"ACCEPTING AND EMBRACING MY DISABILITY": DESCRIBING THE LIFE EXPERIENCES OF LATINAS/OS WITH PHYSICAL DISABILITIES WHO HAVE ABUSED SUBSTANCES

By

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A DISSERTATION

Submitted to
Michigan State University
In partial fulfillment of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

Family and Child Ecology

2010

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ABSTRACT

"ACCEPTING AND EMBRACING MY DISABILITY": DESCRIBING THE LIFE EXPERIENCES OF LATINAS/OS WITH PHYSICAL DISABILITIES WHO HAVE ABUSED SUBSTANCES

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Latinos in the United States continue to experience health and mental health disparities. Of particular concern are disparities associated with substance abuse and mental health. Although all Latinos in the United States experience health disparities in general, a Latino subpopulation that has been grossly overlooked in marriage and family therapy research and practice refers to Latinos with disabilities. In spite of the fact that Latinos with disabilities are more likely to develop substance abuse and mental health problems, relative to their non-disabled and non-Latino counterparts, a dearth of research exists aimed at working towards a better understanding of the life experiences of this population.

The primary goal of this study was to obtain a detailed description of the life experiences of a group of Latinos with disabilities who have abused licit and/or illicit substances. A secondary research goal was to explore risk factors and challenges associated with disability and substance abuse in the lives of participants, as well as the barriers that they consider should be overcome in their communities to better serve the Latino disability community. Finally, this study identified protective factors in the communities where participants live, which can foster a culture of accountability and solidarity toward Latinos with disabilities who abuse substances.

A community-based participatory research design was implemented in this study as informed by the photovoice methodology. Data analyses followed the tenets of descriptive phenomenology. A total of n=17 focus group interviews were completed. A total of n=28 participants participated in the initial focus group and n=21 participants also participated in two additional focus group interviews.

Six life-world features emerged in this study: (a) being put down by my family, (b) being challenged by my community, (c) experiences with health and mental health professionals and service providers, (d) women experiencing exclusion and discrimination, (e) being supported by my family, and (f) being supported by my community. Five phenomena of lived experience were also identified: (a) experiencing the struggle of living with my disability, (b) not giving up and wanting to change, (c) accepting and embracing my disability, and (d) wanting more understanding, help, and increased awareness in the community.

Results indicate that Latinos with disabilities may be at increased risk for substance abuse and mental health problems because of the intense contextual and lived experience challenges associated with being an ethnic minority, having a disability, and abusing substances. Finally, specific protective factors were reported by participants which could significantly inform research and service delivery efforts focused on Latinos with disabilities with a history of abusing substances.

ACKNOWLEDGEMENTS

Completion of this dissertation would not have been possible without the love and support of numerous people. Each one of you provided me various systems of support to facilitate the completion of my doctoral studies and proved critical in helping me overcome numerous challenges experienced during this process.

Completion of this dissertation research would not have been possible without the funding support of the Department of Family and Child Ecology, School of Social Sciences, and the Substance Abuse and Mental Health Services Administration (SAMHSA)/American Association of Marriage and Family Therapists (AAMFT).Specifically, this research was supported in part by the John Hildebrand Dissertation Completion Fellowship through the Department of Family and Child Ecology, Michigan State University, Dissertation Completion Fellowship, College of Social Sciences, Michigan State University, and the Minority Fellowship Program, SAMHSA/AAMFT.

I would like to especially thank my partner, best friend and wife, Lilly. You moved half way across the U.S., giving up important systems of support including your family and friends so that I can pursue a professional and life goal and for that, I am forever in debt to you. You were there for me during the difficult and trying times in which I struggled and doubted myself during my graduate studies and for that, I love you. You provided me the unconditional love and support needed throughout this process and words cannot express how grateful I am.

I would like to thank my daughters Gianna and Chloe. Both of you have also made tremendous sacrifices so that I could complete this dissertation. Seeing the both of you tucked away under your blankets and sound asleep in your bed provided me a source of strength, particularly during times in which I would get home late and exhausted. Both of you are my angels and I love you.

To my parents, Josie, David and JIm. Thank you for the numerous sacrifices you have made so that I could pursue my graduate studies. Each of you in your own special way provided me the guidance, nurture, love and support, critical to ensuring a positive trajectory. All of you provided me a foundation which allowed me to reach my full potential. I am grateful for all of your sacrifices and I love you.

For my grandparents, none of this would have been possible without your strength and courage to leave your home country and come to the United States. I understand the numerous contextual challenges you have experienced as a first generation, foreign-born Latino, and without your strength, courage and resiliency to persevere in trying times, none of this would have been possible. I hope that through this dissertation, I have made you proud and the numerous sacrifices you have made have not been in vain.

Thank you to both the Flores and Cordova families. Our shared experiences were a significant motivator in writing this dissertation. Thank you for all the sacrifices you have made and continue to make. For all those who come before me, we have come a long way from working the fields in the San Joaquin Valley.

I would also like to thank my dissertation committee. Thank you Drs. Parra-Cardona, Fitzgerald, Carolan, Johnson and Blow for your guidance and support throughout this process. Your feedback and guidance was invaluable during this process and proved key in helping me work towards completing this study. Furthermore, thank you for the multiple roles you played during my graduate studies including professor, supervisor, mentor and friend.

I would like to especially thank Dr. Parra-Cardona. Thank you for your mentorship, support, and most importantly friendship. Thank you for seeing the potential in me and challenging me to break through barriers I didn't think possible. Thank you for your *personalismo* to our relationship in an academic context which doesn't promote such relationships between professor and student. You are a true inspiration to me and I hope that I can become at least half the mentor you are to me.

