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# INTO LIGHT California: A University-Community & Interdepartmental Collaboration

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# INTO LIGHT California: A University-Community & Interdepartmental Collaboration

#### **Abstract**

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#### **Keywords**

Bereavement, death, grief, drug overdose, drug poisoning, service learning, narrative counseling, legacy, stories, museum.

#### **Author Statement**

Lorraine Hedtke, MSW, ACSW, Phd is a professor in the counseling program in the Watson College of Education at CSUSB. She teaches, researches, and writes about innovative practices of grief counseling, born out of narrative counseling and remembering practices.

Arianna Huhn, Phd is a professor of Anthropology and the Director of the CSUSB Anthropology Museum. She has a particular commitment to community-centered museum work, and using exhibitions to uplift hidden stories and promote social justice.

#### **Cover Page Footnote**

The authors would like to acknowledge the important work of the INTO LIGHT Organization whose work is shifting the narratives around drug-related deaths. We are indebted to many funding sources and community partnership that made this project possible including the Department of Behavioral Health whose coalition helped to create awareness and pragmatic steps to reduce substance abuse deaths. The Office of Community Engagement at CSUSB has generously funding much of the nuts and bolts of this project. We would further acknowledge the hours of commitment provided by the graduate counseling student volunteers to speak with loving care in the completion of narrative interviews and our heartfelt thanks to Elizabeth Jones, whose beautiful artistic skill brought to life the graphite portraits of forty individuals so we could all see their preferred likenesses. And finally, we wish to acknowledge the friends and families who lent us your hearts and words so we could meet your loved ones and fold them, and you, into our arms. We are grateful.

# INTO LIGHT California: A University-Community & Interdepartmental Collaboration

Abstract: The INTO LIGHT California project created a venue to rescue the living stories of those who died from drug overdose and poisonings through interviews, portraiture, a museum exhibition and community involvement to reduce the impact of the silencing stigma of substance abuse. In partnership with two separate university programs alongside a not-for-profit national organization, the project created opportunities for forty bereaved family to be interviewed by graduate counseling students using innovative narrative counseling practices to shine light on deaths that are often relegated to the shadows of grief.

On September 9th 2022 the California State University, San Bernardino's Anthropology Museum opened an exhibition entitled INTO LIGHT California. The exhibition featured biographical narratives, hand-drawn portraits, and the personal belongings of forty-one individuals who lost their lives to a drug overdose or drug poisoning.¹ Forty of these individuals lived in California. The last individual is Devin Hart Bearden, the son of Theresa Clower who is the founder of the non-profit organization INTO LIGHT Project. Clower was inspired by the grief she experienced at the loss of her son to take up portraiture – first drawing Devin, and later expanding to others who passed away in similar circumstances. Her passion evolved into a national agenda to open a unique exhibition in each US state, all featuring Devin alongside forty individuals with connections to the host state, with the goal to "put a human face on the disease of addiction" and erase the stigma and shame of Substance Use Disorder (SUD).² INTO

<sup>&</sup>lt;sup>1</sup> While both the terms "drug overdose" and "drug poisoning" refer to a person ingesting more of a substance than their body can safely process, the term "drug poisoning" distinguishes situations where a lethal substance was unintentionally ingested, for example fentanyl-laced drugs. This project followed the lead of participants in using terminology that reflected their emotions and descriptions rather than imposing our own in the context of the exhibition.

<sup>&</sup>lt;sup>2</sup> Clower intentionally chose graphite portraits for INTO LIGHT for the symbolism imparted by combining black, white, and every shade between. We are all made up of both "black" and "white" – our low moments and

LIGHT California was the seventh INTO LIGHT exhibition, following Maryland, North Carolina, Ohio, Pennsylvania, Virginia, and Florida. The latest INTO Light exhibition opened in Delaware, and nine additional exhibitions are in various stages of planning.

While there are certain aspects of each INTO LIGHT exhibition that are the same – the name (INTO LIGHT plus the state in which the exhibition is prepared), the color scheme (black, white, gray, red), and the format of graphite portraits paired with biographical narratives – each exhibition is also uniquely prepared to fit the venue and the host organization's own capacities and goals. For the California exhibition, project directors Dr. Arianna Huhn (Department of Anthropology) and Dr. Lorraine Hedtke (MS Counseling program) innovated and prioritized: service learning opportunities for CSUSB students; participants representing the diversity of the state of California; the incorporation of objects from participating families; sharing the exhibition beyond museum walls; K12 outreach; and robust programming partnerships. Each of these objectives was accomplished, sometimes with growing pains as Huhn and Hedtke learned to merge and balance disciplinary standards, and academic freedoms butted up against INTO LIGHT Project's organizational norm, practices and business protocols. This paper will speak to the process of organizing and justification for the exhibition, preparing for the exhibition, and evaluating the INTO LIGHT California exhibition, the exhibition itself and its impact, as well as noting some of the benefits and challenges of collaboration and looking forward.

# **Project Organizing and Justification**

There is an epidemic of people dying from drug overdose, and specifically synthetic drugs like fentanyl. According to the CDC<sup>3</sup>, there has been an annual increase in drug related deaths in the US with current estimates of 107,622 fatalities in 2021. No corner of the United States, no racial groups, nor gender markers, nor economic status, has escaped the tragedies of drug addiction and drug overdose and death.

#### **Review of the Literature**

Drug overdose has been the leading cause of unintentional injury deaths in the United States since 2013, when the numbers first surpassed vehicle accidents (Olaisen, et al 2019). The

our most cherished; nobody deserves to be remembered for their darkest moments alone. While INTO LIGHT Project does not shy away from discussing the pain and traumas associated with addiction, for those with SUD and their loved ones, these moments are counterbalanced by highlighting other elements of each individual's life, presenting who they were holistically.

