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Melissa Ann Morelli
More Than Just An Exchange: How
Does Access To Syringe Exchange
Impact Actively Using Participants'
Emotional Well-Being

ABSTRACT

This qualitative, exploratory study examines how accessing Syringe Access Services (SAS) directly impacts program participants' emotional well-being. The purpose of this research is to give voice to individuals who utilize SAS services; to gain personal and valuable information about the nature of the participant; and to reveal the emotional and mental health outcomes linked with SEP's. Twelve individuals who have been program participants of SAS for over a year were interviewed for this study. Participants were interviewed indoors at one of SAS's fixed needle exchange sites in the Bay Area. In-person semi-structured interview questions elicited participants' experience with various services in their community and their experience with SAS. Qualitative analysis was used to analyze the data, uncovering naturally emerging themes and patterns. Participants described experiences with community services and direct services providers as both positive and negative. Positive experiences included services that included harm reduction, free from stigma, and non-judgmental, with service providers who were authentic and trustworthy who were able to assist clients with their current needs. Negative experiences included services that had requirements attached to receiving care, long waits, and services providers who were judgmental and dishonest. Participants describe the important role the SAS services play in reducing stigma and providing services that catered directly to their needs. The findings attest to the benefits of having a safe, nonjudgmental, and reliable

space that provides clean injection equipment as well as a space to create authentic meaningful relationships with service providers. This finding is exceptionally important given that majority of those interviewed are chronically homeless, mentally ill, and with very little connection to various services. SAS played a critical role in improving participants' self work thus impacting their emotional wellbeing.

**MORE THAN JUST AN EXCHANGE: HOW DOES ACCESS TO SYRINGE
EXCHANGE IMPACT ACTIVELY USING PARTICIPANTS' EMOTIONAL
WELL-BEING**

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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June 2013

Acknowledgements

I dedicate this thesis to those we have lost due to substance use, overdose or various complications related to substance use. To all of the participants of Syringe Access Services, your voice has inspired this study and will continue to inspire the change that this world needs. Thank you for being you and for revealing a side of yourself that can be difficult to expose; your bravery has not gone unnoticed. This is also dedicated to anyone who has struggled with substance use, family and friends of those who lost someone to an overdose, and to those who have been a part of someone's life that struggled with drugs and alcohol.

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CHAPTER I

Introduction

The purpose of this exploratory and descriptive study was to understand the impact that syringe access services (SAS) have on program participants' emotional wellbeing from the perspective of the client. The research question was inspired and guided by the number of questions that the researcher would often receive from various members of the community inquiring about what needle exchange is. A common comment that was received was "So that's all you guys do? You just pass out needles?" While it's understandable that individuals who were not exposed to harm reduction services might not be able to conceptualize syringe exchange, it also brought to light the lack of education and research available about what syringe exchange does and how it impacts program participants. There is a need for further examination of how syringe exchange is understood and what impact it has on individuals who utilize the services by using the voices of the program participants. For the purpose of my thesis, the literature review will address how syringe exchange is understood and the interviews and findings chapter will address how syringe exchange impacts program participants.

Long held myths about syringe exchange pervade, inhibiting its effectiveness and the ability to expand services. The two most powerful myths about syringe exchange are that this service enables drug users to continue to use and harm reduction services are not an efficient intervention when working with drug users. Numerous researchers and studies have refuted both of those arguments; however,

these myths continue to impact the effectiveness of syringe exchange services throughout the country.

Syringe exchange services in San Francisco strive to reach program participants by conducting services where there is need within in the city. The harm reduction approach of meeting clients "where they're at," is literal, as syringe exchange sets up in non descript storefronts or in ally ways where participants frequently congregate. The unique setting and form of outreach with the chronically homeless, drug using community, and the mentally ill often creates a more relationally based approach enhancing the relationship that syringe access service providers are able to form with program participants.

Harm reduction is the theoretical frame and foundation that syringe exchange operates in to reach communities that are marginalized, oppressed, and stigmatized because of their substance use. Syringe exchange aims to build trust with program participants by working at creating a space that feels safe and welcoming, without judgment, and free from stigma and shame. Because stigma is so prevalent, it can be almost impossible to escape. Self-stigma is a subjective process and often influenced by social and structural stigma (Livingston et al., 2012), commonly used as a tool to defer individuals from engaging in problematic behaviors such as substance use. In an attempt to eliminate stigma related consequences, harm reduction principles acknowledge that individuals who use substances should not be punished for their choices but met with practical solutions that can be implemented into their lives (International Harm Reduction Association, 2011; Mate, 2010).

The purpose of this research is to explore the impact that Syringe Access Services has on program participants' emotional well-being by interviewing individuals who frequently utilize SAS services. In Chapter II of this study literature on stigma, syringe exchange, harm reduction, and emotional well-being will be reviewed. In Chapter III the methodology of the study including data collection and analysis will be presented. In Chapter IV of the study the findings of the participant interviews will be described. Finally, in Chapter V a discussion of the implications of the findings will be presented.

Chapter II

Literature Review

Addiction, Stigma, & Abstinence Only

The views we have about drug users shape the way we believe that individuals should be cared for, treated, and interacted with. The year 2011 marked the 40th anniversary of the “War on Drugs,” first declared by President Nixon on June 17, 1971 in his Special Message to the Congress on Drug Abuse Prevention and Control. “If we cannot destroy the drug menace in America,” he warned, “then it will surely, in time destroy us.” In the ensuing 40 years, while the government’s anti-drug effort has escalated steeply in size and cost, the problem of drug addiction and overdose, as well as the profits of the illicit drug trade and attendant violent crime, have increased in even greater proportion (McVay, 2011). This common ideology about drugs and drug users leads to devastating consequences weakening America as a whole and profoundly impacting individual lives. The war on drugs affects drug users themselves, most of whom face harsh penalties in the criminal justice system as well as increased risk of viral infections due to lack of access to clean syringes and other using supplies. The effects of the War on Drugs also rip families apart and assist in the needless murders of uninvolved bystanders, struck by stray bullets in drug trafficking incidents (Mate, 2010, p. 298). Zero tolerance policies and *Just Say No* campaigns are abstinence based responses to the war on drugs aiming to ultimately put a stop to illegal drug use. The United States is dedicated to eliminating drug use and drug trafficking with little regard for the harmful consequences it has on the individuals involved. Drug policy laws have changed to

help eliminate stigma to those who use drugs or have been convicted of a drug charge. Alternatively, policies have shifted slowly and currently don't aim to reduce harm related consequences to drugs and drug use. Instead, drug related policies perpetuate stereotypes and limit the range of ways that individuals who struggle with drug use can approach their addiction.

These common feelings of isolation and stigma can perpetuate feelings of low self worth, continuing the lonely cycle of addiction. The general public often views drug users as "less than," leading drug users to adopt feelings of low self-esteem and self worth. Often, this pushes users to avoid contact with non-users and in turn only building relationships with individuals who are also using, ultimately isolating themselves to a community where they feel accepted (Lloyd, 2010). Stigma describes a socio-cultural process in which social groups are devalued, either anticipating or experiencing rejection, blame, or exclusion on the basis of a socially discredited circumstance, quality, or attribute devaluing a person or group (Livingston et al., 2012; Scambler, 2009). Stigma can be best understood by exploring multiple concepts: social stigma, self-stigma, and structural stigma. Each of these elements must be considered and explored when understanding how stigma affects individual lives. Social stigma is a universal phenomenon shaped by cultural and historical elements (Livingston et al., 2012). Social stigma is how the general public negatively views individuals who often don't meet societal norms or expectation, which leads to discrimination against specific groups of people (Corrigan, 2004; Palamar, 2012). Self stigma is a subjective process exemplified by negative feelings about one's self, a maladaptive behavior, resulting from an

individual's experiences, perceptions, or anticipations of negative social reactions (Livingston et al., 2012). Structural stigma exists through negative attitudes, views, and behaviors by those working in public establishments such as in health care or criminal justice institutions (Livingston et al., 2012). Drug users often experience stigmatizing attitudes and rejection from family, friends, people, and other people within their community contributing to severe social isolation or marginalization. Drug use is illegal and thereby those who use drugs are often highly stigmatized by policy makers, services providers, and community members (Macneil & Pauly 2010). Consequences from stigmatizing attitudes and behaviors are directed at individuals who use drugs.

Substance users are one of the most highly stigmatized groups of individuals, even more than those whose lives are complicated by various health conditions (Livingston et al., 2012). Stigma is used as a tool to marginalize and discourage problematic behaviors and lifestyles, in this case substance use. Substance users are often affected by other health conditions such as HIV/AIDS, hepatitis, and mental health illnesses. Linking common using behaviors with these specific health conditions perpetuate stereotypes, in turn, marginalizing individuals and groups of people. Many of these common stereotypes derive out of some truth and have a small degree of accuracy making it difficult to challenge and counteract stigma at times (Livingston et al., 2012). However, many of the stereotypes that are mentioned about those who use substances are not accurate across the board and do not accurately represent the population of substance users.

The misconceptions of substance users and addiction are incessant and the impact is detrimental to individual lives. Substance use is perceived as a behavior that individuals do or should have complete control of, ultimately placing the responsibility and blame on the individual, increasing stigma and creating hesitation for people to provide services to those who are in need of help and support (Corrigan, Powell, & Rüschi 2012; Livingston et al., 2012). Livingston (2012) states, “Stigma ascribed to people with substance use disorders exacerbates social alienation and has the potential to impact adversely all domains of life, such as employment, housing and social relationships” (p. 40). Stigma impacts the recovery process, access to health care, the way individuals are treated, and increases potentially dangerous choices that people who use drugs make throughout their life.

Combating stigma means dispelling the myths about addiction and having the ability to feel empathy for those who are struggling with substance use. Carl Rogers states,

When the teacher has the ability to understand the student’s reactions from the inside, has a sensitive awareness of the way the process of education and learning seems to the student, then again the likelihood of significant learning is increased.... [Students feel deeply appreciative] when they are simply understood – not evaluated, not judged, simply understood from their own point of view, not the teacher’s (Rogers, 1967).

