Expressive Arts Therapy in Performance as Trauma Work for Individuals with Intellectual Disabilities: A Community Engagement Project

Capstone Thesis

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Abstract

People diagnosed with an intellectual disability (ID) are at a substantially higher risk of experiencing trauma than typically abled individuals. In addition, the nature of ID makes it especially difficult to cope and access treatment. The goal of this research was to examine how expressive arts therapy can support treating this population for trauma. Information was gathered on Trauma-Informed Care, Psychodrama, Drama Therapy, Interactive Behavioral Therapy, Eye Movement Desensitization and Reprocessing, and The Storytelling Method. This investigation led to a community engagement project between August 2019-February 2020 that involved the researcher meeting one-on-one with nine individuals diagnosed with ID. A variety of expressive arts therapy interventions were used to prime their stories for a performance series that would take place at the end of the engagement. Each client had a significant trauma history and the researcher’s goal was to use the expressive arts to cultivate emotional regulation, positive self-concept, and improved self-esteem. Each performer attended sessions regularly and prepared fully realized pieces that were performed to sold-out audiences over the course of three nights. These findings implicate that trauma treatment for this population is crucial and possible through the expressive therapies.

Keywords: intellectual disability, developmental disability, expressive arts therapy, drama therapy, trauma, trauma-informed care, therapeutic theatre
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Introduction

“I never thought I’d have the opportunity to express this,” he said, tears welling up in his eyes. The client, a 23-year-old man diagnosed with Asperger’s syndrome and cerebral palsy, sat in a large conference room after speaking the monologue he had composed for a therapeutic theatre performance entitled “I Am You.” This performance would take place a few months later with a company of nine individuals diagnosed with a variety of intellectual disabilities. Each client spent seven months meeting with the researcher individually and as a group in order to identify the parts of their story they wanted to tell and how they wanted to tell them.

Upon initially meeting these clients and getting to know them, it became clear that each one had a significant trauma history. Research indicates that individuals with intellectual disabilities (ID) are at a substantially higher risk of experiencing trauma while also at a greater disadvantage in acquiring treatment for it than those without ID (Razza, Tomasulo, & Sobsey, 2011, Woods and Freedman, 2015, Mrayyan, Eberhard, and Ahlström, 2019).

The population with the highest rates of trauma should receive the greatest amount of effort to establish prevention and treatment. Unfortunately, this is not the case. There is a glaring lack of research on this topic and even fewer established, evidence-based treatments for it. It is vital that clinicians deepen their exploration of interventions that could lay the foundation for long-term work within this population due to the outstanding amount of trauma that they statistically endure.

Traumatic events threaten an individual’s self-perception but facilitating insight into their story has the ability to repair those perceptions and create a more resilient self-concept
(Hemenover, 2003). Creative arts therapy interventions are among the most common approaches to treatment for clients diagnosed with ID and can provide ample opportunity to repair this rupture. (Tomasulo and Razza, 2006, Mevissen et al., 2011, Snow et al., 2017). “I Am You” was designed to break down barriers between clients with ID and non-disabled audience members, but more importantly it created an entry point for those clients to begin exploring their own stories.

This paper will establish research that demands further treatment options for this population as well as outline the process of “I Am You.” It will also explain how this kind of intervention may lay the foundation for trauma work. Most importantly it will establish that people with intellectual disabilities have a right to this kind of treatment and are capable of benefiting from it.

**Operational Definitions**

Intellectual Disability: “characterized by deficits in general mental abilities, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience. The deficits result in impairments of adaptive functioning, such that the individual fails to meet standards of personal independence and social responsibility in one or more aspects of daily life, including communication, social participation, academic or occupational functioning, and personal independence at home or in community settings” (American Psychiatric Association, 2013, p. 31).

Trauma: “stimulation that exceeds the individual’s ability to cope,” defined by whether or not the event disrupted the individual’s foundational beliefs about self and world (Dalenberg, Straus and Carlson, 2017, p. 15).
Complex Posttraumatic Stress Disorder (CPTSD): “ICD-11 (11th Revision of the International Classification of Diseases) CPTSD includes the three PTSD clusters (re-experiencing of the trauma in the here and now, avoidance of traumatic reminders, and a persistent sense of current threat that is manifested by exaggerated startle and hypervigilance) and three additional clusters that reflect ‘disturbances in self-organization’: (1) affective dysregulation, (2) negative self-concept, and (3) disturbances in relationships (Karatzias et al., 2017, p. 2).

**Literature Review**

Individuals with intellectual disabilities (ID) are at a substantially higher risk of sexual abuse, physical abuse, neglect and exploitation than the rest of the population (Razza, Tomasulo, & Sobsey, 2011, Woods and Freedman, 2015, Mrayyan, Eberhard, and Ahlström, 2019). These various forms of trauma create even greater barriers for these individuals to communicate their needs, express their emotions, and cultivate meaningful lives (Razza, Tomasulo, & Sobsey, 2011, Woods and Freedman, 2015, Mrayyan, Eberhard, and Ahlström, 2019). However, there are very little resources for trauma treatment within this population. The goal of this research is to investigate how expressive arts therapy can be especially beneficial for treating trauma in individuals with intellectual disabilities.

