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Technology-Supported Art as a "Way to Participation"

Abstract

Brianna Vitale provided the painting featured on the cover of the Spring 2014 issue of *The Open Journal of Occupational Therapy*. Brianna completed the painting, titled "Flamingo," using a mouth joystick (joust) to draw the image on her computer and an assistive device to translate her computer artwork into the watercolor painting. At 12 years old, Brianna has been living for the past 9 years with tetraplegia, the result of a spinal cord injury (SCI). Through technology and with the support of family, friends, and health care professionals, Brianna energetically engages in a variety of creative, social, and philanthropic activities.

Keywords

Occupational Therapy, Art, Music, Spinal Cord Injury, Participation, Rehabilitation, Technology, WaterColorBot

Credentials Display

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Brianna Vitale provided the painting featured on the cover of the Spring 2014 issue of the *Open Journal of Occupational Therapy*. Brianna completed the painting, titled “Flamingo,” using a mouth joystick (joust) to draw the image on her computer, and an assistive device to translate her computer artwork into the watercolor painting. At 12 years old, Brianna has been living for the past 9 years with tetraplegia, the result of a spinal cord injury (SCI). Through technology and with the support of family, friends, and health care professionals, Brianna energetically engages in a variety of creative, social, and philanthropic activities.

Brianna is among the estimated 273,000 people in the United States living with SCI (The National Spinal Cord Injury Statistics Center [NSCISC], 2012). A variety of illnesses, such as tumors, infections, or degenerative conditions, can cause SCI, but the majority of the estimated 12,000 new cases of SCI each year are sustained as a result of a traumatic injury (NSCISC, 2012). Children who sustain a SCI represent a small and unique population. According to the Christopher and Dana Reeve Foundation, those who sustain injury under the age of 20 represent only 1% of those who sustain SCIs yearly (2013). Pediatric SCIs require a unique approach because the injury occurs in the midst of important emotional, social, and physical development. Of those who sustain SCI due to motor vehicle accidents, children under age 8 are more prone to high level cervical spine SCI's (C2-C3), resulting in tetraplegia, than adolescents and adults because of the immaturity of the spinal cord and the disproportionate weight of childrens' heads.

SCIs, such as Brianna's, result in altered abilities to participate physically in occupations of childhood, including play, school, and chores (Calhoun, Schottler, & Vogel, 2013; Smith et al., 2013). Occupations of childhood are also impacted by the new social and emotional challenges that accompany SCI (Smith et al., 2013). Additionally, the challenges youth with SCI face will change throughout their lifetime based on their developmental stage and injury-related complications (Calhoun et al., 2013; Smith et al., 2013). Occupational therapy (OT) practitioners play a key role in assisting children with SCIs and their families to remain engaged in occupations throughout the many developmental stages and changes in medical status.

The value of enabling and supporting participation in occupations is foundational to OT practice. Participation in the occupations of childhood results in children fulfilling their interests and needs, and in learning skills and behaviors that are built on throughout life (Humphry, 2009). Therefore, a primary focus for OT practitioners treating children with SCIs is on participation in the everyday occupations of childhood, including social and play activities. A study examining the relationship between participation and quality of life for girls with SCIs concluded that increased participation in social and job-related activities leads to decreased depression, and decreased depression leads to increased quality of life (Gorzowski, Kelly, Klaas, & Vogel, 2010). Formal, community-based activities provide the most opportunity for youth with SCI to be socially engaged (Klaas, Kelly, Gorzowski, Homko, &

Vogel, 2010). Unfortunately, studies have shown that youth with SCI participate more in unstructured, informal, independent, and sedentary activities than peers without disabilities (Kelly, Klaas, Garma, Russel, & Vogel, 2012; King, Petrenchik, Law, & Hurley, 2009). In a thematic analysis by Mulcahey et al. (2010), children with SCI and their parents expressed apprehension to participate in occupations based on concerns about being hurt physically or socially during activities. Klass et al. (2009) recommends that rehabilitation practitioners assess and support engagement in social and community-based activities to address the important value of participation. OT practitioners can work with children with SCI and their family members to address concerns about safety, and adapt environments and activities to increase safety and independence.