The empathy that Carl Rogers speaks of is a principle equally pertinent to individuals who use drugs. The less empathetic understanding we have and the

more that individuals are stigmatized, the harder it becomes for the individual to move forward in a positive direction (Livingston et al, 2012).

Stigma not only affects how individuals feel about themselves, but it also affects their choices about making the decision to reduce, limit, or discontinue their use. Individuals who are using or dependent on substances often lead chaotic and stressful lives. Additionally, they might have co-occurring and stigmatizing mental health and other health issues only adding difficulty to their ability to function. The countless conditions associated with substance use makes diminishing or abstaining from substance use extremely difficult (Mate, 2010).

Who defines what problematic drug use is? When do we notice that our drug use is even problematic? And how should we alleviate some of our problematic behaviors associated with drug use? The answer to these questions will vary depending upon who you ask and the basis of their beliefs. Abstinence only treatment is one of the most widely accepted ways that people who struggle with drug use are expected to treat their addiction. Many public services have requirements of abstinence, excluding those who are currently using drugs or alcohol, limiting the amount of services those who are actively using are able to access. Limiting the amount of service that individuals can obtain may create more isolation and segregation within the drug using community. Abstinence only communities are an important part of the recovery process for those who are invested in living a life free from drugs and alcohol. The concern isn't that there are abstinence only based communities but that basic human rights such as health care, mental health services, and various other basic needs are denied to those who are

currently engaging in problematic behaviors such as substance use. Abstinence based services are important; however, having abstinence a part of a balanced array of services that also include comparable amounts of service options for users who are not ready to be abstinent. This lack of balance is what leads to a lack of justice and denial of human rights. This injustice perpetuates a sense of powerlessness that is often unspoken, forcing individuals into what seems as the only choice they have, abstinence. Wallerstein states, "Personal empowerment is not something that can be delivered as a service; rather, as a process whereby people gain power from within and advocate, themselves, for change" (2006). Many services limit clients' ability to advocate for themselves on both a community and individual level, often when providers or policies dictating individuals' course of action to improve specific problematic areas in their life. This country has a strong push for abstinence only based services and treatment taking away the right to choose how to live life based on personal preferences.

Often, when treating those struggling with addiction we tend to focus on alleviating the symptoms of addiction, dealing with overcoming the psychological dependence and working on easing the painful withdrawal symptoms that individual bodies go through. Even though this is an important part of overcoming a drug addiction, too often we forget that we are not just dealing with those aspects of addiction, but battling something much bigger, such as various emotional health concerns (Saah, 2005). Overcoming addiction doesn't have to begin once a physical dependence is alleviated or once the individual has demonstrated and committed to eliminating their drug use. It can begin while the individual is still using. There are

multiple intersections within a person's life that that can influence individual health and wellness. Reducing physical harm, acknowledging social and economic stressors, and addressing mental health complications should all be recognized when working with individuals who use substances. Without doing so we are unable to work on improving emotional wellbeing. Improving emotional and social health is a way to improve how a person thinks and feels about themselves and their place in the world (Tsey et al., 2009). Treating substance use begins when the individual is still using, aiming to improve health, both physically and emotionally, acknowledging that all people are in various stages of change but deserve the same amount of respect.

Harm Reduction

Harm reduction is a philosophy that attempts to alleviate the social, legal, and medical consequences associated with individuals who struggle with addiction. Davis (2008) takes a humanist approach to working with vulnerable populations and advocates for harm reduction when working with addicts. In doing so, this approach can decrease harmful consequences, such as HIV and hepatitis transmission, violence, criminal activity, and early death, without attempting to "cure" the addiction (Davis). Using a harm reduction based model when working with individuals who engage in high risk behaviors or are unable or unwilling to abstain from drugs is a way to engage people in the prospect of positive change (Ruefli & Rodgers, 2004). The theoretical basis of the concept of harm reduction acknowledges that individuals who struggle with substance use can be so entangled

in their addiction that they need practical solutions that can be implemented into their lives (Gabor Mate, 2010).

Though harm reduction approaches are common when working with drug using communities, they are not limited to those who use drugs but to those people who might struggle with gambling or co-occurring disorders as well. Harm reduction is a way of looking at individuals' choices through a lens of wanting to improve addicts' ability to function in society rather than punishing addicts for their inability to maintain abstinence (International Harm Reduction Association, 2011). Denning (2000) believes that the primary principle in using a harm reduction approach is accepting the fact that people are going to engage in high risk behaviors and that we must be willing to assist people who are using drugs and alcohol to reduce the harm that is associated with those behaviors.

Harm reduction practices don't only benefit the individuals who are using, but their family, friends, and the community as a whole (Tarantola, 2012). The European Monitoring Center for Drugs and Drug Addiction (EMCDDA) published an in depth scientific monograph centered on harm reduction definitions and practices when working with addicts that states, "Harm reduction encompasses interventions, programs and policies that seek to reduce the health, social and economic harms of drug use to individuals, communities and societies" (2010). The common thread that I have found in all of the literature thus far is that harm reduction uses a humanistic approach to improving the lives of individuals who are actively using drugs (EMCDDA, 2010; IHRA, 2010; Davis, 2004; Tarantola, 2012; Ruefli & Rodgers, 2004; Denning, 2000). EMCDDA (2010) envisions harm reduction as a package of

interventions tailored to local settings, the primary emphasis being to reduce the harms of drug use. Abstinence-orientated drug policies need to be complemented by practices that can successfully reduce the harms that drug users are exposed to, providing practical supportive options (Davis; IHRA; EMCDDA; Tarantola).

Rogers & Ruefli's (2004) research demonstrates the importance and principles that harm reduction practices have with drug users. Harm reduction is a form of treatment, an important option that should be made available for those who are interested in choosing it. Fewer resources are made available for those drug users who do not want to enter formal abstinence based treatment, but want to partake in interventions that continue be helpful. In alliance with many of the previously referenced organizations and journals, Rogers & Ruefli (2004) used harm reduction as a tool to set goals that are attainable instead of abstinence being the only option. Research has proven that harm reduction based programs have clearly shown a decline in transmission of HIV and Hepatitis C among injection drug users when given access to sterile syringes (Des Jarlais et al., 1996; Macneil & Pauly 2010; Rogers & Ruefli, 2004; Watters et al., 1994). Unfortunately, there is little research about how other harm reduction based services, such as mental health services, primary care, and counseling, impact the lives of those who are highly marginalized, at-risk IDUs (Intravenous Drug Users). Using organizations and services to empower and support drug users, provides a much-needed social and psychological safety net to help them move forward in several areas of their lives while using harm reduction as the basis of the approach (Davis, 2008; EMCDDA, 2010).

In summary, harm reduction is a controversial model for treating drug users (Rogers & Ruefli, 2004), especially those who are actively using. Harm reduction does not exclude abstinence; rather it meets individuals where they are in their lives, with dignity and respect. Harm reduction is based on using a humanistic approach that supports and empowers individuals to make changes in their lives, choices that are made independently. The results of this research also brings to light socially acceptable ways of approaching and measuring change among this extremely marginalized population who have developed their own set of pertinent social structures, relationships, and adaptive nontraditional strategies for addressing life's challenges.

Harm Reduction In Needle Exchange Programs

A harm reduction approach can be used with any therapeutic intervention, regardless of the setting. Syringe exchange programs (SEP) use the foundation of harm reduction to reach individuals using substances. Syringe exchange has been and continues to be a highly controversial topic all over the world. Syringe exchange has been highlighted and praised because it helps in preventing the spread the HIV and Hepatitis C but has also been criticized by opponents who believe that SEPs facilitate and enable individuals to use drugs. A brief history and understanding of the evolution of syringe exchange, how it's viewed by society, and how it affects individuals' lives is important in understanding how SEPs impact emotional health.

Syringe exchange programs in the United States were implemented in the 1980s in response to the AIDS epidemic. It has now been over 25 years since the

discovery of HIV among injecting drug users and more than 20 years since the implementation of the first SEPs in the U.S. The first ever syringe exchange program was established in Amsterdam, the Netherlands, in 1981, in response to a hepatitis B outbreak among intravenous drug users (IDUs) (Burns et al.,1996). The implementation of SEP's in the United States as a whole has been slow because of the explicit rejection of harm reduction and strong support for a zero tolerance approach to drugs in the US. Des Jarlasis, McKnight, Goldblatt, and Purchase, (2009) examined syringe exchanges throughout the United States, tracing the growth of SEPs from 1994-2007. Des Jarlasis et al., state, "SEPs in which sterile needles and syringes are exchanged for used, potentially HIV contaminated needles and syringes, have come to symbolize harm reduction programming for drug users." (p. 104) The study showed that in 2007, there were 186 SEPs currently organized in the United States. Though clean syringes are the main focus of SEPs, there are a wide variety of supplies provided. Almost all programs provided condoms, safer injection equipment, referrals to substance abuse treatment, safer sex and safer injection information, and hepatitis and HIV education. More than half of the programs also provided additional health care and referrals including HIV testing, overdose prevention, and STD screening (Des Jarlasis et al., 2007). This form of Harm Reduction, meeting the individual needs of SEP clients, provides an opportunity for people to access various forms of health care.

Syringe exchange is a service that uses a harm reduction based approach to reach communities that are marginalized, oppressed, and stigmatized because of their substance use. A qualitative study by Ruefli & Rodgers (2004) demonstrates

how drug users define and measure their own progress in harm reduction programs that support the idea that drug users are people who are interested in creating positive change in all areas of their lives

Macneil & Pauly (2010) look at the overall role that the needle exchange program had in participants' lives. This article focuses on how a program aiming to reduce HIV and Hepatitis C (HCV) can and does also reduce stigma while developing meaningful relationships, with service providers and volunteers. Macneil & Pauly state:

These findings support the notion that unlearning the dehumanizing discourse around substance use is desperately needed by the community at large. NEPs are one link to a myriad of supports and comprehensive services that clients who use injecting drugs need to break the cycle of addiction and homelessness and marginalization (p. 31).