As of 2019 national health surveillance for this population is virtually nonexistent. Administrative data from the developmental disability service delivery system estimates that only about 20% of individuals with intellectual or developmental disabilities are known to state agencies and only 17% received Medicaid or state-funded services (Havercamp & Krahn, 2019). The identification of individuals with ID is not represented in disability screenings, which consist of a six-item question that assesses functional limitation in hearing, cognition, vision, mobility,

Lack of screening is largely due to the varying operational definitions of intellectual disability. For example, some providers include attention-deficit disorders and learning disabilities while others do not. The U.S. Department of Health and Human Services does not include a set of items to identify ID within the disability group and therefore the healthcare system is not equipped to properly identify this population’s health status, determinants or needs (Havercamp & Krahn, 2019). Ultimately, “We (those with ID) are invisible in the data. We can’t make people believe we need more services if we don’t have data to back us up” (U.S. Public Health Service, 2001, p. 5).

Of the individuals with ID who are identified in their communities, it is estimated that children diagnosed with ID are 3.7 times more likely to be neglected, 3.8 times more likely to be emotionally abused, 3.8 times more likely to be physically abused, and 4.0 times more likely to be sexually abused than typically developing children (Razza, Tomasulo and Sobsey, 2011). In addition, they have more than double the risk of being diagnosed with affective disorders and anxiety disorders (Mrayyan, Eberhard and Ahlström, 2019). These numbers are likely much higher due to lack of screening. Moreover, living with an intellectual disability often creates communication barriers that make it challenging to engage with clinicians effectively. This often results in unsatisfactory treatment plans (Mrayyan, Eberhard and Ahlström, 2019).

The U.S. Supreme Court did not rule that all people (including those with disabilities) have the right to live and participate in community-based settings until June of 1999 (Havercamp & Krahn, 2019). This discrimination prevented individuals with intellectual disabilities from accessing educational opportunities, socializing within their communities, and participating in
recreational activities. Isolation has remained a chronic problem for this population to this day resulting in ongoing stigma and further traumatization (Havercamp & Krahn, 2019).

Researchers found that the chances of being diagnosed with a comorbid psychiatric illness was eleven times higher for clients with ID than compared with the general population (Mrayyan, Eberhard and Ahlström, 2019). It’s also extremely difficult to properly diagnose this population due to the nature of various intellectual disabilities. The barriers include restricted memory, difficulty articulating needs, impairment of executive domains, and differing communication styles (Woods and Freedman, 2015).

It’s important to define trauma for the purpose of this research. In a psychodynamic approach, trauma is characterized by “stimulation that exceeds the individual’s ability to cope” (Dalenberg, Straus and Carlson, 2017, p. 15). A person-centered definition of trauma can be defined by whether or not the event disrupted the individual’s foundational beliefs about self and world. If the experience shattered a global schema that the person held (i.e. that life is fair, that self is good, that God protects, etc.), or forced a change in their perception of self, it can be categorized as trauma (Dalenberg, Straus and Carlson, 2017).

People diagnosed with ID are more likely to experience trauma and there is growing evidence that developmental level is crucial to a person’s ability to cope with that trauma (Razza, Tomasulo and Sobsey, 2011). If the definition of trauma is centered on this ability to cope, then the population that is the most susceptible to abuse is also the most vulnerable to traumatization. Brain development is significantly impaired by early onset abuse as well, which creates a vicious cycle of damaging effects for people with ID (Razza, Tomasulo and Sobsey, 2011).

Chronic trauma shortens the strand of DNA associated with life expectancy, hormonal regulation and immune functioning. It also compromises brain functioning by disrupting the
amygdala, hippocampus, and prefrontal cortex (Woods and Freedman, 2015). These areas of the brain tend to emotional regulation, memory, and executive functions respectively (Woods and Freedman, 2015).

Experiencing trauma at an early age, even as a typically developing person, jeopardizes development in all areas – cognitive, behavioral, affective, biological, and psychological (Razza, Tomasulo and Sobsey, 2011). Slowed neurodevelopment is also compounded by chronic trauma. Therefore not only are people with ID more prone to trauma, but their disability (defined by deficits in neurodevelopment) becomes more acute.

Cognitive vulnerabilities, lack of risk awareness, stigma, and isolation cultivate a fertile ground for traumatic experiences (Woods and Freedman, 2015). Furthermore, the awareness of having a disability can be traumatic in and of itself (Woods and Freedman, 2015). To make matters worse, ID may create a lack of insight and limited sense of self that may lead to underreporting of both trauma and symptoms (Woods and Freedman, 2015).

Complex Posttraumatic Stress Disorder (CPTSD) might be a more appropriate diagnosis for individuals with ID who experience various forms of abuse and neglect. This diagnosis is defined by repetition of trauma, prolonged exposure to trauma, infliction by caregivers, and developmentally vulnerable timing (Bleuer and Harnden, 2018). The American Psychiatric Association does not yet recognize this diagnosis but the International Classification of Diseases (ICD-II) defines it as re-experiencing of the trauma, avoidance of reminders pertaining to the trauma and hyperarousal symptoms (symptom clusters required for a PTSD diagnosis), in addition to difficulties regulating affect, interpersonal relationships and negative self-concept (Karatzias et al. 2017).
It’s important to define core symptoms that result from surviving trauma as well as foundational phases of the recovery process for the purpose of this research. People who survive trauma often report a lack of control over their emotional state. Therefore, emotional regulation is a vital component of recovery (Woller et al. 2012). Complex trauma also negatively impacts self-concept, which manifests in low self-esteem, guilt, and shame. Establishing positive self-concept is thereby central to healing as well (Woller et al. 2012).

