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Movement Without Boundaries

Abstract

Johnson Simon, an artist based in West Palm Beach, FL, provided the cover art for the Fall 2017 edition of *The Open Journal of Occupational Therapy* (OJOT). “Dancing in Motion” is a 36” x 60” painting made from acrylic on canvas. Johnson always wanted to become a dancer. He was born with cerebral palsy, and therefore physical limitations make it difficult for Johnson to coordinate his body movements. Through use of vibrant colors and bold strokes, Johnson’s expressionist paintings evoke movement and motion. Occupational therapy helped Johnson discover his artistic abilities. Painting empowered him to move without limitations.

Keywords

Occupational therapist, occupational therapy, Johnson Simon, art, painting, Model of Human Occupation, cerebral palsy

Motivation is a powerful agent for change. For an individual with a physical disability, motivation to participate in a new occupation may be low when the match between the person, occupation, and environment is not optimal. In contrast, successful participation in a meaningful occupation provides motivation for repeated efforts. Over time, body movements become more automatic. Practice leads to skill refinement. Skill mastery brings an enhanced sense of self. Successful participation in meaningful occupations helps to create our occupational identity (Cole & Tufano, 2008). Motivation and occupational identity are key concepts in the field of occupational therapy. Several theories of motivation exist, but perhaps none as well-known as the Model of Human Occupation (MOHO) (Kielhofner, 1995). The MOHO is a holistic and client-centered model. Internal subsystems include volition (motivation), habituation (behaviors), and performance (mind-brain-body) capacity. Function involves competent performance in meaningful occupations.

The Model of Human Occupation (MOHO) emphasizes that through therapy, persons are helped to engage in occupational behaviors that maintain, restore, reorganize, or develop their capacities, motives, and lifestyle.

Through participation in therapeutic occupations, persons transform themselves into more adaptive and healthy beings.

(Kielhofner & Barrett, 1997, 204-205)

Identity develops through self-appraisal, accepting personal responsibility, and knowing what one wants in life (Cole & Tufano, 2008).

Johnson Simon provided the cover art for the Fall 2017 issue of *The Open Journal of Occupational Therapy* (OJOT) (see Figure 1). The piece, titled “Dancing in Motion,” is a 36” x 60” painting made from acrylic on canvas. Johnson always wanted to be a dancer. Born with cerebral palsy, physical limitations have made it difficult for Johnson to coordinate his body movements. In a recent interview, Johnson shared how occupational therapy helped him discover his artistic abilities, and how painting empowered him to move without limitations.

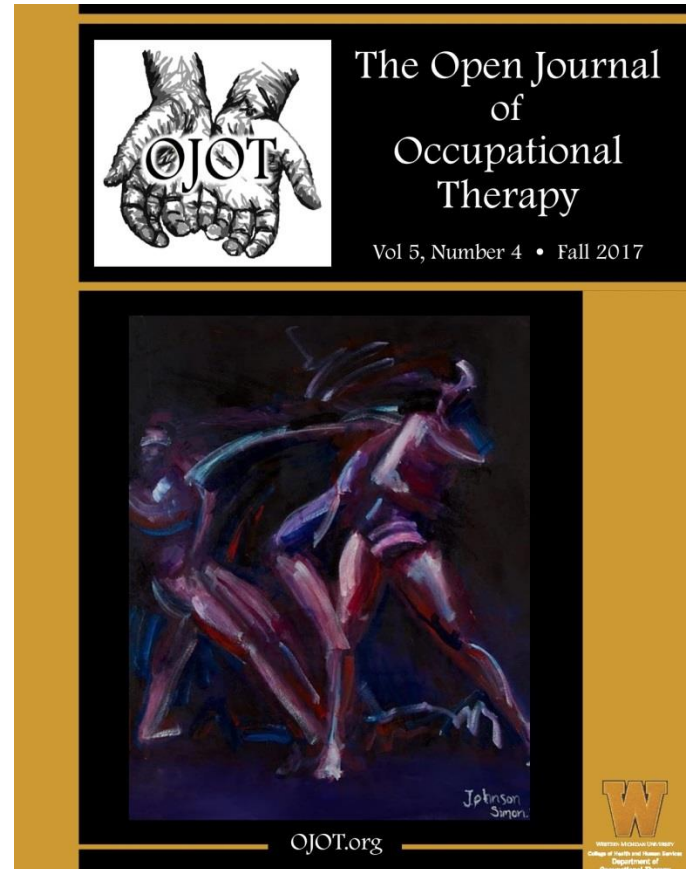


Figure 1. Cover of Fall 2017 issue of OJOT

Johnson Simon was born in 1990 on Grand Turk Island in the Turks and Caicos archipelago. Originally from Haiti, Johnson’s parents moved to the Turks and Caicos to pursue job opportunities.

Johnson's mother, Esperanta Pierre, was pregnant during this time. Doctors anticipated a troubled birth, so Esperanta chartered a plane to Grand Turk Island to deliver Johnson at the main hospital.

