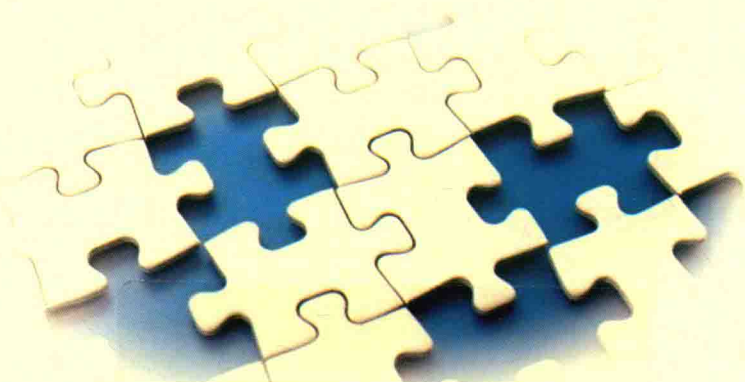


Navigating Transitions

风雨同舟

——自闭症，你的人生过客



【美】MICHELLE LIU 著



北京燕山出版社

第101号

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BEIJING YANSHAN PRESS

图书在版编目 (C I P) 数据

风雨同舟 / Michelle Liu 著. —北京: 北京燕山出版社, 2017.9

ISBN 978-7-5402-4674-7

I. ①风… II. ①M… III. ①缄默症—儿童教育—特殊教育 IV. ①G766

中国版本图书馆 CIP 数据核字 (2017) 第 227119 号

风雨同舟

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印 刷	廊坊市博林印务有限公司
开 本	889mm×1194mm 1/32
字 数	60 千字
印 张	8.625
版 次	2017 年 9 月第 1 版
印 次	2017 年 9 月第 1 次印刷
定 价	32.00 元

出版发行  北京燕山出版社
BEIJING YANSHAN PRESS

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Preface

Michelle Liu is a talented writer and passionate young woman. Her idea to write this book stems from her compassionate nature to help others. After she introduced the idea of a student run club to help people and families affected by autism, Michelle began to learn as much as she could about autism and the impact on families affected by autism. Her relentless pursuit of knowledge and her genuine personality allowed her to meet families and learn their stories. After many hours of research, Michelle has collected the narratives of these families in this work to share with others.

Dennis J. Lepold

Principal

West Windsor-Plainsboro High School South

Self-Introduction

Transitions can be hard for everyone. Whether it is moving to a new school or home, or becoming an adult, such changes interrupt everyday routine. Those of us who have had to adjust have learned the importance of planning ahead.

For parents with children on the autism spectrum, such planning takes years and requires extensive research. Preparation must start after the initial diagnosis.

At Rutgers Medical School, I worked with Dr. Walter Zahorodny to review the reports of hundreds of children (aged 2-8) with autism. In these cases, parents expressed elevated concerns about their child's behavior- impulsivity, delayed communication, and troubles with sleeping and eating. I was struck by their perseverance. Although there are manuals

available to them through doctors or websites, I wanted to provide a personal resource in which families could draw directly from similar experiences of others. A small success is sometimes the result of months, or years of determination and to reach a milestone is an unforgettable moment. As children on the spectrum become adults, even more goals are set. It is a difficult time, but with proper support and guidance, the likelihood of independence, and being able to handle responsibilities is increased. In a society that “may be inadequate to accommodate the needs of youths with ASD” (National Institute of Health) , preparing for different transition stages is essential. I hope my book will highlight the important steps parents and individuals with autism should take when navigating this journey.

This book would not have been possible without the tremendous support of my mother, Jian, Dr. Zahorodny, and my advisor Dr. Jim Ball. For the last three years, Dr. Ball, co-chairperson of the Autism Society of America, has welcomed my questions about autism. He generously shared his expertise in the field and encouraged my involvement in research. In addition, I thank everyone who I spoke with- their willingness

to share their stories testify their kindness. I thank Scholastic Art and Writing Awards for recognizing my work and to my past English teachers- Ms. Hutchinson and Ms. Glassband- who fostered my passion for writing. Finally, I thank each and every one of the children I have worked with. They have taught me how labels such as autism do not limit our beliefs or experiences. While it may be hard, choosing to embrace these differences makes each step forward all the more courageous.

