

Successful Transitions to Adulthood: Learning from the Autobiographies of People with Autism Spectrum Disorder

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Most people's transition from adolescence to adulthood is marked by new changes and challenges. One might expect that the transition into adulthood of people diagnosed within the autism spectrum would be uniquely challenging, considering symptoms like marked impairments in social interaction and communication. Few studies, however, have concentrated on the internal states and points of view of individuals with ASD. The increasing number of autobiographies written by people with ASD represents a virtually untapped resource of insight into the personal experiences of people with ASD. This study qualitatively analyzed autobiographical material written by people with ASD to shed light on their distinctive experience, and to identify traits associated with a successful transition from adolescence into adulthood. Insight into this important developmental period could be valuable to families, teachers, service providers, and people with ASD.

Over 30 autobiographies were read and four were analyzed in detail. The autobiographies were located by referencing a list compiled by A.M. Baggs (www.autistics.org) as well as previously-published papers. Ghost- or co-written books were excluded, as were self-help/creative writing books, and those by authors under age 18. Based on these initial elimination criteria, 35 books by 25 different authors were located (see Table 1 for author characteristics). Interestingly, 15 of these authors were female while only 12 were male, which does not match the typical gender distribution for ASD.

To keep the analysis manageable, four of the remaining 35 books were selected. The authors of the selected books were from North America, spoke English as a first language, did not use facilitated communication, had received a formal diagnosis, and explicitly described their 'transition period.' The four books were: *Look Me in the Eye* by John Elder Robison, *Thinking in Pictures* by Temple Grandin, *Songs of the Gorilla Nation* by Dawn Prince-Hughes, and *Pretending to be Normal* by Liane Holliday Willey (Table 2).

The four external assets are Empowerment, Boundaries and Expectations, Constructive Use of Time, and Support (see Table 3 for supporting quotations). "Empowerment" encompasses assets such as community valuing youth, and youth as resources. The theme that matches this is "Feeling Valued and Useful." "Boundaries and Expectations" includes assets such as positive peer influence, adult role models, and high parent/teacher expectations. The corresponding theme is "Role Models and Encouragement." "Constructive Use of Time" is an asset category that describes creative activities, youth and religious programs, and time at home; "Goals and Aspirations" is the corresponding theme. The fourth asset category is Support. This category contains assets like family support, other adult relationships, and positive family communication. This is consistent with "Support and Understanding," which was the most frequently reported external asset and theme in this study. This last category describes the value of supporting and

encouraging interests, abilities, and growth; playing to strengths; positively redirecting obsessions and interests; interacting to facilitate independent thinking and ideas; allowing independent discovery and not ‘over-helping.’

Commitment to Learning, Positive Values, Social Competence, and Positive Identity are the four internal assets (see Table 4). “Commitment to Learning” includes achievement motivation, school engagement, and bonding to school. The corresponding theme is repeated from the external assets. Perhaps because of support (an external asset), the authors developed an internal asset: a commitment to learning. Although all of the authors experienced great difficulty in school at some point due to unsupportive teachers who did not understand their complex needs, when placed with a supportive teacher, they excelled. “Positive Values” encompasses assets like caring, equality and social justice, integrity, honesty, and responsibility. “Advocacy” is the corresponding theme. There are no specific quotes to support this theme; the writing of these autobiographies speaks highly to the authors’ sense of justice, advocacy and equality. “Social Competence,” or “Protective Factors” includes resistance skills (like resisting negative peer pressure and dangerous situations) and decision making. “Positive Identity” is the last and most frequently reported internal asset, and is also a superordinate theme for three separate themes (“Self Esteem,” “Goals and Aspirations,” and “Niches and Roles”). Positive identity (along with support and understanding) is perhaps one of the most important characteristics of a successful transition for people with ASD. Other assets may support creating a positive identity and a self-perceived valuable place in the world.

Some themes were discovered that did not fit into any asset category. Perhaps they can be seen as ‘unique to ASD’ assets for a successful transition (see Table 5). All of the authors discuss using ASD to their advantage; capitalizing on what makes them different and turning it into success—this theme is titled “Capitalizing on Differences.” “Self-Understanding” refers to the process of understanding and reflecting on how having ASD affects one’s life, and coming to terms with it. “Adaptive Coping Mechanisms” is a unique asset defined as adaptive strategies for combating harmful things like stress and anxiety, or other difficult symptoms of ASD. Interestingly, the strategies the authors frequently used to cope with life (nature, building cattle chutes, working with machines, reading or writing) became large parts of the careers they now hold. The last unique asset is “Strategies and Behavior Change,” which describes author-devised strategies that focus mainly on social interactions. These strategies appear to have developed out of a need to ‘adapt’ and live in the world more ‘normally.’

I really enjoyed attempting to study ASD from ‘the inside-out,’ and wish I could have shared more of these wonderful autobiographies’ insights. I encourage you to seek out autobiographies, creative writings, or self-help books by authors with ASD. These authors are from different countries, they have different talents, and are different ages. Some are verbal, some are nonverbal, and some have other problems that they must cope with, but all of them have a unique perspective that contributes something valuable to our understanding of ASD.