<sup>&</sup>lt;sup>3</sup> According to a recent CDC press release dated May 11, 2022, deaths from opioid overdose and poisonings has exponentially increased in the past three years. More can be seen here: https://www.cdc.gov/nchs/pressroom/nchs press releases/2022/202205.htm

most recent, provisional data from the CDC suggest that the epidemic is only deepening, with a record high of 93,331 drug overdose deaths recorded in 2020. This number is more than 20,000 above the previous high, set only a year before (Baumgartner and Radley 2021). Synthetic opioids (such as fentanyl, methadone, pethidine, levophanol, tramadol, and dextropropoxyphene) are currently the leading driver of drug overdose deaths. These are laboratory-produced drugs that mimic the analgesic effects of natural opioids (like opium, heroin, and morphine). In the Inland Empire (San Bernardino County and Riverside County, the service region of CSUSB), soaring overdose deaths mimic national patterns. Between 2017 and 2020, fentanyl-related deaths increased by 808% in Riverside County and 960% in San Bernardino County. In Riverside County, a Fentanyl Awareness Task Force was organized in June 2021. In the same month, San Bernardino's James Ramos introduced AB-1373 in the state legislature to demand investigations into criminal liability for unintentional fentanyl ingestion. The issue of drug overdose is particularly relevant for the Latinx population, which has experienced a rapid increase in overdose deaths across the state (Drug Policy Alliance 2021).

One reason addiction has taken such a tremendous toll in this country is the connotation of a personal failing or deliberate choice rather than a disease. Persons with Substance Use Disorder (SUD) are conceived as dangerous and morally bereft, which leads to negative attitudes that can fuel general discrimination and social distancing of family and friends. Stigma is also associated with structural barriers to treatment, the connotations of addiction fueling suboptimal care. Alexander C. Tsai and colleagues (2019) write that the many dimensions of addiction stigma – structural, public, enacted, internalized, and anticipated – "serve to reinforce each other, resulting in poorer health outcomes" (2019: 7). They conclude, "These dimensions of stigma must be overcome to facilitate the requisite policy and programmatic changes needed to effectively address the opioid overdose crisis" (2019: 2). Similarly, Sarah E. Wakeman and Josiah D. Rich (2018) find that despite evidence on the effectiveness of lifesaving medications for SUD, access is limited because of the separation of addiction treatment from the rest of the medical system. "Even the widely adopted terminology to refer to opioid agonist therapy, medication-assisted treatment, implies that medications are an adjunct to treatment rather than lifesaving interventions in and of themselves," they write. In sum, "Stigma is a major driver behind the lack of access to opioid agonist therapy" (2018: 330).

Research on stigma reduction is underdeveloped; however, a recent NEA (2020) report provides preliminary evidence that the arts can significantly affect substance abuse treatment and prevention, including stigma reduction. Likewise, the arts are being explored as an effective mechanism for decreasing and combating societal biases and negative connotations for other stigmatized conditions (Gaiha, et.al 2021). Randomized message-testing experiments suggest that sympathetic narratives emphasizing societal factors (such as poverty, trauma, and

structural barriers to treatment) rather than individual choices also show promise for combating stigma (McGinty and Barry 2020).

INTO LIGHT Project puts these experimental and promising techniques for stigma reduction to work through exhibitions that center on sharing the personal stories of individuals lost to the overdose epidemic, highlighting their unique character and identity outside of addiction. These are the memories that families of those who have died from causes regarded as deviant, or where the deceased is considered complicit in their death, often do not have the chance to share. Those grieving "bad deaths" are, in fact, frequently left with negative images and perceptions that truncate the stories that they tell themselves and others about the person's life. Their suffering, worsened by rumination that replays events and searching for clues as to why it happened and how things could have turned out differently, is compounded by exposure to stigmatizing comments that blame them or the deceased for the death and a general absence of acknowledgment and support beyond pity. The situation can lead to marginalization and deepened grief (Feigelman, Feigelman, and Range 2020; Feigelman, Jordan, and Jordan 2011; Templeton et.al 2016).

INTO LIGHT provides participants with the opportunity to have a conversation that encourages storytelling about the deceased in ways that are not (only) posthumously past tense but (also) form beneficial alliances between the stories of the living and stories of the dead. Specifically, emergent research suggests that crafting new meanings and connections with lost loved ones, thus continuing and enhancing relationships with the dead rather than letting go of them, can provide a healthy and effective framework for grieving (Hedtke and Winslade 2017; Hedtke 2020; Neimeyer 2015). This approach of re-remembering draws from the work of anthropologist Barbara Myerhoff (1982, 1986) in an elderly Jewish community in Venice Beach, California. Specifically, Myerhoff attended to how people perpetually shifted and reaggregated the membership in their life story as "re-membering." Social worker and family therapist Michael White (1997) adapted Myerhoff's ideas for counseling purposes through a narrative therapy that consciously constructs the membership of an individual's "club of life" (the persons who matter most to us and influence our identities) in recognition that who we are is crafted through our relationships with others, rather than an egocentric model where "self" is experienced in highly individualized terms. The method of re-membering was later adapted as a grief counseling strategy for shifting conversations about death from recollection, in the past tense, to creative transformation, in the subjunctive, to promote the possibility of new points of connection in relationships with those who have passed in physical form, rather than rupture (Hedtke and Winslade 2005; Hedtke and Winslade 2017). This shift is premised on recognizing that typical bereavement counseling guides individuals to a resolution of goodbyes that prematurely close off options for new stories to emerge -- stories that might be useful for those living with ongoing emotional pain and of particular import when the death holds stigma

where the stories of death often overshadow the ways in which a person lived. Project lead Lorraine Hedke is the leading international expert in this humanities-informed grief counseling technique founded in narrative counseling.

