent et al., 2017, p. 309). Despite their challenges, the participants’ writing expressed a sense of optimism and resilience. In addition, Vincent et al. (2017) identified sensory issues as a major concern of university life-writers,

reporting that “for some students, sensory issues—loud noises, intense lighting, and overcrowding—created significant barriers to social interactions” (p. 309). Other investigators also noted the topic of sensory differences in autistic autobiographical writings. For example, using the works by four different autistic autobiographers, namely, Grandin (1986), Williams (1992; 1994), Mukhopadhyay (2000), and Tammet (2006), Hacking (2009) found that these works include information about these authors’ hypersensitivities. In addition, Conn (2015) found that sensory issues informed the development of play and friendship in the published autistic autobiographies that she analyzed, namely, Daniel Tammet’s *Born on a Blue Day*, Jen Birch’s *Congratulations! It’s Asperger Syndrome*, Wendy Lawson’s *Life Behind Glass*, Donna Williams’s *Nobody Nowhere*, Liane Holliday Willey’s *Pretending to be Normal*, Dawn Prince-Hughes’ *Songs of the Gorilla Nation*, and Jon Elder Robison’s *Look Me in the Eye*. Conn found that the autistic autobiographies revealed the various ways in which sensory rather than social aspects of play engage autistic children, concluding that the latter aspect of play was secondary to the former for these children.

The geographers Davidson and Henderson (2010) also identified the topic of sensory differences in various genres of autism writings including full-length autobiographies. One theme that emerged from their qualitative analysis was the emphasis on “difference” rather than a “deficiency, disability, and deviance” (p. 465). In addition, the investigators found that these writings consistently provide information about strategies for “sensory survival” (p. 466). Like other investigators, Davidson and Henderson note that some of the authors emphasize skills and strengths that are associated with autism, such as being detail oriented.

Causton-Theoharis, Ashby, and Cosier (2009) focused on the single topic of social interaction in seven autism autobiographies, four of which Conn (2015) analyzed, namely those

by Tammet, Williams, Prince-Hughes, and Robison. Causton-Theoharis et al. (2009) reported that these autistic authors' challenges in social interaction were related to their differences in the sensory domain noting that difficulties arose from "unconventional responses to sensory information," deep interests, and a need for predictability (Causton-Theoharis et al., 2009, p. 88).

Cognition is a domain that has been addressed in both the scientific literature on autism and in autism autobiographical analysis. Psychologists Happé, Briskman, and Frith (2001) suggest that people on the autism spectrum have a "central coherence deficit," which is a tendency to focus on smaller details at the expense of the larger perspective. In addressing this cognitive problem, Costa and Grinker (2018) note that several autistic biographies counter this notion. Drawing on personal accounts, including those by Blackman (2001), Higashida (2013), Mukhopadhyay (2011), Shore (2003), and Tammet (2006), the investigators provide evidence that these autistic individuals are, indeed, cognitively competent. For example, Shore's (2003) account includes his "experiences of 'agency,' 'authorship,' 'self-awareness,' 'self-knowledge,' et cetera" (Costa & Grinker, 2018, p. 168), abilities that are incompatible with a central coherence deficit in autism.

Dunn and Burcaw (2013) analyzed the published narratives of six individuals with different disabilities, including one with autism (as cited in Saperstein, 2010). Like the other investigators, these researchers used a thematic analysis to explore the writers' concerns. They reported that discrimination was a dominant theme in the narrative of the autistic author who "struggled through college and had difficulty securing and maintaining a job" (Dunn & Burcaw, 2013, p. 153) facing challenges in the social demands of higher education and employment.

The review of the above literature indicates that autism autobiographies provide insight into the topics, issues, and concerns of those on the spectrum. This suggests that this genre of



life writing could serve as a pedagogical tool to enhance pre-service clinical education. However, further research is warranted using additional books that were not previously investigated and additional categories. Several previous studies focused on only one topic, such as sensory issues, for example, Conn (2015), Davidson and Henderson (2010), Causton-Theoharis, Ashby, & Cosier (2009); or cognitive differences (Costa & Grinker, 2018). An investigation into a wider range of content areas expressed in the life writings of the autistic autobiographers is merited to explore the feasibility of using these books as a teaching tool to supplement textbooks and journal articles. Specifically, the present investigation analyzed the themes and content categories in twelve autism autobiographies, four of which have not been previously analyzed, with an eye toward determining if this genre of life writing could be a tool for teaching students in applied clinical fields. The investigators approached the analysis of the autism autobiographies without *a priori* pre-determined categories. The research was focused on exploring the following questions:

1. What consistent topics, ideas, and concerns emerge in selected autism autobiographies?
2. Which categories are most prevalent in particular autism autobiographies?
3. Which broad-based themes capture the content of the autobiographies?

