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Expressing eMotions Through Participation in Painting

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Abstract
The cover of the Winter 2013 Open Journal of Occupational Therapy, titled Miles eMOTION, was created by Miles Scharfenberg, an 18-year-old young man with multiple developmental impairments. Miles’ story and his artwork provide a reflection on the ways in which creativity and art can enhance the lives of people with disabilities and their families. Miles’ art exists because of his drive toward engagement and participation in life, but also essential is his mother’s commitment to providing opportunities for him to be creative. The Miles eMOTION series of paintings can inspire occupational therapists, families, caregivers, and people with disabilities to incorporate art making as a part of their occupational profile.

Keywords
Art, Occupational Therapy, Cerebral Palsy, Developmental Disabilities

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The cover of the Winter 2013 *Open Journal of Occupational Therapy*, titled Miles eMOTION, was created by Miles Scharfenberg. Miles is an 18-year-old young man with multiple developmental impairments. Born 15 weeks premature, Miles spent the first 3 months of his life in the hospital. He required a ventilator to breathe, underwent surgery to repair a heart valve, survived a pneumothorax, and experienced an intraventricular hemorrhage. He was diagnosed with Spastic Quadriplegic Cerebral Palsy, Retinopathy resulting in legal blindness, and Bronchio-Pulmonary Dysplasia. With the support of his family and medical professionals, Miles was able to leave the hospital after 3 months. He required a feeding tube, oxygen, heart monitors, and received nebulizer treatments. In his first year of life Miles had seven eye surgeries and audiology testing resulting in a diagnosis of hearing impairment and placement of hearing aids. His mother, Carol, recalls their home being a “mini medical center” during that time.

Miles has received multiple medical and therapy services throughout his life. He has travelled nationally and internationally for evaluations and interventions to address muscle tone, vision, and central nervous system infections. Miles is non-verbal and communicates with gestures, noises, and a picture system. He has received occupational therapy, physical therapy, and speech therapy services since the age of two, both in private practice and in the school system. He attends a local school 2 days per week and a special education center based school on the other days. He uses a power wheelchair for locomotion, but also participates in standing using a walker and rides an Amtryke. His home is adapted with a stair lift, tub lift, and a van lift. He wears glasses, hearing aids, ankle foot orthotics, and hand splints. Miles requires 24-hour supervision and care provided by family and personal care takers.

Miles was born to loving parents and older siblings. Miles’ family, like other families of children with disabilities, is strong, resourceful, and resilient. Additionally, Carol is an occupational therapist who has been practicing in mental health and pediatric settings, working with people who are severely disabled, for over 20 years. Carol’s education and experience as an occupational therapist and her creative spirit and unwavering love for Miles has helped facilitate the artwork on the cover. Miles’ artwork is a display of his creativity, enthusiasm, connection to others, and unique life experiences.

Although Miles has multiple impairments, he is an inquisitive, active, and loving young man. His mother states, “He is always looking for new experiences and likes to go nearly anywhere and do anything. He doesn’t like to watch but wants to be involved as much as possible.” Although he does not speak, Miles makes his needs known, expresses opinions, and identifies preferences for the activities he participates in and the care he is given. One of Miles’ favorite activities is swimming, which he participates in at least weekly at the local pool. He also enjoys horseback riding and going to the zoo, bird sanctuary, and state parks. Another favorite activity Miles participates in is art making. Miles has had opportunities throughout his life, at school and at home, to engage in art. His interest in art began to flourish 2 years ago when he received an
easel and Carol adapted the painting experience to support his full engagement in painting. Since that time he has created multiple pieces which hang throughout their home.

Miles enjoys creating art by painting with acrylics and water colors on canvas, as well as using colored pencil and markers on paper. As seen in the accompanying video, Miles engages his whole body in the creative process, using his arms, trunk, and head to move the pencils, markers, and paint around the paper. Miles enjoys creating art while listening to music. He moves his body to the beat of the music. Using vivid and contrasting colors, the lines and brush strokes represent the rhythm of Miles’ movements and mood.

Miles requests to participate in art often and after completing a piece will ask to do another and another and another. Creating art is a vital part of his routine. Art making provides Miles with the tools to express himself through color choices, composition, and brush strokes. Additionally, it provides a valued active leisure opportunity, something that people with developmental disabilities are often lacking (Renwick, 2004). Leisure activities, such as creating art, are a form of occupational engagement for both Miles and Carol. The American Occupational Therapy Association’s Occupational Therapy Practice Framework (2008) reminds us that “occupational therapy is founded on an understanding that engaging in occupations structures everyday life and contributes to health and well-being” (628).