Research on "counter-storytelling" (autobiographical narratives by those whose existence and experiences are silenced or made invisible by dominant discourse) stresses opportunity to speak one's truth and to de-naturalize and de-center majoritarian stories can empower storytellers (Solórzano and Yosso 2002; Wagaman, Obejero, and Gregory 2018). Such narratives can also profoundly impact listeners, facilitating emotional engagement in ways distinct from cognitive inquiry (Bonnell and Simon 2007; Fischer, Anila and Moore 2017). The power is enhanced by displaying resultant narratives in a museum setting, research suggesting that such venues can spark challenging conversations (Ellis 1995; Cavness 2019) and position viewers in ways that precipitate critical consciousness (Bonnell and Simon 2007). These capacities are related to positive public perceptions of museums as trustworthy sources of information (Merritt 2015), making them safe and supportive atmospheres for meaningful experiences. While the effects of storytelling on museum visitors specifically are poorly documented (Arnold-de Simine 2013), research from other fields demonstrates that narratives trigger the release of neurochemicals that support attentiveness, understanding, and action (Zak 2015), make information more memorable, and can generate less defensive responses from listeners than other forms of communication (Bruner 1990). Elena Gonzales (2020) draws from neuroscience to argue that museum-enabled, embodied, emotional responses can result in long-lasting memories, which are more likely than others to engender critical thinking that leads to action. In this way, narrative storytelling in museums has the potential for personal and societal transformation, drawing on the power of emotion as integral to the development of critical consciousness (Langstraat and Bowdon, 2011). Project Lead Arianna Huhn has been honing the art of narrative storytelling at the CSUSB Anthropology Museum since 2016 (Huhn 2018, Huhn and Anderson 2021)

#### **Project Protocol**

To collect the data and share stories of individuals who have died as a result of drug poisoning and overdose, care needs to be taken with the potential emotional tenderness for the bereaved. Dr.'s Huhn and Hedtke requested an institutional review of the project to ensure all safeguards were in place to interview, transcribe, and exhibit the likenesses and stories of those who have died, as well as to write about the exhibition in academic publications. To meet the demands of kindness, respect and counseling acumen that fit the demands of work with bereaved individuals, our research protocol specified that counseling program graduate students with specialized training in grief counseling and addictions counseling, and with advanced counseling skills would complete the interviews. All graduate students who

committed to the project also completed the necessary training regarding confidentiality and working with human subjects.

Following Institutional Review Board (IRB) approval (FY2022-83) in November 2021, interviewees were recruited through campus listservs, outreach to counseling placement sites, using social media, and reviewing in memoriam websites and obituaries and directly reaching out to eligible participants with project information. The INTO LIGHT Project has set the number of persons represented each show at forty-one which includes Clower's son Devin, and thus, we needed to recruit forty participants. We prepared to interview up to sixty people, as participation was voluntary and it was possible that some would elect to discontinue at some point. However, all forty individuals interviewed continued participation through to and including the exhibition. All participants were required to sign a consent form before any data pertaining directly to the project was collected. In this consent form they agreed to their deceased loved one's full name and biographical details being publically shared as a part of their participation. They also acknowledged that they understood their own name and image may be associated with the exhibition, and that data would also be used for academic publications and presentations. For these latter purposes, however, participants were informed that they would be identified anonymously. The consent process was completed electronically and the interviews completed remotely to comply with University Covid-related restrictions on in-person research during the period of data collection.

Individuals expressed their interest in participation by completing a Qualtrics survey that ensured they met the basic qualifications for project participation. This included a clear connection to the state of California, being over 18 years of age, and having lost a loved one to a drug overdose or drug poisoning. A follow-up phone call with prospective interviewees screened out anyone assessed to potentially find the interview to be too emotionally taxing, thereby potentially harming them. This included individuals who reported that they were or recently had been suicidal. All prospective interviewees were offered a resource sheet with information on counseling services and hotlines. Prospective participants were screened until we had reached our maximum number (forty) of those who wanted to share their loved one's stories and likenesses in the California exhibition.

Once individuals were screened for suitability and eligibility and had completed the consent process, interviews were scheduled. Several individuals were also screened but never completed the consent process. In these cases, three follow-ups were made, by email and by phone. If there was still no response after the third attempt, no further contact was made. Interviews were semi-structured in nature and lasted up to two hours. The interviewers were provided a set of standard questions. Some of the questions collected demographic information about the person who died (questions such as, "What was your loved one's name and what did

they prefer to be called" or "how long has it been since they died?") and information about the deceased person's relationship to addiction (for example, "how many years did they live with addiction?"), but most of the questions were posed to access stories about the aspirations, values, personality, and accomplishments of the deceased (like, "What were some of their accomplishments in life?", or "what kind of things did they value?"). The interviewers were also encouraged to follow up participant responses with additional questions where appropriate.

While many of the interview questions were provided by INTO LIGHT and standard to their operations, given the students' training, and the interests of project lead Hedtke, additional questions were developed to explore places where the legacy of the deceased could give way to opening an ongoing posthumous relational connection. Questions to this end were fashioned by our project team, such as, "How is it that your loved one continues to play a significant role in your life?". Additional questions folded the deceased into a posthumous future, for example, "How do you envision carrying their stories forward into your future?". Equally important was to inquire about who else knows the stories of the life of the deceased, intended to support noticing where new connections might give way to an ongoing team of people linked together by the life of this person who is no longer living. Questions such as "Sometimes, after the death of a loved one, we hear stories about how they influenced someone's life. Have you heard any stories like this about your loved one?" promoted new communities and new knowledge about the ways in which a deceased loved one was admired and lived. The ways in which the bereaved took up new tasks or had nascent purposes as a result of their loved one's death was also inquired about, for example questions such as, "Has having someone in your life [with substance use or abuse] changed how you speak or think about SUD or caused you to be an advocate around this issue?".

All interviews were fully transcribed using a voice to text system, and then manually checked for accuracy. Participant volunteers were provided a copy of their transcript for review if requested through the consent process, and they were able to add to their interviews after the conversations if they felt information had been left out, or if additional people wanted to add their voice in sharing the legacy of the person who died (in such cases, these additional persons also completed consent forms). Participants were contacted several months after the opening reception for a follow-up interview about their experience with INTO LIGHT, and these conversations were also transcribed and are considered below. Only approximately one-half of the original participants were reached for comments.

# **Preparing for the Exhibition**

Once the project was vetted by the University and the IRB was complete, we were positioned to recruit participant volunteers and graduate students who would interview people

who had experienced the loss of a loved one to drug overdose or drug poisoning. Students from the MS in Counseling program would complete the interviews following a model of service learning that incorporates practice under supervised tutorship to prepare students to work independently as professional counselors. This pedagogy supported on-going supervision meetings prior to the actual interviews commencing to further assist students in being responsive to the familys' narratives. Simultaneously, we solicited applications from artists to complete the portraits. These initial steps took place over a couple of months and as part of the preparatory work for the resulting exhibition.