## **Methodology**

### **Autobiography Selection**

The database for this research consisted of twelve autobiographies written by adults with autism and published in English between 1994 and 2012 (see Table 1), the years in which Asperger's disorder appeared the *Diagnostic and Statistical Manual of Mental Disorders-fourth edition* (American Psychiatric Association, 1994). The titles of eight of the books indicate that their

authors had Asperger's syndrome (AS), which is referred to as Asperger's disorder in the medically oriented literature. The other four titles specified that their authors had autism. Seven authors were female and five were male. The age of the authors at the time of publication ranged from 28 to 57 years. Books written by those who had not reached adulthood by the time of publication were excluded. Only books written in English were included. The list of included autobiographies emerged organically from a combination of investigator familiarity, student interest, colleague recommendation, and autism advocacy organization websites. The books were published when the course referred to in the introduction was offered. The investigation included four autobiographies that were not previously analyzed. Collections of autobiographical essays, poems, letters, and online discussions were excluded. The selected books ranged in length from 118 to 295 pages. Table 1 lists the citation for the twelve books, the age of the authors at the time of publication, and the dominant categories that appeared in each book.

**<Refer to table 1>**

### **Analysis Procedures**

This research blended qualitative and quantitative analysis procedures. The qualitative analysis sought to identify recurrent content categories based on procedures described in Maxwell and Satake (2006), and was conducted in stages described in Braun and Clarke (2006). The analysis did not begin with a list of preconceived categories that appeared in previous autism autobiographical research. Rather, the authors developed the categories based on what emerged from their reading of the texts. At the time of the course, neither the instructor nor the students were familiar with the research literature on autism autobiographies. This project developed spontaneously out of student interest in a graduate level course. The first author of this investigation and two graduate students enrolled in the course (a) each read four of the

autobiographies, namely, Prince-Hughes (2003), Robinson (2008), Tammet (2007), and Williams (1994) and tagged sections of the text noting initial topics or ideas; (b) generated initial codes from the identified segments collating relevant data; (c) identified potential topics categories from the coded data; (d) reviewed the categories and recoded the data as necessary; (e) defined and named the categories, and (f) organized them into broader, hierarchical themes. For example, in the first reading of Robison (2008), the first investigator put topics, events, and concerns on a list, which eventually evolved into 18 categories that were identified across most of the books. The list included topics such as difficulty having conversations, engaging in small talk, understanding the thoughts and feelings of others, and understanding nonliteral language. These topics were collapsed into the speech-language category, which was subsumed under the broader, hierarchical Differences theme.

The quantitative methodologies used in this study consisted of the process of counting the number of instances of text that fell into the specific categories and broader themes. The entries were counted within each book and summed across books. Absolute and proportional frequencies were calculated for each category and theme.

**Coding Forms.** The first author developed a template that included 18 categories that were subsumed under five broad themes. The coding form assisted in the organization of examples of text that represented the categories and their eventual quantification. One coding form was used for each autobiography. The coding form listed key phrases that aided in identifying the categories. For example, the phrases “early indicators” and “receiving a label” were written on the coding form for the diagnosis/identification category. The page and line number where the selection of relevant text began were entered on the coding form. The codes captured most of the content of each book. The length of the portions of continuous text that

reflected a particular category varied from a single paragraph to a few pages. The template that was used for coding appears in the Appendix.

**Verification and Reliability of the Coding.** Reliability of the coding was ascertained by having two readers independently code the same four autobiographies, namely Lawson (2000), Paradiž, (2002), Robison (2008), and Shore (2003). Using the formula number of agreements/(number of agreements + disagreements) X 100, reliability was 92%. In addition, ten readers, who were graduate students enrolled in an autism certificate program and trained on the coding system in a subsequent semester, were asked to identify five instances for each of the 18 categories from one of five of the selected autobiographies, namely, Lawson (2000), Paradiž, (2002), Robison (2008), Shore (2003), or Willey (1999). The ten student readers verified the codes by identifying five instances of text for each of the 18 categories. Their successes in identifying such examples suggest the psychological reality of the codes.

## **Results**

### **Data**

The readers identified 1,989 examples of text in the books that were organized into 18 different categories subsumed under five broad themes. Figure 1 provides a visual overview of the organizational framework for the data analysis.

**< Refer to figure 1 >**

The first research question asked what consistent topics, ideas, and concerns emerged in the autism autobiographies; these categories are listed in table 2, with their descriptions and examples from the texts.

**< Refer to table 2 >**

**Hierarchical Themes.** The third research question asked which broad-based themes capture the content of the autobiographies. Five themes captured the 18 categories that emerged from the readings. The *Differences* theme included the cognitive, speech-language, behavioral, sensory, deep interests, and medical categories. Differences were conceived relative to neurotypicals, a term that originated with the neurodiversity movement (Brownlow, 2010). The *Psychosocial Dynamics* theme consisted of the interpersonal relationships, social concerns, and psychological concerns categories. The *Strengths-based Perspective* theme consisted of the accomplishments, resilience, and coping strategies categories. The *Pedagogy* theme consisted of the didactic mode, autism identities and culture, and historical perspectives categories. The *Clinical-educational Experience* theme consisted of the diagnosis/identification, services/treatment, and disclosure/advocacy categories. Figure 1 contains the number and percent of instances of the 18 categories within and across the five themes across all books. The Differences theme was the most prevalent, accounting for 42% of the data. The four remaining themes, Psychosocial Dynamics, Strengths-based Perspective, Pedagogy, and Clinical-educational Experience, together accounted for 58% of the remaining data in descending frequency of occurrence.

