Qualitative Approaches to Create an Inclusive Musical Experience

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Funding

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

Abstract

Light in the Well is a unique, multi-sensory experience, using original music to present the emotional journey of including a loved child with disabilities in a family. The purpose of this study was to apply a phenomenology qualitative approach to better understand the audiences' experiences of this multi-sensory music production that featured people with disabilities, and to incorporate that feedback into future performances. The findings of this study confirmed that there is a great need for 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.

Keyword: Audience experience, multi-sensory, disabilities, qualitative.

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Social inclusion benefits everyone in the community. The ecological model of social networks and community participation defines social inclusion as "the interaction between two major life domains: interpersonal relationships and community participation" (Simplican, Leader, Kosciulek, & Leahy, 2015). Many factors are included in this model, for example, individual, interpersonal, organizational, community, and socio-political (Simplican, Leader, Kosciulek, & Leahy, 2015). Creative arts such as theater, painting, music, film, and photography are powerful tools to convey philosophical expressions, establish aesthetic values, and influence culture (Gabriel, 2021; Rodowick, 2015). The collaborative nature of creative arts provides a welcoming environment for people with and without disabilities to express and engage in a meaningful way (Roy, 2022). The motivating and engaging characteristics of music facilitates and promote social learning and communication skills (American Music Therapy Association, 2012). Structured music intervention promotes social responsiveness (Finnigan and Starr, 2010). The sensations and emotions provoked through the aesthetic experiences help the audience interpret and understand the message, via self-reflection and processing with others; and, therefore, form a more complexed point of view (Herbert, 2011; Calasso, 2020). Telling stories through music was not only enjoyable and relatable for the audience, but also a powerful way to connect with people on an emotional level.

The experience of raising a child with disabilities can potentially be like living in a well – it can be dark, cold, and lonely. However, when provided with opportunities, these families and their children with disabilities have the potential to create the light needed for a brighter future, telling their own stories within the context of musical expression. *Light in the Well* (LITW) is a non-profit organization serving people with and without disabilities through supporting them to

create multi-sensory experiences, weaving together music and real-life stories to promote the inclusion of children, youth, and adults with disabilities and their families. LITW brings together people with and without disabilities (see: https://www.cbsnews.com/minnesota/news/light-in-the-well-brings-together-musicians-with-and-without-disabilities/) through an open-ended process establishing communities of caring and support through creative arts and music. LITW communities are inclusive of all people, including traditionally marginalized populations, where members can be themselves, express their talents, develop a purpose in life, and transform both themselves and their communities. The vision of LITW is an inclusive world where people with and without disabilities learn from, appreciate, and embrace one another. Its mission is to bring people with and without disabilities together to enrich each other's lives through creative music experiences, storytelling, therapeutic intervention, education, and relationship building.

All too often, people with disabilities feel marginalized and lack the support to envision and work toward their personal visions for the future. This is especially the case when such individuals are members of other marginalized communities including BIPOC and LGBTQIA+ communities. In addition, many people without disabilities are unaware of how to interact with those with disabilities, whose gifts are often not recognized or valued. LITW provides the opportunity for such people to participate in an inclusive, creative process in which their lived experiences play a critical role in generating multi-sensory experiences for community members. Many people with developmental disabilities are challenged in their verbal communication but can freely and creatively express themselves through music (MacGlone et al., 2020; Mino-Roy et al., 2022). LITW enables them to do this. The original music was composed based on interviews with featured families, all of which are affected by disabilities. Based on the transcripts, a consistent thread of the five steps of grief: denial, anger, bargaining, depression, and acceptance

(Kubler-Ross, 2005) emerged. The love parents held towards their children overshadowed each stage of grief. Therefore, the five steps of grief became five themes of the music, with the theme of love traveling throughout the music.

The entire orchestral music score has six movements. The first movement, the grand opening, introduces each theme of the music. Each of movements 2 through 5 focuses on one of the featured families, where their own stories were told through music. The last movement, the grand finale, restates the themes ending with the theme of acceptance into a *Song of Acceptance*. Each featured family has a role on stage. The featured individuals introduced themselves at the beginning of their own movement. Followed by their parents stating the music themes the audience was about to hear in that movement, and the emotions they represented. The featured individual then performs with the orchestra through singing, dancing, and playing drum, piano, and kazoo. The audience was invited to sing along, tap with the beat, interact with the narrators, and the freedom to step out of the performance if the emotions were too strong. The featured families were seated on stage among the orchestra performers.

The first LITW 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, LITW 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

The initial funding of this production came from a professional development grant at the researcher's work, a local community music center. They also provided the performance venue for the first production as an in-kind donation. Towards the first performance, the researcher conducted a fundraiser to raise enough funds to compensate the production team and cover the production cost.

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?" The purpose of gathering this feedback was to evaluate the program, ensure quality assurance, and improve performance for future music production. The specific study aims were:

- 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

The participants of this study were the audience who came to the first performance. The event was advertised on social media (Facebook and Instagram), Eventbrite, and the local community music center's website. Printed flyers were distributed by featured families and production team members to their networks. Electronic flyers were also sent to local organizations serving people with disabilities via email. The event was sold out (n=120). The event venue was physically accessible and sensory accommodations were provided. The researcher received 50 audio recordings of the audience responses.

