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Interior Design for Autism

From **CHILDHOOD**
to
ADOLESCENCE

A. J. Paron-Wildes



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INTERIOR DESIGN FOR AUTISM FROM CHILDHOOD TO ADOLESCENCE

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A.J. Paron-Wildes, Allied Member ASID

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CONTENTS

Overview vii

1	RISE OF AUTISTIC SPECTRUM DISORDERS: IS IT REAL?	1
2	RELATIONSHIP OF TOXINS AND NEUROLOGICAL IMPAIRMENTS	5
3	NEUROFUNCTIONS OF AUTISM AND HOW THEY RELATE TO THE DESIGNED ENVIRONMENT	9
	Acute Visual Processing	10
	Canalesthesia: Object in Content	13
	Canalesthesia: Sensory Integration	16
	Impaired Assignment to Incoming Social Stimuli	18
	Decrease in Affiliative Behavior, or Imitation	21
	Impairment in Distinguishing Stimuli and Their Significance	24
	Brain Dsfunction: Asociality	26
	Reduced Attention Selection and Recognition	28
	Delayed Attention Shifting or Transitioning	33
4	TYPES OF SPACES	35
	Home Environment	36
	School Environment	49
	Traditional School Environments	57
	Collegiate Environments	59
	Work Environments	60

Therapy Environment 61

Clinic Environment 66

Residential Placement 73

5 PROJECT PLANNING AND RESEARCH 79

Find a Consultant 80

Listen 80

Pilot Areas or Mockups 82

Codes and Officials 82

Research 82

Checklists 82

6 IMPLEMENTATION AND CONSTRUCTION PROCESS 91

General Contractor Selection 92

Off-gassing or Flushout Period 92

7 OUTCOMES AND CELEBRATIONS 93

Metrics 94

Celebrations 95

8 CONCLUSION 97

ADDITIONAL RESEARCH 101

INDEX 103

OVERVIEW

Admittedly, I would agree with most mothers when they say their world changed completely the day their child was born. However, I would also add my world collapsed the day my son was diagnosed with autism. Not only did my world change, but I was transported suddenly to another universe—a drastically different, nonsensically altered universe.

It was depressingly frustrating to recognize that I could muster so little strength to offer my child, strengths to bring to bear in my child's fight, my child who would need so much. I could not provide him with the tools of change he needed, the tools a speech therapist could provide or a behavior therapist could provide or a psychologist could provide. However, I remembered I was a creative designer by trade and by personality a designer who loved to problem-solve, and this was the most important problem of my life.

The following is my story. It is a very difficult tale to tell and may be difficult to read. However it will give insight to the importance of the research.

My son was diagnosed with severe autism at the age of three. Up until 15 months he was developing normally in his speech, in his motor coordination, and his social skills. He was a beautiful, engaging baby boy who loved to hug and interact—for example, playing hide and seek. He had some basic word development at one year of age such as saying “mama,” “downstairs,” “outside,” and “cheese,” but all of that started to slip away after he was 15 months of age. He regressed significantly and very suddenly. All verbal expression ceased, and he became distant as if he were in his own little world. We were all perplexed as to what was happening to him. By the time he was properly diagnosed, he was in the depths of severe autism and was exhibiting self-injurious behaviors. He bit his arms till he bled, banged his head on the floor till it was bruised, and refused any contact or touch from others. My husband and I were devastated. My loving and animated young son vanished and was replaced by this shell of a human being.

Searching for answers, I started reading. I so desperately wanted to reach this child of mine, but the rules of engagement were all changed. I did not know what he was thinking or even what he wanted. It was such a terrible time in our life. One book in particular really touched me. Temple Grandin's *Thinking in Pictures: My Life with Autism* (2010). She described how she experienced the world around her, and it was nothing like how *normal* people perceive it. Sensory integration (the ability to process sensory stimulation) was at the heart of the difference. As I thought about design, it dawned on me this was the key. We designers design to the experience of our senses: what we see, what we hear, what we taste, what we feel, and what we smell. Obviously, our

design will not satisfy the needs of individuals with altered sensory issues. If their designed world and their environmental experiences are totally different from ours, then their environmental design requirements are completely different as well.

This was the basis and the passion of my research. You see, when my son was three years old, we could not take him out of his known environment. We could not take him to church, to the store, to a playground. He could not interpret his surroundings because they were overstimulating and unpredictable; he would respond with a tantrum that would last for hours. With almost no receptive language capability, he lacked the ability to process what was being said to him; as with other autistic children, he did a little better with sign language than with the spoken word. However, he had very little intellectual resources to communicate his needs and his wants other than throwing a tantrum.

I knew he was intelligent by his uncanny ability to master complex toys and puzzles and he could understand me visually by my actions and where I pointed. However, by no means did he act *normal*. The depths of despair for a parent with a young child with autism is wondering how he or she will survive in life, especially after his or her parents are gone.

A young child learns and develops by seeing, imitating, practicing, and engaging. Children with autism do not perform those activities naturally. They need to be motivated, inspired, and taught what is instinctive to others.