The 18 content categories were well represented across the autobiographies. Three of the books, all written by authors with Asperger's Syndrome (AS), demonstrated all of them (Carley, 2008; Hammond, 2010; Shore, 2003) and three included 17 (Birch, 2012; Paradiž, 2002; Prince-Hughes, 2004). Two of the books incorporated 16 of the categories (Robison, 2008; Williams, 1994) and four contained 15 (Finch, 2012; Lawson, 2000; Tammet, 2007; Willey, 1999). These results indicate that the content categories recurred across the selected autobiographies

suggesting that, in answer to the first research question, the narratives do contain consistent topics, ideas, or concerns.

Certain autobiographies varied in their focus on a particular category. For example, Birch (2003) contained 51 instances of the cognitive differences category. In fact, all six categories within the Differences theme were prevalent throughout her book. However, Birch's focus on the Pedagogy theme was limited, as her autobiography exhibited no instances of autism identities and culture, a category within that theme. In contrast, Carley (2008) emphasized autism identities and culture with 22 instances of that category, but the cognitive differences category was coded only twice. Other categories within the Differences theme were less prevalent in his book suggesting that these were not dominant (see Table 1). The second research question asked which categories are most prevalent in the autism autobiographies. The answer to this question allowed for the identification of books that align with particular aspects of autism. Table 1 lists the three most dominant categories for each autobiography, with their proportional frequency of occurrence within that book.

## **Discussion**

### **Analysis, Clinical-educational Implications, and Limitations**

This study analyzed twelve autism autobiographies published between 1994 and 2012, the years when Asperger syndrome was part of the *DSM-IV* (American Psychiatric Association, 1994). This period was characterized by greater public awareness about autism and Asperger syndrome (Heilker & Yergeau, 2011), a growing respect for differences (Bates, 2010; Brownlow, 2009), increased recognition of neurodiversity (Van Goidsenhoven & Masschelein, 2016; Brownlow, 2010), an established disability rights movement (Solomon, 2008), and the proliferation of autism advocacy organizations (Solomon, 2008). In terms of the literature

reviewed, this investigation, not surprisingly, found some of the same categories that were identified in previous autism autobiographical research that analyzed some of the same stories — Birch's *Congratulations! It's Asperger Syndrome*, Lawson's *Life behind Glass*, Prince-Hughes' *Songs of the Gorilla Nation*, Robison's *Look Me in the Eye*, Shore's *Beyond the Wall*, Tammet's *Born on a Blue Day*, Willey's *Pretending to be Normal*, and Williams's *Somebody Somewhere* (Causton-Theoharis, Ashby, & Cosier, 2009; Conn 2015; Costa & Grinker, 2018; Duffy & Dorner, 2011; Hacking, 2009; Murray, 2008). The current study, consistent with previous investigations, identified themes such as Differences (Foss, 2009), especially sensory issues (Causton-Theoharis, Ashby, & Cosier, 2009; Conn, 2015; Davidson and Henderson, 2010; Vincent et al., 2017), accomplishments and resilience (Foss, 2009; Vincent et al., 2017), social concerns and interpersonal relationships (Causton-Theoharis, Ashby, & Cosier, 2009; Vincent et al., 2017). The categories of diagnosis and identification as well as autism identities and culture were also previously investigated, although in only one previous study (Foss, 2009).

Four of the autobiographies analyzed for this research (Carley's *Asperger from the Inside Out*, Finch's *Journal of Best Practices*, Hammond's *My Life with Asperger's*, and Paradiž's *Elijah's Cup*) had not been previously investigated. Based on our search of the extant literature, this was the first study to analyze those autobiographies. Paradiž wrote primarily about cognitive, speech-language, and sensory differences. Hammond and Finch highlighted interpersonal relationships. Finch and Carley emphasized various coping strategies used to address challenges. Carley wrote didactically with an eye toward explicitly informing his audience about some aspect of autism and Asperger syndrome. Paradiž and Carley emphasized autism identities and culture.

The results of this research indicated that the selected autism autobiographies contain consistent, recurrent themes that could increase students' depth of understanding of autism. The twelve autobiographers investigated here wrote mostly about their differences, which accounted for 42% of the thematic content in the present study. Six categories were subsumed under the Differences theme whereas only three categories were subsumed under each of the other four themes. The larger number of categories subsumed under the Differences theme could account for the greater number of instances of that theme relative to the other four which each had three categories. However, even if the number of instances in the Differences theme ( $n=836$ ) were halved ( $n=418$ ), it would still be the theme with the largest number of instances.

The background literature reviewed for this study reported some similar findings regarding the Differences theme. For example, Davidson and Henderson's (2010) work on full-length autobiographies and collections of personal stories focused exclusively on sensory issues. Hacking (2009) reported that the four autistic autobiographers he studied wrote about their sensory experiences and behaviors. These two categories accounted for 13.3% of the data in the present study and appeared with greater frequency in four of the autobiographies, namely, those by Birch (2010), Lawson (2000), Paradiž (2002), and Tammet (2007).

Although the categories that emerged from the life stories were not pre-determined, some of those that were identified upon reading the texts reflected its authors' clinical backgrounds in the field of speech-language pathology. For example, the diagnosis/identification and services/treatment categories subsumed under the Clinical-educational Experience theme were familiar constructs for the investigators. However, the researchers did not anticipate disclosure/advocacy, the other category in Clinical-educational Experiences theme, which seemed to reflect the autistic authors' *inside* perspective and an important topic in disability



studies. Similarly, the three categories subsumed under the Strengths-based Perspective theme, namely accomplishments, resilience, and coping strategies, reflected the voices of those on the spectrum. Thus, the analysis of the twelve selected texts reflected both the *outside* clinical and the *inside* autistic perspectives.