Drug use is highly stigmatized by those who find SEP's enabling or immoral. Conservative voices argue that drug policies should be exclusively open to primary prevention and abstinence, suggesting that harm reduction encourages drug use (Mangham, 2001). However much of the current research points out that harm reduction practices are essential, humane and a socially just response to drug use (Ball, 2007; Jackson et al., 2010). There is significant evidence that proves that SEP's reduce the spread of HIV and HCV (Ball, 2007; Des Jarlais et al., 1996; Watters et al., 1994; Macneil & Pauly, 2010), but less scientific evidence that shows that needle exchange adds value and meaning in those participants' lives, thus reducing internal stigma affecting emotional health. Recently, there has been an increase in research that shows that SEP's do more than prevent the spread of deadly infections; they care for individuals on a level that improves their quality of life (Des Jarlais et al.,

2009; Macneil & Pauly, 2010; Ruefli & Rodgers, 2004). This study shows that SEP's add great depth and value in the lives of individuals who have access to syringe exchange. Macneil & Pauly sampled 23 men and 10 women with the average age of 40 years old, who currently are injection drug users and participants in the needle exchange program in Canada. As the authors state, "All of the clients accessing the needle exchange services unanimously described the needle exchange as a safe haven in an often unsafe world, characterized by stigma and other harms associated with street drug use." Much of the literature, and scientific data conclude that harm reduction based approaches, such as syringe exchange, dramatically reduces the spread of infectious diseases among injection drug users. Macneil & Pauly (2010), Des Jarlais et al., (2009), and Ruefli & Rodgers (2004)'s research clearly indicates how harm reduction principles can be applied to create support and trust with individuals who are marginalized in society.

Emotional Well-Being

There is no single definition to fully encompass the meaning of well-being, therefore framing this definition as simply as possible for research purposes is most effective. The CDC states that the working definition of well-being includes the presence of positive emotions and moods (e.g., contentment, happiness), the absence of negative emotions (e.g., depression, anxiety), satisfaction with life, fulfillment, and positive functioning (2011). Subjective well-being (SWB) is defined as the affective and cognitive evaluation of life (Diener, 1984; Diener & Lucas, 2000); emotional health is something that is self reported, therefore subjective. As stated in the research by Ruefli & Rodgers (2004), extremely marginalized

populations, such as drug users, have their own set of values and beliefs generally not congruent with those of mainstream society. Because of this, the participants' understanding of their own emotional wellbeing might not be measured only by the absence of negative emotions but rather by their own life circumstances. For example, this might include an individual's perception of their position in life in relation to their culture, values, and goals and how that intersects with the relationships they have with others as affected by both their physical and psychological states (Camfield, L., & Skevington, S. 2008).

For the purpose of my research, emotional health will be defined and used as "an umbrella term for different valuations that people make regarding their lives, the events happening to them, their bodies and minds, and the circumstances in which they live" (Diener, 2006). This definition has been used by various international researchers to define subjective well-being and is more vague than traditional definitions, such as that of the CDC, to create flexibility to evaluate life in various economic classes, community perspectives, and cross-cultural ideals, allowing the framing of quality of life (QoL) solely in terms of the individual (Camfield, L., & Skevington, S. 2008).

Social and emotional wellbeing is informed by culture (Tsey et al., 2009) and, for injection drugs users, the nature of the culture can change depending on many variables. One of the foundational pieces of drug using culture includes the commonality in being an addict - feeling and being stigmatized, and being oppressed and marginalized by society at large because of their addiction. It can be seen in the way drug users are referred to as a "junkie" in various articles or the local paper,

using abusive and vilifying language to talk about those who use drugs. Being marginalized by mainstream society leaves individuals with less control over their lives and less available resources causing lower self-esteem, self worth, and various psychological problems (Sagric et al., 2007). Current research states that emotional well-being (EW), QoL, and SWB overlap but are used in a variety of ways for different types of research and perspectives (Camfield & Skevington, (2008).

Camfield & Skevington, (2008) state that SWB has been argued by many as an inaccurate measurement because it is based solely on the interpretation of the individual reporting and, therefore, distorted based on it being solely their perspective. Research suggests that regardless of experience, the individual's perception is their reality, keeping them as the expert and making their understanding of their own reality completely valid (Christopher, 1999). For the purposes of this research, we will assess SWB based on how the participant views their own well-being, not how the world around them views it. However, the views of mainstream society greatly impacts and affects how individuals feel and view themselves on both an unconscious and conscious level.

Christopher (1999) states that subjective well-being places the responsibility of defining, understanding, and determining well-being on the individual as the one who determines the standards and the criteria against which one evaluates his or her life. Christopher evaluates SWB, in relation to liberal individualism. He defines "liberal individualism as notions of the self and as normative prescriptions for the good or ideal person". The connection between SWB and individualism is specifically linked with the freedom to choose - the

freedom to pursue happiness, as defined by the individual, and as promised by the Declaration of Independence. The importance of connecting liberal individualism to subjective well-being is that without the freedom to choose and define parameters that are specific to the individual we lose a part of our independence.

Subjective well-being refrains from making strong claims about this idea of the good life and the good person, giving the individual the right to be seen as the expert about their own life. Christopher states that different components of our individual ideology of psychological well-being (like independence or happiness) don't necessarily have a universal meaning in every culture, as it may impose a risk of serious misrepresentation and misunderstanding. Therefore, when researching those who struggle with drug addiction, the same principles must be applied to accurately understand how individuals evaluate their own well-being. Communities and cultures will each have a different set of parameters to define what emotional well-being means to them. In order to measure individual SWB, it is important to understand what those parameters are.

Summary and Motivation For The Study

My literature review begins with a brief history of the War on Drugs and how public opinion and drug polices perpetuate stigma, oppression, and abstinence only based treatment as the preferred option to end addiction. The literature moves one to state how harm reduction is often unfavorable to many who perceive the sole purpose of helping addicts as to "cure" the addiction. Frequently, this method of treatment can be concerning to many and seen as a way of enabling individuals who use, to continue down a destructive path. Harm reduction is seen as the opposite of

abstinence, which many regard as the only goal of treatment for addiction. In an ideal world having a magic wand to cure addiction would be ideal, but unfortunately there is a lack of systematic, evidence-based approach to addiction treatment making a cure only a dream to many (Mate, 2010). Because of this, harm reduction plays an essential part of treatment process. In addition, drug policy, the legal system, medical system, access to mental health services, and the continual ostracism of substance users only heightens a drug problem exacerbating health consequences and diminishing quality of life. Syringe exchange is an example of a harm reduction based service that focuses on reducing health consequences related to substance use, meeting each client who walks in the door where they are at, using human connections to help heal and improve lives of individuals who walk through the door. Gaining a deeper understanding for how syringe exchange engenders an authentic healing connection with participants will demonstrate how emotional health outcomes are affected.

CHAPTER III

Methodology

The purpose of this study is to explore how access to needle exchange programs impacts the overall emotional wellbeing of participants. It is important to gain the perspective of clients who actively use the exchange; therefore, qualitative data will be collected and used to analyze the meaning of emotional wellbeing and the impact it has had on their lives from the perspective of the participants. A qualitative design provides the most flexibility in engaging with vulnerable and marginalized populations (Rubin & Babie, 2013). Throughout the interviews I hope to highlight and draw awareness to the influence that syringe exchange has on participants' lives. The importance of this study lies in the fact that it gives clients a voice to express their experiences, providing valuable information to service providers to better understand program effectiveness and limitations. This chapter presents the methods used in this study to discover this perspective, including study design, sample selection, data collection, and data analysis procedures.

Study Design and Sampling

Qualitative nonprobability sampling is most appropriate for such a vulnerable population. A combination of purposive and convenience techniques will be used for my sample selection. The knowledge I have of the population, its elements, and the direction of my research based on my judgments and purpose of this study make purposive sampling the most effective technique (Rubin & Babbie, 2013, p.172). Convenience sampling will also be used to give program participants the option to participate in my research. This sampling technique selects

participants simply because of their availability and convenience (p.172).

Throughout my research, I have discovered that other studies have had a great deal of success with qualitative nonprobability sampling and proved to be effective, as well as non-judgmental and approachable, when recruiting participants to be a part of the research. Flexibility is required when conducting interviews because the wide range of individuals using the services will have fluctuating mental health, levels of intoxication, and comprehension levels that could contribute to the possibility of misinterpretation of my questions. The use of this method is ideal for gaining information from the perspective of the client based on their personal experiences and how the syringe exchange services impact their emotional health.

Syringe Access Services (SAS) is program within the San Francisco AIDS Foundation, a non-profit organization in downtown San Francisco. SAS has eleven syringe exchanges currently operating throughout San Francisco at various locations and times throughout the week. The site I will be conducting my interviews from is at the only indoor site that SAS owns and operates for twelve hours per week. The surveyed participants are individuals who are injection drug users, stimulant smokers, drinkers, sex workers, without health care, homeless, marginalized, and cycling from single room occupancy (SRO) hotels to the streets. Many of the program participants live in the downtown San Francisco area; however, many travel from other parts of the city as well as come from outside of San Francisco to access services. Clients who access SAS range in age, gender, sexuality, ethnicity, race, drug preference, mental health diagnosis, and socio-economic status; however, most are low-income or destitute.

Participants will be entering the exchange from the streets to receive various services including syringe collection and disposal, safer sex items, medical care, overdose prevention trainings, and/or receiving HIV and hepatitis C counseling and testing. Clients also come in to get a snack, beverage, or can receive support or referrals from the volunteers or staff. The exchange is located in a non-descriptive storefront on an energetic street in San Francisco. Clients enter through one door and access these services on an informal drop-in basis. Client interactions can vary in length of time. It is up to the participant to choose how long they would like to remain in the building after they receive services. Grabbing condoms can take 20 seconds and testing or trainings can take up an hour. This is contingent upon the client and what they are in need of that day.

There are multiple ethical issues that may affect my study. My biases as an employee of the organization may inadvertently affect my role as a researcher. I may have greater access to program information and personnel, more knowledge about the program as well as more sensitivity to the research needs and obstacles because of my employment with syringe access. On the contrary, bias, commitment to the program and supervisor might skew my objectivity (Rubin & Babbie, 2011, p. 323). I also recognized that my bias is a prominent obstacle in my research because of my dedication and strong belief in the importance of syringe exchange.