#### **Interviews as Service Learning**

In addition to combating stigma through humanizing addiction and art activism, our project provided the opportunity for twelve MS Counseling students in the final semester of their three-year training (and thus poised to become professional counselors) to learn about addiction through deeply emotional, one-on-one conversations where their goal was to listen and to guide the drug death bereaved toward re-membering (rather than forgetting, or recollecting) those they have lost to nuance the relationship they have with the deceased as a member of their "club of life" (White, 2007) and to encourage a comforting, life enhancing, and sustaining approach to living with a socially stigmatized death. Specifically, eleven students served as interviewers, and one student served a lead role in organizing communications, scheduling, and transcription.. As counselors-in-training, the students additionally were able to offer therapeutic support and relief to the bereaved. The project thus directly benefited from and benefitted their training in narrative counseling modalities through exposure to practicebased learning about grief, addiction and counseling. Students were not given any financial compensation for their work, but were able to use the experience towards required practicum hours. Students also had to complete project training and agree to weekly remote supervision sessions prior to conducting interviews. These activities were voluntary and outside of any individual class requirements.

Students met throughout the duration of the project to address topics that arose in their conversations with bereaved loved ones and to talk through potential problem areas, whether logistical or related to counseling knowledge. Initially everyone met every other week, but during the concentrated interview schedule we shifted to meeting weekly. All meetings were conducted on Zoom and under the educational support and supervision of Dr. Hedtke. Students offered topics for discussion to improve their counseling and interviewing skills. Some of these topics included: the role of self-disclosure in counseling conversations; the complexities of non-Covid related deaths during the pandemic; addressing compassionate responses to tears in counseling conversations and interviews; practicing counseling skills of reflection; how to handle sensitive information like if the people being spoken of were minors;

assessing suicidality; providing therapeutic practices to support the witnessing of the deceased person's legacies; and therapeutic letter writing.

A therapeutic letter is a particular practice in narrative counseling that captures aspects of the conversation and reinforces the burgeoning preferred ways of being (Fox, 2003). With remembering conversations, therapeutic letters are an opportunity to have the practitioner address the ways in which they have been changed by being the recipient of the stories. This removes the artificial construct that therapy is only benefiting the client when in fact the relational nature of counseling is a transformative process for both client and counselor and in this case, of graduate student and participant volunteers. Myerhoff (1980) speaks to reciprocal exchange exactly, "A story told aloud is of course more than a text. It is an event. when it is done properly, the listener is more than a mere passive receiver or validator, he [sic] is changed". In preparation for the exhibition opening, all students wrote therapeutic letters for each person who they interviewed. These letters were more than a thank you note, but an acknowledgment of the ways in which the deceased person's stories impacted the writer. Comments such as, "During our conversation we touched on so much about her life, but one thing I will always hold with me is the close relationship the two of you shared", or, "Your willingness to share his beautiful story moved me in ways that I didn't even know were there. I admired how you share with your other children and am taking this to heart with my own children as memories arise." And finally, "I just wanted to reach out and thank you for sharing your son's story with me. I was driving by a car dealership and it had the inflatable stick guy that dances. I instantly thought of him and I laughed to myself as I imagined him dancing along with it. As I see the state of the country, I remember your son and his willingness to stand up for the underdog and show compassion and kindness always. As I pursue a career in mental health, I hope to embody that compassion he always showed others. Please know that through this project, his story will continue to touch other people's lives, just as he has done mine. It was an honor to share space with you both". Each participant received their letter at the museum opening from the person who interviewed them.

#### From Interviews to Narratives

All interview questions were designed to both provide the information necessary for the writing of a narrative that would accompany the portraits for the exhibition, and to provide reflective opportunities to rescue stories of a person's life that stood outside drug addiction and the stigma of a death that resulted from drug use. These rescued stories could then continue to grow into full blown narratives that would intertwine the living bereaved persons with that of dreams, hopes and values of the deceased person. Responses to an anonymous survey suggest that these narratives were also successful in making an impact on museum visitors, with the depth and wholeness of each person's story helping to humanize addiction for

both those with and without personal experiences with drug-related deaths. Below are just a few examples from the 135 responses received:

"As a student nurse here at CSUSB, I see the effects of addiction in my clinical hospital rotations ... I've seen the effects of addiction, and what it looks like to relapse and struggle and re-enter a treatment facility. Addiction is a cruel problem, and one that seems so dark because it appears to be self-inflicted. This exhibit had me in tears, and wanting to know how to help."

"Today marks one year that I lost my dear friend to drugs/suicide and I was not expecting to be touched by the exhibit this deeply. My friend struggled with addiction and it led him to end his life similarly to the stories I read. I remember him as more than just his addiction. He was a beautiful soul and there was much more to his story that people don't know and might never know. I was comforted by the stories I read today because they depict people in a different light than what most people think an addict is. The people in the exhibit are more than their addiction and I am extremely happy to see that is being portrayed in the exhibit."

"I attended the opening and was deeply moved by the narratives, photos, and family members and friends. The exhibit presented addiction in an entirely different light, humanizing the victims of addiction rather than vilifying them. It exceeded my expectations and I would (and have) recommended the exhibit to others."

"I thought it was very eye opening to see everyone's narratives and how their drug addiction impacted them and their families. It was interesting to see how young most of the people were and really touched my heart. I will definitely be changing the conversation about drug addiction and help people realize it is an illness and not a sign of failure."

"I was moved to tears - I lost my brother to addiction and suicide - thank you for opening a door to show that people are more than one thing"

"It is a beautiful tribute to the people who had passed. We are too quick to judge people on drug uses when we don't know the stories that lead them to it. This museum does a great job humanizing their stories. I felt such a great sadness in my heart as I read each of their stories. I understood the hardships of life and the comfort some drugs can offer. I hope people see these types of museums as to show people that we are not so different and some people's roads are hard than others."

As a part of our project protocol, and informed by best practices in community engagement work for museums, narratives were provided for participants to review and (if desired) to edit before they were incorporated into the exhibition. While some participants did not request changes, and others preferred to be surprised and read the narrative for the first time at the exhibition opening, many requested moderate or extensive revisions. While perhaps a sign that the narrative writing did not always capture what participants felt was important to include, this can also be used as a gauge of trust and true partnership, participants feeling heard and supported enough to bring up their concerns rather than worrying about the institutional and power hierarchies that often plague and bog down University-community cocreative activities. Participants were also provided with the option to leave the project at any time up through the exhibition opening, though none chose to at any point. We believe this was reflective of the importance of honoring their deceased loved ones.