According to object relations theory, it is especially damaging when caregivers inflict the trauma because that rupture becomes internalized as part of an individual’s self-structure (Stadtmann et al. 2017, Greenberg and Mitchell 1983). People with ID are more likely to experience child abuse committed by family members or caretakers (Catani & Sossalla, 2015). This is likely due to more acute dependence on the caregiver and may look like withholding medication, food, or needed support (NCCJD, 2015). Increased burnout, turnover, environmental stress, and lack of recognition also result in higher rates of neglect, abuse, and exploitation from staff members who serve as caretakers for clients with ID (Keesler, 2015).

Trauma-informed care (TIC) is critical in the context of supporting survivors of abuse and neglect. TIC is “a systems level philosophy of service delivery which integrates choice, collaboration, empowerment, safety and trust to create an organizational culture sensitive to trauma” (Keesler, 2015, p. 481). This approach is growing rapidly but there is a deficiency of research on TIC with those who are diagnosed with ID, which is especially detrimental because this population often relies so heavily on institutions for support (Keesler, 2015).

Perhaps most importantly, a TIC approach views individuals’ behaviors as coping mechanisms that manifest from a trauma response by asking “what has happened to, rather than what is wrong with them” (Keesler, 2015, p. 482). This method also encourages clients to be
active participants in their care, offering choices and options in both their daily lives and overall treatment planning. It’s interesting to note that this approach can be destabilizing for some people with ID who have experienced restrictive care throughout their lives, which is quite common (Keesler, 2015).

Play and the expressive arts can provide an integral outlet for the early stages of working through trauma. Trauma impacts verbal processing and the survivor’s ability to articulate the traumatic event (Harris 2009). Play creates the opportunity for alternative ways of expressing those distressing thoughts, emotions, and experiences through metaphor, symbolism, embodiment, and dramatic enactments (Bleuer and Harnden, 2018). Dramatic embodiment can increase clients’ engagement in their own individual therapy. Creative expression allows for an aesthetic distance, which is “the optimal balance between cognition and affect that helps clients access all of their resources” (Landy 1993, 1997).

Johnson (1998) articulated the psychodynamic model of creative arts therapies that involves projection, transformation, and internalization. Projection involves exploration of artistic expression. Transformation is the mediation or “working through” of the piece that is created, and internalization is the process of reintegrating that experience into the client’s psyche (Johnson, 1998, p. 85). This process allows for non-verbal exploration of experiences while also incorporating an aesthetic distance and re-integration of the exploration into self-concept. A diagnosis of ID often results in communication barriers. Therefore the creative arts therapies’ range of communication styles may be more accessible to this population.

Psychodrama shows a lot of promise for this population (depending on their level of functioning) due to its external properties. Its practice proposes engaging the individual as fully as possible and expanding the therapeutic process beyond purely cognitive activities (Razza,
Tomasulo and Sobsey, 2011). Psychodrama invites participants to physically reenact traumatic scenes, test out novel responses to stressors, and engage both behaviorally and emotionally.

Interactive Behavioral Therapy (IBT) was created specifically to adapt psychodrama for participants with intellectual disabilities. This approach incorporates an orientation and affirmation piece to the traditional psychodrama model, which also includes a warm-up, sharing, and enactment (Tomasulo & Razza, 2006). The sharing is a time for group members to offer emotions or personal experiences with the ensemble and the enactment invites individuals to play out that scenario (Tomasulo & Razza, 2006). The key differences are the extra steps taken in orientation to facilitate a more in depth overview of the process (in addition to the warm-up) as well as the affirmation, which invites the audience to share something positive about the protagonist (as opposed to a more abstract sharing of what they observed in the enactment) (Tomasulo & Razza, 2006).

Drama therapy, a distinctly different approach than psychodrama, is also used effectively within this population, as evidenced by The Centre for the Arts in Human Development (CAHD). CAHD employs various creative arts therapies for clients with a variety of developmental and intellectual disabilities. One of their most notable programs engages clients in two years of clinical sessions followed by a drama therapy process that results in an original musical (Snow, D'Amico and Tanguay, 2003).

Data was collected over the course of one iteration of this process throughout rehearsal, performance, and post-performance. Upon evaluation of this data, researchers found a pronounced increase in participation, spontaneity, self-expression, empowerment, confidence, communication, socialization, sense of responsibility, and expanded sense of self (Snow, D’Amico & Tanguay, 2003). One client-actor explained the importance of experiencing the
audience laughing *with* them and not *at* them, which reduced stigmatization (Snow, D'Amico & Tanguay, 2003). Barbara MacKay explains the potentially long-lasting effects of this process:

‘It is impossible always to know what long-term effect experiences like these have on participants. I have long felt that we cannot speak of cures, but rather of experiences of healthy functioning and healthy relationships which may become benchmarks in future development’ (as cited by Snow, D'Amico and Tanguay, 2003, p. 81).

The Centre also sponsored a six-month research project investigating how Ethnodrama Therapy (EDT) could benefit this population (Snow et al., 2017). Mienczakowski originally developed ethnodrama in Australia in the 1990’s, combining performance and social science research (Snow et al., 2017). Snow conceived of combining drama therapy with Mienczakowski’s methods, resulting in EDT (Snow et al., 2017). From January-April 2014, the team at CAHD, in dialogue with the client participants, produced an ethnodrama script entitled “The Amazing Adventure of Relationships” which explored intimacy, romance, and sexuality (Snow et al., 2017).