There are also multiple syringe exchange sites that run within the organization; therefore, using only one of the fixed sites will narrow the population to one area within San Francisco.

Recruitment Process

The recruitment process of this study includes active outreach at a fixed indoor needle exchange in the greater San Francisco area. To help promote my research, flyers were posted throughout the exchange site publicizing open availability to participate in research to clients. The recruitment process and the interviews were conducted on Saturdays during the hours from 3pm-7pm and only when I was present. This time was also stated on the flyer. The recruitment process included a designated volunteer actively advertising the opportunity to participate in the study. An interested exchanger may inquire about the study to volunteers or the site supervisor. Clients who were interested in participating, were guided to another room where the designated volunteer conducted the set of screening questions. If there were an over abundance of clients at one time wanting to participate, clients were asked to sign up using only their first name and last initial on a sign-in sheet located in the room that only staff has access to. For clients who were deemed eligible to participate, the interview was conducted at that time. If there were multiple eligible participants waiting to be interviewed they were asked to schedule an interview. It's important to note that all interviews were conducted the same day the applicants were deemed eligible. At the initial contact, the researcher confirmed the client met the inclusion criteria and affirmed that they wished to participate in the study. Because the exchange is run on a drop in basis, and due to the unpredictable lifestyles of the participants, interviews needed to be conducted on the same day to ensure that the process will be completed.

In order to qualify, clients must have met the inclusionary criteria: Clients must have used the SAS program for a minimum of one year, actively be using drugs, not exclusively drink alcohol, be over the age of 18 years old, and able to understand and speak English. Clients who fit the inclusionary criteria and participated in the interview were paid for their contribution to the study. The funds for the study came from my own funds.

My sample is representative of the overall population of drug users who access syringe exchange within San Francisco. Clients who use SAS vary in age, gender, race, ethnicity, sexuality, drug of choice, and length of time using drugs. It's important that my sample be representative of the population in order to generalize the evaluation results throughout the drug using community IDU's that utilize syringe access services.

The information gathered from the interview is confidential, as I was the only person conducting the interviews. Participating in the study is not confidential because the supervisor or other clients were able to see who met with me. Participants' identities in this study were kept confidential, as I used a pseudonym instead of their actual name in my reporting the study results. All consent forms were kept separate from the audio recordings and hand written notes and both will be kept locked in a secure location. Electronic information will be kept password protected and audiotapes and hand written information will be kept in a locked box in the privacy of my home. All of the obtained data will be kept secure for three years as required by Federal regulations and, after that time, will be destroyed or continued to be kept secured as long as they were needed. Throughout the interview

I was sure to not address participants with identifying information. This research is confidential because I will be the only person who knows the individuals participating in the research. Research advisers will have access to the data obtained from participants after identifying information has been removed.

Data Collection Methods

Data was collected by audio-recorded interviews by permission of the participant at a private location at SAS. Procedures to protect the rights and privacy of participants were outlined in a proposal for this study and presented to the Human Subjects Review Board (HSRB) at Smith College School for Social Work before data collection began. Approval of the proposal (see Appendix A) indicated that that the study was in accordance with the NASW *Code of Ethics* and the Federal regulations for the Protection of Human Research Subjects. Prior to each interview participants were given an informed consent document describing their participation in the study and their rights as human subjects, as well as any potential risks or benefits of participation (see Appendix C).

Once participants met the inclusionary criteria the informed consent was given to and signed by participants and monetary compensation was distributed for their participation. Demographic and background data was then collected followed by nine interview questions asked sequentially. Basic demographic and background data included ethnicity, age, gender, drug of choice, and length of time participant has been utilizing SAS. The nine interview questions asked where intended to bring forth participants' experiences at the exchange and how those experiences have emotional impacted them (Appendix D). The topics included three main areas:

participants' thoughts on various services they have accessed in the community, what they look for in service providers, and their experience with syringe access services and how impactful that experience has been in correlation to their emotional health. Interviews were conducted using a set of fixed guiding questions used for consistency.

Data was collected through formal interviews conducted in person. The interview took place at an indoor syringe exchange site at SAS, free from distraction, in one of the private spaces available while the exchange was running. Most of the interviews were conducted free from interruption. One interview was interrupted due to an SAS client who was speaking so loudly in the other room that both the interviewer and interviewee could no longer concentrate. The interview was briefly paused to address the issue and when it was resolved the interview was able to resume. Flexibility was required when conducting interviews because of the wide range of individuals who have fluctuating mental health, levels of intoxication, and comprehension levels that could contribute to the possibility of misinterpretation of my questions.

All data collected and notes taken were by the researcher were kept separate from the consent form and pseudonyms were given as identifiers. All identifiable information from participants was removed and disguised from transcriptions and findings in the final thesis project. At times the researcher clarified questions and gave time at the end of every interview for participants to add anything that they felt was important to add. The average length of the interviews was 17 minutes long with a range of 8 minutes to just under 40 minutes.

Sample Characteristics

The majority of the participants identified as male and ethnically as Caucasian. Four participants were in their twenties, four were in their thirties, and the other four were over the age of 52. The average length of time that the participants used SAS is 13 years with the median of 14.5 years, and a range of one year to thirty years. The most common drug of choice named by the participants was opiates. Coke, alcohol, speed, and benzodiazepines were also mentioned multiple times, as many of the participants are poly drug users.

Data Analysis

The data collected was coded for themes, ideas, and categories that underpin the participant's response. In addition to emerging themes in the topics covered, findings that suggest associations between the participant's emotional response to services provided and relationships that have been developed with service providers were examined.

The researcher had the audio-files transcribed by an anonymous third party. Once transcribed, the researcher began coding data, adding initial comments, and noting any quotes that seemed poignant to include in the findings section. The coding process consisted of the researcher listening and reading the interviews numerous times and analyzing the interview content for themes and noting content that didn't fall into thematic areas. Themes were compiled and analyzed for consistencies and patterns that were relevant or significant to the research.

CHAPTER IV

Findings

This chapter will present the findings of a qualitative analysis of interviews with twelve participants who have been utilizing the services at Syringe Access Services (SAS). This study was an attempt to answer the following question: How does access to syringe exchange affect actively using participants' emotional well-being? The interview contained thirteen questions organized around the following major themes: direct experiences with various services, emotional responses to utilizing services and interactions with service providers, experience utilizing SAS, the impact of SAS on how individuals feel about themselves, and the perceived perception that others place on SAS participants. Other themes that were relevant were various services accessed while at SAS, and personal experiences and stories that were significant to the participants' connection to SAS.

Five areas of major findings emerged from the interviews. The findings will be presented as follows: 1) demographic data of participants; 2) participants' experience with various services accessed in the Bay Area and their experience with service providers; 3) their experience accessing SAS; 4) how SAS has impacted how they feel about themselves; and, 5) messages that participants receive about themselves.

Participant Demographics

The following section offers information pertaining to the participants' drug of choice and length of time that they have been accessing syringe exchange. This study was comprised of twelve clients who utilize services at SAS (five female and

seven male). Four participants were people of color and eight were Caucasian. The age range was between 23 and 62 years old. Eight participants reported opiates as their drug of choice, although almost all stated that they were poly-drug users. One participant was a former heroin user, now on methadone, who exclusively smokes cocaine. The other participant recently began taking methadone due to her pregnancy and didn't report using another substance at this time. Length of time that participant's utilized services at SAS ranged from a little over one year to thirty-three years.

Community Services and Service Providers

This section reports various services that client's access in the Bay Area, what their experience is like with those services, and how the interaction with service providers has personally impacted them. The data is presented in the following sub-sections: the impact of services that are liked and disliked; and, desired relationship with service providers and how it affects participants.

The Impact Services That Are Liked and Disliked

In discussing services that client's access in the Bay Area, participants were asked about their experiences with various services and how those experiences and interactions with service providers affected them. Participants described utilizing as few as one service up to several in their community. Participants described having both a strong like and dislike for various services utilized. Several participants (n=12) reported using services including: General assistance office, social security office, numerous medical clinics, The UFO study, the VA, Homeless Youth Alliance, ward 86, needle exchange, methadone, Saint Anthony's, Glide, and a

variety of community harm reduction and support groups. After participants listed the services they access the question asked was, "Now, more specifically, can you tell me about one particular place that you like? What about it do you like? How do you feel when you go there?" Participants stated a number of services that were viewed positively for a number of reasons. Major themes that were expressed by participants were comfort, safety, comprehensive, harm reduction friendly, and commonly, "it feels really good when I have a good experience."

When discussing services that participants felt good about and why, one person described this as their experience,

Remember when you saw me yesterday and I came in and I was smiling real big? Well, that's generally how I feel when I go to HYA (Homeless Youth Alliance) because it's like seeing friends -- it's like when you've been in a city for a while and a good friend of yours just randomly show up in town. That's how I feel when I go up there, you know, because most of the time I kind of get stuck in my own world and so when I actually do go up there, it's like I haven't seen them in a while so -- I'll get caught up on all my affairs, I guess, yeah.

Another participant said, "I like to go to the exchange on Fridays. I get to turn in my old ones (syringes) and so I use the clean ones when it's done, you know, I can talk to people I know. People are friendly and nice and they don't make me feel like a dope fiend." Lastly, another participant shared,

That would be my buprenorphine group that I go to during Thursdays. It's a support group. Really just for opiate users but its through the bup program that I have been involved in. I've been involved there for three years. And it's probably one of the best groups that I've ever gone to because most of the people there have been going there for a long time, so we know each other and we know each other's problems. I feel really safe there and I am person who doesn't trust easily. And I have a lot of social anxiety so it's nice that we all have a place, that's right and good, where we can totally be open and totally comfortable to share what's on our minds and not feel like embarrassed or ashamed or anything.

One participant reported not having any services that were comfortable to access.