Despite their training as speech-language pathologists, the authors of this study attempted to minimize the ableist, normative language of “differentiation and division” (Duffy & Dorner, 2011, p. 211) that typifies much of the clinical literature based on the medical model. Instead, they endeavored to frame the content of the autobiographies in the language of neurodiversity, “embracing a wide range of neurological makeups, autistic being one of them” (Brownlow, 2010, p. 252). For example, one of the core characteristics of autism is the presence of repetitive behaviors and restricted interests (American Psychological Association, 2013). This notion of “restricted interests,” which is framed in a deficit perspective, can be conceived in terms of “deep and focused interests” (Paradiž, 2012, p. 71), talents that could develop into life-long careers or hobbies (Grandin & Duffy, 2008). This view echoes Prizant’s (2015) observation that what some might call autistic obsessions can be viewed as “passions.” In addition, the authors decided to use “Speech-Language Differences” as a category rather than the *DSM-5* characterization of the other core characteristic of ASD as “deficits in social-emotional reciprocity and nonverbal communicative behaviors” (American Psychological Association, 2013, p. 50). Embracing alternative representations of autism as an example of neurodiversity, rather than impairment, has broad connections to the disability literature and the social model (Brownlow, 2007).

### **Clinical-educational Implications.**

Knowing which books relate to specific content areas could interest pre-service clinical students in preparing for different fields. For example, psychology students might find the life-stories that emphasize cognitive or behavioral difference as particularly relevant to their education, such as those by Birch (2012), Lawson (2000), Tammet (2007), Willey (1999), and Williams (1994). Psychology, social work, and education students might also benefit from reading the works by Finch (2012) and Lawson (2000), which emphasize interpersonal relationships and social concerns. Speech-language pathology students, such as the one mentioned in the opening paragraph of this article, could benefit from reading the books by Finch (2012), Paradiž (2002), Robison (2008), Tammet (2007), and Willey (1999), which emphasize speech-language differences. Both speech-language pathology and psychology students could learn from Tammet's (2007) autobiography, which emphasizes the cognitive, behavioral, and speech-language categories of difference. Career counsellors and disability service providers in university settings might be interested in autobiographies that focus on deep interests, such as the one by Birch (2003), which could guide individuals on the spectrum to explore career choices that capitalize on their passions and strengths, with an eye toward steering them toward meaningful work. This becomes important in light of the fact that individuals with autism are usually unemployed or underemployed (Hendricks, 2009).

Not surprisingly, Clinical-educational Experience was the theme least emphasized across the twelve books. This suggests that, although autistic autobiographers wrote extensively about their differences, they wrote less frequently about the clinical-educational management of those differences. This finding was consistent with the themes in the Brownlow's analysis of asynchronous online discussion among subjects on the autism spectrum who rejected the idea of making people "more normal" and "less autistic" through therapeutic intervention (Brownlow &

O'Dell, 2009, p. 7). The only autism autobiography analyzed in this study that highlighted the process of diagnosis and identification was Hammond's (2010). The related topics of services, treatment, disclosure, and advocacy together accounted for only 4.3 % of the content across the twelve books. In contrast, the autistic autobiographers wrote more often about their resilience, accomplishments, and coping strategies adopting a strengths-based perspective on their lives, which accounted for 16.1% of the content across books. Narratives by Carley (2008) and Shore (2003) were notable for their use of the didactic category in which they explicitly provided their readers with information about the autism spectrum.

The autobiographical accounts analyzed for this study provide insight into autism identities and culture, especially the books by Carley (2008) and Paradiž (2003). The autobiographies by Prince-Hughes (2004), Robinson (2008), and Shore (2003) refer to their accomplishments more frequently than in the other books. Further, all of these authors shed a positive light on autism with their emphasis on difference rather than disorder or disability. Reading about the accomplishments and resilience of others on the spectrum fosters positive self-identities and garners increased understanding from those who inhabit the neurotypical world. The books by Carley (2008) and Finch (2012) expose the reader to the coping strategies they used successfully to navigate challenging situations. Finally, these stories can offer those with autism and their significant others a greater understanding of life on the spectrum. In referring to his own autobiography, Stephen Shore (2003) states

...if this work has assisted even one person in developing a more meaningful relationship with a person on the autism spectrum; if only one person with autism had been helped—then I have achieved my goal of developing more understanding and building bridges to a better tomorrow. (p. 184)

In discussing the creation of natural critical learning environments in higher education, Bain (2004) notes that students in clinically oriented programs such as speech-language pathology learn best when confronted with “real clinical cases” (p. 106). Davidson and Henderson (2010) note “an original work is almost always the richest source of insight” (p. 473) and provides a “contextualized and complex” (p. 473) approach to understanding the nature of the differences in individuals with autism. In teaching about varied disabilities, Smead (1999) provides her university students with “specific people in specific situations” (p. 79). Smith-Chandler and Swart (2014) note that disability narratives challenge negative stereotypes. The twelve autobiographies analyzed for the present study could serve as teaching tools on the university level. They encourage students to think critically and broadly about autism in relation to a variety of clinically oriented academic disciplines, such as education, psychology, and speech-language pathology. A specific book could be selected as a common read, which all students discuss. Alternatively, individual students or small groups could read different books, sharing their reactions, thoughts, and impressions with other members of the class. A template such as the one developed for this investigation could be used to guide their reading, or students could develop their own analytic tool.

