



Proxy Parent Foundation newsletter

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PROXY PARENT FOUNDATION

We are Trustee of the PLAN of California Master Pooled Trust. We are open to any disabled person in California.

We offer Personal Support Services for beneficiaries with a mental illness or brain disorder who have joined our Master Pooled Trust.

We coordinate public and private social services and we also provide access to healthcare. Our mandate in working directly with beneficiaries is to maintain a family-like atmosphere that promotes a better quality of life for them.

Proxy Parent Foundation is a dba of Planned Lifetime Assistance Network (PLAN) of California, a 501(c)(3) nonprofit corporation.

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Message from Our Managing Director

Bruce Lewitt



In August, a very dear friend of Proxy Parent Foundation passed away at the age of 84. As his obituary in The New York Times noted, Dr. Robert

Lieberman was a world-renowned pioneer in establishing new methods to prove that mentally disabled individuals could improve their interpersonal and independent living skills and enjoy a better quality of life. His research revealed that comprehensive, continuous, coordinated, and compassionate treatment could foster improved socialization skills. His books covered a wide range of disabilities and were translated into 24 languages. Our foundation was fortunate to have Dr. Lieberman serve on our Board of Directors.



He worked with several of our beneficiaries. He was able to establish relationships with them that were deep, warm, and trusting. He also fully embraced the participation of family members in his patient's treatment. Because Dr. Lieberman had such an open and collaborative practice, I would frequently confer with him when a beneficiary was facing a complicated crossroads. He was always available to me. He always provided me with his insights. His expertise on dual diagnosis was invaluable. He even applied his vast knowledge and expertise in filling out SSI applications for his patients. He was a rare resource. We will miss him.

After the Diagnosis

*by Baron L. Miller**



One of my current pleasures is being interviewed about my book. For the time being, at least, some people are interested in my personal motivations and plans. It's heady stuff for a guy who doesn't ordinarily receive this kind of attention.

Recently I was asked if I had any words of wisdom for parents of children who have just received a diagnosis of severe mental illness,



Who will care when I'm not there?

i.e., those new to the process. That's a hard subject, one I didn't feel particularly wise about, and I was hesitant to answer.

The book is based on legal knowledge I have acquired over decades, and I feel comfortable sharing it with others. And if people are inquisitive about my individual journey, I am happy to tell them about it. But handling the emotional consequences of having a child diagnosed with a severe mental illness is not something to which I profess expertise.

Those attending the interview were eager for information though, and parenting a child with a severe mental illness is something I have experienced. It is something I am still experiencing. So I gave it a go.

First, I said, we've suffered a shock and we need to take time to feel lousy. It's not like being told our child failed chemistry or a driver's test where she takes a hit to her ego but gets a re-do with our encouragement. It's a pretty devastating diagnosis, not only for our child, but for us, and denying the severity of trauma does not portend long term success.

I said that while we'll never feel good about the diagnosis, we will settle in and get used to it, and accept it as a new normal in our lives. I mentioned there are medications that work, and pragmatic ways to deal with symptoms, and degrees of the illness, and often ways to minimize its deleterious effects.

Of course I also offered that we are not to blame, that it is no one's fault when someone exhibits auditory or visual hallucinations, or agitated states of mania, or delusions of persecution or grandeur, or major depression. Mistakes in parenting has consequences, but the creation of a psychosis does not appear to be one of them.

Blunders by parents might contribute to the development of anxiety, insecurity, sadness, or loss of self-regard, all disabling in their ways. Parents' errors also could trigger a psychosis or exacerbate an existing one. But regardless of the relative merit of our parenting styles and actions, for our child to develop a psychosis she is going to first need a structural/chemical defect in her brain, and that is way beyond anyone's control.

At least some of this was likely helpful to the audience, but they too might have been questioning my wisdom when I went on to say that in a sense we were fortunate to have a child with a severe mental illness. What I mean is we are required to effectively deal with prodigious adversity in order to help our child, and that produces a special significance in our lives.

It is ironic to think that those of us whose children have received a shattering diagnosis might be the lucky ones, and surely there will be plenty of moments when we'll need reminding of just how lucky we are. Yet there is truth to it.

Our children especially need us to be great parents. We've been presented the challenge and opportunity to do a seemingly impossible job that can make a difference for our child. Perhaps it isn't as bad a deal for us as it seems to be.