Editor's Introduction

Most Chinese people are unfamiliar with autism, a serious neurological and developmental disorder. When trying to help a child on the autism spectrum they feel unprepared and overwhelmed. There are millions of autism patient in China. Survey shows parents of autism children have qualms about the future, stressing over whether their child may achieve independence when they reach adulthood. How to complete a smooth transition from adolescence to adulthood is an important step in integrating individuals with autism into society.

Compared to developed Western countries, China is in its initial stages of autism acknowledgement, treatment, recovery, education, employment and social security. In the United States, education professionals and scientists have

been researching the best methods for autism intervention and therapy since the 1940s. The results of their studies prompted governments and institutes to establish an intricate system which offers comprehensive support to individuals on the spectrum, such as early intervention, enrolling autism children in public elementary and middle school, then vocational school, even for college.

The young author of this book, Michelle Liu, is a Chinese-American. For a long time, she has worked and volunteered with autistic youth. Not only has she helped build their confidence, but she has also coached them to embrace life with positivity. Michelle not only is the founder of Ambassadors for Autism at her high school, but she also is involved with several New Jersey autism advocacy groups. From raising over a thousand dollars to support autism research to organizing a summer camp for autistic children, she is an active member in the community. During this period, as Michelle interacted with families impacted by autism, she collected information about their individual cases. In this book, she has selected seven representative stories. Her work provides precious information to parents and interested people who hope to understand autism.

Autism is no longer to be scared of, and no one should feel unprepared or overwhelmed. With more attention and love from society, children with autism will better be able to transition to adulthood.



对于大多数中国人而言，自闭症是遥远和陌生的。当它近在咫尺时，又是深感恐惧和无助。在中国，患自闭症的人口可能数以百万计。调查显示，多数患者的家长对孩子未来成人后有独立生活的能力缺乏信心。如何顺利完成从少年到成人的过渡是帮助自闭症患者回归社会的重要一步。

与西方发达国家相比，中国对自闭症患者的认知，治疗，康复、教育、就业、安置和社会保障等几个重要环节中还处于刚刚开始阶段。以美国为例，从 20 世纪 40 年代教育和心理学专家、学者对这一病症积极探索其病因、治疗手段、干预方法等，累计了大量的研究成果。政府和社会机构相应建立了一套完整的体系：从患儿被诊断、接受早期干预、融入主流小学、中学，进入职业教育或者大学，一路的成长过程中都提供了一条龙服务，为自闭症患者最终独立生活提供有效的帮助。

本书的小作者 Michelle Liu，是一位出生在美国的华裔女孩。

长期以来，她一直关注和热心参与辅导社区自闭症青少年，帮助他们建立信心，乐观的去面对生活。她不仅在所在高中成立自闭症学生帮助组织，更是多个美国新泽西州自闭症组织的活跃分子，从参与为自闭症患者募捐的马拉松到策划组织为自闭症儿童开办夏令营。Michelle 在和自闭症孩子及家属互动过程中，她积累了大量个案信息。在采访多位自闭症患者和家属后，作者在本书中记录了七位具有代表性的自闭症少年到成年过渡的过程。给有兴趣关注了解自闭症的父母及相关人士提供了值得参考的宝贵经验。自闭症并不可怕，家长们也不再无助和焦虑。越来越多来自社会的温情和关注如何在帮助自闭症青少年顺利过渡到成年期。

编辑组

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James

James is a 33-year old with Asperger's-he's juggling a job at Shoprite, a relationship with his boyfriend Mark, and a potential singing career. James is also eloquent-his vocabulary is tantamount to an English professor's-and fluid with his words. But as a disabled dependent, a victim of PTSD, social anxiety, and depression, James's life was not always happy-go-lucky. In fact, most of it, he says, has been plagued by suppression and abuse.

In 1982, James Albright was born as the son of two strictly-Catholic, Irish parents in Staten Island, New York. On the surface, he lived a modest lifestyle-his father was a stockbroker at Morgan Stanley, and his mother was the caretaker of James's two younger sisters and older half sister. Past this facade, James was suffering deeply.