I would like to thank my research team, Kendal, Sheena and Rocio. I will truly miss the one hour of personal conversations and the 15 minutes of "we have to hurry up and talk about our research plan." Your friendship and support in this journey played an instrumental role in the completion of this dissertation. I will truly miss being around you all.

I would like to thank the faculty of the Marriage and Family Program at Michigan State University. Thank you for believing in me and accepting me into the program. You have opened up doors of opportunity I would have never imagined possible. Thank you for your mentorship and guidance throughout my graduate studies. I will miss having you as professors, supervisors and friends.

I would also like to thank my colleagues and students of the MFT program. Thank you for the various ways in which you challenged me in class and clinic nights. Thank you for your friendship outside of the clinic and classroom. I will always remember and cherish both the difficult and happy times we shared in our graduate studies.

Finally, I would also like to thank the Department of Family and Child Ecology. Throughout my graduate studies, you have provided me both fiscal and non-fiscal mechanisms of support. These systems of support proved invaluable in helping me to obtain my doctoral degree.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Images in this dissertation are presented in color.

CHAPTER I: INTRODUCTION AND STATEMENT OF PURPOSE

"It's a tough road…everyday is a fighting and challenging day...understand my pain, understand what I'm going through."

"I woke up this morning and I woke up crying…and I said to myself, 'How long are you going to have light in your eyes, how long?'…There's times I don't feel like getting up and dealing with the world." [Losing vision because of diabetes]

The preceding quotes were expressed by two Latinas/os[1] with disabilities who participated in a pilot study that informed the current investigation. These preliminary findings were presented as a poster at the 2007 annual conference of the American Association for Marriage and Family Therapists (Córdova, Holtrop, & Parra-Cardona, 2007). There were rows and rows of posters at the conference presentation. The authors all stood proudly next to their theoretical, research or practice work, displayed with brilliant colors and ideas, some glossy, some not. Yet, out of the hundreds of posters, ours was one of only a handful that overtly addressed disability. I could only stand there and ask myself, "Why?" Is this a wrong topic for my field? Do I need to attend a rehabilitation conference to see issues of disability being addressed? Then I thought, "We work with families. To what extent are most families affected by disability in one way or another?" Whether it is your own child born with a developmental disability, a cousin with a psychiatric disorder, a sign in the community to caution drivers of a deaf or blind child, or an *abuela* [grandmother] with a physical disability who can no longer walk up a flight of stairs, disability is a common life experience. However, based on the findings from this study, disability continues to be a reality that we struggle

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[1] The researcher acknowledges the need to address gender. For the purposes of readability, the researcher uses Latino as a gender neutral term to refer to both Latinas and Latinos, respectively.

to recognize and accept in our society. This avoidance can lead us to remain hesitant to accept and disclose a child's disability, communicate with our "disabled" cousin, or pay attention to the signs in the street reminding us of various forms of disability. In addition to disability, what happens with our identity if we have additional components of our identity that have been historically marginalized, such as being an ethnic minority?

What is it like to be an ethnic minority in the United States (U.S.)? What is it like to be an ethnic minority in the U.S. with a disability? In addition to being an ethnic minority with a disability and the multiple stressors associated with such an identity, what would it be like to have an added stigma due to abuse or dependence of licit and/or illicit substances? At the intersections of ethnicity, disability and substance abuse, a complex identity emerges that historically and currently remains at the margins (Koch, Nelipovich, & Sneed, 2002). The end result is a triple stigma of having a disability, a substance abuse problem, and the devalued status of being an ethnic minority (Boros, 1989).

My desire to focus my dissertation on the life experiences of Latinos with disabilities who have abused substances comes from the fact that I am a Latino with a disability. The transition from denial, anger and pain, to acceptance and happiness was my greatest challenge and has been a milestone in my life. I turned something that many members of society perceive as a weakness or flaw, my disability, into my strength and reason to persevere. I have not been alone in this journey because I have been very fortunate to have family and friends who support me, nurture me, love me, empathize with my experiences, and accept me for who I am. I also recognize that I have been able to experience their support because I have allowed them to enter my life by openly sharing with them my struggles, challenges, and hopes. Family and friends who realize my identity is not solely one of disability, but is embedded within multiple contexts (i.e., Latino, male, heterosexual, educated). I also recognize the imperative role education and the educational community context had to empower me and to change my perceptions of disability. In addition, faculty who saw my potential, believed in me, and opened doors of opportunities I would have never imagined. Unfortunately, not everyone has the privilege of having access to formal education and/or various types of support that are critical to overcome the challenges associated with a disability. As such, not all individuals are empowered to change their perceptions of what disability means for them, or the oppressive attitudes and actions of others with regard to marginalized identities. I feel very fortunate for my voice to have been and continue to be heard by multiple audiences. I only hope that through this dissertation, I can privilege the voices of participants by describing the experiences that most accurately describe their daily challenges and struggles, as well as their hopes, dreams, and extraordinary sense of resilience.

Scope of the Problem

The U.S. health system has not fully addressed the needs of Latinos and other marginalized populations (USDHHS; U.S. Department of Health and Human Services, 2001). The urgent need to eliminate health disparities experienced by underserved populations has been consistently expressed by the

U.S. Surgeon General, who has also encouraged scholars to find alternatives to reduce the multiple barriers that ethnic minorities experience when attempting to access health and mental health services (USDHHS, 2000). The present research seeks to contribute towards the reduction of health disparities experienced by Latinos with disabilities by providing in-depth descriptions of their life experiences. This study also constitutes the initial step of a program of services research aimed at serving the Latino disability community by developing mental health interventions for this population based on a thorough understanding of their realities.