The next set of questions focused on services that participants had a negative experience with and why. There was then a follow up question asking how that experience made them feel. Participants discussed both the environment of the service provided and the interaction with service providers explicitly when sharing their experiences. Common themes such as unhelpful, traumatic, and emotionally difficult, surfaced when discussing services that participants' found valuable. Examples included statements such as, "I've had a couple -- two panic attacks since I've been there and a really long manic episode. And I haven't had any panic attack in a long time" and "They want me to stay and do appointments while my dog is hooked up out front, which like gives -- it gives me anxiety. I mean I'm not leaving my dog out front. My dog is a service animal!" and lastly, "You have to go in multiple times before you actually get them so you have to suck it up and take all that bullshit until you get your food stamps."

Further findings that emerged from participants' experiences with service providers relate to judgment when accessing various services. Several participants (n=8) expressed their concern, stating,

When they find that you're a heroin addict and you're there for an abscess, they (doctors) do these outrageous cuts on you and they just, they just talk to you like you're a piece of shit, you know. They don't have any respect for you. They think you're, like, scum of the earth.

Another participant shared,

There are some people that, um, help people and it goes to their head. It really doesn't help people, you know, because they start chastising with words and directions and whatnot. Um, you shouldn't do this. You should do that.

Another example of this common feeling of judgment was reported by another participant stating, “I walk in and you just automatically have an attitude and start treating me like, you know, either I’m just going to steal shit or fuck this off. I’m not like that.” Five participants stated that because of the negative experience with a particular community service they have discontinued going there for services.

Desired Relationship With Service Providers and How it Affects Participants

Participants were asked to discuss the ideal relationship they would like with service providers when accessing services within the community. Participants commonly expressed the need to be treated with respect, without judgment, and to have honesty and trust as a significant part of the relationships. When a SAS client was asked, “What type of relationship do you look for with service providers” the response was, “People (providers) that, that give life. People that have the same kind of, uhm, thoughts, you know.” Another participant stated,

I mean someone who is accepting of the lifestyle, and understanding of it, and not judging, and that’s – that’s my experience with pretty much all the people (providers) in San Francisco everywhere. That they understand what’s going on and that the homelessness is an epidemic, and its pretty hard, and also, for them to be happy, and maybe lend an ear for a while, because it’s nice to talk to someone, so, definitely that.

In line with the previous stated themes, one participant stated that working harder to improve her life seems more feasible when the person who is serving her actually cares about her. This is an example of a participant describing her will to take steps in a direction that feels positive for her, as she answers the question “How do you feel when you are treated with respect from service providers?”

I feel so good. I feel like, I start shivering when I have my therapy. You know, it's like I'm in a room, you know, and a professional is closing the door to the room. And the answers found, you know, are much less important, you

know, but, you know, she makes me feel that my, you know, that my time matters, you know and I matter. So I want to work therapy like I'm supposed to, you know, cause like so many of us addicts have, we started to shut down for so long and I mean that's why I'm such a screw up. It's not like, you know, therapy's here and it's sprinkled over you -I work at it, you know, with her help. And then when I leave, I'm light, you know. It's like I'm able to survive all of that.

Many of the participants did not state that they need services to improve their life; however, the overarching theme that I continued to hear was the services they currently access or wanted to access, are directly linked to improving various aspects of their life. Participants often expressed that without trust, respect, and a non-judgmental approach, accessing services become emotionally challenging for them and the deters them from moving forward.

Participants (n=9) voiced that having a service provider who is helpful is important to them. A participant stated,

Trust, honesty, mainly honesty, yeah, that they don't bullshit me and have me thinking one way and it's not, you know -- just being honest with me about what they can provide, you know, what they can't provide, just honesty, really.

A second participant shared, "Long-term, long-term, you know, someone who can help me with my needs and that way I can, you know, somewhere I can go and they can help--me with my needs."

As the participant's quotes indicate, providers following through and meeting the needs of their clients, instills trust, which can begin to instate change.

Syringe Access

This section details clients' responses to questions pertaining to syringe access services. The data is presented in the following subsections on participants' experience on an average day at SAS; the perception of the participant by others; the

impact that SAS has on how clients feel about themselves; and, how participants are treated in other parts of their life.

Experience at Syringe Access Services

In discussing participants' experience of accessing services at SAS the question was asked, "Describe an average day coming into SAS? What is your experience like?" With a follow up question of, "What services do you access when at SAS; HIV & Hepatitis C testing, D.O.P.E Project (Drug Overdose Prevention and Education Project), medical, or The Speed project." The five salient findings of this question were that SAS is: a welcoming experience with friendly faces; a place without judgment; a place where participants feel seen; a place that meets current needs; and, a place to utilize D.O.P.E services. There was cohesiveness in participants experience utilizing syringe access services.

The first finding was that participants' (n=?) experience at SAS was welcoming. Four participants described SAS as a place where they can see people who are their friends. Friends were described as staff members, volunteers, other service providers, and others who access services at SAS. One participant stated,

It's like -- well, for me at least because I've been going to exchanges for a while and a lot of the same people work at, you know, at different sites. It's kind of like, you know, I don't want to say going to a party but it's like, you know, going to a coffee shop and seeing your friends. You know what I mean? Even though there's no real, like, you know, client whatever friendship, there's still like that, I don't know, like, I've gotten close enough to be able to confide in people, you know, to be able to share my feelings and, you know, when I see somebody (a SAS participant) that's being rude or whatever, I feel that I should stick up for the people (staff, volunteers, and other providers) there, you know, which I think says a lot.

Another participant shared something similar, stating,

You know, I've also made some, you know, good relationships have come out of this place. Like -- I mean, like P---- (staff members name) and I, like, have a lot in common, you know. So I feel like after I'm done and gone to leave San Francisco I'm still going to talk to him. He's helped me to feel better in all situations when I felt bad about them and that's -- it's a very good thing 'cause there isn't any other place in the city where I've gotten that from. Even if I didn't need needles I'd come here.

Other participants described feeling welcomed less directly but an emphasis on feeling welcomed was still present. An example of this was described by a participant,

Yeah, I try to get to know the staff and the people that at the Needle Exchange. I tried to make, you know...I don't know how to say it, I don't like friendship but I like to be known. I go to certain Needle Exchanges because I'm comfortable with people that work there and I like to have it to where "Hey T--- (SAS client), how are you doing?" You know, they know me and I could go, "Oh, Hey M--- (staff member), how are you doing? How was your day?" and interact with them.

It's important to note, that before this question was asked, the researcher reiterated that the responses to the next set of questions would be keep confidential and this research would be used to help improve services at SAS. Four of the participants responded to that statement by saying they were happy to help the researcher finish her thesis and attain her degree.

The second finding almost all of the participants (n=11) explicitly stated that SAS is a place where they feel no judgment placed upon them when they walk in the door. Most participants noted that this was one of the most defining and important characteristics of SAS.

One participated stated,

95% of the people there (staff and volunteers at SAS) are totally nonjudgmental. Either they have been in my situation or know that, you know,

at any moment they could be so there's no real, like, distinction between social or economic class, you know.

A second participant describes SAS as a place where they can be their authentic self without judgment, "There's no pressure to be anyone other than yourself. I feel like I could come in and say a million things or come in and say nothing and still it's going to be okay. It doesn't matter."

A third participant shared,

Uh, I appreciate the fact that it's there, that I -- I never feel judged or scrutinized or -- or any kind of bad attitude or anything or had a bad experience. Um, and I guess, in that sense, it makes me feel a little more like dignified, I guess, you know.

A fourth participant stated, "You know, everybody that I meet here is friendly, yeah, and they're not overwhelming and they're not pushing people to do this and do that, and they're not judgmental. Period."

The third finding was that eight of the participants stated that they feel seen when they walk in the door at SAS. One of the participants stated,

We (provider and participant) know each other, even when it's been a long time, you know what I'm saying? And I appreciate that because it's always -- you don't change, and if something's wrong, you say hey, what's up? You know, you can always tell by my body language I guess, you know?

Another exchanger discussed how she feels and how she perceives the interactions between providers and clients at SAS,

And when they come in and feel welcome by you guys, it just changes, you know, a lot of people lives, you know. And cuz you actually care. You don't just say, "Here do you need this, do you need that" You say, "Hey, are you okay?" You know, you're like just like a one-on-one, you know people. And you actually taking the time to know them and take a challenge to know what they're needing.

The fourth finding was that several of the participants (n=10) explicitly stated that SAS is a place where they could go and get their needs met. Many of the participants frequently expressed their frustration with many of the community services because their needs were constantly unmet; therefore, SAS was held in high regard due to the fact that the needs of the client were met every time and without judgment. One of the participants stated,

This here is better than going and buying stuff on the streets. You know what I'm saying? Yeah. It makes me want to really stop that much more because I don't know if it's my pride or faith. You know what I'm saying? You make it pleasant for a person to come and get what they need without having people judge you for coming in. You know what I'm saying? I don't leave here feeling embarrassed, you know. I feel good when I'm walking out of here and I think I try to be that type of person that people would get, you know, because they do a mass service that I do appreciate.

A second participant described her experience at SAS as a place where, "I get in and I get what I need and I have a good feeling about what I'm doing and I always come in and get stuff for other people too."

A third participant shared,

It's, um, I don't have to go far to get my supplies. I don't have to go through bullshit, um -- say well, you got to do this. It's not program where, when you come here there are -- they have a policy where you can't come here unless you do this for us and then -- it's not like that. It's really here to help the individuals who come through the door.

The fifth finding was clients' response to various services accessed at SAS. Unanimously (n=12), participants stated that they utilized the D.O.P.E project. The D.O.P.E project educates clients on the risks of opiate overdoses and how to respond to an overdose. Nalxone, is the drug that brings one back from an overdose, is distributed to participants once they have been trained how to use it.

Perception of the Participants

In discussing how community services providers and SAS employees and volunteers treat the participant, it was important to explore how the participant felt the rest of the world perceived them. The question asked was, "How do you think people perceive you when they meet you? Are there any messages you receive about yourself?" The two salient responses were that participants: feel the heavy burden of stigma and shame as they feel judged, fear, and emotional distress; and, feel that they are good, compassionate human beings.

The first salient finding was that several participants (n=6) felt that people, including friends, family, and strangers, had preconceived ideas of who they were based on their appearance or their current knowledge of the participants drug use.

