



Fostering Understanding and Promoting Inclusion for Individuals with Disabilities

Yue Wu, PhD, MT-BC, Neurologic Music Therapy-Fellow

Institute on Community Integration, University of Minnesota

ABSTRACT

Light in the Well is a unique, multi-sensory experience, using original music to present the emotional journey of having a loved child with disabilities. The findings of this study confirmed that there is a great need of integrated programs that involve both people with and without disabilities. Partnership and collaboration bring opportunities when bringing a variety of talent and expertise together. The purpose of programs like this is to focus on what people can do together, as one inclusive community.

INTRODUCTION

The first *Light in the Well* performance occurred October 3, 2021, and included a live orchestra, pictures and bullet points projected on a screen, featured individuals narrating and performing their own stories, as well as sensory devices such as weighted cushions, fidgets, and earmuffs. Since then, *Light in the Well* has not only held a second live performance (October 16, 2022) but has also formed a non-profit organization of the same name to continue this work. The purpose of this phenomenological study (Creswell, 2007) was to understand the audiences' experiences of this multi-sensory music production that featured people with disabilities, and to incorporate that feedback into future performances.

METHODS

After the first public performance, volunteer research assistants interviewed the audiences with this question: "What's your experience being a part of this music performance?" (UMN IRB STUDY00013953).

Purpose: to evaluate the program, ensure quality assurance, and improve performance for future music production.

Study aims:

- To get feedback from the audience to improve the program
- To learn about the audience's perception of the performance
- To better understand the audience's description of their participation within the production

Participants: Audience members

Procedures:

- Audio recorded
- Confidential and de-identified
- 1-5 minutes

Data analysis:

- Transcribed – analyzed using Nvivo (version 12)
- Meaning units were extracted from the audiences' own words.
- Initial codes were created and categorized into themes for thematic analysis.

RESULTS

Audience Interview Quotations (n=50)
Loved It
"It's magnificent, loved it, loved it, loved it."
"It blew me away!"
"Everything was so creative."
"I'm sitting there learning about and from those families... Amazing, amazing, amazing."
"Definitely a unique experience and obviously very different from a standard concert at a concert hall, but in a very good way. I was engaged the whole time."
Telling Stories Through Music
"One of my favorite parts was that it wasn't just a composer making music, it was a music with stories. I like the unique sounds he brought into it and how that conveyed emotions."
"From the beginning to the end, I loved the stories, and they are very intimate. Just hearing the kids and their parents speak is a wonderful experience."
"At first, I felt like it's a lot of information from different instruments, just so many elements in there, and very surprised. But later, my whole being was in there and I feel a lot of healing and love and then lot of effort too from the musician. I feel that they are putting so much in there and with love and passion."
"To hear the stories and the music go hand in glove with one another and putting yourself in the family's place while the music is going on. And it was very great to hear the explanation of the music and then hear the music that was so fascinating."
"Light in the Well was more than the sum of its parts; it was truly a unique way to capture a glimpse into the lives of people with disabilities and their caregivers. I was struck by how there can be a pattern in the stages of grief, but also how there were distinctions between the stories of the featured individuals. The music itself not only made the audience aware of some of the emotions involved but also allowed us to experience them and literally feel along with them. The wild range of excitement, joy, confusion, grief, bargaining, stress, anger, frustration, comfort, and acceptance are all emotions we encounter as people living in a broken world."
Touched In Deep Ways
"I was holding back tears almost the entire show... emotional in an inspiring way."
"Amazing job, thank you for making me cry."
"Wonderful! I can't get over it. I'm shocked."
"Yea, we cried, it was so beautiful."
"Ah... (started crying; with choked voice) I'm touched in deep ways... I'm a little bit at loss of words because I'm feeling more than I am thinking."
"I'm speechless. Absolutely absolutely amazing. Far surpassed what I could have imagined. Just absolutely amazing. I really am speechless thank you. Hopeful! Hopeful! Hopeful!"
"I came with no expectations but really found that those themes are the stages of grief encompass so much of life and what we experience, but oftentimes we get stuck ourselves. And so seeing that as a production really makes me be more aware of what's going on around me and inside me."
"It was very energizing and disturbing at the same time. And nothing I could say or hear would adequately express what I was feeling. Because I could feel the despair, I could feel the hopelessness, I could feel the joy. The children, the birth, the lullaby and so forth."
"The words for the beauty and the joy in the exuberance. Really the humanity and the hope. I just don't... but at least you know I loved it. I think it's still working on me. It's definitely a lasting memory once in a million experiences."
Being In Their Shoes
"We all have a story. It's an insight into somebody else's life, and how we all have those same moments in life."
"I noticed myself having different facial expressions at each sound that I saw, and it reminded me of my own memories that I've had in my life, so very relatable."
"It was really wonderful, because it gave me a glimpse of feeling of what disabled people experience emotionally, and how they benefit how they grow through music."
"It was eye opening, and it allowed me to just step back for a moment and think about my life and to be grateful. And to just be more aware of what's going on."
"The whole awareness of disabilities and need for hope. I mostly taught and worked with gifted students so focused on that area. I need this reminder so it's good."
"As a family member with a loved one who lives with disability, all we really want for them is everything that is available to people who live without disabilities."
"It was very uplifting. I have a number of family members that have had this experience including one of my children, so this meant a lot to us."
"My youngest sister also has a developmental disability, so seeing people bring that in all that raw emotion, I can resonate with a lot of that stuff. It was a beautiful, beautiful time."
"We've got to see side of stories that we don't really get to see from the different people that we don't think about. We should think about more."
"To see how compassionate other human feelings were about people with those conditions, to see the kindness of those people show up and it's really great experience."
"I appreciated the opportunity to hear music that described my own emotions as well as enter into greater empathy with these individuals and families."
"Compassion ran forth and was on display in such a way that it moved the hearts of many in audience including mine."
Creating Opportunity
"We got to see how successful these special people can be when they're given the right support and compassion, and just how much love can impact people as well."
"It was really nice to see them in that light to see them prosper and have fun experience themselves."
"This is an opportunity for these performers to be engaged with professionals and yet to be revered as contributors."
"I really like to see James because I heard about him. So I hope I can hear his piece more."
"I thought this show taught me a lot about people with disabilities that I never knew before."
"This was on a level of not only like entertainment for me but like a professional development."
"The audience got a front row seat to seeing the giftings, the talents and also the real-life challenges that these special people and their caregivers have faced and are facing along their journey."
"When I say entertainment, not that I guess for entertainment meaning like I'm going to an orchestra concert, but when it comes to late professional development, in my opinion, it's like I'm learning something that I can take with me to the classroom or for families that have students with a diagnosis and are part of the SPED (special education) world. Different strategies that could be used or different ways of incorporating music into their child or children's lives to make an even more positive impact."
Impacting Lives
"Life changing."
"Wonderful! I'm moved beyond words."
"As far as the show went, I cannot express... the tears that I had in the show... how beautiful it was, how impactful it was, how important it was, how amazing it was."
"To see people encouraged in their darkness and brought to a new level of hope is the heartbeat of Light of the Well."
"It caused me to reflect on the true source of light and hope in the midst of such strong emotional experiences."