Procedures

The event was held in a professional music hall at the local community music center. The performance was 90 minutes long, with no intermission. The audience was given the freedom to come in and out of the music hall throughout the performance as needed. After the performance, research volunteers approached the audience and asked about their immediate reaction to the event. An open-ended interview question was presented to the audience: "What was your experience being part of this music performance?" The audience's answers were audio recorded. All collected data was confidential and de-identified at the time of data collection. Each response required approximately 1-5 minutes.

Data Analysis

All interviews were audio recorded, verbatim transcribed by the researcher, and qualitatively analyzed using NVivo (version 12). Qualitative content analysis was used to report and describe findings from the interviews (Vaismoradi, M. & Snelgrove, S., 2019). The researcher followed the six-phase developed by Braun and Clarke (2006): become familiar with the data, generate initial codes, search for themes, review themes, define themes, and write-up. Emergent coding was implemented to identify patterns and themes emerged from the data Bias reduction was applied by using the participants' own words to describe a theme. The descriptive information compiled throughout the interviews were coded into meaning units. In Vivo coding and emotion coding were applied in this study. In Vivo coding "uses words or short phrases from the participant's own language in the data record as codes" (Miles, Saldaña, & Saldaña, 2014).

This coding strategy helps capture meanings as experienced by the audience. Emotion coding "provides insight into the participants' perspectives, worldviews, and life conditions" (Miles, Saldaña, & Saldaña, 2014). For example, samples of audience member responses include "I was

holding back tears almost the entire show." "Yea, we cried, it was so beautiful." "(with choked voice) I'm touched in deep ways" resulting in meaning units labeled "cried" which, when these types of responses were compared, became part of a theme called "touched in deep ways". In this way themes emerged from the data, maintaining the audience voice throughout the process. After coding the individual interview transcript, themes were categorized and color coded across all interviews. All study related data including audio recordings, meaning units, and themes were stored in the BOX secure system two years after the completion of this study.

Results

The audience's responses (n=50) were overwhelming. Some members of the audience cried and stated that they were touched in a deep way. Most audience felt they saw a glimpse of what it is like to have a child with disabilities and felt they were partaking in the performance instead of just watching. Seven themes were developed based on the audiences' comments and reflections.

Loved it

The audience reported that they really enjoyed the unique and creative performance.

Audience used words such as, "beautiful," "amazing," "unbelievable," "impressed,"

"wonderful," "masterful," "superb," "brilliant," and "awesome" to describe their experiences.

The audience freely expressed positive feelings: "It's magnificent, loved it, loved it, loved it." "It blew me away!" "Everything was so creative." The multi-sensory component allowed audience to fully experience the stories through different aspects: "I'm sitting there learning about and from those families... Amazing, amazing, amazing." The uniqueness kept the audience's attention, "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

The audience reported that music as the vehicle for telling stories was "intriguing". They were moved by the stories and felt the music really spoke of the emotions. "One of my favorite parts was that it wasn't just a composer making music, it was music with stories. I like the unique sounds he brought into it and how that conveyed emotions." The idea of unique variations on a theme connected with the components of grief was powerful.

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. And then with us, just felt right here in the moment and it was absolutely wonderful.

As the music evolved, the audience started to develop connections with the musicians.

At first, I felt like it was 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.

A narrator explained the music before each movement so the audience could attend to certain sounds and better travel in the space created by the music to experience the stories themselves.

To hear the stories and the music go hand in glove with one another and put 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.

Although the audience experienced many emotions throughout the performance, the feeling of hope triumphed over disparity. "I liked the feeling of hope for people who have difficult experiences."

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

Many audience members came to the performance expected to be entertained, but left the event being educated and touched. "I was holding back tears almost the entire show... emotional in an inspiring way." The audience became emotional during the interview with choked up voice and tears. "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!

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 more aware of what's going on around me and inside me.

The performance strove to be interactive, with the featured individuals with disabilities introducing themselves and playing major roles during their own stories, among professional musicians. "[Chocked-up voice] This whole process is such a beautiful journey." Audience stated they felt the experience was "overwhelmingly filled with love."

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. Some audiences were at loss for words when interviewed and were still processing it after the performance.

The words for beauty and 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

Many people who came to the performance had no experience or exposure to people with disabilities. "For the most part disabled have been people over there [pointing to a far direction]." *Light in the Well* helped the audience put themselves in the shoes of people with disabilities and empathize with them. "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." The audience reflected that the music helped them understand the experience of living with a disability or having a child with disabilities. They were able to relate to what people with disabilities experience, through the expression of music. "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."

Being able to learn more about the experience of having a child with disabilities helped the audience appreciate their own lives more. "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." Having exposure to people with disabilities also brought awareness and reminded the audience that there is a group of people that were overlooked. "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."