The clients were treated as “co-researchers” in this project “as they were the knowledge holders of their own experience” (Snow et al., 2017, p. 244). There were limitations due to the clients’ intellectual and cognitive abilities, but their stories were the foundation for the script. The objectives of this project were to empower participants to find their authentic voice, evaluate the audience’s response through a post-performance questionnaire and to determine the efficacy of EDT (Snow et al., 2017).

Ultimately, the findings were that both the audience and participants believed that people with developmental and intellectual disabilities have the same feelings and rights as “normal
people,” that love is a “natural and inalienable right” and that everyone deserves love and has a right to a full life. The client-actors reported feelings of empowerment and that they were offered more sex education through this platform than they’d had in the past (Snow et al., 2017).

In terms of more explicitly clinical treatment, Eye Movement Desensitization and Reprocessing (EMDR) is currently one of the most effective evidence-based treatments for trauma (Engelhard, van den Hout & Smeets, 2011, Gunter & Bodner, 2008). Clinical outcomes corroborate that eye-movements during recall of traumatic memories reduce their intensity (Engelhard, van den Hout & Smeets, 2011, Gunter & Bodner, 2008). Once these memories are evoked, they become labile. Executing a secondary task, such as eye movement, decreases their vividness. With typically abled adults, the secondary task involves a clinician guiding their eye movements bilaterally using fingers, buzzers, or lights (Mevissen et al., 2011).

This approach has been adapted in various ways for people with ID. Adaptations include clinicians putting stickers on their fingers, using buzzers, tapping the client’s hands or knees bilaterally, and employing auditory stimulation via headphones or speakers on either side of the client. Activating the trauma memory requires more adaptation depending on the client’s mental age. Clients may be asked to draw images to represent the memories and communicate their distress levels via facial images (Mevissen et al., 2011).

Another adaptation for communicating traumatic memories involves the Story Telling Method, which was originally applied to children under the age of 3. It entails the parent or caregiver telling the child the story of the traumatic event while employing pictures, drawings, or objects to activate the survivor’s senses and elicit the traumatic memory further before engaging in adapted forms of bilateral stimulation with the clinician. The exercise concludes with a
positive ending or affirmation that is to be integrated into the psyche following the traumatic recall (Mevissen et al., 2011).

EMDR traditionally invites the client to visualize traumatic memories, which may be too abstract for some individuals with ID (Mevissen et al., 2011). The Story Telling Method allows the client to verbalize or draw images of the trauma from an aesthetic distance in order to elicit the visualization. The modification of audio speakers and hand buzzers is also more concrete, which increases accessibility for individuals who do not have the developmental capabilities to follow the traditional model (Mevissen et al., 2011).

Overall, it is clear that there is a distinct need for further research into trauma treatment for this population and the creative arts therapies offer fertile ground for it. Expressive Arts Therapy, which offers an intermodal transfer between art forms, allows individuals to move through a variety of non-verbal, non-linear communication styles. Therefore it may be of particular benefit. It also provides the opportunity to embody experiences that may otherwise feel too complicated to articulate (Levine & Levine, 1999).

However, there is still a large gap in research that directly connects trauma work with this population and the creative arts therapies. It’s vital that there are more evidence-based opportunities for clients with ID to explore this kind of work due to its accessibility and promise.

**Methods**

This community engagement project began in August 2019 and culminated in a three-night performance series in late February 2020. The researcher was invited to direct a series of vignettes to showcase the stories of clients at Stone Belt in Southern Indiana, which is a nonprofit organization designed to provide resources and support to individuals with disabilities.
Michelle Yadon originally conceived “I Am You” in 2008 when she was a recreational therapy student at Indiana University. Yadon was an intern at Stone Belt and began meeting with clients individually to offer therapeutic support. One client asked Yadon to type up their story. Other clients learned that this was happening and began asking her to type up their stories as well. Yadon saw an opportunity to share the stories of her clients to a larger audience and advocated for a professional performance. In November of 2008, Yadon managed to secure a local theater space for one night and sold out the performance to community members. Audience members were invited to empathize with performers, not just sympathize with their diagnoses.

Yadon went on to direct three more seasons of “I Am You” between 2008-2014. She is thankful that the tradition carried on and said, “It’s so rare and beautiful when your passion project is also someone else’s” (M. Yadon, personal communication, March 25, 2020). She became trained as a playback theatre conductor over the course of that time and implemented that element in later seasons. This involves an ensemble of actors creating improvisational responses to audience member’s stories and will be explained in further detail later in this paper. “I Am You” took place in both 2016 and 2018 after Yadon’s departure.

The researcher was selected as the director of “I Am You” for the 2020 season. Coordinators at each Stone Belt location recommended clients for participation. These included programs in Bloomington, Bedford, and Columbus, Indiana. Eleven clients were initially nominated, and the researcher was able to work with nine through completion of performances. Two of the clients disengaged with ongoing meetings for various personal reasons. Diagnoses ranged widely from person-to-person, but all fell under an iteration of intellectual disability. Co-occurring diagnoses included cerebral palsy, autism spectrum disorder, bipolar disorder, depression, and Williams syndrome.
Performances in the past have been limited to monologue style deliveries with some musical interludes. This year was the first time “I Am You” was directed by an expressive arts therapist in training. Under this direction clients were able to communicate in a larger variety of modalities with the implementation of expressive therapies interventions including poetry, movement, music, collage, writing, visual art, and percussion.