Substance Abuse in the Latino Population. In 2002, the economic costs of substance abuse and its related problems (i.e., health expenditures, loss in productivity, crime, and non-health direct expenses) totaled 180.9 billion (ONDCP; Office of National Drug Control Policy, 2004). Alcohol related economic costs were estimated to be 185 billion (Harwood, 2000). Although rates of substance abuse have declined in the non-Latino Euro-American population, Latinos continue to be disproportionately affected by substance abuse (NIH; National Institutes of Health, 2006). For example, findings from the Monitoring the Future study reveal that Latino 8th graders' use of licit and illicit substances was higher than White and Black 8th graders across all substances, with the exception of amphetamines. This trend appears to continue into late adolescence and early adulthood as, compared to other ethnic and racial groups, Latino 12th graders have the highest use of crack, heroin, methamphetamines, and Rohypnol (Johnston, O'Malley, Bachman, & Schulenberg, 2006). These figures are alarming as research has indicated that early onset of use of substances is strongly associated with future substance abuse and dependence (Amaro & Cortés, 2003). In addition, Latinos are also likely to experience more negative health and mental health consequences from substance abuse than their Euro-American counterparts (Caetano & Clark, 1998), such as increased risk for intimate partner violence (Lipsky & Caetano, 2008) and increased incarceration rates (Morín, 2008).

Latinos with Disabilities. Approximately 51 million people in the United States report having at least one disability (U.S. Census, 2006). Persons with disabilities (PWD) are exposed to intense contextual challenges. For instance, PWD are 5 times more likely to be involuntary unemployed (Turner & Turner, 2004), are more likely to report experiencing a variety of health problems, and have lower incomes than persons without disabilities (U.S. Census, 2005).

Latinos with disabilities account for 14% of the disability population in the U.S. (U.S. Census, 2006). In addition to facing challenges similar to those experienced by members of the disability community, Latinos with disabilities are exposed to additional contextual stressors such as various forms of discrimination by people who devalue their ethnic ancestry (Finley, 1998). Thus, potential experiences of stigma and social isolation already associated with ethnic background, may be further increased if a Latino has a disability and experiences substance abuse problems (Koch, Nelipovich, & Sneed, 2002).

Research on Substance Abuse and Disabilities. In spite of the fact that persons with disabilities are more likely to abuse substances than persons without disabilities (Center for Substance Abuse Treatment, 1998; Turner, Lloyd, & Taylor, 2006), there is a dearth of research focused on the co-occurrence of substance abuse and disability (Beatty, 2003; Turner et al., 2006). This lack of knowledge is particularly damaging for Latinos with disabilities because despite their high risk for developing substance abuse or dependence (Turner et al., 2006), they are likely to experience barriers that decrease their opportunities to engage in culturally relevant health and mental health interventions (Beatty, 2003; Turner et al., 2006). As Domenech-Rodriguez and Wieling (2005) have stated:

> There is a lack of conceptual, theoretical, and methodological frameworks that appropriately position families and communities of color within a historical, political, and socioeconomic context that accounts for their experiences (p. 313).

Significance of the Study

Research has thoroughly documented the deleterious effects associated with disability such as loss of income, unemployment, discrimination in the workplace, higher risk for divorce, and diverse health and mental health problems (Jones, 1989; Piercy & Piercy, 2002; Rolland, 1994). However, little attention has been focused in the family therapy field with regard to clinical practice with families affected by disability (Rolland, 2006). As marriage and family therapists, we understand the importance of context when working with families. However, the disability community has been and continues to be overlooked in our field as demonstrated by the lack of research, training, and best practices aimed at serving the disability community (Rolland, 2006). This constitutes a serious limitation of our profession because when substance abuse issues are associated with a disability, the potential for serious problems at the individual, couple and family levels clearly increases (Jones, 1989). Despite empirical evidence indicating the various mental health problems faced by individuals with a disability and substance abuse (Boros, 1989; Moore & Siegal, 1989), there is a dearth of research aimed at understanding the unique challenges faced by Latinos with disabilities who also abuse substances (Drake, Mueser, Brunette, & McHugo, 2004; Miranda, 1989). Therefore, there is a great need to address this gap in research because in addition to coping with the challenges of disability and substance abuse, Latinos are likely to experience clear contextual challenges when attempting to access resources to address their needs. Examples of these are lack of culturally sensitive health care programs, lack of culturally relevant screening programs aimed at identifying the co-occurrence of disability and substance abuse, potential discriminatory practices by service professionals, and lack of culturally relevant mental health interventions aimed at addressing substance abuse in Latinos with disabilities (Kemp et al., 1999; Brucker, 2007).

Purpose of the Study

The primary goal of this study was to obtain a detailed description of the life experiences of a group of Latinos with disabilities who have abused licit and/or illicit substances. A secondary research goal was to explore risk factors and challenges associated with disability and substance abuse in the lives of participants, as well as the barriers that they consider should be overcome in their communities to better serve the Latino disability community. Finally, this study identified protective factors in the communities where participants live, which can foster a culture of accountability and solidarity toward Latinos with disabilities who have abused substances.

Findings from this study will be used to promote community awareness with respect to the life experiences of the Latino disability community who have abused substances. In addition, present findings constitute the foundation of a program of services research aimed at developing and disseminating culturally relevant mental health interventions specially designed for this population.

Research Design, the Photovoice Methodology, and Descriptive Phenomenology

This investigation is qualitative in nature because the primary goal of the study is to describe the life experiences of participants as lived and understood by them (Porter, 1995). This study utilized a method of data collection that provides participants with the opportunity to provide clear descriptions of their most relevant life experiences (Wang, Burris, & Xiang, 1994). Data analysis followed the tenets of descriptive phenomenology in order to obtain detailed descriptions of the life experiences shared by participants (Porter, 1998).