Family members of people with disabilities who came to the performance expressed their deepest desire: "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." Some members of the audience resonated greatly with the performance. "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 development 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."

Light in the Well brought up a lot of feelings of compassion and empathy from the audience towards people that they don't usually think about that often. It became an important reminder to people. "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." The compassion and kindness were palpebral and experienced publicly by the audience. "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 an experience for audience to feel the emotions the featured families experience helped people to be more compassionate for persons affected by disabilities, so that people can better relate to one another.

Creating Opportunity

Light in the Well provided an opportunity for people with disabilities to shine and play alongside professional musicians under the spotlight. "It was really nice to see them in that light to see them prosper and have fun experience themselves." This may open other opportunities for the featured individuals to perform elsewhere and increase awareness. "This is an opportunity for these performers to be engaged with professionals and yet to be revered as contributors."

At the same time, *Light in the Well* also provided the opportunity for the public to hear the stories of people with disabilities and want to know more about them. "I really like to see James because I heard about him. So I hope I can hear his piece more." It also became an educational opportunity for the public. "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.

With the right support, everyone can shine. "And 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." This message also provided audience the practical ways that they can use when interacting with people with disabilities.

Impacting lives

Light in the Well had a big impact on the audience. The audience felt the event was "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." It also caused the audience to reflect on deeper issues and the meaning of hardships. "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."

Telling stories through music was not only enjoyable and relatable for the audience, but also a powerful way to connect with people on an emotional level. The audience experienced compassion towards those affected by disabilities as they became more aware of the emotional journey experienced by these families. They also think a program like LITW can create opportunities for those who have disabilities and impact lives both with and without disabilities.

Discussion

The purposes of this research were to get feedback from the audience to improve the program, to learn about the audience's perception of the performance, and to better understand the audience's description of their participation within the production. Volunteer research assistants interviewed the audiences with the question "What's your experience being a part of this music performance?" The research findings reflected the audience's experiences when immersed in the stories of those who are affected by disabilities. Findings from the current study not only benefit the field of music therapy but also all professions that work with families who have children with disabilities. Other types of therapies such as occupational therapy, speech language pathology, and physical therapy can take the research results about client- and family-centeredness into their practice. It is important to understand the emotional journey families who are affected by disabilities experience in order to better serve them.

Ableism still exists in our society through both direct and subtle discrimination and social prejudice against people with disabilities. This is especially the case when one considers the intersectionality of disability with other forms of diversity (e.g., racial/ethnic, gender, and cultural group members) leading to segregation, bulling, and microaggression in school and work, as well as social exclusion. Previous research showed that both students with and without disabilities who attend inclusive schools had a sense of belonging and responsibility to include everyone (Shogren et al., 2015). Gathering people with and without disabilities to make music together might create opportunities for friendships and social connections (Carlson, 2016). Creative arts offer a unique way to address such issues and promote social inclusion. The collaborative nature of creative arts provides a welcoming environment for people with and without disabilities to express and engage in a meaningful way. 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). In LITW, music fulfilled the role of a storyteller. It carried the love theme and five stages of grief throughout the performance. In this case, each of the musical themes was a character in this production. This challenged the traditional view on the role of music and invited more discussions on how to put music as the center, not just the diverging role.

The findings of this study also confirmed that there is a great need for integrated programs that involve both people with and without disabilities. Compared to the traditional segregated and exclusive models, society has made great progress in making arts accessible. Sensory-friendly events are one model to provide safe environments for people with disabilities to experience 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. Partnership and collaboration bring opportunities when bringing a variety of talent and expertise together. 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. Production designers and performers are better able to create truly inclusive events with a deeper understanding of the audience.

We all have a desire to succeed, so do people with disabilities. 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 independence 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.

Since the beginning of 2021, LITW has become a 501(c)(3) non-profit organization. The mission of LITW is to build bridges between people with and without disabilities to provide hope, enrich lives and influence culture through creative music experiences, storytelling, and education. One of the focuses of the organization's mission is to apply research results to social change. The organization hopes to build a culture that restores the damage of division with the unity of hope, fosters relationships and promotes conversations via music. The goal of the program is to be therapeutic to those who have disabilities, and educational to those who don't. The immediate target of this program is families who are affected by disabilities and helping professions such therapists, social workers, special education teachers, and students. People without disabilities who have never had a shared experience with those who have disabilities may find this program helpful in understanding the emotional journey families who are affected by disabilities experience; and, therefore, develop compassion and get involved in the lives of those who have disabilities.

Limitations

The author is also the initiator and project manager of LITW. To reduce bias, the researcher practiced reflexive journaling, and verified the themes with the production team and featured families. Negative feedback might not be collected because the audience did not enjoy the performance left before the interview. Moreover, the audience came out of an emotional high from the performance and had nothing but good to say at the interview. This study only focused on the audience's experience. The rich data from the participating families and musicians were

left out. Therefore, the story seems not complete without multiple perspectives. Future study should explore the experiences of participating families and musicians as well.

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.

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