Personal narratives have gained wider acceptance in the medical, clinical, and educational fields as a means of training future professionals. Autism autobiographies, including those that are commercially successful, have de-stigmatized autism and contributed to broader views of neurodiversity that benefit all (Van Goidsenhoven & Masschelein, 2016). Of note, three of the autobiographies that were analyzed for this research appeared on *The New York Times* Best Sellers list (i.e., Finch, 2012; Robison, 2008; Tammet, 2007) and some autism autobiographies are in their second edition (e.g., Shore, 2003; Tammet, 2007; Willey 2015). A

revised edition of *Elijah's Cup* (Paradiž, 2002) was published in 2005. For further discussion regarding the relationship of publishing to autism autobiographies the reader is referred to Garden (2010), Rose (2008), and Van Goidsenhoven and Masschelein (2016).

**Limitations.** This research used a small sample size since it involved only twelve autism autobiographies, all published in English and written by speaking adults on the spectrum. More individuals with autism had written their stories (e.g., Blackman, 2001; Gerland, 2003; Hammerschmidt, 2008; Mukhopadhyay, 2000; 2008; Sanders, 2004; Saperstein, 2010) by the time this research began, but a decision was made to limit the number analyzed (see Rose 2005, for additional titles) to make the analysis of data more manageable within a reasonable time frame. An additional limitation is that autism autobiographies represent only those who are verbally and cognitively able to convey their experiences eloquently in written text, consequently excluding those who are unable to express themselves through conventional written language. This limits the generalizability of the findings because the sample is not representative across the broad spectrum of individuals with ASD. This factor also results from the non-random selection of autism autobiographies. Further, only one genre of autobiographical writing, the book-length narrative, was analyzed for this study. Collections of essay-length personal accounts by persons with autism (e.g. Grandin 2012; Perner 2012; Prince-Hughes 2002) and other genres of writing such as poetry and blogs (e.g., *The Aspie Life* (Soraya, 2019), *The Autism Diva* (2018), and *Whose Planet Is It Anyway?* ("abfh," 2010) were excluded from the study and merit their own review. Duffy and Dorner (2011) note that blogs and You Tube videos, such as Amanda Baggs's (2007) *In My Language* video, provide additional venues for "autistic presence" (Murray, 2008), as do the some autism advocacy websites (e.g. Autistic Self Advocacy Network (ASAN, 2019) and Autism Network International (2011). Brownlow's (2007) study of online

discussions by people on the autism spectrum revealed that diagnosis including self-diagnosis, therapeutic interventions, and autism spectrum identities were among the topics in Internet discussions.

### **Future Research**

Future research should involve analysis of additional autism memoirs including those written in languages other than English, those by adolescent authors, authors from diverse backgrounds, non-speaking authors, and those who co-authored with parents. In addition to the full-length autobiography, other narrative forms, such as essay-length accounts, should be investigated. Future research would evaluate the generalizability of the content categories, themes, and organizational framework described here to study other autism autobiographies and, perhaps, other forms of life writing. That framework should be evaluated for applications and adaptations in a variety of courses including clinical/educational practicum seminars and independent studies. Students who read similar texts or other genres of narrative would evaluate or even revise the framework. Students would identify particular aspects of the disability about which they had limited knowledge prior to reading the personal account and report how reading the autobiography shifted or expanded their thinking. Future research would also identify additional categories that could be classified as strengths, such as different areas of accomplishment and various types of coping strategies. In addition, because the Differences theme was so large, additional studies can seek to distinguish those differences that are strengths from those that are challenges.

Future research should also examine the age of the authors at the time of diagnosis, as this could be a mediating variable that impacts the broad-based themes and categories. For example, diagnosis as an adult versus as a child would impact the receipt of services and

treatment, coping strategies, interpersonal relationships, as well as psychological and social concerns. Age of diagnosis would have had a potential role in the results of the present investigation and warrant future research. Similarly, differences in age of diagnosis or self-diagnosis of authors with Asperger's syndrome as compared with ASD may have influenced their experiences with the broad-based themes and categories such as clinical-educational experience. Future research should also focus on students' responses to the autobiographies in terms of how they expanded their views of this disability and the ways in which they found them helpful, insightful, and complementary to textbooks and other traditional sources of information.

### **Summary and Conclusions**

This study consisted of a thematic content analysis of twelve full-length autism autobiographies published between 1994 and 2012. Eighteen categories and five broad themes captured the content of these books. The autistic autobiographers wrote most frequently about their differences and least frequently about their clinical-educational experience. The strengths-based perspective of these autobiographies provides readers with the inside perspective of life on the autism spectrum and can enhance pre-service clinical education in various fields. The authors of this study join autobiographer and autism advocate Liane Holliday Willey (1999) with hope that

...as society continues to break the boundaries of normal, the boundaries so many cannot see and so many cannot find, this blight which robs good people of growth and happiness will ebb into a distant hollow, unseen and forgettable. And then, maybe then, the world really will welcome all people (p. 75).

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Table 1.

The citations for the twelve autobiographies used in the study with authors' age at the time of publication and dominant categories with their proportional frequencies by book.