Johnson was born with the umbilical cord wrapped around his neck. His brain was deprived of oxygen for several minutes. As a result, Johnson was diagnosed with spastic quadriplegic cerebral palsy.

Cerebral palsy (CP) is caused by damage to the developing brain before, during, or shortly after birth. Oxygen deprivation, or intrapartum asphyxia, during labor is a known cause of CP (Centers for Disease Control and Prevention, 2017). According to Reddihough (2011), CP is the most common cause of physical disability in childhood. Although many cases of CP are genetic, other risk factors include abnormal brain development, premature birth, and bleeding in the brain. Individuals with CP exhibit a variety of symptoms that affect movement, balance, and posture. Functional implications include lack of muscle coordination during voluntary movements, stiff muscles, exaggerated reflexes, weakness in one or more extremity, difficulty with precise motor movements, and difficulty speaking (Cerebral Palsy Foundation, 2017). Therapeutic intervention services are typically provided by a multidisciplinary team of medical professionals, including occupational therapy, physical therapy, and speech therapy. The role of occupational therapy in early intervention includes addressing function and independence in occupations related to self-care, school, and play (Case-Smith & O'Brien, 2010). Early intervention can lead to improved function, independence, and quality of life.

In 1991, Esperanta delivered her second son, Johnnie. Johnson's parents left Turks and Caicos in search of a better life for their family in the United States. Johnson and Johnnie were sent to Haiti to live with their grandparents. They remained in their care for five years. Johnnie was enrolled in school; however, Johnson was denied access due to his disability. "The staff was not equipped to support a child with cerebral palsy," he said. In 1996, the family was reunited in West Palm Beach, Florida. Johnson was six years old. "My grandparents raised me. When we moved to Florida, it was like meeting my parents for the first time," he said.

One advantage to relocating to the United States was that Johnson was now eligible to attend school and receive therapeutic intervention services. School-based intervention services are available to children with disabilities through the Individuals with Disabilities Education Act (IDEA) (U.S. Department of Education, 2017). Originally passed in 1975, IDEA guarantees children with a disability access to a free appropriate public education in the least restrictive environment. Johnson looked forward to attending school and interacting socially with his peers. Unfortunately, the school could not provide an inclusive environment where Johnson could learn alongside his non-disabled peers. This created a new set of challenges for Johnson. "The school thought since I had a disability I belonged in special education," he said. "They did not want to take the time to accommodate me." Under the MOHO, environmental conditions influence one's source of motivation, behavior, and performance (Cole & Tufano, 2008). "I wasn't getting an appropriate education. It was too easy for me. This

put me behind my peers academically,” he said. Johnson also believes some of his teachers gave him special privileges that were not afforded to his peers. “I just wanted to be treated normally,” he said. Johnson knew he did not belong in special education. He was determined to work his way out of the system.

Johnson began receiving occupational therapy services in the first grade. “My OT (Linda) was like a second mom to me. I could go to her if I needed anything,” he said. Johnson often went out of his way to see Linda during the day. Linda used activities that were meaningful to Johnson, such as sports, to help him develop new skills. She tapped into his love for sports, and often took him to the playground to play basketball and kickball. Johnson credits Linda for helping him discover his artistic abilities. “I always knew I wanted to become an artist,” Johnson said. “Linda encouraged me to start drawing and develop my skills.” Through the therapeutic use of occupations, Linda facilitated occupational competence and adaptive performance in Johnson. Occupational therapy practitioners appreciate the internal subsystems of their clients, and how the environment provides opportunities and/or barriers for occupational performance (Cole & Tufano, 2008). One afternoon, Johnson returned to class with a drawing he completed during a session with Linda. His peers were very impressed. “A classmate asked me, ‘How did you do that?’ It felt good,” Johnson said. The positive feedback he received provided motivation to further develop his skills. “Linda introduced me to a whole new world. This changed my life,” said Johnson.

When Johnson’s father left the family home, Esperanta began working seven days a week as a home care nurse. She often brought the boys along to avoid leaving them home alone after school. In 2001, Esperanta introduced Johnson and Johnnie to Michael Tischler, one of her patients. Michael experienced limited mobility due to juvenile rheumatoid arthritis. He looked forward to Johnson and Johnnie’s visits, and he quickly developed a bond with the boys. Johnson regarded Michael as his mentor. “Michael always wanted children of his own. He took me and my brother under his wing and made sure we stayed in school,” he said. Michael also took an interest in Johnson’s artistic abilities. During elementary school, Johnson focused solely on developing his drawing skills. It was not until middle school that Johnson discovered his love for painting. “Painting opened up a whole new world for me,” he said. Johnson was excited to share his new talent with his mentor. “Michael knew I could draw, but he had no idea I could paint!” said Johnson. Michael encouraged Johnson to enter one of his paintings in the middle school art competition. Johnson felt honored when he learned his painting earned second place. The encouragement, support, and positive feedback Johnson received provided incentive to rise above challenges and chart a path for the future. Throughout his life, Johnson has overcome several difficult challenges. For example, in elementary school, administrators told Esperanta that Johnson had a low IQ and would never graduate high school or go to college. Johnson attended several different public schools over the years, yet with each move one thing always remained the same. He was the

target of relentless teasing from his peers. “Being different makes you stick out,” he said. “Growing up was rough. It got to the point where I did not want to go to school anymore.” Johnson believes nothing in life is easy. “It’s about how bad you want to be successful.”

