

Recommended Books for the Special Needs Community

As lawyers in elder and disability practices, Special Needs Alliance members have many experiences that feed our empathy and understanding, but not all of us have parents with dementia or a child with a disability. One thing we have learned, though, over many years of practice, is that if you have seen one child or one adult with special needs-you are familiar with that one individual's unique circumstances.

In our effort to broaden our wealth of information about disabilities and diseases, and to deepen the understanding of each Alliance member about different conditions and circumstances, we have an active "special needs" book group. Twice each year, we undertake to read one book about a different disability. So far, we have read stories about individuals or family members with brain injury, Down syndrome, Alzheimer's, epilepsy, mental illness, autism, Asperger's, and post-traumatic stress disorder (PTSD) (see below). We then gather at our bi-annual meetings to discuss the writing, the events and the underlying circumstances facing the individual in each story. Sometimes, we watch a documentary or see a film in addition to the book. Last year, for instance, Captain Luis Montalvan, author of Until Tuesday, A Wounded Warrior and the Golden Retriever Who Saved Him, was our keynote speaker. He discussed his experience with PTSD, his recovery through his golden retriever, Tuesday, and we even got to meet Tuesday! This fall, we read Far From the Tree by Andrew Solomon, a book about parenting children with disabilities. Solomon interviewed roughly 300 families and this book describes raising children with (among other things) autism, mental illness, multiple disabilities, and children who are hearing impaired. At our meeting we discussed the book, watched Solomon's TED talk, and a panel of parents (SNA members) critiqued the book in light of their own experience raising a child with a disability. It was eye-opening to realize the depth of personal wisdom and understanding within the SNA.

Sometimes, when meeting with clients back in our offices, one of the books will come to mind as we listen to their stories-and we recommend a book to them. Our clients find solace between the pages just knowing they are not alone or seeing things from a different perspective. These books can give words to difficult feelings and hope when there feels like there is none. Reading a great book that speaks to a client's circumstance can be like attending a private support group.

For anyone touched by illness or disability, or really, for everyone (because you may someday be touched by illness or disability), these books can be a common ground for

understanding and support. We think maybe our reading can help others find an entrance to the literature of special needs. We encourage others to sample from our reading list.

Special Needs Alliance Book Club History

Spring, 2010 – Down Syndrome

Jewel by Bret Lott (1991). With five healthy children, Jewel and Leston Hilburn were happy and believed life would continue in a slow-paced Mississippi way. But when Jewel and Leston's sixth is born a "Mongolian Idiot," as the New Orleans doctor declared, their life changes and Jewel leads her family on a journey to California that will bring all manner of hardship and joy. A client with a 38-year old brother with Down syndrome wrote "this novel was lovely. Jewel was real and brave. I hope my folks come to her final place of peace and acceptance that John will be ok."

Fall, 2011 – Brain Injury

A Three Dog Life by Abigail Thomas (2006). When Abigail Thomas's husband, Rich, was hit by a car, his brain shattered. Subject to rages, terrors, and hallucinations, he must live the rest of his life in an institution. He has no memory of what he did the hour, the day, the year before. This book is the story of how Abigail rebuilt her new life-it is a story of great courage and great change, of moving to a small country town, of a new family composed of three dogs, knitting, and friendship, of facing down guilt and discovering gratitude. It is also about her relationship with Rich, a man who lives in the eternal present, and the eerie poetry of his often uncanny perceptions. This wise, plainspoken, beautiful book enacts the truth Abigail discovered in the five years since the accident: You might not find meaning in disaster, but you might, with effort, make something useful of it. This is being made into a movie starring Salma Hayek and John Travolta.

Spring, 2011 – Epilepsy

The Spirit Catches You and You Fall Down by Anne Fadiman (1997). The Spirit Catches You and You Fall Down explores the clash between a small county hospital in California and a refugee family from Laos over the care of Lia Lee, a Hmong child diagnosed with severe epilepsy. Lia's parents and her doctors both wanted what was best for Lia, but the lack of understanding between them led to tragedy. This is an amazing book about epilepsy, families, Hmong history and culture. It is a "must read."

Fall, 2011 – Asperger's Syndrome

House Rules by **Jodi Picoult** (2010). From the author's website: House Rules is about Jacob Hunt, a teenage boy with Asperger's Syndrome (AS). He's hopeless at reading social

cues or expressing himself well to others, and like many kids with AS, Jacob has a special focus on one subject-in his case, forensic analysis.

He's always showing up at crime scenes, thanks to the police scanner he keeps in his room, and telling the cops what they need to do...and he's usually right. But then one day his tutor is found dead, and the police come to question him. All of the hallmark behaviors of Asperger's-not looking someone in the eye, stimulatory tics and twitches, inappropriate affect-can look a heck of a lot like guilt to law enforcement personnel-and suddenly, Jacob finds himself accused of murder. House Rules looks at what it means to be different in our society, how autism affects a family, and how our legal system works well for people who communicate a certain way-but lousy for those who don't. This book rings true to life for parents' of children with Asperger's.

Spring, 2012 – Early Onset Alzheimer's

Still Alice by **Lisa Genova** (2007). Still Alice is about a 50-year-old woman's sudden descent into early onset Alzheimer's disease, written by first-time author Lisa Genova, who holds a Ph.D. in neuroscience from Harvard University. I have multiple copies of this book in my office and give it to clients whose parents or spouses are in the throes of Alzheimer's disease. It is amazingly accurate as it describes the descent into this most insidious disease.