For the first time in six years the performance had a second act dedicated to an inclusive playback troupe composed of other Stone Belt clients and community members. These troupe members were selected separately from “I Am You” participants. Playback Theatre is a community storytelling ritual that involves actors improvising responses to personal stories from audience members (Fox, 2007). Whitney Sullivan, a Registered Drama Therapist and Licensed Clinical Social Worker, served as the conductor of the troupe. In the context of the inclusive troupe of Stone Belt members, this ritual had the added benefit of creating a bridge of empathy and compassion between the audience and actors with ID.

Clients initially met with the researcher one-on-one for thirty minutes once a week at the day program location in Bloomington. Prior to these meetings, the researcher went through training on each individual’s behavioral support plans. These included a general overview of their history, current concerns, target behaviors, and any risk plans (i.e. falls, medical issues). Every individual’s documentation differed based on the agencies they worked with outside of Stone Belt. Some were engaged with mental health services, some worked with other residential agencies, and others received very minimal services. There was often very little documentation outside of a basic support plan.

It was important that the researcher employ the tenants of TIC in order to work with these clients. Each individual was treated as the expert of their life. This involved a balance between
using information provided by the agency, clients’ guardians, clients’ staff, and the clients themselves. Ultimately, they were regarded as co-researchers, much like the participants at CAHD (Snow et al., 2017). The research attempted to foster a collaborative dynamic that felt safe enough to develop trust.

Variations in documentation made it challenging to have a uniform approach in the initial engagement. Therefore, the research focused on building rapport with each individual and learning their communication styles. Some clients had one-on-one staff assigned to them, which often made communication easier. These assigned staff knew the clients well enough to translate some of their responses in a way that was clearer to the researcher. However, sometimes this reinforced narratives that were tied to the client within the agency. For instance, a particular staff member listed off all of the things that the client liked to do before the researcher was able to ask any questions.

The researcher created a binder with tabs for each client and began to keep documentation for each session. This ranged from mind maps of information they shared to linear case notes to lists of themes that were coming up. The harder the researcher tried to create homogenous documentation for each person, the clearer it became that each required distinct approaches based on their unique differences. Also, the harder the researcher tried to elicit results or responses that shaped a standard performance, the more challenging it became to communicate with the client.

Consistently showing up for the individual meetings became the most important aspect of the relationship. This consistency allowed for clients to open up in their own time and their own ways. Each session began with some kind of check-in but would ultimately unfold in surprising and substantial manners. The basics were covered – where they were born, how old they were,
where they currently resided, who was important to them, what was important to them, and what
they wanted to share. However, some individuals did not communicate in a way that was
conducive to that kind of questioning. The researcher used documentation that was provided
within the system to fill in some blanks but focused on allowing the art making to take it from
there.

An array of materials were supplied to each individual in order to see what best served
them and their stories. These included visual art supplies (paper, paints, crayons, markers,
colored pencils), musical instruments (two djembe drums, a guitar, a speaker for recorded
music), writing prompts, a computer for searching out content that was meaningful to them, and
an open space for movement. These offerings also offered opportunities for intermodal transfers
between art forms, following an expressive arts therapy approach (Levine & Levine, 1999). The
researcher would ask the client how they wanted to begin and support the individual throughout
their exploration.

Explorations looked different for every person. Most began to gravitate towards one or
two modalities in particular after several sessions. Then it became the researcher’s responsibility
to focus the exploration and begin to shape their performance. Balancing aesthetics and
authenticity to the client became increasingly challenging and important. The majority of
audience members would be typically developed, and the goals of the performances were to
bridge the gap between Stone Belt clients and the larger community. Therefore it was important
that it was entertaining and translatable to that community. However, a person-centered approach
demanded that the essence of each individual was honored and maintained in their pieces and not
diluted in order to be palatable for an audience.
Once the individual pieces took shape and began to solidify, it came time to bring the group together as a whole and run through what they had co-created with the director. After meeting individually for twelve weeks, all nine “I Am You” performers came together along with the playback troupe and presented their pieces to one another and several staff members. This occurred in mid-November of 2019. The opening of the show would consist of every individual (including playback troupe members) holding up a sign that read “I Am…” and an aspect of the client’s identity that they chose and wrote on the sign. They would speak their sentence, i.e. “I am loveable” and then the audience would be invited to raise a hand if they identified with that statement. After everyone had shared, the entire ensemble would say “I Am You” in unison and point to the audience.

The group continued to refine their pieces individually and convened again several times in January 2020 before going into the theater space the second week of February. There was another all group rehearsal followed by individual meetings in the space with the director, a technical rehearsal incorporating lights and sound, and then three evening performances. All members of “I Am You” and the playback troupe were joined by a large team of staff who provided coordination, transportation, backstage assistance, and overall support throughout this process.

It was important to work on group dynamics and team building when rehearsing as a whole. The clients began to form an ensemble that was experiencing something personal and profound as a group. There was excitement around getting to see each other at these larger rehearsals and it built a sense of unity and support for performance week. It was also intended to support the building of healthy relationship skills. The performance of “I Am You” itself ran about an hour with nine individual acts followed by a brief intermission and then an hour of
playback performance. The playback members also supported several “I Am You” clients in their pieces by mirroring their movements. This served to amplify their individual expressions and represent an integration of self – fragmented pieces creating a whole.