Even "suffering" might be an understatement, however.



On the eve of his first birthday, James burnt himself when a pot fell from a kitchen cabinet, splattering hot coffee onto his skin. The incident scarred his left hand, right in the area between his thumb and third finger.

Although he doesn't recall the exact sensation he felt, James replays this traumatic moment over and over as an adult and recognizes the accident as a predecessor to his future pains. "I learned to live in abject fear and severe vulnerability," James says.

From a young age, despite being "very spoiled," James developed a rocky relationship with his parents and grew to despise their large trust fund. In fact, his father showed no understanding of his emotions, revering him as a paragon of virtue, providing his son a slew of toys and games.

"My family was toxic," James admits, "they thought I was some trophy they could revere. In a sense, I was dehumanized; everyone around me was wiping away the down parts that made me human. They would deny I had any flaws and they would spoil me regularly. They put me so high up that they couldn't even see who I was anymore. Once, my father spent a \$1000 DJ kit for me when I was 12 and experiencing with mixtapes. In another case, on



our first family trip to Disney World, I wanted this foot-tall Eiffel tower from Epcot. So, since I pretty much inherited my father's narcissism, I sat there and refused to leave the store without it. I think my parents expected me to follow them after they left the store, but to my surprise, my father came back and said to me, 'I'll get you the tower.' I said, 'Are you sure? Do you really want to do this?' and he replied, 'I hate to refuse you.' He should have never [bought me the tower] in hindsight. And what upsets me is that my father never taught me the values of hard work; he just plopped everything right into my hands, hoping I would just cooperate with him and basically, agree with whatever he said. Spoilage."

James's father was also incredibly stubborn, adamant that his son takes on a "respectable position" similar to his own. James' father brought him to work, introducing his son to his office above Wall Street. To appease his parents' wills, James said "yes" to stockbroking. Consequently, he experienced Stockholm Syndrome, "the psychological response in which captives begin to identify their captors closely."

"They would make me feel guilt, shame, and fear as if I was doing something wrong whenever I disagreed with them on even



the most subjective topics. They would portray sex, for example, as evil.” James claims.

His father, in particular, would blackmail him emotionally, convincing James that “he would do nothing to harm his son now, would he?” Essentially, if James's opinions deviated even slightly from his elders, he was reprimanded.

“In Catholicism, you are taught to be very, very obedient and to succumb to your parent's demands.” James says, “But respect is a two-way street. So, for most of my youth, I was denied of my opinions. I was living in a nightmare, but at the same time, a fantasy world where I was sheltered-naive-and wasn't exposed to the real world. My entire family handled me like china, but they held onto me so tight, that I eventually shattered. Their treatment is also a huge part of why they dismissed so many of my struggles-especially with Aspergers-they thought I was perfect.”

As a loquacious and socially active child, few adults suspected James possessed any form of autism, however. When he was a toddler, he attended a Montessori daycare and made many of his most precious memories at the school. But in elementary school, his disability surfaced.

James vividly recalls his confrontations with Mr. Paulson, a



narcissistic middle school teacher. “I’ve always had many specific interests throughout my childhood-that’s a common autistic trait, we fixate on a specific subject and devote 110% of ourselves to learning about it and enjoying it. So, at the time, I was obsessed with the Superman logo. And I was spending most of the days in computer class drawing it on the computer. And at one point, Mr. Paulson said to me that he wanted me to try out something else. Well, I didn’t feel like trying out something else, so I redid it. What did my teacher do? He banned me from the computers for a few minutes and told me to write down what I did wrong. And he said to me, ‘I am very disappointed in you,’ among other things. But how dare he force me to give up what I wanted at that moment and implore me to do something I did not want to do. In another incident, every week we would go swimming at the YMCA. One day, I did not feel like going swimming, and I tried to explain that to Mr. Paulson. And what did he do? He threatened to take away some of the classes I enjoyed, like computers and what not. That got me in the pool. He blackmailed me, just like my father. People realized I was too perfect for that school and they were jealous of me. So, I think much of the experience I had in the public academy was pretty traumatic.”