I chose to implement the photovoice methodology because this method is informed by community-based participatory research (CBPR) principles. The need to implement methodologies informed by CBPR principles has been expressed by Miranda (1989):

> Advocates for institutional change can have a major effect on program accessibility and the creation of quality alcohol and drug abuse services

> for persons with disabilities. Although institutionalized treatment systems often appear lethargic in meeting the needs of the physically impaired, such systems can be invigorated through a process of activism, documentation of existing problems, and education. (p. 154)

The photovoice methodology offered participants an opportunity to actively reflect on their life experiences, document existing problems related to having a disability; as well as to generate relevant data aimed at educating individuals, families, and communities with regard to common life experiences of individuals with disabilities who have abused substances.

In addition, I followed the tenets of descriptive phenomenology to conduct data analyses in this investigation. I chose the methodological guidelines proposed by Porter (1994, 1995) because she integrated a methodology that integrates methodological rigor with phenomenological principles (Porter, 1998). According to the principles of this methodology, researchers need to explain the philosophical basis and source of motivation that inform their research (Porter, 1998).

Research participants were encouraged to constantly reflect on the main research questions of this investigation as they engaged in research activities. Specifically, all research participants were asked to engage in a process of permanent reflexivity based on the following research questions:

1. Can you please describe to me your life as a Latino with a disability?
2. Can you please describe to me your life as a Latino with a disability who has taken substances?

3. Can you please describe the strengths within your community in reference to the disability community?

4. What changes would you like to see in your community in order to better serve the disability community?

Bracketing

Bracketing consists of working towards identifying and monitoring preconceived ideas and biases in order to participate in the data collection and data analysis with an open mind (Porter, 1995). In addition to conducting a thorough literature review, one of the most critical steps of the bracketing process refers to reflecting on my personal experiences as a Latino with a disability in order to identify the biases and preconceived notions that I bring into the study. Below is my personal narrative.

At the age of 18, I was diagnosed with a rare degenerative eye illness known as retinitus pigmentosa (RP). I did not completely understand what that meant at the time. I remember the doctor telling me that although RP is different for everyone, given the fact that I was diagnosed at such a young age, there was a good chance that I would lose most if not all of my sight. I also remember walking out of his office thinking he did not know what he was talking about and had misdiagnosed me. There was no way I could be going blind. Besides, no one in my family had this RP that the doctor was talking about.

About two years later, I began to notice that I was having difficulty seeing from my peripheral and my night vision was getting worse. It was then that I realized that, yes in fact, I was losing my sight. It was like I had been cruising my whole life in a shiny red sports car with the top down, the wind hitting my face and hair blowing everywhere and the warm sun pressing up against my skin, when all of a sudden I slammed into a solid brick wall.

I remember the sleepless nights that came shortly thereafter, filled with anxiety and despair. I felt like I couldn't be close to anyone, both emotionally and physically, no matter how hard I tried. As I think back about what that was like for me, I could really empathize with the participant's words above who said, "... understand my pain, understand what I'm going through." Because for me, I felt as if no one could understand neither what I was experiencing nor the pain that I felt. Similar to that of the participant, there were many times when, "I woke up this morning and I woke up crying...and I said to myself, 'How long are you going to have light in your eyes, how long?'" I was very anxious about what life would be like without the ability to see anymore. I didn't want to live that type of life. For me, it felt like I was drowning, gasping for air and I just wanted the pain to stop so badly.

These feelings of despair lasted approximately two years. It was a very dark and trying time for me, a time that I was convinced that those feelings would never leave. However, these feelings slowly diminished and most of them eventually disappeared. Interestingly, today, my visual impairment is not something I think about on a regular basis. I no longer fear that one day I could eventually lose my sight, a thought that previously had consumed my everyday life. In fact, my disability is not at the forefront of my identity. For example, if I had to describe myself, I would first say I am Latino, a father, a husband, and a graduate student. I also acknowledge, however, that adapting to my disability has been a slow and challenging process, particularly as it referred to challenging the negative ideologies I had internalized with regard to my disability. In addition, I also understand that not everyone may understand what it is like to be a Latino with a disability.

As I listened to the participants that I interviewed, it brought back many memories of some of my experiences. There were also times that I wanted to take off my researcher hat, put my clinician hat on and offer therapeutic services. But I didn't, I sat there, listened and probed, "What was that like for you? Can you tell me a little bit more about that?" There were times that I felt empathetic and sad, wishing they didn't have some of these feelings and attitudes. There were also times that I felt reactive, not so much at the participants, but reactive toward society in general. Specifically, as some participants shared their feelings of inferiority, I identified with having experienced similar feelings and confirmed that they are heavily influenced by societal negative labels and stigma commonly associated with disability. Thus, I found myself continuously reflecting about my own journey with disability as participants described their stories of emotional pain, struggle, and success. There were also conversations in which my experiences did not relate to those of participants. As such, I understood the importance of letting them tell their stories in order to accurately understand and describe their challenges and testimonies of resilience.

CHAPTER II: LITERATURE REVIEW

Conducting a thorough literature review is a necessary step prior to engaging in the process of phenomenological analysis (Patton, 2002). Specifically, it is necessary for scholars to identify the conceptual frameworks that guide their research questions in order to ensure that the method of inquiry contributes to a better understanding of the life experiences of the population under study (Porter, 1998). In addition, researchers must identify preconceived notions that may bias their descriptions of the life experiences of participants (Moustakas, 1994; Porter, 1994).

Latino Population in the U.S.