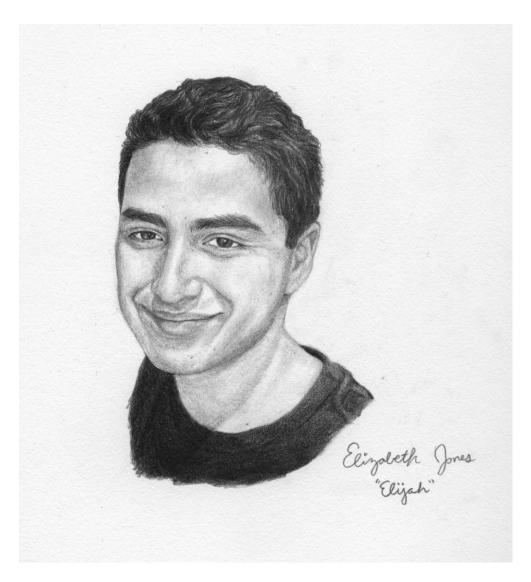
#### The Artwork

For previous INTO LIGHT exhibitions, founder Theresa Clower has personally drawn all or most of the portraits on display. For the California exhibition we requested permission to use a local artist. This turned out to be an important move, as an injury during the exhibition preparations meant that Clower would have been unable to draw the portraits herself. The artist selected for the INTO LIGHT California portraits was Elizabeth Jones, a non-binary artist of Jamaican Creole descent residing in Pomona. Jones' body of work is borne of their interest in the effects of isolation, and a fascination with healing from and living with trauma as a barrier to connection. They utilize a combination of portraiture, surrealism, abstractions, and interviews to explore neglect, food access, addiction, and interdependence, as well as examining generational trauma, seeking understanding and acceptance through open conversations about love, fear, and shame.

Jones aims to create art that portrays whole people, and this - in combination with beautiful portraiture work - attracted us to their work. Jones was also very forthcoming about their own struggles with drug use. They explained, "Possibly the largest barrier to recovery from substance misuse for me was shame. In my upbringing, it wasn't normal to talk about and work through emotional pain ... With INTO LIGHT, California my hope is that by destigmatizing drug addiction we can have a collective conversation, out loud, that will make space to talk about these things in order to look directly at what isn't working in our society." Jones has since been added to a national team of approved INTO LIGHT Project artists, who are taking on more and more of the portraiture work as the project grows. At the closing reception for INTO LIGHT the participants are always gifted the framed portraits that hung in the exhibition. At the closing reception in California, Jones directly handed each family their loved one's portrait in an emotional moment of joy, pain, and reflection.



Perla Mendoza receiving the portrait of her son, Daniel Elijah Figueroa. Photo by James Trotter, CSUSB



Portrait of Daniel Elijah Figueroa, bu Elizabeth Jones.

#### The Exhibition

The exhibition opened September 9, 2022 and hung in the anthropology museum for the academic year until June 10, 2023. During this time there were over 2,000 visitors to the museum.

# **Opening**

The exhibition presented each interviewee's loved one in a fourteen by seventeen framed portrait and a short biography distilled from the interview. Half of the interviewees additionally volunteered to loan an item of significance for their loved one, and these were

displayed in cases alongside the portraits and narratives. Participants were invited to an opening reception, along with their families and friends, to view the show, but also to gather in a community of bereaved people with shared experiences having lost people to substance use. The opening event brought people from all around the country and in fact several from other countries, as well. The museum was filled for the evening with parents, siblings, partners, and friends who also had experienced the death of an important person. This gathering gave way to tender moments of hugs and tears and at times a silent reverence for what we were all experiencing. In spite of this being a challenging event, for many this was the first chance to speak of their loved one publicly. Some reported not holding funeral services, as the death occurred during Covid when logistics and gathering became prohibitive. Others had felt too heavy of a burden of stigma and shame to share the circumstances of their loved one's death with others. When interviewing participants about the opening evening a few months later, comments were overwhelmingly positive and spoke to the transformative impact to be in the space with others who had similar life events. One mother explained it this way: "We lost my son in 2020 to accidental fentanyl poisoning. It was the worst thing that ever happened in my life, and it is still. Sometimes I don't know how I'm even breathing. It was really helpful in meeting some of the other parents that were involved. Because then you didn't feel like you were so alone. So I think it really does help with the stigma that's attached to addiction."



Jaime Puerta, father of Daniel Puerta-Johnson, and Steve Filson, father of Jessica Filson, embrace at the opening reception for INTO LIGHT California. Photo by CSUSB.

Wearable buttons to memorialize those featured in the exhibition further supported connections and conversation. Each button had the phrase, "Ask me about" and a picture of one of the persons honored in the exhibition. Most attendees chose to wear the button of their loved one, and these served as entry points to connections and sharing of stories. Families were also given physical copies of the INTO Light catalog containing all forty-one people whose portraits, narratives and items were on display.

Following the initial gathering in the museum, attendees relocated to an auditorium for a handful of short speeches. Among these, Dr. Hedtke spoke directly to those who had lost someone to addiction:

If I may, I would like to speak directly to those here who are holding the stories of people who are no longer living; the stories of people who are physically no longer with us having suffered from the effects of addiction, drug use, overdose, drug poisoning, and even death.

When we love and care for someone who is no longer living, we become the holders of their joy, as well as their trials in life. We are left to tend to their stories, looking after them as we step forward in ways that asks us to take care with their legacies. We become tasked with the weight of finding openings to transform the gifts that they brought both in life and in death so that we may give these gifts of legacy to others, and perhaps these gifts connect those to people who never met them in life. By sharing with more and more people, those who have died are introduced to others, their stories are bestowed as a living legacy that can have a new kind of life. This sharing can even have the power to shape new meanings, offering a new life for the person who has died and those who are living with grief. And sometimes, the gifting of their stories and these important introductions can help to ease the pain, and maybe answer the lingering questions that feel unanswerable.