The entire ensemble celebrated after the final performance by signing each other’s matching “I Am You” T-shirt’s, eating cake, and singing together. It was important to honor all of the work they had accomplished in spite of all the barriers faced. There were many challenges throughout the process, including one “I Am You” member not being able to attend any performances due to medical complications. The week of performance consisted of several long days and nights, which was incredibly demanding for performers and staff. Several other clients had to manage medical needs in the midst of rehearsals.

Overall performers were engaged, present, and very professional. Each night had a full audience. The show closed each night with a group sing-along to “Lean on Me” by Bill Withers. The researcher was completely overwhelmed by the group participation and overall quality of performances. It was dynamic, original, authentic, and memorable.

Results

The researcher sought to learn how an expressive therapies approach could support clients in finding ways to share their stories with an audience. The researcher also wanted to know if this exploration and performance series could lay the foundation for trauma work by instilling positive self-concept, emotional regulation, and healthy relationship skills. Expressive therapy interventions would lay the groundwork for this foundation through metaphor, symbolism, embodiment, and dramatic enactments. Creative expression of identity would allow an aesthetic distance for clients to explore their stories with a safe enough balance between cognition and affect.
The result of this engagement was nine vignettes. Clients names were changed for the purpose of confidentiality. Betty was the first performer. She sang “Ring of Fire” by Johnny Cash while the researcher accompanied her on guitar. This was prefaced by a dialogue between the researcher and client about her survival and where she came from. Early on in sessions, Betty had shared her story of growing up institutionalized in various hospitals throughout Indiana and the abuse she endured there. However, she chose to keep these details between herself and the researcher, letting the song symbolize her story. She also wrote out “My Ring of Fire,” which was projected behind her while she sang.

Craig was the second performer. This young man had shared hours’ worth of stories with the researcher throughout their meetings, which mostly consisted of traumatic memories. With the support and facilitation of the researcher, he was able to distill these stories into various themes. From these themes, he was able to articulate a poem that echoed the essence of these memories without deregulating himself or the audience. It was important to balance his needs with the needs of the show. Craig asked the researcher to read the poem aloud while he “acted it out.” He was able to devise movements for each stanza to accompany the reading. The playback troupe mirrored his movements as he performed, heightening the expression. A volunteer community member who acted as musician for the playback troupe also accompanied several “I Am You” performers, including Craig. His movements were supported by corresponding melodies as well as a painting he created to be projected behind him.

Keith was next. He had explored many art modalities throughout meeting with the researcher. He also shared details of a complicated romantic relationship with another Stone Belt client that he wanted to process. Keith chose a song that he wanted to dedicate to this individual. He rehearsed it with the researcher’s accompaniment on guitar. As details of this relationship
became clearer to the researcher it was important to protect the identity of the other client involved. Therefore, Keith and the researcher decided to reframe the piece as a dedication to his joy of music and capacity for love. He brought in a large array of photos of himself and his family, which accompanied him as a slideshow on the projector over the course of his performance.

Ralph followed. He was immediately drawn to writing with the researcher. He brought in some of his poetry and shared them in sessions. The researcher began to engage him in a variety of therapeutic writing exercises – acrostics, sentence stems, dialogue. Over the course of this exploration, a dialogue began to appear between himself and his disability – Williams Syndrome. Ralph would speak and then “William” would respond. The researcher invited him to begin physically enacting this by moving between seats and speaking to his other “part,” much like an empty chair exercise in drama therapy. Ultimately, this resulted in a “confrontation” of sorts between himself and “William” that never truly reached a resolution, leaving the audience unsettled with this dichotomy.

Jeff was the next performer. He also explored almost every art modality with the researcher throughout their initial meetings. He drummed, sang, painted, wrote, and moved. His speech was difficult to understand so the researcher’s goal was to find a way to translate his values and honor his spirit while also making him feel understood by the audience. Jeff was a celebrated athlete in the Special Olympics and was also very patriotic. He entered as the pianist played “The Star-Spangled Banner” while he held his hand over his heart. The playback troupe joined him as the researcher asked him questions about what was important to him. Jeff answered, the researcher repeated the answer for the audience, and he chose a movement to demonstrate that value, which the playback troupe mirrored behind him (i.e. dribbling a
basketball, holding his hands together in prayer, swimming in the ocean). He had also constructed a visual art piece with these values written out and painted to be projected behind him as he performed.

Next was Penelope who decided to collage her feelings. She experienced “big emotions” and took time to select images from magazines that symbolized them. She created two contrasting sides, one “positive” and one “negative” (i.e. happy/excited and sad/angry). After completing this, she was hospitalized for several weeks due to seizure activity. She was able to return to day program and re-engaged with the researcher after approximately a month of recovery. With support from the researcher, she wrote a poem to accompany her collage, which would be projected behind her. Unfortunately, her seizure activity became so disruptive that she was unable to perform. However, the researcher got permission to project Penelope’s collage and recite the poem on her behalf. For the last show, a staff member was able to retrieve a recording of Penelope performing the poem and this was played for the audience.

Next up was Natasha. She was already an accomplished visual artist in the community and had been selling her original texture pieces through Stone Belt’s art program for years. Natasha was accompanied to her individual meetings by her Stone Belt art teacher, Tracy Ault. She had developed a specific technique with Ault over the last two years that involved tactile sensations (i.e. smoothing, rubbing, spreading paint with her hands) that helped Natasha feel calm. She chose to work on a new texture piece over the course of her time with the researcher. They also developed an interview together that she would share with the audience. This covered a lot of her background and her experience as an artist. Her mother sent the researcher a note with Natasha’s various challenges and diagnoses as well as all her accomplishments and passions. Natasha chose not to include these details but to let her artwork speak for itself. The
researcher took process photos of the piece, which were projected behind her as she performed. At the close of the interview, Natasha chose to demonstrate how she uses various tools to craft her pieces. The playback troupe joined her onstage to mirror these movements as the pianist also provided musical accompaniment.