Demographics. Latinos currently constitute the largest and fastest growing ethnic minority group in the U.S. There are more than 44 million Latinos in the U.S. and only Mexico and Colombia have a larger Latino population worldwide (U.S. Census, 2007). The Latino population has grown by 56% over the past ten years and is expected to reach approximately one-fourth of the total U.S. population (i.e., 102.6 million) by the year 2050. Approximately 40% of Latinos in the U.S. are foreign-born and have immigrated into the U.S. for a variety of reasons, ranging from economic and social advancement to political freedom (Suarez-Orozco & Suarez-Orozco, 2001). In addition, Latinos are very diverse in ethnic ancestry (e.g., Mexican, Caribbean, etc), cultural backgrounds, cultural preferences, and experiences related to migrating to the U.S. (Suarez-Orozco & Suarez-Orozco, 2001). Mexican origin Latinos currently comprise 64% of the total U.S. Latino population and are the largest of the Latino subgroups in the U.S. (U.S. Census, 2007).

Latino Sociodemographics. Significant differences can be found on a number of sociodemographic characteristics between Latinos and Euro-American non-Latino populations. The U.S. Census Bureau (2007) reports that Latinos: (a) are younger with a median age of 27.4 years compared to 36.4 for the general population, with 34% of Latinos under the age of 18, (b) have larger family households, (c) reside in more geographically concentrated areas (48% live in California or Texas), (d) are more likely to be unemployed, more than 20% live in poverty, and have significantly lower median household incomes compared to Euro-American non-Latino population households ($37,781 compared to $52,423), (e) are more likely to have lower education levels (two in five Latinos aged 25 and older have not graduated from high school), and (f) constitute 14% of the total U.S. population, yet represent 30% of those who lack health insurance (U.S. Census Bureau, 2007). In addition, the Latino population is the only group in the U.S. that exceeds the necessary number of births to replace the previous generation. As the Latino population continues to increase, there is a growing concern to eliminate health disparities experienced by this population (USDHHS, 2001). Specifically, Latinos are underrepresented as recipients of general health and mental health services (Cervantes & Acosta, 1992; Vega et al., 2007). Although it is not well understood the contextual challenges Latinos in the U.S. face with respect to accessing health and mental health services, the sociopolitical climate has been documented in the literature as a significant barrier (Berk, Schur, Chavez, & Frankel, 2000; Derose, Escarse, & Lurle, 2007).

Sociopolitical. The current sociopolitical climate in the U.S. poses serious challenges for the well-being of Latinos (Berk et al., 2000; Derose et al., 2007). Fear of deportation among undocumented immigrants, anti-immigrant attitudes, health and educational disparities, and racial and ethnic discrimination are just some of the many reasons that constitute important contextual challenges that negatively impact the lives of Latinos in the U.S. These factors also constitute barriers that prevent Latinos from accessing and receiving culturally appropriate mental health services (Berk et al., 2000; Derose et al., 2007; Williams, Neighbors, & Jackson, 2003).

In spite of these contextual challenges, research has suggested that Latino cultural values may serve as protective factors in the lives of Latinos (Castro et al., 2006; Parra-Cardona et al. 2009). For example, because of the importance of familism in the Latino culture, research has highlighted the ways in which using extended family to promote family cohesion could serve as a protective factor in preventing maladaptive behaviors (Germán, Gonzales, & Dumka, 2009).

Latino Cultural Values. Specific Latino cultural values have been consistently reported in the literature (Falicov, 1998). *Familismo* refers to one's dedication and commitment to the family. It has been noted that this cultural value may act as an important protective factor in the lives of Latinos. For example, immigrants exposed to challenging working conditions may reframe such a hardship as a necessary step towards achieving a better quality of life for their families (Parra-Cardona, Bulock, Imig, Villlarruel, & Gold, 2006). In contrast, *familismo* may also deter individuals from achieving individual goals. For example, Latinos from disadvantaged backgrounds may consider that pursuing a higher education represents lack of solidarity towards their family because the immediate need is to join the workforce and alleviate economic strains (Falicov, 1998). The importance of establishing and maintaining interpersonal relationships in various social contexts is referred to as *personalismo*. *Colectivismo* is defined by highlighting the importance of committing to a social network as well as to the larger community (Falicov, 1998). Lastly, *respeto* highlights the need to inform all relationships based on deference and respect (Falicov, 1998).

The Disability Population in the U.S.

There are approximately 51 million people in the United States who report having at least one disability. Of those, approximately 46% report having multiple disabilities and 64% report having a severe disability such as cerebral palsy, Alzheimer's disease or the inability to perform activities of daily living (U.S. Census, 2006). Because recent biomedical advances have increased the life expectation in the general U.S. population, there is also a risk for individuals to experience at least one form of disability in their lifetime (Miller, McDanial, Rolland, & Feetham, 2006).

Sociodemographics. A significant amount of health disparities can be identified when examining the sociodemographic characteristics of the disability population in the U.S. Specifically, compared to persons without disabilities, persons with disabilities are: (a) less likely to complete higher levels of education, (b) more likely to be unemployed, (c) more likely to be living in poverty with a 20% poverty rate compared to 7.7% for the non-disabled population, (d) less likely to report good perceptions of health and more likely to report poor health, and (e) report a significantly lower median income than persons without disabilities (U.S. Census, 2005). In addition, women report a higher prevalence of disability than men, are more likely to live alone or with non-relatives, are less likely to have health insurance, and live in households with lower household income (Steinmetz, 2006).

Latino families with disabilities account for 14% of the disability population in the U.S. (U.S. Census, 2006). Latinos with disabilities face unique challenges in the United States because in addition to the devalued status of being an ethnic minority, Latinos are also challenged by the stigma associated with disability (Finley, 1998), and may be further stigmatized when issues of substance abuse are present (Koch, Nelipovich, & Sneed, 2002). In addition, disability also differs with respect to severity and typology, both of which vary with regard to the stigma attached to the specific disability (Koch et al., 2002).