For those of you who have lost someone to the debilitating pain of drug addiction and drug poisoning, you have given all of us a gift. By sharing the stories of those who are no longer living, they have become a beacon of light that shines the direction on where and how their lives can live on. It is this beacon of light that has brought us here today, almost as if they have called us together, to give new purpose to their lives. By sharing their stories, you have spoken them into existence and spoken them in to our lives. You have introduced them to those of us who are here today as well as all who will still come to the exhibition in the coming months. You have shared their stories about their talents and preciousness of their lives and your enduring love for them. It is this

beacon of light that has rescued their words and their love from what could otherwise silence them in stories of shame, regret, and the depths of sadness. This light washes over all of the hardest of edges so that they may live in new possibility as we all carry them forward.

These words continue to capture the authors' sentiments about the importance of this exhibition, for the participants, for the visitors to the exhibition, and for ourselves. It is to an evaluation of the project's impact that we turn now.

#### **Evaluation of the Project's Impact**

The most telling evaluative tool of this year-long endeavor has been participants' personal reflections. But a palpable impact of this exhibition additionally extends to the students who conducted the interviews, the cross-campus partnerships that ensued and the community events and other educational opportunities that this exhibition made possible. Those interviewed and those completing the interviews were at the center of our care, but the project's impact extended well beyond their powerful reports of transformational change as a result of participating in the project.

#### The impact on those who lost loved ones.

In the months that followed the exhibition opening, people who were originally interviewed for the project were contacted for follow-up and to understand the impact, if any, of their participation. Approximately one-half of the original forty people interviewed were reached by a newly recruited graduate student for a short, recorded conversation. The questions were geared for feedback to see if the project was useful or if there were places for improvement. For example: "Would you share your experiences about the project? It will help us understand the impact as to what worked and what can be improved," and "What was it like to be involved in the INTO LIGHT Project?" or "Have you noticed any changes in your relationship with your loved one after your participation in this project?". The responses were exceptionally positive and enthusiastic, with many of the conversations going well beyond the anticipated twenty minutes. Below are a selection of quotes from these calls that are emblematic of the overall responses:

"I think having him honored in this exhibit really meant to me that he's not forgotten; that he is part of a bigger picture."

"I'm thinking it was healing, being honest, saying the truth. It made everything better for me, too".

"It was very therapeutic, and in the same sense it was uplifting, and it was hard. I say it was hard in the sense that it was emotionally hard, but at the same time it was very gratifying. Like, I feel like I had done something for my brother that allows his name and his story to live on, and at the same time helping raise awareness."

"It's hard to describe, but just that feeling that, I've done something to help keep his memory alive. I don't know, that's just somehow — It's been helpful to me, and the thought that for over these next nine months that so many people are going to read his story - it's sort of like, you brought him back to life in some way, you know?"

"I don't want to say healing, but it was somewhat cathartic for me to participate in it. My grandson passed during Covid, so we weren't able to have a regular memorial service for him."

"... but just walking in, it's like you know when you're outside in the cold, and you walk in, and somebody's got the furnace on. It's like that blast of warmth. It was just as if emotions walking in there and seeing these parents and seeing pictures of kids that you feel like you already know. And you've known their whole life. But you really just have never met them before."

# **The Closing Ceremony**

On June 10, 2022, a closing reception for the exhibition was held to again honor those who had died and the families that shared their stories making this exhibition possible. Families and friends were gifted with the artwork that hung in the museum for ten months and many participants spoke about their experience with INTO LIGHT. One parent focused her comments on the unique approach of INTO LIGHT that made her feel that she was honoring her son: "When I lost my son, I pulled my love for him, my memories, everything so close to my heart, and I didn't want to let anything go. And then I heard about INTO LIGHT ... and I knew that this was something that I wanted ... to be a part of. And I knew that [my son] would be understood here, and he would be respected here, and he would be loved. And it's been that way every step of the process ... It's just been a beautiful, beautiful experience." Another parent spoke about her appreciation of the project's unique approach to holistic representation: "I have to say that with the non-profit that I run ... we present to schools. So often I'm talking about my grief for [my son] or how [my son] died. It's not often that I feel like people want to hear about [my son]. And what made [my son] [my son] ... When I did my interview, I truly felt like he [the counseling student] really wanted to know [my son], like he was talking about his own family member. And it was such a privilege and an honor to walk in and see it so beautifully written,

about who my son was, not how he died." This comment captures the heart of re-membering conversations that rescue the stories of relationship and life that become fodder for shaping a new kind of relational connection with those who have died. Still another parent spoke to the experience of reading back the transcript of her interview, "Reading my story back, I didn't realize some of the things I'd said! But you guys got it with such good detail, and it was amazing. I was like, 'Oh, I didn't even know I talked about that.' So, thank you ... for being so gentle with us."

Some families focused on another aspiration of the project; that being the relief they felt in seeing their loved one's story reaching others, one parent stating that seeing his daughter's portrait in the show "assured our family that her death was not in vain ... lives can and will be saved." Another echoed the point, sharing that using the word "overdose" has been difficult because of the stigma, but the project changed this, knowing that "my son's story is saving lives, educating people, changing the way we look at overdose and addiction." Another parent stood only to say that INTO LIGHT was the beginning of her healing after losing a child to fentanyl, "Because of INTO LIGHT Project I am able to say, 'On June 18th 2021, my son passed away from an overdose,' without shame or fear of judgment." Another participant spoke of her brother's death, "I was dealing with the loss of the best little brother one could ever ask for, and I was doing it silently ... I didn't know how to tell people he passed from fentanyl poisoning, and I felt helpless and alone. INTO LIGHT provided a community, and a medium to share his story, while giving me a better understanding of what I can do to ease the stigma of substance use disorder, with one hard and honest conversation at a time." Another parent spoke also to the sense of community gained through participation in the project, addressing the audience and stating, "Now you all are our brothers and sisters, as we share a connection nobody else knows."