DISCUSSION

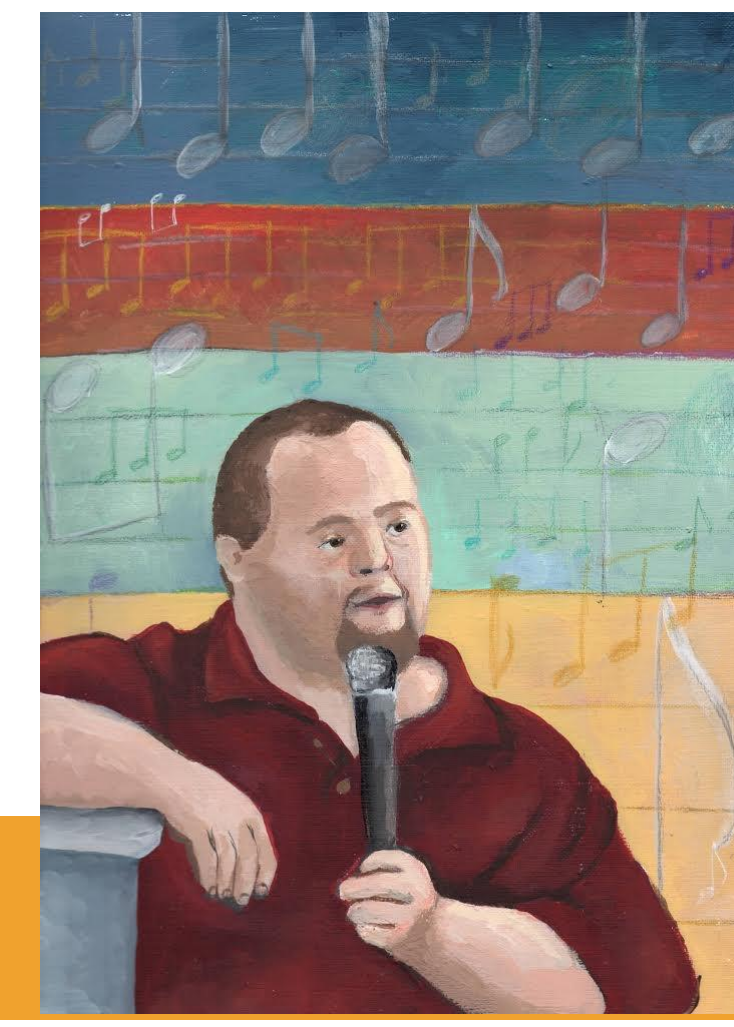
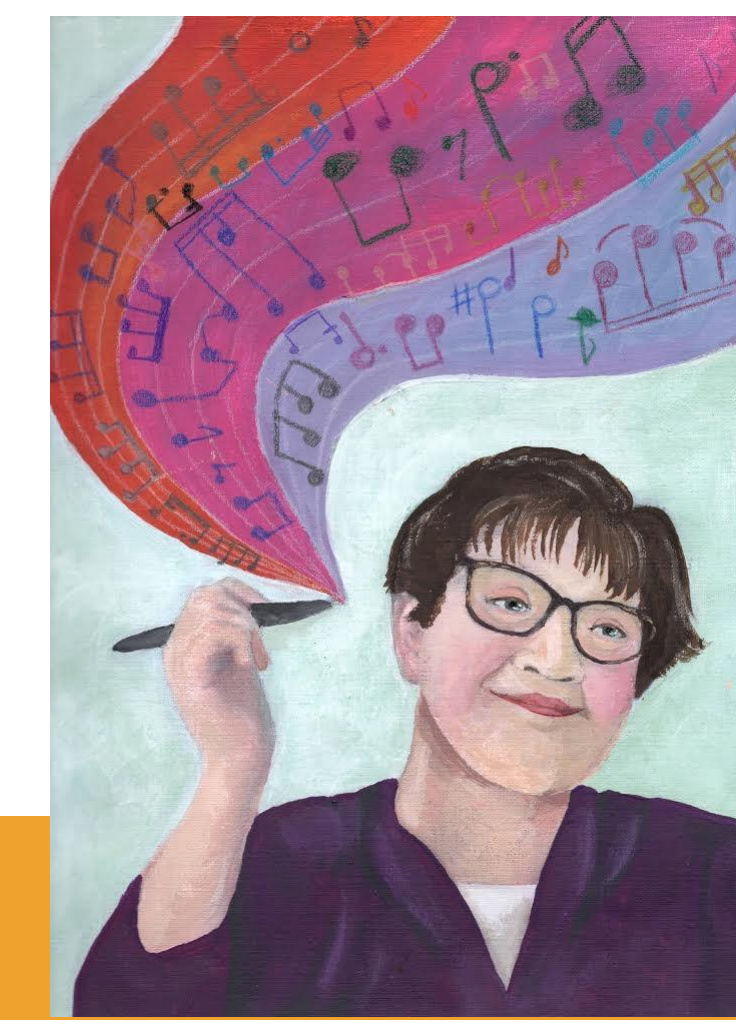
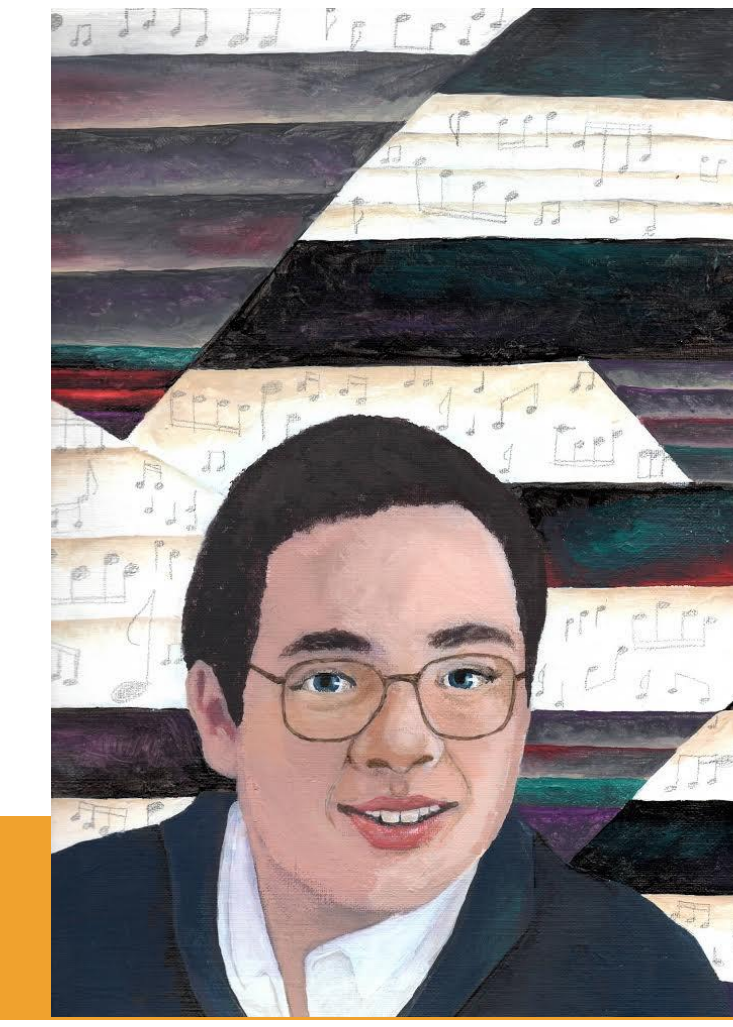
Visual and performance arts not only have aesthetic values but can mold and transform understanding and perspectives of people.