Brianna has received OT in several settings to support her participation in occupations of childhood. After sustaining a SCI at the age of 3, the result of a car accident, Brianna spent 89 days in the hospital recovering. During this time she was placed on a ventilator, which she currently uses, and learned to use a power wheelchair with a mouth controlled joystick for ambulation. Since her injury, she has been able to gradually increase the amount of time she can spend off of her ventilator, but continues to speak in a soft voice. Her direct therapy services have also decreased over time, but she continues to use equipment in her home, including a stander, quadriciser, and a functional electrical stimulation (FES) bike. Each year she attends Kennedy Krieger Institute's International

Here, she uses FES devices to complete activities, such as feeding herself, drawing, and walking. Additionally, she works with the rehabilitation practitioners to develop a home program to continue throughout the year. At school she does not receive direct OT services, but has in the past. Brianna and her family have also worked with an OT practitioner to adapt their home environment, not only to meet Brianna's medical and therapy needs, but also to support her participation in the daily activities of a typical young girl. This includes having appropriate space to socialize with her siblings, friends, and dogs; to be a part of the flow of the family routine in the kitchen and living room; and to participate in her valued leisure activities, including games, art, and socializing on her computer using assistive technology.

In Brianna's living room there is a table set up with a computer connected to a mouth controlled joystick, which she uses independently with set-up assistance from her mother. Brianna uses her computer for social media, email, homework, coloring, and to create art projects. Recently, she began using the WaterColorBot, a "robot" that translates the art work Brianna creates using her computer to water color paintings. As Brianna creates the image on the computer, the WaterColorBot creates the image on paper. This technology supports her full participation in art creation by providing the media for her to create and complete a project independently with minimal set up. In addition to visual arts, Brianna also participates in making music through the D-Man Foundation. The D-Man Foundation employs assistive technology and music therapy to help

people with disabilities create musical tracks.

Brianna enjoys creating music so much that she has donated money to the D-Man Foundation so that other children with disabilities can experience making their own music as well.

Brianna's desire to give support to others is an inspiration. Several years ago she expressed an interest in opening a lemonade stand to raise money to help other kids in need. She and her mom worked with a local Home Depot to build a lemonade stand that she sets up at local events. She donates her profits each year to the D-Man Foundation, as well as to the Make-a-Wish Foundation, in order to provide opportunities for unique experiences to other children. Those who know Brianna have recognized her kind and caring attitude, and she has been honored with several awards. She received the Spirit of Life Award from the Rehabilitation Institute of Michigan's Center for Spinal Cord Injury. Also, Brianna's name is included in the Walk of Fame at Morgan's Wonderland, a wheel chair accessible theme park in Texas, indicating she is a champion for those with disabilities.

Brianna has also been an inspiration and friend to another young girl in her community with a SCI. Evelyn Edwards, like Brianna, sustained a C2 spinal cord injury as a result of a motor vehicle accident at the age of 3. Evelyn, now 5 years old, has undergone a similar recovery. Evelyn spent 1 month in the hospital after her accident, and another 2.5 months in rehab. She also uses a ventilator for the majority of the day, although she is working hard to spend significant amounts of time off of mechanical ventilation. She uses a power

wheelchair with mouth controls at school and in the community, but because of space limitations, she is unable to navigate around her home effectively in the power chair. She receives outpatient physical therapy, in home OT, nursing, and massage therapy. She also receives OT and PT at school in her kindergarten classroom. She uses a FES bike and an electrical stimulation suit as part of her regular routine. Evelyn and her family have also worked with an OT practitioner to design a home that will support Evelyn's independence, as well as participation in normalized routines through assistive technology. Her family looks forward to Evelyn having some control over her physical environment and the ability to engage fully in family routines. Evelyn likes to go to school, play games, watch movies, use stickers, and travel, but most of all, she seems to enjoy joking with her family. Prior to the accident, Evelyn enjoyed making art. She continues to enjoy art and is proud to show off her completed projects, although she currently participates only in making decisions about how the art is completed, guiding others to complete the work for her. Unlike Brianna, she does not have the space or technology in her home or at school to participate independently in art making. With help from her family, she is able to create digital art on an ipad using a mouth stick. Increasing independence with art-based activities can increase her sense of autonomy, an important developmental achievement (Mulcahey et al., 2010). Evelyn looks forward to opportunities, technology, and training in the future to be able to create art independently.

Both Brianna and Evelyn demonstrate the value of participation in occupations of childhood, including play and social activities. Elburt Hubbert, an artist who inspired the foundations of the OT profession through his involvement in the Arts and Crafts Movement, stated, “art is not a thing, it’s a way.” This quote exemplifies the role art and creative activities can have in the lives of young girls with SCI. Brianna enjoys engaging in creative activities, but those creative activities have also

provided a way for her to achieve important developmental milestones, to inspire others, and to positively impact the lives of other children with disabilities. OT practitioners can employ creative activities, supported by technology, to guide children with disabilities along the path to full participation.

To view samples of Brianna and Evelyn's art work, visit:

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

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