# The Impact on the Graduate Students Interviewers

Students reflected on the impact of completing the interviews as a part of the ongoing supervision discussions. As counseling is always a reciprocal relationship, the students were transformed and transported to new thoughts as a result of talking with bereaved people. "The conversation was heartwarming and easier than what I was imagining. It let me reflect on my own losses, including the death of my brother", commented one student. "Even though this sounds a bit weird when talking about death, the conversation was energizing. The way in which his mom responded to my questions gave me confidence and it was a great experience", said another student. Another shared, "each conversation was so moving and humbling." And still one more student explained, "It was great to not focus on the overdose, but speak about his life, what kind of person he was outside of the drugs, and it felt more loving than a typical grief conversation. "Each student who participated in the interviewing has now graduated and

gone on to a counseling-related positions, many in schools and all in the Inland Empire of California.

#### **Cross-Campus Connections & Collaborations**

In order to begin this project, Dr. Huhn submitted a request to INTO LIGHT Project for the CSUSB Anthropology Museum to be considered to host their California exhibition. The request was vetted and accepted, and plans were made to open the exhibition in 2021. Then, the Covid-19 pandemic hit and exhibition planning was postponed. When it was revived in 2021 for a 2022 open, Huhn reached out to Dr. Hedtke based on her credentials as an international expert on grief. During our initial meeting in the early fall of 2021, we discovered many points of intersecting interests that could support bringing the museum exhibition to life. Most notably, we discussed how to use our diverse skills and knowledges to coordinate and fold students into a successful project. This partnership fruited as the service learning project described above, and in the joint oversight of project logistics thereafter. It was also the first of many cross-campus partnerships associated with INTO LIGHT California, all aimed at supporting the goal of increasing awareness and education about addiction, overdose deaths, and drug poisonings.

As a part of the exhibition development process, connections were also forged with the Music Department, and specifically Assistant Professor Kevin Zhang. We asked Zhang to consider selecting music that could play during the exhibition's open hours. Zhang instead proposed to compose an original score for the exhibition, which he did by mapping the alphabet on a musical scale and then artistically playing the initials of the forty-one individuals represented in the INTO LIGHT California exhibition. The resultant ballad is haunting, and when the meaning of the music was revealed at an opening reception for the exhibition the crowd audibly gasped. One parent explained the impact of the music this way: "In grieving my son, I have a hard time but the music hit me on a different level and it was really moving to feel like I was experiencing something in a different way. The music is just such a nice touch, adding on to everything else. And the whole thing is phenomenal, really powerful, in my opinion. But the music has this really nice additional element to it. It was very creative and very cool and just kind of like . . . On first listen to it, like, this sounds interesting, but then, like you read what the composer did with it. It's like, oh, dang, that's awesome".

Partnerships were also sought and secured to offer programming in collaboration with the university's offices of Pre-College Programs and Counseling and Psychological Services (CAPS). The Cal-SOAP (California Student Opportunity and Access) Program is a college readiness and access program under the purview of the Office of Pre-College Programs. Cal-SOAP partnered with the Anthropology Museum to host K12 school groups for a campus tour, museum tour, faculty-led lesson in storytelling (based on the INTO LIGHT exhibition), and a

presentation by the local non-profit organization Inland Empire Harm Reduction. Through Cal-SOAP organized programming, over 400 high school students visited INTO LIGHT and deepened their knowledge, understanding, and thinking about Substance Use Disorder stigmas, treatment options, and mental health. Additional traffic by CSUSB students, staff, and faculty were brought into the museum through bi-monthly Wellness Workshop series programming, offered by Counseling and Psychological Services. The most popular of these programs for in-person attendance was by far the Fentanyl Awareness and Narcan Training workshop presented by Alexander Cordova of the San Bernardino County Department of Behavioral Health, which is the organization that also sponsored the California exhibition.

The exhibition also served as a point of entry for classes to meet for projects. Faculty in departments of Art, Sociology, Anthropology, Theatre, Art and Design, Nursing, Criminal Justice, Counseling, and Social Work brought students through the museum for curricular activities during the academic year. One such example of this was an undergraduate course entitled "An Introduction to the Helping Professions (COUN 3101)." This course used visiting the exhibition as an assignment tied to understanding addictions and reflections about counseling practices that make a difference. The students reflected on what they learned. One shared, "Before visiting the Anthropology Museum, I wasn't prepared to be moved the way I was, I spent my afternoon reading each and everyone's story. Every story touched my heart and made me view the medical industry and the drug industry from a different perspective." Another student reflected, "The exhibit was moving and heartbreaking as we saw the beautiful faces of 41 individuals who struggled with addiction and ultimately lost their life to it. The room felt heavy as I read each story. It included individuals with many different backgrounds and experiences. I hope that more people take a moment to learn and realize how addiction can occur anywhere". Another student mentioned, "All individuals displayed in the INTO LIGHT Project left a burning impression of the mental health struggle in the world"

The San Bernardino County Department of Behavioral Health (DBH), a major financial sponsor of the exhibition, also organized two resource fairs, bringing to campus dozens of local organizations offering addiction treatment, counseling, and other mental health services. DBH also offered five Naloxone (Narcan) distribution and training events, giving away hundreds of units to students, faculty, and staff. The success of these events caught the attention of Student Health Services, and a partnership is underway to ensure that Narcan and fentanyl testing strips are available on campus year-round. The work of DBH to support INTO LIGHT and to bring resources to the CSUSB campus was recognized by the National Association of Counties with an Achievement Award in the category of Arts, Culture, and Historic Preservation in 2023. INTO LIGHT California has additionally inspired a county-wide drug death awareness and prevention campaign that will (with their consent) feature participants' loved ones, spreading their stories

even more broadly and capping off our work with the assurance that the exhibition has extended its reach far beyond museum walls.

Finally, a partnership with Academic Technologies and Innovations (ATI) is preserving the exhibition in a way that will be accessible and long lasting, by developing a virtual 360 exhibition tour. This tour uses the open-source software H5P to present HTML5 content with interactive options that present screen-reader-accessible text and meaningful descriptions of visual content in a photo-based environment. In this way the exhibition has created additional student learning opportunities in both content creation through service learning and also through content use, with faculty able to continue sending students through this virtual environment to experience the exhibition instead of only reading static content.

#### **Lessons Learned**

With any undertaking as large as this one has been, one would expect the need to adjust and adapt as the project unfolds. So was true for this project, as many people with differing backgrounds and stakeholders with separate agendas came together, which occasionally created challenges but also made the project better and further reaching than what we could have imagined on our own.