The paintings Miles completes reflect the ways in which participation in art making have and continue to influence Miles’ health, development, relationships, and life satisfaction. The process engages Miles’ “whole self,” including physical and emotional aspects of his being. Miles sits in front of an easel in his wheelchair with a canvas in front of him. Carol has adapted the traditional painting palette, using cups to hold the paint, making it easier for Miles to access. Paint brushes have large handles or foam attached to accommodate his grasp. Sitting in his wheelchair, Miles scoots toward the easel, activating trunk muscles and sustaining an upright posture. He uses a sideways glance to take in the colors and composition of the painting. Using a gross grasp on the paint brush, he fills the bristles with paint, raises his arm and hand to the canvas, and begins to paint. Although he does not have full range of motion in his upper extremities, he reaches to cover the canvas with paint using varied brush strokes. He uses techniques including dotting, swashing, and whacking the brush across the canvas to create different effects. One of Miles’ favorite techniques is to use a catsup bottle to blot the paint onto the canvas. Carol suggests more paint or a different color and Miles is clear in his decisions about whether to follow Carol’s suggestions or continue on as he is. He paints within one area of the canvas and Carol will move the canvas to accommodate painting on other areas. Light and soft colors are used first and then Carol offers bright contrasting colors at the end. This contrast in colors provides visual stimulation and cues for Miles to accommodate his visual impairment. Throughout the process, Miles adjusts his physical position in order to engage with the painting materials, stretching, reaching, and holding

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challenging positions in order to complete the painting. Additionally, participating in painting builds relationships and a connectedness with others with whom he creates artwork. The strength of the relationship specifically between Miles and Carol helps facilitate the creative process. Carol is attuned to his needs, recognizes the non-verbal signs of communication, and responds to him. Carol helps set up and organize the painting for Miles, indicating that she focuses on facilitating, not choosing for him. She offers choices to Miles that will result in an attractive product, but Miles ultimately makes the decisions and the focus is on the process, not the product. He communicates when he wants a new color by handing the brush to Carol or he simply stops painting, which prompts Carol to investigate his needs. Miles often stops the art process to request “eye lash” kisses from his mother, his way of expressing love and thanks to her. He also beams when others comment upon and compliment his works. Both the creative process and the outcome provide opportunities for Miles to engage in relationships and interactions with others.

In her practice as an occupational therapist, Carol has noted that often people who are severely impaired are not offered opportunities to engage in creative and expressive processes, such as art making. She believes that all people are capable of creative expression and too often they are not given the opportunity to engage in these activities. Carol has made creative opportunities accessible for Miles by adapting his environment, but also by fully engaging in the collaborative process, allowing Miles to make decisions and express his preferences. Dyches, Smith, Korth, Roper, and Mandleco (2012) performed a meta-analysis of studies published about parenting styles and children with disabilities. The authors found that a positive parenting style, including praise/reward giving, engagement/responsiveness, guidance/facilitation, empathy/understanding, and affection/warmth had a moderate effect on functional outcomes of children with disabilities. Carol displays these positive parenting styles during the process of creating art with Miles. She and Miles embrace the collaborative relationship-building opportunity offered in painting. Miles’ artworks and the process of creating them is a wonderful representation of the beauty of the connection and collaboration between children with disabilities and the people who care for them.

Another essential part of the process of creating art with Miles is deciding when a piece is finished. Pieces will sit for weeks or months as Miles and Carol decide if it is truly complete. This openness to changes and unforeseen shifts in perspective is an important part of the process of art making, but also in living life in the presence of a disability. Life changes, crises, and/or perspective shifts occur throughout the lifetime of a person with a disability, and being open to these shifts is core to resiliency. Miles’ creative process demonstrates the beauty that resides in embracing the multitude of changes and often unresolved issues in lives of people with disabilities, their families, and their caregivers.

Miles’ story and his artwork provide a reflection on the ways in which creativity and art can enhance the lives of people with disabilities and
their families. Miles’ art exists because of his drive toward engagement and participation in life, but Carol’s commitment to providing opportunities for him also is essential. Although not used as a formal occupational therapy treatment modality for Miles, the artwork he creates addresses many aspects of occupational functioning. The physical engagement with art materials provides motivation to challenge his body systems, the collaborative participation provides opportunities for social involvement, and the successful completion of art works provides a sense of mastery. The Miles’ eMOTION series of paintings can inspire occupational therapists, families, caregivers, and people with disabilities to incorporate art making as a part of their occupational profile.

To view samples of Miles’ art work and a video of Miles painting, visit:

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