Disability Categories. Disabilities can be categorized into three broad domains: (a) communication, (b) physical, and (c) mental (Steinmetz, 2006; Waldrop & Stern, 2003). A person is identified as having a disability in the communication domain if any of the following criteria is met: (a) difficulty to hear, see, or speak, (b) blind or deaf, (c) one or more related conditions as the cause of a reported activity limitation (blindness or vision impairment, deafness or hearing impairment, or speech disorder).

With respect to physical disability, a person is identified as having a physical disability if any of the following criteria is met: (a) use of a wheelchair, cane, crutches, or walker, (b) difficulty with one or more functional activities (e.g., walking a quarter of a mile, climbing a flight of stairs), or (c) one or more related conditions is identified as the cause of reported activity limitation (e.g., head or spinal cord injury, cancer, paralysis, etc.).

Lastly, people who fall into the mental domain meet any of the following criteria: (a) one or more specified conditions (e.g., a learning disability, mental retardation, or some other mental or emotional condition), (b) a mental or emotional condition that interfered with everyday activities, (c) difficulty managing finances, and (d) at least one condition is identified as the cause of reported activity limitation (e.g., learning disability, Alzheimer's, dementia).

In addition to the three major domains by which disability is characterized, it is also important to understand the two major models of conceptualization of disability, which refer to the medical and the social model of disability.

Models of Disability. Two major models inform the ways in which disability is conceptualized and approached in the U.S. (Hargreaves, 2000). According to the medical model, disability is primarily viewed as a medical condition rooted and treated at the individual level (Hargreaves, 2000). This model examines biological and genetic factors associated with disability. Although of high relevance, this model has also led to a deficits perspective because critical environmental and contextual factors are overlooked (Goffman, 1997; Hughes, 2002). In contrast, the social model of disability identifies the disability within social and cultural factors (Hargreaves, 2000). Thus, the capacity to adapt to a disability will depend on the type of social resources as well as contextual challenges experienced by each individual. It has been noted that one of the limitations of the social model refers to potentially overlooking the physical challenges associated with various forms of disability (Hughes, 2002).

The categorization and conceptualization of a disability is particularly relevant because of the stigma and discrimination a person may experience for having a disability (Austin, MacLeod, Dunn, Shen, & Perkins, 2004; Koch et al., 2002). For example, society may attach fewer stigmas to persons with learning disabilities which they may perceive as less evident, relative to a person using a cane or wheelchair (Austin et al., 2004).

Disability and Stigma. For many persons with disabilities, coping with the stigma associated with a disability is often times worse than dealing with the disability itself (Austin et al., 2004). Whereas persons with disabilities were once accepted and considered “normal” by able-bodied members of society (Foucault, 2006), many societies have historically stigmatized the disability population. The end result was institutionalization, forced sterilization, the killing of babies born with a disability, and mass murder to prevent persons with disabilities to be a part of society (Smart, 2001). According to Admi and Shaham (2007), “There is a reciprocal relationship between the stigmatized person and the stigmatizing surroundings, creating a cycle in which people with a chronic disease are affected by the reactions of their surroundings, interpret these reactions, and decide if they will conceal or expose their illness" (p.1178).

In addition to the need to understand the extent to which stigma is associated with a specific type of disability, equally important is to identify the stigma associated with the perceived level of control that a person had over the onset of the disability (Hargreaves, 2000). For example, Latinos whose disabilities include substance abuse or HIV/AIDS would be perceived at fault for their disabilities due to their individual behaviors. In contrast, a person who acquired a disability as a result of trauma experienced in war would not have as much stigma attached as the disability is the result of the individual's commitment to serve a larger purpose and noble endeavor.

The exposure to stigma and various forms of discrimination are commonly experienced by persons with disabilities (Hargreaves, 2000; Susman, 1994). A particularly important area of study refers to understanding how individuals with disabilities who experience intense contextual challenges, including stigma and discrimination, are at an increased risk for substance abuse (Turner, Lloyd, & Taylor, 2006).

Substance Abuse and Latinos in the U.S.

Substance abuse and co-morbid behaviors are a major social and health concern in the U.S. Although substance abuse is present across all racial and ethnic groups, Latinos are disproportionately affected by substance abuse (Vega & Gil, 1998) and are more likely to experience negative health and social consequences from substance abuse than their Euro-American counterparts (Caetano & Clark, 1998).

This issue is further complicated due to health disparities commonly experienced by ethnic minorities who engage in drug abuse behaviors (Vega, Sribney, & Achara-Abrahams, 2003). Specifically, a limited number of evidence-based interventions have been culturally adapted to serve Latino populations who abuse substances (Castro, Barrera, & Martinez, 2004). In addition, multiple contextual barriers such as economic problems, language barriers, and discrimination may prevent Latinos from accessing mental health services aimed at helping them adapt to their substance abuse problems (Castro et al., 2004).

Because there is a high prevalence of illicit drug use among Latinos in the U.S. (SAMHSA, 2005), there is an urgent need to address the health and legal disparities commonly experienced by Latinos who abuse drugs. Unfortunately, "there are great differences in the consequences of drug use for racial/ethnic minorities, creating a great need to better understand the unique prevention, treatment and health services needs of these communities" (NIDA, 2005, p. 1).

Substance Abuse and Stigma. Historically, people who abuse substances have been at risk of being labeled as morally flawed or lacking will power (Urbanoski, Cairney, Bassani, & Rush, 2008). This stigma continues to be present in society, despite research indicating that substance abuse and dependence are complex phenomena resulting from the interaction of biological, psychological, social and environmental factors (Volkow, 2006).