One participant shared,

Well, like, if I'm not outside panhandling, I've noticed the people definitely have a preconceived idea of me like they, they judge me based on my appearance and based on the frequency of the ideas they have of what people have told them or what they've seen in the media, you know, because people generally, like, people generally fear me or, like, you know, or think I'm a bad person and going to take their stuff or just ask them for money or something and when I'm panhandling, I don't even ask for money. I tell people, "Have a good day," and my sign says, "I need help with food." Like, you know, that I'm a criminal, that, you know, I'm somebody that they obviously don't want to interact with or be around. You know what I mean? That, like, at any moment I could just get up and rob them which is, like, the farthest thing from the truth, you know, and I get my little bit of satisfaction when somebody actually takes the time to stop and they realize that I am intelligent, you know, that I am a real fucking person, that I do exist and all their preconceived ideas are ass backwards, you know. I'm serious. Like, I am more afraid of them than they are of me. You know. Yeah, like, seriously. I mean, it hurts being conceived this way, you know. I do, I do have feelings, you know, and they're constantly being stepped on, like -- it's hard to not become the person that I'm trying to tell them I'm not, you know. It really is because, like, 24/7 you got these people telling you or, you know, their body language telling you that you're a piece of shit, that you're going to steal their shit, like, you know, they as soon as they see you they put their precious phones away or hiding their tablets or, you

know, grabbing their purses tighter or, you know, throwing their money in their pocket as fast as possible -- you know what I mean? Or, like, you know, like, pulling their kids closer or even going so far as, like, not letting their dogs come near you. You know what I mean? Like, really? Homelessness is not fucking contagious, you know. Like, I'm sorry but it's not and I'm pretty fucking proud that I have not let that get to me you know, that I haven't become that person that that they fear I am. Yeah. That's one of the things I take pride in, you know. It's one of the things that keeps me from becoming them, I guess.

A second participant responded by saying,

I think people perceive me as a drug addict or some type of one-- I'm not where I should be, with my potential, and my ability, and it's sad but -- maybe it was just my mind telling me that people think that I'm a drug addict, but I don't know--because it's sad, really fucked up. I've walked into many places and been looked at like I'm going to steal something, or that I probably shouldn't be there, or that generally an outsider type of attitude. It's sad, it is. It hurts, you know, because I'm -- me personally, I've never experience that in my life and then it's humbling in a way but it's also like how I let myself get like that.

The third participant stated,

Well it's either -- they either don't like me or trying to judge me based on the way I look or they want to know me because of the way I look too. [Laughs] You know what I mean? Like it's kind of a novelty for them. So, I don't like that either.

The second finding was that participants (n=7) felt like they were viewed as a good-hearted person. A few of the same participants' (n=3) first response to the question was feeling judged; however they also felt they many people were also able to view them as a good person. One participant shared,

I don't know that. I just hope that I can help someone, you know. I try to be helpful as much as I can and I know everybody is not going to like me but, you know, I just try to be a good Christian and a good person and help if I can but I don't know how they perceive me. I really don't. I can't read their brains. But hopefully they perceive me good because I try.

Another participant stated,

Yeah, that I was a nice person, you know, pleasant to be around. Some of them say that I'm slow, that you know, that I don't participate in drug activities and

all that. That's good. That's a good thing but I don't know about so much of it as being a slow type thing, you know, not streetwise, that's what they mean.

This last participant said,

You know, that's kind of hard. I have never been -- I think that, you know, the general type of being -- I'm a nice guy. (Long pause) I'm a nice guy. I'm respectful. Nice and respectful. I'm respectful for my own. I don't know.

Two of the participants were unable to answer the question. Six of the participants became tearful when this question was asked.

Impact of Syringe Access

In discussing with participants their experience of utilizing SAS services, the question was asked, "How do you feel that coming to SAS has impacted how you feel about yourself?" Participants reported that utilizing SAS services has: improved their sense of self-worth; provided support for self-care; and, caused some conflicting messages about their drug use.

The first finding was that all participants (n=12) discussed how utilizing syringe exchange has improved their sense of self worth. A few of the participants (n=4) stated helping others in their community greatly impacted their self worth. These four participants shared how utilizing SAS services was for both personal use as well as a way to assist others in their community. A participant stated, "It works for everybody that I know and I help others that can't come, you know," and another said, "I can access a lot of things and then share it with other people."

Participants discussed various ways that SAS improved how they feel about themselves. One participant discussed his recent HIV diagnosis given to him at SAS,

It's just sad, I never thought that I would be in the position I'm in but the way they (SAS employees) handled it -- I put myself in some really bad situations, and came here to get tested (for HIV), it was almost like I was invincible. The

Hep C (hepatitis C) test came first, and they said, "Okay, you're negative," and then, they've told me in the other room, and I just started crying because I knew (participant is referring to a positive HIV test result). I was just like, "It's unbelievable," and they (SAS employees) just comforted me, and talked to me, and told me that...they were very assuring and there's not much you can do for something like that. But I left here (SAS) not crying so that's good. And I didn't just fucking bolt or do some shit, which I want to do, but they help me stay, and talk about it a little bit. So, that's amazing, and then one of the guys I was talking with was a fucking volunteer, and so, he sat there for 15 minutes with me and the doctor, and I'm sure he felt obligated to do that but he did that out of the kindness of his heart and it was beautiful.

A second participant shared,

Which makes me feel like I've been successful to a certain extent, which is like a small little fraction of my day. But it's still -- it's still enough for it impacts my -- my outlook on the rest of my night and kind of just like how I feel, you know. You guys have positive feedback, which helps me probably more than you know.

A third participant noted how helping others helps her:

You know, everybody takes me for who I am, and how I act, and how I present myself. And that's all I wanted, you know, that's all I want. And like I said, also it's a very -- I feel very positive about coming here and I feel positive about helping other people as much as I can. You know, like who don't -- you don't know about the programs and come here and I always try to take all the fliers and everything. And I hand out schedules to everybody and -- it's just, I feel good about that. You know, and any time I feel like I advocate for it like, because outside of here. You know, the needle exchange programs in the city are not like any other I've ever been to.

A fourth participant said,

Uh, I appreciate the fact that it's there, that I -- I never feel judged or scrutinized or -- or any kind of bad attitude or anything or had a bad experience. Um, and I guess, in that sense, it makes me feel a little more like dignified, I guess, you know.

The second significant finding was that participants (n=6) found that utilizing services at SAS was an avenue that provided the opportunity to contribute to self-care. One participant noted that that the exchange impacted her, "Because I can do something different instead of just the same old rut...you know what I'm

saying? I'm trying to do something positive, you know?" Another participant discussed,

Yeah, it was like, you know, we were trying to do something good like keep ourselves healthy and clean and so anyway, uhm, but now it's, it's a lot more cleaner and safer and not judgmental and you get so much more than just, uhm, like I've, I've said-- yeah, you get so much more than just you know, your paraphernalia or your condoms or you know. You, you get more than that. You better smile on it and somebody that actually is giving you that actual thought of care, you know.

The third salient finding was that three participants felt conflicted about what it meant to access syringe exchange. Participants were able to state several ways that SAS has positively impacted the way they felt about themselves but also referenced feelings of confusion about utilizing services at SAS. One participant stated, "Oh, yeah, let's go to needle exchange. It's like fuck -- I have needles and stuff. I would love not to come here. That would be great," and another shared, "Well, I really don't like coming to this place or any places to get supplies, you know, to enable me to do what I'm doing."

Treated Differently

In discussing participants' experiences outside of syringe exchange the question asked was, "Are there any ways you are treated differently at SAS than how you are treated in other parts of your life? If so how is it different?" Participants expressed two main points about their experiences outside of SAS: being seen and feeling cared for. In addition, participants expressed two main points about feeling comfortable and being able to take a break from the rest of the world.

Most of the participants spoke at length about the difference in accessing services at SAS than what they experience throughout their day due to the stigma and judgment that is placed upon them. One participant said that

Yeah, it's cool because coming here -I have none of that (judgment). You know what I mean? It's just like I don't -- I don't have to show you guys who I am because you already know. You know what I mean? Like, I come in -- and you're like, "Oh, there's A----- (client stated his name)" you know. You're not, like, hiding all the fucking valuables, you know?

Another participant shared, "I feel --I don't know, kind of relieved somewhat of the luggage that be on my shoulders, you know, from the presentation, you know?" A couple of the participants talked about how overwhelmed they felt by the rest of the world and how utilizing syringe exchange was a way to escape from the chaos.

I mean I don't want to call it like a safe haven, but like, I don't know, for just like a minute, like even if I'm in here for like three to four minutes, three or five, or maybe five minutes, like -- it's just like a break. Like -- just like constantly -- I go and go and go and go and worrying about everything. I mean it's like, kind of may be twisted to the outside world, like, I look forward going to needle exchange. They'd be like "The Needle Exchange? Why?" You know, like you're getting injecting supplies but, it's -- I don't know. I feel like it's -- it's more than that, you know, so.

The next chapter of this study will discuss the relevance of the findings to the literature previously reviewed. Additionally, the next chapter will discuss the significance of this study's findings to social work practice, theory, social work policy, and limitations of the study.

Chapter V

Discussion

The purpose of this exploratory study was to examine how syringe access services (SAS) impacts program participants' emotional well-being from the perspective of the client. The results indicate that SAS profoundly impacts participants' emotional well-being. All of the participants reported that SAS was a community service that provided a space that was impactful in numerous ways. Key findings were as follows: 1) Participants felt that there was a mutual friendship and/or relationship that was developed between SAS providers and participants; 2) participants' perception of how others perceive them varied depending on the weight of the stigma that they had experienced; 3) DOPE project services were unanimously sought out; 4) When participants feel cared for, they are able to take care of themselves better and feel motivated to care for others; 5) Stigma is a barrier to accessing services; 6) Harm reduction based services provide injection drug users a sense of safety and a place where they feel cared for; 7) Participants have conflicted feelings regarding the meaning of utilizing SAS services; and, 8) Participants' emotional well-being was enhanced because of their experience accessing SAS services.

