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Youth and Down Syndrome: A Canadian Practice of Inclusion, Communication and Creative Arts

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Abstract

This Participant Action Research Project (PAR) was a collaborative & qualitative research project which explored creative and visual arts as a method for social inclusion and communication. Six youth with Down syndrome (DS) from Nova Scotia were participants. This active participation within a creative and visual arts modality explored and share individual experiences from participation in a social inclusion project during the COVID- 19 lockdown period. Youth experienced community song writing, creative dance, photo collage, and photo voice sessions as a mode of expressive communication. The project aim was to establish an increased awareness and knowledge specific to the achievement gap and understand various modes of expression and communication practices for youth with disabilities. Additionally, examine how creative and visual arts could aid within overall expression for youth with Down syndrome. Limited research is available which supports PAR for youth with intellectual disability. Six participants are striving to close the academic and social achievement gaps they experience every day. Inequities faced by students with Intellectual Disability (ID) have been documented and explored in recent. Results indicated that feelings of belonginess were expressed during creative arts sessions and acts of empathy throughout various art projects were documented. In addition, data suggested that exposing youth to new methods of communication and expression can promote community engagement and social inclusion for youth with disabilities.

Keywords: Youth; Down syndrome; communication; intellectual disability; creative art; visual art; expression; inclusion; participatory action research

Abbreviations: ID: Intellectual Disabilities; DS: Down syndrome, PAR: Participatory Action Research; UNESCO: United Nations Educational Scientific Organization.

Introduction

Down syndrome (DS) is a developmental disorder resulting from an error in cell division. 95% of cases involve an extra copy of chromosome 21 (trisomy), while in the remainder, either the extra copy occurs in some cells (mosaicism) or parts of chromosome 21 attach to another chromosome (translocation) [1]. Down syndrome (DS) is the most common genetic cause of intellectual disability, impacting approximately one in every 691 live births [1,2]. This condition is associated with specific physical features (e.g., distinct facial characteristics, low muscle tone); medical conditions including congenital heart disease; and intellectual disability. Individuals with Down syndrome also meet academic challenges or delays in all facets of education. In addition to intellectual disability,



the DS neuropsychological phenotype is characterized by specific neurocognitive impairments, especially in the domains of language [3]. According to Potier & Reeves [4] congenital intellectual disabilities such as DS originate from the earliest stages of development acquisition of cognitive skills and thus this occurrence results in neurodegenerative pathologies which are cumulative. With respect to communication and language, infants with DS show delays in oral language skills, which have additionally been linked to reading. In Canada, there are 45,000 individuals with Down syndrome [1]. Examining the clinical picture of individuals with DS, it has been reported that complications may be exacerbated by the presence of functional deficits, behavioral symptoms, nutritional and social problems, all of which have increased prevalence with age [5]. Sociality and social interactions are important for individuals with DS, who identify family involvement and affection as main supporting pillars in life [6]. Early researchers have noted that students with Down syndrome have unique learning needs due to delays with communication, academic functioning, and comprehension abilities [7]. Evidence also suggests that life expectancy for this population and those with developmental disabilities is nearly 20 years below that of the general population, and mortality is significantly higher across their lifespan [8].

Gap in Existing Evidence for Participatory Action Research and DS

There is comparatively minimal published research that transparently charts the contribution of youth with an intellectual disability within a collaborative research process (Stevenson, 2014). This is supported by evidence presented by St. John, et al. [9] who reported that participant action research methodologies may empower and protect marginalized individuals; however, they remain underutilized. Limited studies have investigated the impact of participatory action research, specifically on individuals with an intellectual disability (ID) [9]. According to Schwartz et al., [10] including individuals with intellectual disability (ID), bring a stakeholder-engaged & inclusive research approach. This may foster and enhance community collaborations. More importantly, this may optimize these relationships and support the involvement of people with ID in stakeholder-engaged research projects within our communities. This collaborative multi-stakeholder approach, which aims to engage individuals with intellectual disabilities can be an effective model for conducting research. This was well documented within recent findings from Jose et al. (2020), who examined participatory research with adults who had autism. Autistic adults and their caregivers can make the research process more open and accessible and make its outputs more relevant, useful, and meaningful to the wider autistic adult community. Within research, self-advocates have expressed the key concept being; that they are the stakeholders with the most at stake for enhanced communication, education and community engagement [11].

Youth Engagement

During this PAR, 6 youth with Down syndrome were active participants who engaged in various community social inclusion activities which aimed to offer opportunities for communication that focused on creative and visual arts. Sessions included painting, clay, song writing and photo collage creation. As Hartigan et al. [12] explained additional and reimagined arts education programs in schools can incorporate creative arts therapies. These practices can be a valuable tool for youth with disabilities. Using these methods of creativity to support expression, participants designed various pieces of art and shared the meaning within the local communities. Community sharing sessions included the local university, police station, performing arts stage, school, and online with invited special guests.

Down Syndrome and Communication

According to a study completed by Wilson, et al., [13] results indicated that 97.8% of participants with DS met criteria for speech disorders and 97.8% met criteria for motor speech disorders, including childhood dysarthria (37.8%), speech motor delay (26.7%), childhood dysarthria and childhood apraxia of speech (22.2%), and childhood apraxia of speech (11.1%). Ataxia was the most prevalent dysarthria subtype. Nearly all participants with DS in the present sample had some type of speech and motor speech disorder [13]. The National Down Syndrome Society [14] explained that research and clinical experiences demonstrated that some areas of language are generally more difficult for children with Down syndrome while other areas are relatively easier. Children with Down syndrome have strengths in vocabulary and pragmatics (social interactive language). They often develop a rich and varied vocabulary as they mature. They have good social interactive skills and use gestures and facial expressions effectively to help themselves communicate. However, while auditory shortterm memory and auditory processing can be areas of weakness, children with Down syndrome often have excellent visual memory (Mann, 2017).