Title	Age	Dominant Categories
Birch, J. (2012). <i>Congratulations! It's Asperger Syndrome.</i> London, UK: Jessica Kingsley Publishers.	57	Cognitive Differences, 37.5% Deep Interests, 18.4% Behavioral Differences, 16.9%
Carley, M J. (2008). <i>Asperger's from the inside out: A supportive and practical guide for anyone with Asperger's syndrome.</i> New York, NY: Penguin Group.	43	Coping Strategies, 13.5% Autism Identities and Culture, 11.5% Didactic Mode, 8.9%
Finch, D. (2012). <i>Journal of best practices. A memoir of marriage, Asperger Syndrome, and one man's quest to be a better husband.</i> New York, NY: Scribner.	34	Interpersonal Relationships, 18.5% Speech-Language Differences, 13.9% Coping Strategies, 12.6%
Hammond, M. (2010). <i>My life with Asperger's.</i> Sydney, AU: New Holland Australia.	38	Diagnosis and Identification, 11.3% Social Concerns, 11.3% Interpersonal Relationships, 9.3%
Lawson, W. (2000). <i>Life behind glass: A personal account of autism spectrum disorder.</i> Philadelphia, PA: Jessica Kingsley Publishers.	48	Behavioral Differences, 14.4% Social Concerns, 9.6% Cognitive Differences, 9.6%
Paradiž, V. (2002). <i>Elijah's cup: A family's journey into the community and culture of high-functioning autism and Asperger's syndrome.</i> New York, NY: The Free Press.	39	Speech-Language Differences, 14.9% Autism Identities and Culture, 12.8% Sensory Differences, 8.8%
Prince-Hughes, D. (2004). <i>Songs of the gorilla nation: My journey through autism.</i> Goshen, NY: Harmony.	40	Interpersonal Relationships, 12.4% Coping Strategies, 11.4% Accomplishments, 8.6%
Robison, J. E. (2008). <i>Look me in the eye: My life with Asperger's.</i> New York, NY: Random House.	51	Accomplishments, 13.6% Speech-Language Differences, 13.6% Interpersonal Relationships, 12.1%
Shore, S. M. (2003). <i>Beyond the wall: Personal experiences with autism and Asperger syndrome, second edition.</i>	42	Didactic Mode, 17.6% Cognitive Differences, 9.1% Accomplishments, 7.5%

<p>Shawnee Mission, TX: Autism Asperger Publishing Company.                  Tammet, D. (2007).  <i>Born on a blue day: Inside the extraordinary mind of an autistic savant.</i>                  New York, NY: The Free Press.</p>	<p>28</p>	<p>Cognitive Differences, 16.5%                  Behavioral Differences, 13.2%                  Speech-Language Differences, 10.8%</p>
<p>Willey, L. H. (1999).  <i>Pretending to be normal: Living with Asperger's syndrome.</i>                  Philadelphia, PA: Jessica Kingsley Publishers.</p>	<p>56</p>	<p>Cognitive Differences, 23%                  Coping Strategies, 11.3%                  Speech-Language Differences, 10.8%</p>
<p>Williams, D. (1994).  <i>Somebody somewhere: Breaking free from the world of autism.</i>                  New York, NY: Three Rivers Press.</p>	<p>31</p>	<p>Cognitive Differences, 13.3%                  Interpersonal Relationships, 11.9%                  Speech-Language Differences, 11.9%</p>

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Table 2. Dominant Categories, with descriptions and examples from Table 1 texts the autobiographies

Category	Description	Example
Differences		
Cognitive Differences	Challenges in planning, organization, attention, abstract thinking, perspective taking, and generalization; visual processing strengths	"Of course, it's important to learn how to consider others, but all I could feel was my need. I still find it very difficult to put myself 'in the other person's shoes.' I can only feel my needs and myself – everything outside is foreign and alien to me" (Lawson, 1998, p. 113).
Speech-Language Differences	Reference to any aspect of the form, content, or social-pragmatic aspects of speech, language, or communication; challenges in expressing self or in understanding others.	"Speaking was, for me, often slow and hesitant, as I had to translate from my pictures to words, but this became a problem only when I was pressured and rushed by other people to hurry up. As soon as anyone put this kind of pressure on me, my mind would freeze and I would be totally unable to do the translation into words" (Birch, 2003, p. 118).
Behavioral Differences	Reference to observable repetitive behaviors; motor clumsiness; need for structure and routine; dislike of change	"By the spring, I had settled firmly into my life in Lithuania. I had gradually sense of calm and security and that helped me cope with change" (Tammet, 2007, p. 135).
Sensory Differences	Reference to any of the sensory domains including the auditory tactile, visual, olfactory, kinesthetic, or proprioceptive; sensory seeking or avoidance	"Time to shave. No, I don't shave. Shaving feels like a power sander scraping my skin. As a result, I've had a beard almost from the time I first needed to shave. Using a razor hurt terribly" (Shore, 2003, p. 1).
Deep Interests	Reference to talents, hobbies, passions, and savant skills	"He became compelled by balloons, the same way he had been so mesmerized by the clown's top hats. This balloon fixation became a perilous right of passage toward renewed stability" (Paradiž, 2002, p. 111).