Neuroscience showed that the audience's experiences on sensory, cognitive, emotional, and spiritual levels can lead to long-term neurocognitive changes (Preminger, 2012). Research findings reflected the audiences' experiences when immersed in the stories of those who are affected by disabilities. **These findings benefit the field of music therapy and all professions that work with families who have children with disabilities.** It is imported to understand the emotional journey families who are affected by disabilities experience in order to better serve them.

Fine arts can be a part of rehabilitation intervention outside of the traditional rehabilitation medicine structure. *Light in the Well* explored a new model of therapy, centered in the natural context. Instead of staying in the safety of a therapy room, where the environment is predictable, the participants gain skills and practices in real life situations such as occurs in the performing arts. This challenged participants to be flexible and use skills learned in therapy sessions to support their performance. This model can be used as a transitional program from traditional therapy model to community integration.

The findings of this study also confirmed that **there is a great need of integrated programs that involve both people with and without disabilities.** Sensory-friendly events are one model to provide safe environments for people with disabilities to experiences arts at a separate time from the public. The next step is to bring people with and without disabilities into the same space to share an experience at the same time. This provides opportunities for people to learn about and from each other, gain understandings and practice skills in real life settings. In this event, a sense of comradery and mutual respect were formed across groups. The purpose of programs like this is to focus on what people can do together, as one inclusive community.

Individuals with disabilities thrive on stage when provided with appropriate support. Audience respondents remarked that each performing person with disabilities performed well with prompting from loved ones. Family prompters required coaching to know how much to step in to support just enough, and step back and not perform for their children. To achieve independency and maximum performance for those who are affected by disabilities, it would be helpful to train the everyday support staff to know the balance of how much we can do to help.



CONCLUSION

This research is one of the first studies to look at the audience's experiences in being a part of a multi-sensory musical performance involving both people with and without disabilities. The audience members who responded to the interview felt the performance was not only enjoyable and relatable, but also impactful and transformative in understanding the emotional journey of having a child with disabilities. There is a great need of integrated programs that involve both people with and without disabilities, to show what people can do together, as one inclusive community.

KEY REFERENCE

Creswell, J. W. (2007). Five Qualitative Approaches to Inquiry. In J. W. Creswell (Eds.), *Qualitative Inquiry and Research Design: Choosing among Five Approaches* (pp. 53-84). Thousand Oaks: Sage Publications.

Gabriel, R. (2021). Affect, Belief, and the Arts. *Frontiers in Psychology, 12*, 757234. <https://www.frontiersin.org/articles/10.3389/fpsyg.2021.757234/full#B22>

Kübler-Ross, E., & Kessler, D. (2005). *On grief and grieving: Finding the meaning of grief through the five stages of loss*. New York: Scribner.

MacGlone, U., Vamvakaris, J., Wilson, G., & MacDonald, R. (2020). Understanding the Wellbeing Effects of a Community Music Program for People With Disabilities: A Mixed Methods, Person-Centered Study. *Frontiers in Psychology, 11*, 588734.

Preminger, S. (2012). Transformative art: Art as means for long-term neurocognitive change. *Frontiers in Human Neuroscience, 6*(2012), 96.

Acknowledgement

This study was supported by an Institute for Advanced Study Research and Creative Collaborative Grant from University of Minnesota..

CONTACT

Lightinthewell.com lightinthewell@protonmail.com