According to the National Down syndrome Society [14], most children with Down syndrome can understand much more than they can express. As a result, their test scores for receptive language are higher than for expressive language. This is known as the receptiveexpressive gap. Speech intelligibility (speech that can be easily understood) is one of the most difficult areas for people with Down syndrome at all ages. Many children have difficulty with the strength, timing, and coordination of muscle movements for speech. Speech involves coordinating breathing (respiration), voice (phonation), and the production of speech sounds [14]. Results indicated that students with Down syndrome had basic narrative skills that were weaker than typical students of the same age. Students faced challenges with comprehension and recognizing various concepts. It was concluded that typically developing students progressed and used these skills at an early age, while students with Down syndrome were delayed and possessed weaker skillsets. The findings also discussed the variance in learning abilities and the need for specialized training to assist youth with Down syndrome [15]. This suggested an important direction for future research within the field of Down syndrome and communication strategies. Using various visual schedules can improve or enhance learning for students with Down syndrome. In another study, Bauer, et al., [16] also studied students with Down syndrome and communication interventions. The researchers designed a multiple baseline probe design which explored several components of responses such as the effectiveness of multiple opportunities, prompting, reinforcement, and error correction procedures. A baseline was conducted for both children, strategies implemented by teachers, and a follow up analysis. The overall results determined that when the students were taught simple communication skills, such as verbal imitation, an improvement in effectiveness of communication occurred [16].

Discussion

Utilizing creative and visual arts as a method of research can engage youth with ID in art-based interventions to support individual communication. Creative arts have supported people with ID for decades. Advancing research to include the first-person lived experiences of young people with ID is imperative, as this form of research which includes youth has positive outcomes for research, practice, and the individual themselves [17]. This practice can promote opportunities for social interaction and emotional expression are especially valuable for people with difficulty communicating verbally. Approximately fifty percent of creative arts therapists work with children, young people, and adults with intellectual disabilities [18]. Seminal researcher Sue Buckley was among one of the first early investigators to connect the importance of creativity and communication for individuals with DS [7]. Participants in this study utilized several forms of creative art to enhance personal communication. Using photo voice to create a story, photo collage to describe experiences and song writing to express key concepts of social inclusion were essential aspects of creative and visual arts used by participants.

Creative expression through the arts may be especially important for children and adults with Down syndrome for several reasons. First, most will have major difficulties in expressing themselves through spoken language - through talking or writing. Additionally, many cannot share their feelings through words, but can do so most eloquently through dance and movement or through painting [7]. Initiatives such as photovoice, where the participants use and direct the camera and participate collaboratively in the inquiry process, can become a creative, engaging, and empowering enterprise with much potential for enacting change [19]. Collage is the practice of collecting important materials then cutting, tearing, folding, or crumpling these remnants taken from preexisting pictures, found objects or fabrics, or a mixture of these, and gluing them onto a flat surface to communicate a visual message" [19]. Providing youth with DS an opportunity to express themselves using a variety of creative art modalities may assist overall expression. Collage can be used as a method for individuals to reflect and understand the research process, thus assisting in methods to share their thoughts and experiences. Collage can help individuals to understand the hidden research process in a way that aids in conceptualizing the understanding that might otherwise remain implicit [19]. For those with a disability, the utilization of creative arts can promote coping and resilience as well as providing opportunities for "escapism, creativity, spontaneity and enjoyment" [20]. The creative arts therapies can increase awareness of emotions and enhance capacity for emotional expressions [21]. Participants

within this study utilized various forms of creative art to express thoughts, feelings, and emotions. Story telling of events were also vital for those participants with limited verbal speech. Within this case, participants used photos with one-and two-word phrases to describe an event or activity which was important for them. Using various modes of creative art for communication was successful and engaging for youth with Down syndrome living in Nova Scotia, Canada [22].

Conclusion

With respect to both social and educational development, a precursor to success is acceptance of individuals with Down syndrome [23]. The academic foundation of this research will allow the community to move beyond practical and functional aspects of this type of participatory action research to understand how community dynamics, relationships and communication play a central role in creating socially inclusive opportunities through creative arts [24]. Six youth with Down syndrome engaged within various modes of creative and visual art as a mode to assist with expressive communication. During this engagement, youth were invited to sing, story tell, and meet new individuals within the community [25]. Photo voice, photo collage, and song writing were examples of creative arts utilized to share feelings and experiences during and after periods of isolation during COVID-19 [26]. Results of the research indicated that utilizing creative art modes provided individuals with Down syndrome an expressive opportunity for communication [27].

Conference Proceedings

Lynn Le Vatte, Kristin O'Rourke, Robyn Neal (2022) Social Emotional Learning and Education. Music City Social Emotional Learning Conference. Nashville, Tennessee, USA.

Lynn Le Vatte, Kristin O'Rourke (2022) Profound Intellectual & Multiple Disabilities. International Association Scientific Study Intellectual and Developmental Disabilities Special Interest Early Career Research Conference. Leuven, Belgium.

Acknowledgements

We would like to acknowledge the contributions of the research assistants, who worked so diligently on this project. Natasha Bellows, Renee Duffy and Faith Currie provided critical and essential support to the authors during this project. The families who support individuals with Down syndrome and self-advocates have been an inspiration to all.

Conflict of Interest

No conflict of interest.

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