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## Dis is Ability: How One Artist Disrupts the Narrative on Disability

*Jewel Fraser*

It is Thursday April 18, 2019, the day before Good Friday, and Jon Williams is in Anne-Marie Garcia's modest studio in the Priority Bus Mall. The mall sits at the junction of the Eastern and Southern Main Roads in Curepe, Trinidad, located right after traffic lights in whose vicinity vendors can usually be found selling their goods on the sidewalk.

That morning, I had arranged to visit Ms. Garcia's studio to learn a bit about 38-year-old Jon's artistic process, having a few months earlier attended a successful exhibition of his work presented by one of Trinidad and Tobago's most prestigious art galleries. As I entered the studio, Jon was already there, wearing a T-shirt and long brown pants, neat and clean as always. His mother, Arlene Williams, had brought a set of hot cross buns and she and Ms. Garcia were busily creating a still life for Jon to paint. Mrs. Williams arranged the buns on a blue plate which lay on top of a white dishcloth that had thin blue stripes; a green ceramic jug stood to the left of the plate

and a glass of milk to its right. One of them had provided a red cardboard sheet that was about 15" x 12" as the backdrop for the still life.

Jon's expression was focussed as he unpacked his paints and brush while his mother tied on his apron. The class was now ready to begin.

Ms. Garcia began the class with a few pleasantries, then dipped a brush into paint and indicated to Jon where on the canvas he should begin. She handed him the paintbrush and told him to make circles for the buns. Ms. Garcia again dipped the paintbrush in paint prior to indicating to Jon where on the canvas he should draw the outline for the other objects in the still life. She calmly explained to him whether it was a circle or a straight line that he needed to draw, and Jon then drew the outlines with his paintbrush neatly and precisely with a firm, steady hand: the circle for the plate and the shape for the glass, and finally, the outline of the mug. Occasionally, he decided he wanted to add a different colour to the painting and he did so independently. Then it came time to create two-dimensional and three-dimensional effects. Ms. Garcia took the brush and dipped it in a dark paint as she explained to Jon that he must now paint the areas where he saw dark shadows on his model, such as the side of the jug and the underside of the plate. She pointed out the areas that reflected light and told him to use white to depict this, or a touch of red where the play of the light produced red shadows, and so on.

Jon then filled in other details, such as the pile of books that lay behind the still life to the right.

He painted these as a blur of blues, greens and yellows that gave an impression of the books without the actual lines. It was only then I understood what I had seen in his paintings at his second exhibition at the prestigious Horizons Art Gallery a few months earlier. At that exhibition, I had been



*Source:* Arlene Williams

captivated by the way his art seamlessly melded realistic figuration with surrealistic imagery. Now I could see it was due to his blending colours to depict peripheral objects, showing merely the sensation of their hue and shape as a backdrop to the more detailed compositions in the foreground that he so painstakingly produced under Ms. Garcia's

direction. As Ms. Garcia had told Arlene, his mother, “Jon sees.”

Jon’s works have sold very well at the two art exhibitions he has held thus far, a major accomplishment for a man who was diagnosed with Down Syndrome at birth due to Trisomy 21, meaning that he has three, rather than two, number 21 chromosomes present in every cell of his body. It is the most common type of Down Syndrome and is non-hereditary, his mother explained to me.

Jon Williams was born in 1981 to his Mum, Arlene, who was then a 23-year-old schoolteacher. Her husband, Eric Williams, was away in the US at the time, studying for a degree in Geophysics. Immediately after Jon’s birth, without explaining why, the hospital ran several tests on him. Three weeks later, Arlene sat in the neonatologist’s office listening to the test results and tried to absorb the news that would forever change her life and start her on a lifelong search for purpose—both hers and Jon’s. Recalling her reaction to the neonatologist’s explanation, Arlene said, “I was sitting in the office and I looked outside and wondered, ‘Why is the sun still shining?’”

It took a very long time for Arlene to outgrow the anger and sense of loss. She said, “I was angry, but did not accept the fact, face the fact, that I was angry. It took me a long time to come to the place where I am now.” Acceptance took place incrementally, occurring at various levels as time passed. “The fact that we came to a place early on that this is our child and we have to deal with it” helped her to cope with and shoulder her new responsibilities.

It also helped that Eric was at university in Houston, Texas. Arlene and Jon went to join him about six weeks after Jon's birth.

“Jon's first three years were in the U.S. That really helped us. The kinds of interventions that Jon had, we would not have had here [in Trinidad]. He was exposed to therapists from then. Because Down Syndrome babies' muscle tone tends to be very poor, there was physical therapy. And then the kind of baseline evaluation done was very thorough. We were given an idea of the kinds of things to look out for—upper respiratory tract infections; and the fact that they stick their tongues out because the mouth cavity is smaller. In Houston, we went to parents' meetings as well. You learned from other parents.”