Lionel came next. He had immediately shared with the researcher that he wanted to craft a monologue detailing his life story. This is the same young man who was quoted at the beginning of this paper. He had a significant history of medical trauma, familial upheaval, and adversity. With the support of his staff and family, he was able to provide several photos of himself as a child which were projected as he recited his piece. He required very little support from the researcher in performance and was able to ground himself in the text of the monologue while also making consistent eye contact with the audience.

Dante brought the finale. His verbal communication was minimal, but he spent many sessions typing out his favorite songs on the web browser for both him and the researcher to listen to. Dante’s staff took time to share his various daily activities and hobbies. He was very drawn to flags, both national and collegiate, and was able to draw one to accompany the title of his piece, which was projected behind him during performance. After struggling to find a way to communicate his story to an audience, the researcher discovered that drumming was listed as one of Dante’s coping mechanisms. After some experimenting with djembes, the researcher found that he took to percussion very effectively. He and the researcher found various rhythms and catalysts to perform those rhythms including snapping, clapping, drumming while sitting, and finally drumming while standing. He chose to perform this series of movements to the tune of “Dog Days Are Over” by Florence + the Machine and engaged the audience in clapping along with the rhythm as he sang.
The results of this engagement were a wide variety of stories, communication styles, structures, and creative expressions. The researcher started anew with each client and their own unique process, abilities, talents, and desires with support ranging from minimal to intensive. Diagnoses varied and often that information was not readily available to the researcher. Some clients did not work with a team of clinicians at all and therefore only had basic documentation. The researcher relied on getting to know the client on their own terms and assessing them in session.

Overall there were very few discussions about sociocultural context. The last client to perform, Dante, was a black man and his guardian felt strongly about him honoring his race in other dimensions of his life, which was included in his individual support plan. His guardian was not involved in the process, but the researcher grappled with honoring their wishes while also staying true to what Dante brought to the work. He did not mention his race or heritage. His verbal and cognitive abilities may not have allowed him to conceptualize that. Therefore, the researcher brought these questions to supervision and ultimately decided to continue to let the client navigate the work. Everyone else in the production presented as white.

The researcher noticed a resistance to the exploration of “negative” feelings in several encounters with clients and their staff. Due to the fact that this day program was not a clinical facility, there was no built-in therapeutic support. Therefore, it was important for these individuals to be able to leave the session and not be activated in ways that were not conducive to the overall culture of the site. The researcher was not anyone’s therapist. The goal of these sessions was to provide a therapeutic creative outlet that would prepare them for a performance piece.
Themes that emerged included chronic trauma, family, relationships, love, pride, loss, connection, and big feelings that weren’t being expressed elsewhere. It was clear that overall these individuals were hungry for a space to be listened to and heard. Many of these themes were expressed in great detail in individual sessions. The task of the final product was to hone these stories and focus them in a way that was direct, entertaining, and meaningful to the individual and thereby the audience.

Due to the limitations of this research, it would be unethical to include client artwork. In addition, the conclusion of this engagement was followed by the massive response to COVID-19, an international pandemic that forced Stone Belt to close the doors to day program. This created large barriers to obtaining further results. Therefore the researcher chose to include their own artistic processing and arts-based processing from staff members who were involved throughout “I Am You.”

The researcher wrote this the week after the show closed:

“To hold space – to make space and continue to carve it out for the most vulnerable among us to speak their truths. And what happens when they can’t speak? What happens when they can’t read? What happens when you can’t understand their speech? What happens when every barrier imaginable is up against you and among you? What happens when you are tasked with making this space? What happens when you are given the privilege of translating their truths for others to hear?

What is the ‘other?’ How do we make sense of this division? How do we bridge that gap without putting ourselves above or below one another? How do we ask questions without patronizing? How do we make accessible the very basic needs of our species? To tell one another
how we feel and be met with understanding. To hold a mirror up to our experiences and find the similarities and differences and use those differences to bring us closer and not further apart?

I knew that the excitement of this achievement (if providing people with basic needs could be called an achievement) was coupled with the grief of an ending. A communication of an ending that was cognitively challenging and may never be understood except as another abandonment.

In the middle of his performance a client looked at me and said, ‘Do you work here?’ The audience erupted in laughter and so did I. But the reality is that I think he was asking if I was going to stick around. Later, he asked where I would be in March. I couldn’t help but tell him the truth, which was to say that we would not be there together.

How do you make goodbyes beautiful? How do you hold grief with joy and reward with closure? How do you look someone in the eye and manage to make them know how thankful you are for them? Especially when you don’t speak the same language? Or even share the same kind of mind? I tried to make a client see my pride and gratitude and they quickly asked what was for lunch. I smiled and answered. And hoped. Hoped that a piece of them saw the piece of me that was spilling over with love. Hopefully love is enough, even in this form. Hopefully showing up was enough, even when I stop coming. Hopefully seven months of holding was enough. And now that it’s over, I have to let go and step back and trust that they will keep holding themselves. The way they have their entire lives. I’m just a glimmer of their story and hopefully that’s enough for me.”