Medical Characteristics	Reference to genetics, heritability, seizures, and other co-morbid conditions	“Is there anyone else in the family like me?” I asked him. My father smiled to himself. “There is?” I prompted. “Yes there is,” he replied, a bit embarrassed. “You have a cousin who was a bit like you. She hardly spoke and hid behind her hand till she was about eight” (Williams, 1994, p. 51).
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Psycho-Social Dynamics

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Interpersonal Relationships	Reference to relationships including those with siblings, parents, spouse, intimate partners, friends, and any significant others	"My AS behaviors – the sensory integration problems, literal mindedness, perseverance, and rigid thinking tendencies – acted like arrows tipped in poison and ready to pierce every relationship I ever found" (Willey, 1999, pp. 78-79).
Social Concerns	Reference to the effect of autism on the individual’s social life including, but not limited to, bullying, college life, and employment	"I find that I am only part 'human' and very much something altogether different; I am overwhelmed by the social demands of 'normal life'; and I am lonely" (Prince-Hughes, 2004, p. 85).
Psychological Concerns	Reference to anxiety, depression, alienation, frustration or self-esteem	"I have lost so many weeks, days, even years of my life because of the black hand depression holding me at its claws. It is like deep night totally surrounding me. Life passes by, and I am lost in a time warp. Life stands still. I am trapped, frozen within myself" (Hammond, 2010, p. 87).

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Strengths-based Perspective

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Coping Strategies	Self-discovered or learned adaptations that allow the individual to successfully handle a challenging situation	"Over the years, I have learned some ways to compensate. When I know ahead of time that I’ll encounter in a particular situation, I can prepare. I have a strong tendency to assume characters—versions of myself that are optimized for the social environment at hand. Conversations must be scripted, facial expressions rehearsed, personalities summoned. This strategy has enabled me to succeed at work and in school and to do well enough socially" (Finch, 2012, p. 11).
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Accomplishments	Reference to occupational or educational achievements in education or employment	"I had recited 22,514 digits of pi without error in a time of five hours and nine minutes to set a new British and European record" (Tamm, 2006, p. 185).
Resilience	Reference to cultivating and recognizing strengths; resourcefulness; acceptance; optimism	"I believe having Asperger's does not make me any less than anyone else in the sight of God, or that I am weaker as a result of that. Maybe it even proves that I am stronger and tougher than the average person. I am who I am no matter what happens" (Hammond, 2010, p. 63).

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Pedagogy

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Didactic Mode	Reference to some aspect of ASD that informs or explicitly teaches the reader	"Asperger's exists along a continuum – some people exhibit the symptoms to such a degree that their ability to function alone in society is seriously impaired. Others, like me, are affected mildly enough that they can make their own way, after a fashion" (Robison, 2008, p. 4).
Autism Identities and Culture	Reference to "spectrumites" or "neurotypicals," autism self-advocacy organizations, or renowned people with ASD	"This is a common theme I hear among autistic adults who feel the constant pressures of having to pretend to be normal. As an activist, Jim [Sinclair] is invested in preserving authenticity in autistic communication, which is sometimes threatened by neurotypical preoccupation with the "deficits" (Paradiž, 2002, p. 181).
Historical Perspective	Reference to Kanner, Asperger, or others who made historical contributions to autism; earlier views of disability; disability rights	"Autism was first defined by American child psychiatrist Leo Kanner back in 1943. And to a less-publicized degree, autism clinician Hans Asperger identified Asperger's syndrome only one year later in 1944" (Carley, 2008, p. 33).

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Clinical-Educational Experience

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<p>Diagnosis and Identification</p>	<p>Reference to early indicators or red flags; self-awareness of being autistic; process of diagnosis; receiving a label; misdiagnosis</p>	<p>"To say that this discovery was a bombshell would not be an exaggeration: it was a life-changing event. It reinterpreted most of my life in a new, understandable, and logical way...it helps 100 percent to know <i>why</i> I am different – instead of having to think, as I did before meeting Angela Arnold, that I was 'crazy,' 'stupid,' 'not able to get it all together'" (Birch, 2003, p. 199).</p>
<p>Services and Treatment</p>	<p>Reference to any type of therapeutic intervention or educational experience; includes school (K-12) or any type of therapy</p>	<p>"After eight months, and preparing myself to leave the ward and re-join the outside world, I felt no more capable of this than before. In fact, I was in some ways even more confused about social life than before, due to living in such an inexplicable environment." (Birch, 2003, p. 128).</p>
<p>Disclosure and Advocacy</p>	<p>Informing others about one's autism for the purpose of obtaining supports and accommodations</p>	<p>"Personally, I believe in full disclosure. I have never hesitated to tell anyone and everyone as much as I know about AS, particularly as it affects my life today" (Willey, 1999, p. 123).</p>