The meaning of the word *autism* comes from the Greek word *autos*, meaning “self.” I knew if we assented to this child doing what he wanted, he would shut out the world around him, including his family, who loved him dearly.

I wanted my child to be engaged in the world, with other people, with me. I wanted to have him experience the splendors of the world. I did not want him to grow up in a protective bubble. I instinctively knew I needed to expand his visual and sensory diet of environments. If we could increase his tolerance and his success in the public spaces he would have a chance of one day functioning in the normal world. Selfishly, I wanted a child that I could take to an event or a play; the things that parents do with their *normal* kids that they naturally take for granted.

From a societal viewpoint, everyone wants this child to be able to function in the world and contribute to society, not be a burden to the system for the rest of his life. Most parents have a hard time looking to the future and thinking about what tomorrow will bring; we tend to worry about the immediate needs of getting through each day. Thoughts of living independently seem far-fetched when dealing with a six-year-old who has no language, is in diapers, and is out of control.

Yet that is the goal: integration into society. Independent living not only means holding down a job and taking care of your basic needs, but also means having the freedom to do what you love, the choice of following your dreams, and the opportunity to be happy.

The design problem was how to create an optimal environment to enhance, not deter, learning skills that can be replicated in public or more complex environments. This was the recipe for getting my child to integrate into the world.

I was lucky enough to have graduated from the University of Minnesota in Interior Design, where I had phenomenal professors. When I was in school, I had an interest in designing environments for people with Parkinson's and Alzheimer's diseases. My passion came from my grandmothers both suffering from those diseases. Having understood the significance the designed environment played for patients with Alzheimer's, I thought surely there would be tons of research on autism. Unfortunately, there was very little. I called every well-known designer in health care, and there was a miniscule amount of supporting research, but there was plenty of interest, mainly from the rapid rise in diagnosis within the spectrum of autism.

I was encouraged by my former professors and mentors to put *knowledge to paper* and start researching based on behavioral actions. So, I theorized from medical research important design principles and put them into practice, first trying them out on my own child. I was fortunate enough to have a few graduate students and senior classes in interior design help me with different design concepts. I would then implement the concepts and watch my son's behavior after the change to the environment. Some of the positive results truly amazed me. This was also true for other projects I worked on with other children with autism.

What I found was most of the design principles I developed for individuals with ASD also worked for individuals with other cognitive disorders and surprisingly worked for neurotypical (the politically correct word for *normal*) individuals as well. I was somewhat shocked about that, but it makes sense and we have seen that modeled before with the Americans with Disabilities Act (ADA) design principals. Those design changes not only helped the disabled but the fully able as well.

For sure, I knew we would be establishing ground-breaking design research, which would be critical if the incidences of autism continued to rise. I attached myself to any professional who had an interest in this area or had nuggets of knowledge to share with me. I tried to keep an open mind and heart and a laser-focused interest. Since there was insignificant design research on autism, our best information came from trial and error. Some of my greatest insights came from others who worked with these special populations but had no design background. Professionals and families at ground zero were critical to the research because of their experiences; they understood what was successful and what was not. It was my job and my opportunity to translate the successful strategies into the designed environment and create theories that could be the basis of work to come.

One of my favorite quotes came from an occupational therapist who worked exclusively with children with autism:

"The real problem of autism is not that your child can't learn, but that your child doesn't learn from his environment, the way most children do."

—Dena Farbman, MEd

When we change an environment to accommodate an altered state of view, then we see learning, cooperation, restoration, attention, and the things we need to see in order for the individual to progress. When he or she makes progress and masters the skill in the altered environment, we can transfer the activity to an uncontrolled

environment to enable mastery of the skill. For example, segregating a young child with ASD into a room that has little visual interest, where the only thing he or she can focus on is the therapist, increases his or her progress in speech therapy in contrast to using a traditional therapy room.

Earlier I described my three-year-old son as unable to leave his house to go to the grocery store, church, or a restaurant. Fortunately, by the time he was seven we were taking him to Disney World, five-star restaurants, movie theaters, airplanes, and even Times Square in New York City. His favorite place to visit is Times Square, which astounds most people since it is overstimulating for 99% of the general population. However, my son learned to accept or accommodate himself to the world because we worked on his visual diet and sensory needs. It required an enormous amount of time and concentrated training, but we are reaping the rewards. He is now 18 and doing quite well. He still is considered autistic, but he is well integrated into his community and lives a well-rounded life.

Unfortunately, there are a lot of snake oil salespeople in the world of autism, touting the next best “cure.” I have always had the viewpoint that it was most important to share my research openly and honestly with anyone who asked for it. My purpose is to educate as many other design professionals about my findings, so they can create great spaces for people who most need it. I am only one person, but the design community is vast and can touch many more people than I could ever dream of doing. My goals for this book are to inspire, to lead, to enlighten, and to motivate designers to tackle these increasingly difficult design problems for individuals with neurological impairments.

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Grandin, Temple. *Thinking in Pictures, Expanded Edition: My Life with Autism*, Expanded edition. New York NY: Knopf Doubleday Publishing Group, Vintage Expanded edition, 2010.