Study findings provide a valuable perspective of a generally unknown and unpublicized interaction between vulnerable populations and their experiences with community services. This chapter will relate these seven key findings to prior studies and the theoretical frameworks presented in the literature review. This

chapter will conclude with a discussion of the implications for clinical practice, policy, and research.

The first key finding regarding the participants interviewed for this study is the friendship and/or authentic relationships that participants felt were developed with SAS services providers. When participants were asked what they look for in services providers they expressed key qualities such as trust, relationship, and lack of judgment when accessing services. In contrast, when participants spoke of poor experiences with services providers they commonly felt stigmatized, judged, and underserved, creating a less than balanced relationship between them. Evidence of this common feeling is stated by Macneil & Pauly (2011) who write,

The stigmatization of injection drug users contributes to those who use drugs being devalued, demonized and blamed for societal decay with illegal drug use viewed as a moral rather than a health issue, and 'injection drug users' viewed as undeserving or unworthy citizens. (p. 27)

The equalizing nature of the relationship between SAS providers and SAS clients create an environment where clients felt they could be their authentic selves, thus enabling a genuine friendship between them. This could be due to the safe welcoming environment that SAS works to create but also due to the heavy stigmatic weight that many of the participants expressed carrying and feeling free from when utilizing SAS services. Self-stigma is the often the result of social and structural stigma; therefore, when participants enter a space free from stigmatizing attitudes from providers (Livingston et al., 2012), they themselves are able to release the burden of self-stigma. Many of the participants stated that SAS is one of the only services that many of them felt comfortable accessing because of the trusting relationship that was formed with the providers.

The second finding revealed that the perceived perception that others had of SAS participants varied depending on the length of time that participants have been using substances, age, and previous life experiences. Participants referred to “others” as friends, random pedestrians, services providers, staff in various stores, and people within their community. The overarching theme that I consistently noticed was stigma. All of the previously stated factors are due to the consistency of stigmatizing attitudes and behaviors from numerous individuals. Participants who were under the age of 35 consistently stated that they often felt looked down upon and perceived negatively, while participants who were in their 40’s, 50’s, and 60’s stated that they were viewed as good, compassionate people. These findings may be due to the fact that the longer participants have used substances the more coping skills and defense mechanisms they have developed to mask their response to the perception of others. Many of the participants have had everyday experiences that send them messages about who they are as people. The longer individuals use, generally, the more negative messages that they receive about who they are as people. Also, many of the participants who are 40 years old and older were alive for the beginning of the declared War on Drugs in 1971 by President Nixon (McVay, 2011). The differences in generational experiences could be another contributing factor to the perceived perception that the participants who were over 45 years old had versus those of the younger generation.

The third key finding revealed in the data was that all of the participants utilized the Drug Overdose Prevention project (DOPE Project) services that SAS offers. The aim of the DOPE project is to educate users on the risks of overdose,

while focusing on how to respond and revive someone who has overdosed. A prescription for Narcan, the drug that is administered when someone has overdosed from opiates, is written and filled so participants can carry it with them.

Participants' unanimous utilization of the DOPE project speaks to the concern that they have for people in their community who may be at risk of overdosing. It shows that participants care about one another, value human life, and have the capacity to be of service for those who are unable to care for themselves in that moment.

The fourth key finding suggests that participants are able to care for themselves and others when they themselves feel cared for. As the literature states,

Reducing physical harm, acknowledging social and economic stressors, and addressing mental health complications should all be recognized when working with individuals who use substances. Without doing so we are unable to work on improving emotional wellbeing. Improving emotional and social health is a way to improve how a person thinks and feels about themselves and their place in the world. (Tsey et al., 2009)

When participants were able to find a service that focused on their immediate needs clients felt cared for and showed more motivation to take care of themselves. When service providers were not able to show respect and, consequently, were unable to care for them in the ways that they needed, clients backpedaled, and often discontinued services. All of the study participants stated that they were able to "get what they need" making them feel "good." Participants shared that because of SAS, they were able to take care of themselves, then care for other people in their community by providing them with clean unused supplies, giving them a sense of accomplishment and improving their self worth. Utilizing DOPE project services is yet another example of how altruistic SAS participants are and how that perpetuates their ability to take care of others within their community.

The fifth finding revealed that stigma was a barrier to accessing community services (Macneil & Pauliy, 2011), as much of the literature states. In this research, it was found that stigma was a barrier to utilizing services unless services were within the SAS facility. Harm reduction services are evidence that someone cares about drug users and is willing to take the time to understand and address their current needs, relaying the message to drug users that they are heard, worthy and deserving of care. Livingston et al. (2012), states that drug users are some of the most marginalized and stigmatized groups of individuals thus creating social alienation and difficulty for individuals to utilize community services. Judgment of the participants' drug use and appearance was the most noticeable expressed concern of participants when meeting with a service provider. As many of the participants stated, an increase of anxiety, frustration with the provider, and self worth were all affected when they felt judged and disrespected when receiving a service.

The sixth related finding that emerged was that harm reduction based services provide injection drug users with a sense of safety and a place where they feel cared for. Participants described their experiences with SAS as a place where they felt heard and respected due to harm reduction based interactions that transpired between them and service providers. The literature states, "The less empathetic understanding we have and the more that individuals are stigmatized, the harder it becomes for the individual to move forward in a positive direction" (Livingston et al., 2012; Rogers, 1967). Harm reduction methodology uses a humanistic approach to improve the lives of individuals who are actively using

drugs thus creating an environment with less stigma and judgment present (EMCDDA, 2010; IHRA, 2010; Davis, 2004; Tarantola, 2012; Ruefli & Rodgers, 2004; Denning, 2000). Many of the participants stated that their needs were met while utilizing SAS services due to the large spectrum of services that are available, all within the scope of harm reduction. Because of this, participants feel cared for without being required to fulfill any other objectives. Participants repeatedly stated that harm reduction services were helpful, respectful and safe, enabling them to continue to look forward to utilize SAS services.

The seventh key finding revealed that a few of the participants were conflicted about the meaning of utilizing syringe exchange services. Almost all of the participants stated that exchange services were good; however, a few of the participants felt conflicted due to the meaning of utilizing SAS services. The participants who felt conflicted stated that utilizing SAS services reminded them that they were dependent on drugs, which then meant that they were a bad person. This could be due to overwhelming number of conflicting messages about who they are as people. Participants are told that utilizing services is a way of receiving help and taking care of themselves; on the other hand, it was a reminder of the negative messages that have received about who they are as human beings. Many of these questions were hard for people to respond to because it was difficult for them to tease out what they have been told about themselves as opposed to how they actually feel about themselves.

The eighth key finding revealed in the data was that SAS services provided an experience that enhanced participants' emotional well-being. Throughout the

interview, all of the participants spoke about their experiences at SAS that improved their feelings of self-worth. SAS offered a space that was authentic, accommodating and provided the space for participants to find safety. For all of these reasons, clients found SAS a space free from stigma and shame, feelings that they don't feel free from throughout their day. Participants had an increased sense of the part of themselves that they had confidence in and felt good about, leaving a lasting imprint on their self-worth thus impacting their life and sense of well-being. The clients interviewed in this study were marginalized, oppressed and highly stigmatized in most areas in their life; however, they found staff to be destigmatizing, humanizing, and nonjudgmental. This finding is confirmed in the literature about the use of harm reeducation based approaches that do more than prevent the spread of deadly infections; they care for individuals on a level that improves their quality of life (Des Jarlais et al., 2009; Macneil & Pauly, 2010; Ruefli & Rodgers, 2004).

Strengths and Limitations

This study has several limitations and as well as strengths. The small sample size and the process of recruiting participants at one specific SAS site and in only one area within San Francisco did not allow for generalizability of the findings. However, attention to issues of reliability and validity should be noted as the audiotapes of interviews were transcribed verbatim and the transcripts compared to the original tapes to ensure accuracy. The researcher is currently on staff with SAS, which brings up the issue of bias and possible fear from the participants of bringing up information in the interview that could be interpreted as negative. Because SAS participants were only interviewed there is information lacking about

what keeps injection drug users from utilizing SAS services. With that said, a strength of this study is that this vulnerable population rarely gets the opportunity to express themselves in a safe space, as well as have their voices impact current and future research. Another strength of this study was the use of exploratory qualitative design that generated extremely rich data about the effectiveness of SAS and how it impacts current program participants.

Implications for Social Work Policy and Practice

The findings of this study have significant implications for social work practice and policy. The first major implication revealed by the data is the need to understand individuals who use substances as a highly stigmatized group of people whose use is often perpetuated by immense amounts of shame and guilt. With this shift in understanding individuals in this way and using harm reduction as the theoretical foundation to work with those who use substances, we can begin to change the effectiveness of services.

In regard to practice, the findings revealed that there are many areas of change within community services that can provide more effective and relational ways of interacting with clients. Clinically, working with individuals where they are in that moment and understanding their current need helps create a space that feels safe, where their voices are heard and, in turn, helps people feel like a respected human being. Because of the stigmatizing nature of the society at large, part of a provider's job is to help change how people view themselves and change the messages that people receive, and internalize, from the rest of the world. Repair takes repetition. It's our job as services providers to help mend people and their

souls but, in order to do that, we have to be consistent. Individuals have to feel loved, valued, respected, and cared for repeatedly before change can take place. The framework of harm reduction attempts to do this and from the findings it has proven to be an effective way to interact with people.

The implications for policy are vast. Two of the major implications for policy include destigmatization and decriminalization for those who use substances and legalization for syringe exchange across the country. Drug policy and laws need to be congruent with harm reduction practices to be entirely effective. City, state, and federal funding should be made available for syringe exchange to operate throughout the country. Cities without syringe exchange lose opportunities to help communities in need and decrease the spread of HIV and Hepatitis C. Studies have shown that syringe exchange does not increase the number of people who use or the amount that people use, but creates a space for people to take care of themselves, extending value to their lives and to our communities.

The findings revealed various areas for future research regarding the implication of syringe exchange and the various impacts on individuals' emotional and physical health. The first recommendation for research is understanding the impact of caring for individuals and the impact this care has on the community at large. This study's findings indicate that several participants found an improved sense of self when they were able to care for those in their community who were not able to care for themselves by bringing them clean syringes and injection equipment, medical supplies, and various medical equipment. The second recommendation is for further research about the impact of overdose prevention.