I don't know if all of that counts as wisdom, but hopefully they are helpful thoughts.

***Baron Miller, a long-time PLAN Board member, is an attorney who advises and represents families of the mentally ill. He has written the book, Laws We Need to Know: Understanding Rules and Programs for Persons with Mental Illness. It can be purchased from most booksellers, and at www.baronmillerlaw.com where special pricing is available as needed.*

BOOK REVIEW:

A Voice From the Silence of Autism (Maybe)

Review of *Fall Down 7 Times Get Up 8*,
by Naoki Higashida
(Random House, 2017, hardcover, 206 pp.)

by Timothy B. Taylor*

In 2007, when he was only 13, a non-verbal autistic boy in Japan published a book. But it was not until 2013, when it was translated into English, that *The Reason I Jump* became a bestseller. It also became the center of controversy. Readers of this newsletter will recall my 2019 review of a history of autism which covered the



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practice of “facilitated communication,” in which a parent or caregiver holds the arm of the autistic person while he or she types on a keyboard. Critics say this is tantamount to a Ouija Board, and dismissed *The Reason I Jump* as the wishful thinking of Naoki Higashida’s parents and translators.

Four years later, Higashida, now a young adult, published his follow-on book, *Fall Down 7 Times Get Up 8*. Because facilitated communication was also used in the writing of the newer volume, the skeptics reiterated their doubts. We probably will never know for sure whether the books reflect the young man’s own thoughts, or are instead those of perceptive close observers. Either way, the book has much to recommend it, and more than a little to suggest veracity.

The author separates the world into two spheres: that of the “neuro-typical,” and that of the “neuro-atypical.” Persons with *jiheisho*, Japanese for autism, obviously occupy the latter category: those who are “shut inside self.” In many ways, the book can be seen as a plea to the majority for help: a better understanding of autistic persons venturing out into the neuro-typical world. The author makes plain that most neuro-typicals don’t understand how lonely nonverbal people with autism can be. And he adds, poignantly, “our feelings can be bruised as easily as yours.”

Though he also publishes poetry, Higashida’s examples – presented in a series of short vignettes that render the book very accessible – come from the most prosaic life experiences and things we take for granted. He describes the difficulty autistic persons with receptive language have with abstract concepts or expressions. The phrase “hang on a moment” (*chotto matte kudasai*, ubiquitous in Japan) caused him no end of puzzlement. Hang onto what? How long is a moment?

He asks us to consider how frustrating it is being unable to thank his mother for all she does for him. He confronts the difficulty of learning that just because every shirt has buttons all the way to the throat and every jacket a zipper to the chin, neither has to be done up all the way every time he gets dressed. He describes trying to keep time and schedule as getting lost inside, like a maze. He describes being wordless in a verbal world as agony, far and away harder than the “verbal majority can imagine.”

Those who, like this reviewer, spend a lot of time with non-verbal autistic adult males, will recognize much of what Higashida details. He writes of the difficulty of shedding ingrained fixations, and notes that he wants them to go away. But he adds that stopping ritual behaviors is like trying to stop yourself from vomiting. He writes of the benefits of being presented

with choices (which meal to order, which shirt to wear), but describes a tendency to follow default pattern; he says doing so is easier than facing the stress of not knowing what choice he is supposed to make.

Not all that Higashida portrays is negative. He describes his love of jigsaw puzzles, and how he assembles them not using the picture and colors as the primary guides, but rather the shapes of individual pieces. This ability to see the individual pine needles, and not the trees or the forest, is a hallmark of autism. He also describes how, when he is in a swimming pool at the right temperature, he feels his body is one with the water. Having for many years observed an autistic boy (now man) and his joy upon immersion in a properly heated pool, I must say this description seems quite apt.

Fall Down 7 Times Get Up 8 will not help us solve the mysteries of non-verbal autism. But regardless of its provenance, it serves as a reminder how important patience, insight and empathy are as we go about the frustrating but worthy business of caring for those so afflicted.

**Judge of the California Superior Court, County of San Diego. The views expressed in this, his sixth review for the Proxy Parent Newsletter, are not intended as a commercial endorsement, and are Judge Taylor’s opinions alone.*

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