Arlene said they came back home when Jon was three and by that time “he was in a good place, which I do not think would have happened if I had been here.”

However, there was still a lot of work for them to do as parents. Critical to Jon's superior functioning was his parents' resolve to enforce discipline and establish reasonable expectations for him. He always had chores, both he and his younger sister Dr. Traci Williams, who is now a clinical psychologist. “He has grown up having structure,” Arlene said. “What I found with children who have Down Syndrome is that their parents have not understood that you can put limits to the child, that they will respond to structure.” Her ex-husband, Eric, had taken the position that he could accept Jon having a handicap, but he

would not accept a handicap and bad behaviour. “So the kinds of behaviours I have seen in other children, we did not accept in Jon,” Arlene said.

Consequently, as Jon grew up he found himself welcomed at a Montessori school and later at a school for slow learners. He is currently a member of a gym where he works out each week. “Jon has always had people who accepted him and who gave him room. And I think if you have that, you are free to grow.”

Reflecting on what has helped her to keep going through the years, many of them as a single parent, Arlene highlighted faith in God and a search for purpose. She said matter-of-factly, “Purpose is very important to me.” Her father had taught her that everyone has a purpose on this earth and she wanted to find Jon’s. She had found her purpose in her job as a teacher, at least before she retired. “But I could not see what Jon’s larger purpose was. I think that part of it was showing people that Down Syndrome was not a death sentence. That with Down Syndrome [it is not inevitable] to have a child doing nothing.”

A tragic turn of events in Jon’s life stepped up Arlene’s quest for Jon’s purpose. In 2015, he had a nervous breakdown, diagnosed as psychosis. During that psychotic break, he began making strange accusations against his mother and became violent. The antipsychotic stelazine was prescribed for him, and as the months rolled by Arlene successfully worked with his doctors to reduce the dosage he was required to take. “I want to keep Jon in the stream of life as long as possible,” she

explained. At higher dosages he was lethargic, unable to do much.

It was during this painful period, as she tried to pick up the pieces of their life again, that Arlene decided to enrol herself and Jon in art classes. “One of my colleagues had a friend who is an artist. He was doing a series of art and wine courses.” She saw this as the answer to her prayers, a way to get Jon “back into the stream of life”. But the art class yielded a surprising and thrilling discovery. “I thought [the art instructor] would have to come and help him. And when I saw Jon’s picture I was stunned. It was better than mine. So then I said, ‘Let’s try this,’ and I started looking around for a teacher.”



Source: Arlene Williams

“That is how I came upon Anne-Marie Garcia. She is a retired art teacher from St. Joseph Convent School – St. Joseph. I called her and asked her if she would work with Jon. She gave me a list of things to buy. I took him that Saturday morning; it was in October 2015.” The Saturday morning classes are now part of their weekly routine and though some mornings Jon is not at his best, Ms. Garcia works within his limitations. However, he is always willing to go to the art classes; when his Mum asked him why, he told her, “It makes me happy.”

Jon’s Mum stressed that the art he produces is very much a result of the close guidance and supervision by Ms. Garcia.

As weeks turned into months, his art pieces started to pile up and fill their small apartment. After looking over the growing collection, Arlene decided that she must do something about it. So she mustered up the courage to approach Horizons Art Gallery, in Mucurapo Road, St. James, about a possible exhibition for Jon’s work. “They were very gracious, very willing,” she recalls. That led to Jon’s first exhibition in 2017, on World Down Syndrome Day. The night the exhibition opened, people were queuing up outside eager to enter and view Jon’s work, and all the works on exhibit were sold.

Looking back on her son’s artistic achievements, Arlene felt she might perhaps have finally found Jon’s purpose in life.

“I thought, ‘Maybe this is part of Jon’s purpose.’ He is not going to leave a legacy of children, so I thought when he started to paint, ‘this is what

Jon will leave behind. This is part of Jon's purpose.' That is why the name of his exhibition is DIS is Ability—that in the midst of disability there is ability, creativity, and we should not discount or write off people with mental illness or disabilities. They have something to offer and we need to make room for them," Arlene said.

In recent times, Jon has become much less communicative, talking a great deal less. Arlene accepts this as she has learned to accept other facets of Jon's deteriorating health. However, his art continues to radiate life and joie de vivre. "Sometimes when we talk, we shout; sometimes we whisper," said Arlene. "Jon's art is a whisper, because it is as if he can only whisper, but his whisper is loud."

**Jewel Fraser** is a freelance writer and journalist based in Trinidad and Tobago who writes mainly about environmental and climate change issues for international publications. She is an alumna of the creative writing programme at Humber College, Ontario. Email: jwl\_42@yahoo.com