All participants used DOPE project services, which indicates the level of concern that they have for individuals in their community who at risk of overdose. Further research might help understand the impact that overdose services has on those who have used narcan and those who have overdosed themselves. The third recommendation for research includes a space within syringe exchange program that provides participants' with individual therapy on a drop in basis. This research brought to light the serious need that participants have for an individual confidential space where clients can receive one-on-one counseling as many of the participants continued to talk with the researcher after the interview ended. The fourth and final recommendations for further research is for the study of the relationship between substance use and childhood trauma. Many of the participants in this study had traumatic stories that they shared, stories about who they were before they began using or justifications for their current use, all indications that there are stories linked to individuals' development of substance use.

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Appendix A

San Francisco AIDS Foundation Approval Letter



SAN FRANCISCO AIDS FOUNDATION | 1035 Market Street, Suite 400 | San Francisco CA 94103 | 415.487.3000

November 26, 2012

Smith College
School for Social Work
Lilly Hall
Northampton, MA 01063

To Whom It May Concern:

San Francisco AIDS Foundation (SFAF) gives permission for Melissa Morelli to locate her research in Syringe Access Services (SAS), a program of SFAF. SFAF does not have its own Human Subjects Review Board and therefore requests that Smith College School for Social Work's (SSW) Human Subject Review Committee (HSR) perform a review of the research proposed by Ms. Morelli.

SAS and San Francisco AIDS Foundation will abide by the standards related to the protection of all participants in the research approved by SSW HSR Committee.

Thank you for your assistance with this.

Sincerely,

A handwritten signature in blue ink, appearing to read "Michael D. Siever".

Michael D. Siever, Ph.D.
Director of Behavioral Health Services

sfaf.org



Appendix B

Human Subjects Review Approval Letter



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

January 24, 2013

Melissa Morelli

Dear Melissa,

Thank you for making all the requested changes to your Human Subjects Review application. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

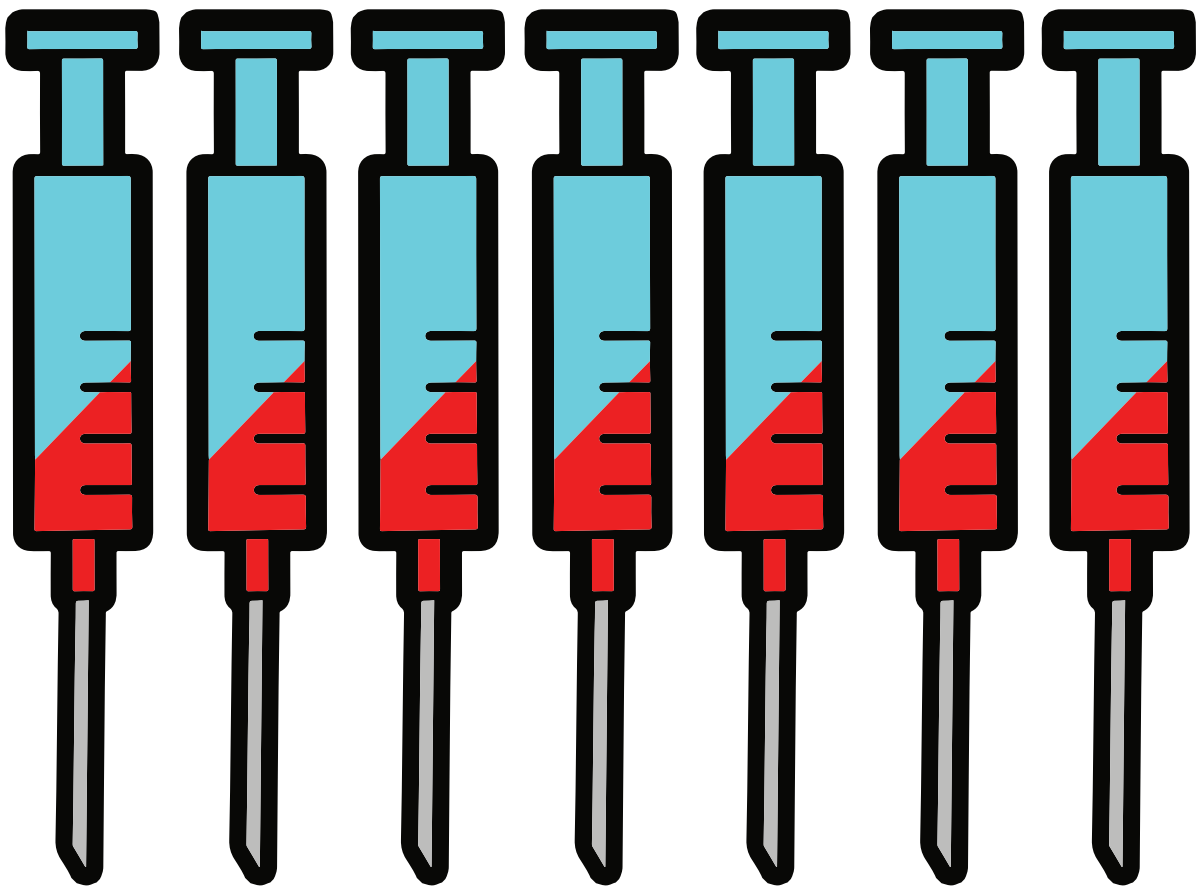
A handwritten signature in cursive script that reads "Marsha Kline Pruett" followed by a flourish.

Marsha Kline Pruett, M.S., Ph.D., M.S.L.
Vice Chair, Human Subjects Review Committee

CC: Fred Newdom, Research Advisor

WANNA BE PART OF A NEEDLE EXCHANGE STUDY?

PLEASE ASK THE SITE SUPERVISOR FOR MORE INFORMATION.



NEX study
Saturdays 3-7pm

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Appendix D

Informed Consent

Dear Participant,

My name is Melissa Morelli and I am a graduate student at Smith College School for Social Work. I am conducting a survey on the perception of current needle exchange participants and how access to needle exchanges has impacted their overall emotional wellbeing and the impact it has had on their lives. Data obtained in this survey will be used in master's thesis and possible presentations and publications.

My interest in this topic derives from my personal and professional experiences I have had with those who struggle with addiction. I was inspired by work with the needle exchange program and the valuable time spent individuals who were involved in the program.

Your participation in this study is requested because you currently access needle exchange. If you are interested in this study you must be an active participant of the exchange for at least one year, currently using drugs and/or alcohol, and must understand and speak English. If you choose to participate I will interview you about your experiences at needle exchange and your understanding of how the program has shaped your emotional and mental health. The interview will be conducted in person and tape-recorded. This whole process from start to finish will last about 30 minutes.

The risk of participating in this study is that some of the questions I ask could bring up uncomfortable feelings or remind you of something triggering from your past. Needle exchange staff will be available after the interview for support and I will provide you with a list of referrals for support outside of the needle exchange.

The benefits of participating in this study are that you can share your story, experiences, and feelings of how access to the needle exchange has impacted your emotional health. Your contribution to this study will help providers, students, and public health officials to better understand how the benefits, values, challenges, and strengths that the syringe exchange community has.

Your participation in this study is confidential and I will use a pseudonym instead of your real name in my writing. In addition, I will lock all written material and audiotapes in a secure location according to federal regulations. I will keep all research information for three years after our interview at which point it will be destroyed. Participation in this study is completely voluntary. You may refuse to answer any interview questions and you may withdraw from the study at any time before March 1st 2013 without question by letting me know that you are no longer interested in participating. If you withdraw from the study, all materials related to you will be taken out of the study and destroyed immediately. Withdrawing from

this study will have no impact on the services provided to you by syringe access services.

If you have questions or concerns please feel free to contact me at (###) ###-#### and leave a message or come to any of the needle exchange sites that I supervise (Hemlock, Tenderloin, and 6th street). You can also contact the Chair of the Smith College School for Social Work Human Subjects Review Committee, Dr. David Burton at (413) 585-7974.

For your participation and contributions to this study, \$20 gift card compensation will be given to you at the end of the interview.

My role as a researcher requires that any information about possible harm to yourself or possible harm to children or elders require that I report this information immediately.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Participant Signature

Date

Researcher Signature

Date

Appendix E

Semi-Structured Interview Guide

Inclusion Criteria Questions:

- 1) Do you speak and understand English?
- 2) Are you over the age of 18?
- 3) How long have you been using Syringe Access Services for?

Background and Demographic Questions:

- 1) How do you identify ethnically?
- 2) What is your current age?
- 3) What is your gender?
- 4) What is your current drug of choice?
- 5) How long have you been using syringe access services?

Interview Questions:

First, I'd like to ask you a bit about how you interact with service providers. When I say "services" I mean things like places you go within the community needing health care, mental health services, methadone, GA, etc. When I say "service providers" I mean the people who serve or help you at those services.

- 1) So can you tell me what kinds of services you generally access in the area?
- 2) Now, more specifically, can you tell me about one particular place that you like? What about it do you like?
 - a. How do you feel when you go there?
- 3) How about one particular place that you don't like? What about it don't you like?
 - a. How do you feel when you go there?
- 4) What type of relationship do you look for with service providers?
- 5) How do you feel when you are treated (in the above way that was stated)?

Now, I'd like to ask you more specifically about your interaction with SAS. Remember, the information you tell me here is private and I will not share what you say directly with the staff at SAS. I will combine all the information from all the interviews so that I can write a report and make recommendations to SAS about the things that they're doing well and the things that they're not doing well. Hopefully, this will help improve services for everyone who comes here.

- 6) Describe an average day coming into SAS? What is your experience like?

- a. Who do you interact with here?
 - b. Which of the following services do you access here?
HIV/HEP C testing, DOPE Project/ SPEED Project/
Medical care?
- 7) Are there any ways you are treated differently at SAS than how you are treated in other parts of your life? If so how is it different?
- 8) How do you think people perceive you when they meet you? Are there any messages you receive about yourself?
- 9) How do you feel that coming to SAS has impacted how you feel about yourself?