Fall, 2012 – Bipolar Illness.

60 Days to Sanity – A College Freshman's Struggle to Overcome Mental Illness by Peter Barnes (2011). The author's description of the book: In the fall of 1989, I was a wide-eyed teenager bound for college. Less than a month later, I was fighting my way out of a padded room. Sixty Days to Sanity is neither a step-by-step guide nor a medical journal about the causes and effects of bipolar disorder. Sixty Days to Sanity is my best recollection of what happened, when at 18, my world was turned upside down by a severe manic episode and diagnosis of Bipolar I. The focus of this story is the human side of bipolar disorder and how these initial sixty days affected me and those close to me. It's my hope that Sixty Days to Sanity can provide valuable insight to those coping with a diagnosis of bipolar disorder and those friends, families and professionals who are attempting to understand it.

Spring, 2013 – Manic Depression

Where are the Cocoa Puffs?: A Family's Journey Through Bi-Polar Disorder by Karen Winters Schwartz (2010). Description from Amazon: As eighteen-year-old Amanda spirals into mania, her father, psychiatrist Dr. Jerry Benson, sees the realization of his worst fears: his daughter is not just moody, but truly ill. With his words, his diagnosis-manic depressive illness-his world and that of his family is forever altered. Carol, Amanda's mother, struggles

with the guilt and shame of having raised a "crazy" daughter. Christy, Amanda's fifteenyear-old sister, denies the illness; after all, my sister's a bitch is so much easier to accept.

Meanwhile, the Bensons' extended family offers up everything from unconditional support to uncomfortable scrutiny as Amanda careens between bouts of frightening violence, cosmic euphoria, and suicidal despair. Then there's Ryan, an architecture student who is initially ensnared by Amanda's manic sexuality, but is ultimately captured and held throughout the chaos by the force of love and strength of family.

Where Are the Cocoa Puffs?: A Family's Journey Through Bipolar Disorder follows a family through the tragedy of bipolar disorder, but it's not tragic. It's funny, sad, and thought provoking-and as real and as raw as mental illness itself.

Fall, 2013 – PTSD

Until Tuesday, A Wounded Warrior and the Golden Retriever Who Saved Him by Captain Luis Montalvan (2011). Description from Google Books: A highly decorated captain in the U.S. Army, Luis Montalván never backed down from a challenge during his two tours of duty in Iraq. After returning home from combat, however, his physical wounds and crippling post-traumatic stress disorder began to take their toll. He wondered if he would ever recover.

Then Luis met Tuesday, a sensitive golden retriever trained to assist the disabled. Tuesday had lived among prisoners and at a home for troubled boys, and he found it difficult to trust in or connect with a human being-until Luis.

Until Tuesday is the story of how two wounded warriors, who had given so much and suffered the consequences, found salvation in each other. It is a story about war and peace, injury and recovery, psychological wounds and spiritual restoration. But more than that, it is a story about the love between a man and dog, and how, together, they healed each other's souls.

Spring, 2014 – Asperger Syndrome, High-Functioning Autism/Savant Syndrome

The Curious Incident of the Dog in the Night Time by Mark Haddon (2003). Description from Goodreads; Christopher John Francis Boone knows all the countries of the world and their capitals and every prime number up to 7,057. He relates well to animals but has no understanding of human emotions. He cannot stand to be touched. And he detests the color yellow. Although gifted with a superbly logical brain, fifteen-year-old Christopher is autistic and everyday interactions and admonishments have little meaning for him. He lives on patterns, rules, and a diagram kept in his pocket. Then one day, a neighbor's dog, Wellington, is killed and his carefully constructive universe is threatened. Christopher sets

out to solve the murder in the style of his favorite (logical) detective, Sherlock Holmes. What follows makes for a novel that is deeply funny, poignant, and fascinating in its portrayal of a person whose curse and blessing are a mind that perceives the world entirely literally.

Fall, 2014 – Parenting children who are profoundly different.

Far from the Tree: Parent, Children and the Search for Identity by Andrew

Solomon (2012). "Solomon's startling proposition is that diversity is what unites us all." This book explores what it is like to raise children who are profoundly different – children with Down syndrome, deafness, autism, mental illness, or children who are prodigies, become criminals, or who have profound multiple disabilities. He writes about families coping with difference and supposes while each of these characteristics is potentially isolating, the experience of difference within families is universal.

One of the themes that flows through the book is the struggle all parents have – how much do you accept your child for just who the child is, and how much do you help them become their best selves. Solomon's writing and interview style is what makes this book compelling – he is able to tell a family's story so that you understand the family's strengths and weaknesses and their struggle to love and compassion.

About this Article: We hope you find this article informative, but it is not legal advice. You should consult your own attorney, who can review your specific situation and account for variations in state law and local practices. Laws and regulations are constantly changing, so the longer it has been since an article was written, the greater the likelihood that the article might be out of date. SNA members focus on this complex, evolving area of law. To locate a member in your state, visit <u>Find an Attorney</u>.

Requirements for Reproducing this Article: The above article may be reprinted only if it appears unmodified, including both the author description above the title and the "About this Article" paragraph immediately following the article, accompanied by the following statement: "Reprinted with permission of the Special Needs Alliance

— www.specialneedsalliance.org." The article may not be reproduced online. Instead, references to it should link to it on the SNA website.