Latinos who abuse substances are also exposed to the negative effects of stigma. However, there is a dearth of empirical research aimed at exploring the risk and protective factors associated with substance abuse in this population, as well as the ways in which culturally relevant interventions should be applied based on a thorough understanding of the role that stigma has on the process of recovery (Amaro & Cortés, 2003).

Research on Substance Abuse and Disability

There remains a critical knowledge gap with respect to substance abuse in the disability population. Studies addressing the co-occurrence of substance abuse and disability did not appear in the literature until the mid 1970's and early 1980's. As early as 1979, research suggested that persons with physical disabilities had a 20% rate of alcohol or other drug abuse, a rate twice as large as the general population (Kirshbaum, 1979). In 1980, the Journal of *Alcohol Health and Research World* dedicated an issue to this topic. A similar issue followed this publication in 1989. More than a quarter of a century later, the literature focusing on persons with disabilities and substance abuse continues to be scarce. Thus, research focused on substance abuse within the disability context remains in its infancy, particularly as it refers to ethnic minorities with disabilities.

The need for research exploring the co-occurrence of substance abuse and disability is greatly needed because the presence of a disability can greatly increase the probability of substance abuse and dependence (Brucker, 2007). Some relevant work has been accomplished to date. For example, greater clarity has been achieved to understand factors that may increase the risk for substance abuse among persons with disabilities. Reilly, Kelley, and Faillace (1986) have identified four factors that are likely to increase the risk of substance abuse following the onset of a disability: (a) increased leisure time and/or boredom, (b) family and friends who enable, (c) uncertainty of being able to return to work, and (d) physical limitations and/or change in mood as a result of the disability.

Brucker (2007) found significant differences in the prevalence of substance abuse and dependence rates among persons with disabilities and persons without disabilities. This study also explored differences among participants based on mental health status. Specifically, participants who had a physical disability reported higher rates of alcohol dependence, illicit drug abuse, and illicit drug dependence, relative to their counterparts. Furthermore, participants who had a disability and a serious mental illness reported a 7.3% prevalence of illicit drug dependence, compared to 1.3% of those participants with a disability but without a serious mental illness. Participants with a disability who had a serious mental illness were also 61% more likely to abuse alcohol and 130% more likely to be dependent on alcohol, when compared to their counterparts without serious mental illness. The major limitation of this study was that the majority of participants were Euro-American.

Although the existing knowledge is relevant, research has predominantly focused on identifying etiological factors associated with disability and substance abuse. Additional studies are greatly needed. For example, there continues to be a gap in research aimed at exploring the ways in which individuals can adapt to having a disability while successfully recovering from substance abuse. Studies are also needed to clarify what are the most relevant life experiences of individuals with disabilities who have abused substances, particularly those that constitute risk or protective factors to their process of recovery (Beatty, 2003; Turner, Lloyd, & Taylor, 2006).

Sociopolitical Climate and Individuals Affected by Substance Abuse and Disability. With the passage of Public Law 104-121, the Contract with American Advancement Act of 1996, individuals who had a disability due to licit or illicit substance abuse and who were receiving Supplemental Security Income (SSI) were no longer eligible to receive such benefits. Included in these benefits was Medicaid, which meant that this population no longer was eligible to receive highly needed health care coverage.

It is estimated that prior to the implementation of the Contract with American Advancement Act of 1996, approximately one-quarter of a million U.S. citizens were receiving benefits from the Social Security Administration, at least partially due to diagnosis of substance abuse (Brucker, 2007). By 1998, approximately one-third of the individuals who lost their SSI benefits, including health insurance, were reinstated or re-qualified for benefits. This percentage (34%), amounted to about half of what policy makers had projected prior to the implementation of the act. The end result was that several uninsured persons with disabilities with dual diagnosis were left without access to appropriate health and mental health care. In addition, persons with disabilities who had SSI benefits did not seek out services due to fear of losing benefits (Hanrahan, Luchins, Cloniger, & Swartz, 2004).

Hanrahan and colleagues (2004) conducted a longitudinal study to examine the impact on health care needs among people who were affected by SSI policy changes. These researchers used baseline hospital service utilization data as an indicator of medical need and medical eligibility. Participants consisted of individuals who were eligible for SSI benefits and Medicaid prior to January 1997. Of the 11,740 participants in the study, 26% were hospitalized at least once in 1995. Of those hospitalized, substance abuse and psychiatric problems accounted for 41% of the primary diagnosis. By June of 1998, however, approximately half of the participants at baseline had lost SSI benefits including Medicaid. In addition, only 43% of those hospitalized with a psychiatric disorder as the primary diagnosis, retained their SSI and health care benefits (Hanrahan et al., 2004).

In a subsequent study, Turner and colleagues (2006) found that approximately 40% of their participants with a disability met the criteria for a psychiatric or substance disorder. Furthermore, compared to Euro-American non-Latino and African Americans, Latinos with disabilities reported higher rates of psychiatric (Kemp, Krause, & Adkins, 1999; Turner et al., 2006) and substance abuse disorders (Turner et al, 2006).

The Need for Research Focused on Disabilities and Substance Abuse. There is a great need for research focused on substance abuse and mental health within the disability population (Hanrahan et al., 2004). Existing interventions for substance abuse do not adequately address the complexities associated with the co-occurrence of substance and disability (Bachman, Drainoni, & Tobias, 2004). Drug abuse prevention and intervention programs are less accessible to persons with disabilities, relative to their non-disabled counterparts (Boros, 1989).

To develop effective substance abuse and mental health interventions for Latinos with disabilities, it is critical to reach a clear understanding of the most relevant life experiences of this population (Brucker, 2007). Current research has clearly demonstrated that the prevalence of a disability can place an individual at greater risk for problems associated with substance abuse. However, little is known about the patterns of substance use, abuse, and dependence among Latinos with disabilities. Implementing these lines of research is critical for the development of culturally appropriate interventions for Latinos with disabilities who abuse substances. Future lines of research should be informed by an understanding of the effects associated with having disability, being an ethnic minority, and being exposed to the stigma associated with disability and substance abuse.