Table 1: Basic Characteristics of the Initial 25 Autobiographies

Characteristic	Number of Participants	Gender of Authors
Authors with Asperger's Syndrome	16	5 male, 11 female
Authors with Autism	9	5 male, 4 female
Non-verbal Authors	4	2 male, 2 female
Country of Origin		
United Kingdom	10	
United States	7	
Australia or New Zealand	4	
Sweden, India, Germany, Canada	1 from each country	

Table 2: Characteristics of Final Autobiographies

Autobiography	Author and Country	Sex	Birth	Current Status	Diagnosis	Current Activities
Look Me In The Eye	John Elder Robison, USA	M	1957	Married, child	Asperger's Syndrome (39)	Small business owner (specialty automotives)
Thinking in Pictures	Temple Grandin, USA	F	1947	Single	Autism (3)	Professor (animal science), researcher, consultant, autism conferences
Songs of the Gorilla Nation	Dawn Prince-Hughes, USA	F	1964	Partner, child	Asperger's Syndrome (36)	Anthropologist, primatologist, author
Pretending to be Normal	Liane Holliday Willey, USA	F	1959	Married, children	Asperger's Syndrome (37)	Author, editor, consultant, autism conferences

Note: Numbers in brackets are age at diagnosis

Table 3: External Assets

Developmental Asset: External (SEARCH Institute, 2003)	Autism Autobiography Themes	Quotes
Empowerment	Feeling Valued/Useful	“For the first time in my life, I was able to do something that grown-ups thought was valuable. I may have been rude. I may not have known what to say or do in social situations. But if I could fix five tape recorders in an afternoon, I was "great." No one except my grandparents had ever called me that before.” - John Elder Robison
Boundaries and Expectations	Role Models and Encouragement	“Mr. Carlock didn’t preach but showed by his own conduct a social perception that I envied and tried to emulate. From him I was learning humanistic attitudes that I lacked because of my autism” - Temple Grandin
Constructive Use of Time	Goals and Aspirations	“I simply enjoyed certain activities and sought ways to explore them. Three particular activities caught my fancy when I was in high school.” - Liane Holliday Willey
Support	Support and Understanding	“A second teacher, Mr. Carlock, was my salvation. Mr. Carlock didn’t see any of the labels, just the underlying talents...Mr. Carlock believed in building what was in the student. He channeled my fixations into constructive projects. He didn’t try to draw me into his world but came instead into mine...” – Temple Grandin “He was the only close college friend I had. The only person who made his way through to me... This friend found a way to meet me in my world without making any demands that I meet him in his... He never questioned or criticized me, he just let me be. If only everyone could be that gracious—maybe then, we would not even need a definition for Asperger’s Syndrome.” – Liane Holliday Willey

Table 4: Internal Assets

Developmental Asset: Internal (SEARCH Institute, 2003)	Autism Autobiography Themes	Quotes
Commitment to Learning	“Support and Understanding”	“The experiences I had in high school prepared me for a bright future, for they gave me strength and insight and confidence to look at myself as an individual and not a parallel image.” - Liane Holliday Willey
Positive Values	“Advocacy”	Autobiographies!
Social Competence	“Protective Factors”	“Heroin was scary. I'd read how you could become addicted with a few pricks of the needle, and I saw how the addicts lived... No way am I going to do that, I thought. I watched it all with the same detachment...” - John Elder Robison
Positive Identity	“Self-esteem,” “Goals and Aspirations” and “Niches and Roles”	“I think cultural and performing arts types must be Aspies. If not... they are at least amenable friends of Aspies. I found great acceptance among my drama peers, most of whom were extremely tolerant and appreciative of diversities and personal visions... Finally, I had found a natural place for me to be.” - Liane Holliday Willey (Niches and Roles) “And that's what I dreamed of being. A craftsman. An artist, working in automotive steel.” – John Elder Robison (Goals and Aspirations)

Table 5: Unique Assets

Unique Asset	Quote
Capitalizing on Differences	“I eventually found success in an activity that charmed, interested, and fulfilled me. I found the speech and dramatic arts club... I was able to flourish in such a warm and supportive environment, finding it to be the best place for me to turn many of my AS traits into real and viable assets.” – Liane Holliday Willey
Self-Understanding	“It was a great relief to finally understand why I don’t look people in the eye. If I had known this when I was younger, I might have been spared a lot of hurt.” – John Elder Robison
Adaptive Coping Mechanisms	“I retreated deeper and deeper into nature” – Dawn Prince Hughes “There were two choices in coping with my nerve problem: I could retreat into my inner world... or... find the most stimulating activity... Horses to gallop and intense physical labor.”- Temple Grandin
Strategies and Behavior Change	“I have learned what people expect in common social situations. So I can act more normal and there's less chance I'll offend anyone. But the difference is still there, and it always will be... I have slowly taught myself how to succeed at conversation most of the time. I have learned to begin conversations with a question, like “How are you?” I have learned a range of questions that are socially acceptable. But my inventory of questions is limited, and it seems other people are a lot more flexible.” - John Elder Robison

“I believe autism can be a beautiful way of seeing the world. I believe that within autism there is not only the group– the label– but the individual as well; there is strength in it, and there is terror in its power. When I speak of emerging from the darkness of autism, I do not mean that I offer a success story neatly wrapped and finished with a “cure.” I and the others who are autistic do not want to be cured. What I mean when I say ‘emergence’ is that my soul was lifted from the context of my earlier autism and became autistic in another context, one filled with wonder and discovery and full of the feelings that so poetically inform each human life.”
- Dawn Prince-Hughes