The researcher was able to meet virtually with Whitney Sullivan, the leader of the playback troupe who participated in every performance and supervised the researcher over the course of this engagement, Dan Lodge-Rigal, the musician for the playback troupe who also sits
on the board for Stone Belt, Eric Ford, a 20-year employee of Stone Belt who provided direct support to clients throughout the performances and works as a Senior Coordinator of the program, and Leslie Green, CEO of Stone Belt for over 40 years. The meeting took place approximately two months after the close of the engagement and consisted of the researcher guiding participants in an hour-long arts-based process.

Each person was asked to free write about their experience of “I Am You” for a few minutes and then choose 10-15 words that stood out to them. They were then invited to use those words to create a poem. From that poem, they were asked to draw an image that represented the performances or their experience of the process. Each participant gave permission to the facilitator to include their images and words below.

“Story connection
Grateful together conduct
Welcome belonging”

- Whitney Sullivan
“The talent...
Their life
Under lights
I Witnessed their fame”
- Eric Ford

“(P)Laying it Out
Amid organized chaos,
there were strong empowering leaders-
and tears.
Actors, proud and exuberant,
sculpted in fluid- respect,
each uniquely supportive and supported”
- Dan Lodge-Rigal
“I brought my strength to the stage
They could see it!
I was my genuine self
They could feel it
I had comradery with the other performers
I could feel it
My family was proud of me
I could see it!”

- Leslie Green

Both the researcher and staff involved noticed a strong sense of community, bravery, authenticity, talent, pride, and support in the ensemble. Images of growth, connection, light, and energy also emerged.

**Discussion**

The purpose of this research was to establish the need for trauma treatment for people with ID and explore how the expressive arts can build the foundation for that work. The approach to the engagement consisted of seven months of individual and group meetings between the researcher and nine people diagnosed with ID. This collaboration took place through a variety of expressive arts interventions resulting in nine individual performance pieces that embodied each client’s spirit and story.

The findings of this research indicate that this population experiences trauma (neglect, emotional abuse, physical abuse, sexual abuse) and mental illness at higher rates than those who are not intellectually disabled (Razza, Tomasulo, & Sobsey, 2011, Woods and Freedman, 2015,
Mrayyan, Eberhard, and Ahlström, 2019). The vulnerabilities of ID (cognitive impairment, communication barriers, physical disabilities, restricted memory, isolation, impaired executive domains, lack of risk awareness, stigma) not only increase the risk of traumatization but also create substantial barriers in accessing both diagnosis and treatment (Razza, Tomasulo, & Sobsey, 2011, Woods and Freedman, 2015, Mrayyan, Eberhard, and Ahlström, 2019).

The findings of “I Am You” indicate that individuals with ID are more than capable of articulating their experiences through expressive arts interventions ranging from music, poetry, creative writing, movement, visual art, and drama. Each client who was physically well enough to engage remained emotionally regulated over the course of three nights of performances as evidenced by their participation and consistency. Each client chose an art modality and story about themselves to share, representing a self-concept that was whole enough to articulate and share with an audience. These expressions were performed to sold out audiences indicating substantial community support.

Each person involved in this project was diagnosed with an intellectual disability and shared varied trauma histories with the performer. These same individuals engaged with expressive arts interventions over the course of seven months and stood up in front of as many as 100 people to share intimate pieces of their lives for three nights. While direct testimonials from the performers were not obtained due to the restrictions of COVID-19 and communication barriers, the sheer results of these people’s efforts over the course of this engagement speak volumes.

The literature not only indicates high trauma indexes for this population but also purports that play through the expressive arts can provide potent outlets for processing trauma (Harris 2009). Johnson’s (1998) psychodynamic model of creative arts therapies outlines a process that
allows individuals to work through their stories in an externalized art piece and then reintegrate that story into the psyche. The performers of “I Am You” certainly projected pieces of themselves through artistic mediums and transformed them into performance pieces. It is unclear how they will be internalized or how this could be measured. However, it is clear that aesthetic distance allowed an appropriate balance between the client’s emotional affect and cognitive ability in order to perform a rehearsed piece (Landy 1993, 1997). This implicates that the expressive therapies could provide substantial support for this population and further trauma work.

There are various models in existence that are appropriate for trauma treatment with people who are diagnosed with ID including IBT, drama therapy, and EMDR (Tomasulo & Razza, 2006, Engelhard, van den Hout & Smeets, 2001, Gunter & Bodner, 2008, Mevissen et al., 2011). The biggest limitation of this project is that the researcher was not in a therapist role. It would be highly beneficial to conduct this project with a team of clinicians who were in collaboration with the researcher. This research would also have benefited greatly from a thorough post-performance survey from participants, which would need to be accessible for each client’s communication style.

This project described the use of expressive therapy interventions that were not explicitly therapy. It was designed to support people with ID while they expressed themselves through art. This was a trauma-informed approach that aimed to prioritize choice, collaboration, safety and trust (Keesler, 2015). Perhaps the most notable result is that the researcher was able to earn the trust of the performers of “I Am You,” as evidenced by their participation. They chose what they wanted to make and collaborated with the entire organization in order to co-create a safe enough space to share their stories. This act would be remarkable in any context. It is especially
noteworthy due to all of the barriers these individuals faced. As one client summarized,

“Sometimes you gotta go and face your fears. It’s worth it.”
References


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THESIS APPROVAL FORM

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In the judgment of the following signatory this thesis meets the academic standards that have been established for the above degree.

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