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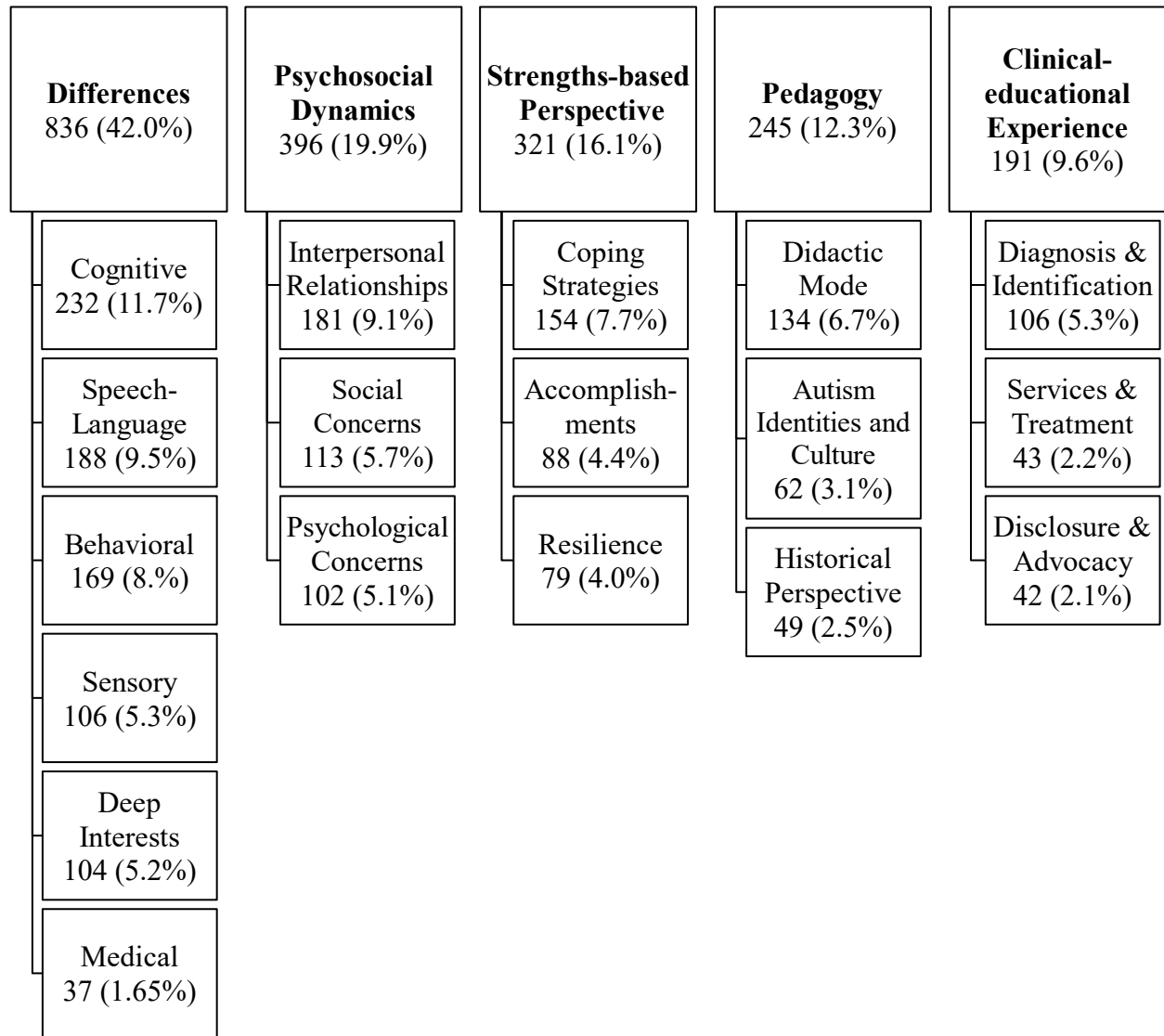


Figure 1. The category by theme organizational framework that emerged from the autobiographies with the number and percent of instances of each category across the twelve books

Appendix

Example of a blank coding form

Complete book citation: \_\_\_\_\_

Coding Form			
Categories	Example from the Text	Page (Line)	Topics Helpful in Identifying the Theme
Cognitive			Learning style including visual processing Planning Organization Abstract thinking Generalization
Speech/Language			Form, content or social-pragmatic aspects of speech, language, or communication Difficulty expressing self or understanding others' thoughts and feelings including nonliteral-language Having conversations Engaging in small talk
Behavioral			Repetitive movements Dislike of change Need for structure
Sensory			Hyper sensitivity Hypo sensitivity Sensory seeking Sensory avoidance
Deep Interests			Talents Hobbies Passions Savant Skills
Medical			Seizures Co-morbidity Genetics Heritability
Interpersonal Relationships			Familial relationships with parents, siblings, spouse, partner, children Non-familial relationships with employer, co-workers, colleagues, friends, acquaintances



Social Concerns			Employment School/college Bullying Isolation
Psychological Concerns			Anxiety Depression Alienation Frustration Self-esteem
Coping Strategies			Self-discovered or learned adaptations Ways of handling challenging situations
Accomplishments			Occupational achievements Educational achievements Personal achievements
Resilience			Positivity Optimism Resourcefulness Recognizing strengths
Didactic Mode			Reference to some aspect of ASD/AS to teach the reader Explicit information about ASD/AS
Autism Identities and Culture			Reference to spectrumites or neurotypicals Autism advocacy organizations or groups Renowned contemporary persons with ASD/AS
Historical Perspective			Reference to Kanner, Asperger, Bettelheim, Wing, etc. Views of disability Disability rights
Diagnosis and Identification			Early Indicators Receiving a Label Diagnosis/misdiagnosis Self-awareness of being autistic
Services and Treatment			Therapy Intervention Treatment Educational/school experience
Disclosure and Advocacy			Informs others about one's own autism to share diagnosis or obtain supports/ accommodations