In 2009, Johnson transferred to Alexander W. Dreyfoos Junior School of the Arts to complete his senior year of high school. “I received a much better education and I could focus on my art,” he said. Unfortunately, this was the same time Johnson’s mentor, Michael Tischler, passed away. “I knew he wanted me to graduate from high school and go to college. I knew he would be proud of me. That’s what kept me going,” Johnson said. Since Michael’s passing, Johnson has remained in close contact with Molly and Stephen Tischler, Michael’s parents. “Still to this day, Michael’s mom and dad are like my grandparents. They are part of our family.”

Through many difficult challenges, Johnson has always found the strength to carry on. One source of strength comes from his art, or occupational identity. According to Erikson (1980), identity formation is the optimal outcome of a crisis resolution process in which exploration and experimentation leads to a commitment (i.e., investment in a sense of values, beliefs, interests, and an occupation) to a positive sense of identity. Johnson says his strongest sources of motivation has always been his faith. “It’s what keeps me positive in life,” he said. “My faith has made me the man I am today.”

As Johnson began to prepare for college, he made the decision to move out of state to gain

independence as an adult. “I was my mother’s first child, and I have a disability on top of it. I can’t have my mother do everything for me.” Johnson knew moving out of state was the only way he would learn to live independently. He applied to two art programs; the Frostic School of Art at Western Michigan University and the Boston University School of Visual Arts. Johnson was accepted into both programs; however, in the end he decided to attend Western Michigan University. “My brother Johnnie was there on a football scholarship,” he said. “I looked forward to attending his football games.” In 2011, Johnson moved from West Palm Beach, FL, to Kalamazoo, MI, to begin his freshman year of college. “It was one of the best decisions I’ve ever made,” he said.

For Johnson, painting is all about self-discovery. “Watching the picture come together is a wonderful gift,” he said. Johnson has always been intrigued by creative expression. “I always wanted to become a dancer because I loved how they move,” he said. Johnson’s disability prevented him from pursuing this dream, so he decided to learn more about what his body could not do. While enrolled at Western Michigan University, Johnson developed an independent study course that allowed him to research human movement. He attended classes held at the Department of Dance to observe and sketch bodies in motion. “I studied the dancers body movements. It was amazing!” he said. As Johnson observed, he replicated the movements on his sketch pad. At the end of the semester, the sketches culminated into a series of paintings, and a piece titled “Disability Without No Boundaries” (see Figure 2). This 10” x 14” screen print features

a sequence of pictures of Johnson's body in motion. It appears he is jumping across several large bricks. Johnson finds this piece very empowering. "I may have a disability, but I can do the unthinkable," he said.



Figure 2. "Disability Without No Boundaries" by Johnson Simon

In 2015, Johnson achieved the unthinkable. He graduated from Western Michigan University with a bachelor's degree in fine arts. "Not only did I graduate from college, I graduated with *honors*," he said. Johnson decided to continue his education by pursuing a master's degree. He was accepted into the Herron School of Art and Design at Indiana University. In addition to his regular course work, Johnson was also assigned a position as a teaching assistant. Johnson has enjoyed his role of instructor and looks forward to teaching independently next semester. Johnson is on schedule to graduate in 2018 with a master's degree in fine arts. Johnson says his dream is to return to the Frostic School of Art at Western Michigan University as a full-time professor.

Johnson Simon refused to let cerebral palsy stop him from pursuing his dreams. Occupational therapy helped Johnson discover his artistic

abilities; however, the occupation of painting empowered him to move without boundaries. Johnson has several future aspirations, including opening an after-school center for at-risk youth. Johnson wants to do for others the same thing his mentor, Michael Tischler, did for him. "I want to provide support and encouragement to youth to keep them on the right track so they graduate from high school," he said. Johnson wants to use the challenges he has endured to encourage others to succeed. If Johnson could offer advice to a young person with a disability who was feeling discouraged, he would say the same thing his mentor, Michael Tischler, said to him. "Never, ever give up. If you don't give up, you will overcome your challenges. Keep pushing, and never give up and you are going to surprise yourself."

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Additional Information

OJOT Gallery:

http://scholarworks.wmich.edu/ojot_occupationandartist/20/

Visit Johnson Simon's website at:

www.artbyjohnsonsimon.com

WMU Stories:

<https://www.youtube.com/watch?v=hQPL4hcYSrQ>