### **University-Non-Profit (Research) Partnership**

Partnering with a not-for-profit, non-academic entity posed some unique challenges that required attention for the project to be successful. INTO LIGHT Project and CSUSB project leads Huhn and Hedtke were guided by differing goals and organizational structures that required negotiation of occasional divergent policies and protocols. The differences were not insurmountable, but required an appreciation for a shared vision to birth the exhibition in ways where all would feel like the mission of the project – to de-stigmatize drug related deaths and visibilize people who have died – was honored. The following are some of the places where we hoped to successfully join with the organization, which required addressing nuanced differences between our professional settings and standards:

• In line with the goal of reducing stigma surrounding drug overdose and drug poisoning deaths, INTO LIGHT Project typically requires that all project participants share their full name in connection with their loved one's narrative. The names of minors are also included by default when writing up the biographical narratives, with the understanding that it is important to family members to see their names as a part of their loved one's story. Additionally, contact information and participant files are maintained using standard business practices, rather than protocols of password-protection, substituting codes for participant names, and so forth that are standard for protecting human

subjects in an academic setting. As a stipulation to our partnership with INTO LIGHT, we required that participants be given the option to decide how they would like their name listed in association with the exhibition (most chose their full name, but not all). We also took the precaution of redacting the names of current minors when reviewing transcripts and before they were sent to INTO LIGHT for the development of narratives. In some cases the names of minors were added into the narratives later, at the request of the interviewee, but in other cases they were not. All project files were password protected and labeled using a naming convention based on first names alone. We did not collect mailing addresses for participants as a part of our gathering of demographic information, as this information was not integral to the research and so could not be justified. These interventions created distress as outside the usual practices of the INTO LIGHT organization and they expressed hesitancy about future partnerships where IRB approvals are required. These differences resulted in the INTO LIGHT organization from adding participants to their mailing list to solicit donations and so forth as this would be outside the bounds of human subject research and potentially be exploitative of grieving family members.

- INTO LIGHT Project typically collects on their own the information from participants that is needed to prepare each biographical narratives. This is sometimes done through a phone conversation, but more often through only an online questionnaire. Either way, the process is geared toward extracting information in a structured format that is historical rather than generative. Because of our priority in creating opportunities for service learning and recruiting student interviewers who were trained in counseling techniques, our approach to gathering information for the biographical narratives was distinct. First, the interviews were semi-structured and conversational, which elicited in many cases in-depth and lengthy discussions. Second, the interviews incorporated therapeutic techniques (as discussed above) that helped the participant to feel heard, understood, and cared for, and that encouraged speculation about continuing bonds with the deceased rather than recalling a historical relationship that ended at the time of death. As a result, each interview transcript, meticulously prepared, was lengthy and contained information that the narrative writers with INTO LIGHT Project found to be superfluous and overwhelming to work through to extract the information needed for writing their standard narratives. This made development of narratives for the exhibition cumbersome and caused delays, which was certainly frustrating for both INTO LIGHT Project and for ourselves.
- INTO LIGHT Project was founded with a mission to bring light to "put a human face on the disease of addiction" and to "change the conversation about drug addiction" (INTO LIGHT Project, n.d.). However, as the overdose epidemic has evolved since the founding

of INTO LIGHT Project in 2019, many who are dying of a drug overdose, and especially drug poisoning, were never suffering from substance use disorder. They may have used an illicit substance once, or by accident, or believed that they were purchasing a licit drug like Xanax or Adderall, though without a prescription and "off the street," but actually purchased an counterfeit version laced with or entirely made up of fentanyl. During the process of recruitment our original language, mirroring that of INTO LIGHT Project, focused on addiction and overdose. But through pushback received from those we talked to, and those who rejected our solicitations, we began to modify our language to make it more inclusive of all drug-related deaths. This included recognizing the distinction between the ways that "drug overdose" and "drug poisoning" are used in the drug-death bereaved community, and the oversized role of fentanyl in drug-related deaths. This decision to adopt the perspectives of our participants was influenced by our training in Counseling and Anthropology (Hedtke and Huhn, respectively), but it did not align purely with the INTO LIGHT Project model. As a result, there were, throughout the project, moments where it felt like the organization and our participants were talking past one another, with INTO LIGHT Project hyper-focused on addiction whereas this was a concern of only some participants.

#### Conclusion

INTO LIGHT Project is a non-profit organization with an important mission that can dovetail with University interests in community partnership, student learning, and lent itself to the anthropology museum's mission as stated on the website, which "... regularly prepares and hosts exhibitions that illustrate and interrogate the cultural contexts and meanings of community histories, events, identities, and behaviors...".

The project has aspired to lift those up to light, both those who are living with the depth of grief and those whose deaths attempted to truncate their lives and legacy. When someone we care about dies, common guidance is to encourage the bereaved that they need to "get over" the death of their loved one. Bereaved people are urged to "move on" and to "let go" so that the deceased may "rest in peace". This kind of advice can cut the bereaved off from comforting stories and from a continued relational connection between themselves and their loved one. This advice also assumes that people had time to prepare for a death, to speak words of love before a death, and to even have a sense of completion in the living relationship that honors a well-lived life. This is often not the case when losing a loved one to addiction or drug poisoning, leaving the bereaved with layers of complex feelings and often at a loss at how to find comfort.

The INTO LIGHT collaboration has been a testimony to the many ways in which relationships do not die when a person dies. The experience of grief can be lessened when

bereaved families and loved ones are guided to find meaning and comfort and telling the stories about those who have passed - in other words, to not "let go" and "move on". By speaking the words and savoring the images that connect with a person who has died, grief is lessened. In doing so, we also honor and celebrate the lives of those who we care deeply about.

This project has worked to uplift the stories of those who have died as a result of addiction and drug poisoning. It has been a project of restoring a relationship between the living and the dead, and bringing hope to places where pain has lived. It has been the express intention through the interviews, the portraits, and the exhibition, to make visible the stories of a life of a person who mattered - to their loved ones, to larger communities of care, and now for all who have been witness to their stories here in the museum. Their stories will live on, carried with traces of their lives, touching hearts, and reminding us of the beauty that has lived and the power of love.

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