Theoretical Frameworks

The following theoretical frameworks inform this study: (a) ecodevelopmental framework, (b) stress paradigm, and (c) community-based participatory research.

Ecodevelopmental Framework. This investigation was informed by the ecodevelopmental framework (Szapocznik & Coatsworth, 1999). However, it is important to clarify that rather than testing the ecodevelopmental model, this theoretical framework facilitated the identification of risk and protective factors in the lives of participants.

The ecodevelopmental framework encompasses the human ecological system (Bronfenbrenner, 1979), development across the human lifespan (e.g., Carter & McGoldrick, 2005) and the structural and social interactional system model (Kurtines & Szapocznik, 1996; Minuchin & Fishman, 1981). The ecodevelopmental model acknowledges that humans are embedded within multiple interconnected and interrelated contexts, including social and cultural contexts that influence human behavior and development (Szapocznik & Coatsworth, 1999). Therefore, the ecodevelopmental model relies heavily on systems theory which postulates that human beings both influence, and are influenced by, contexts in which they are embedded (Szapocznik & Coatsworth, 1999).

General systems theory was formulated by Von Bertalanffy (1972) and dates back to the early 1930s. The notion of systems, however, dates back to pre-Socratics of the sixth century B.C. (see Von Bertalanffy, 1972). According to Von Bertalanffy:

> ...even though the problems of "system" were ancient and had been known for many centuries, they remained "philosophical" and did not become a "science." This was so because mathematical techniques were lacking and the problems required a new epistemology: the whole force of "classical" science and its success over the centuries militated against any change in the fundamental paradigm of one-way causality and resolution into elementary units (1972, p. 409)

General systems theory postulates that the sum is greater than each individual part and is concerned with problems of interrelations which constitute a "whole" (Von Bertalanffy, 1972). Building on the central notion that systems are interrelated, Bronfenbrenner (1979) developed the Human Ecological paradigm.

A core component of ecodevelopmental model refers to the Human Ecological paradigm, grounded in the work of Bronfenbrenner (1979). This theory postulates that human development is embedded within four interrelated contexts that are nested within each other: (a) microsystems, (b) mesosystems, (c) exosystems, and (d) macrosystems.

The microsystem refers to those contexts in which the individual participates and comes into contact with directly. Therefore, it is the context in which the individual lives and has the most interactions with. For example, for a Latino with a disability, one may refer to their family, partner, and peers as the microsystem (Bronfenbrenner, 1979; Szapocznik & Coatsworth, 1999).

The mesosystem is comprised of the interaction of two microsystems (Bronfenbrenner, 1979; Szapocznik & Coatsworth, 1999). For example, a mesosystem may be represented by the connection between family and work contexts, work and church, or family and friends. Complementary and strong mesosystems can result in positive outcomes and adequate development for the individual (Coatsworth, Pantin, & Szapocznik, 2002).

The exosystem represents all contexts in which individuals may not directly participate but that have an influence on their development (Bronfenbrenner, 1979; Szapocznik & Coatsworth, 1999). For example, a stressful job environment (e.g., underpaid, not get along with colleagues) will affect children if parents are experiencing job-related stress and burn out.

Lastly, the macrosystem is the context comprised of the broader social, cultural, and political ideologies in which individuals live (Bronfenbrenner, 1979; Szapocznik & Coatsworth, 1999). Examples of these influences that are relevant to the Latino community include larger sociocultural and sociopolitical factors that impact families such as societal pressure to acculturate or anti-immigration attitudes (Santisteban, Suarez-Morales, Robbins, & Szapocznik, 2006).

The ecodevelopmental framework (Szapocznik & Coatsworth, 1999) takes into consideration the developmental processes of the human lifespan. Specifically, this model also acknowledges that changes in an individual's social ecosystem occur over time and reciprocally have an influence over multiple contexts. Therefore, one cannot study human development without conceptualizing the process of development as occurring over time and embedded within the individuals' social ecology (Szapocznik & Coatsworth, 1999).

The structural and social interactional system was integrated into the ecodevelopmental framework from the work of Minuchin and Fishman (1981) and Kurtines and Szapocznik (1996). The structural and interactional system highlights the ways in which various ecological processes interact to produce behavioral and psychosocial outcomes (Schwartz, Coatsworth, Pantin, Prado, Sharp, & Szapocznik, 2006). As such, the structural and social interactional systems analyze the extent and nature to which systems interact (Szapocznik &

Coatsworth, 1999). For example, Latinos in the U.S. may experience isolation and exclusion from social structures such as lack of relevant policy focused on the Latino disability population, which in turn creates intense barriers to facilitating full integration of Latinos with disabilities into the larger social system (e.g., easy access to health benefits).

Although the ecodevelopmental model (Szapocznik & Coatsworth, 1999) is useful to conceptualize the ways in which individuals are embedded in various contexts, a theory focused on the role of stress on individuals is highly relevant for the current study. Thus, the stress paradigm theory is useful to understand the role of stress in the lives of Latinos with disabilities who have abused substance (Pearlin, 1989; Wheaton, 1994).

Stress Paradigm. The relationship between psychosocial stress and the overall health of Latinos has been and continues to be of important interest to scholars (Cervantes & Castro, 1985; Padilla, Cervantes et al., 1988; Finch et al., 2001). The stress paradigm posits that stressful life events are associated with increased and cumulative psychological, behavioral, and/or somatic disturbances (Pearlin, 1989; Wheaton, 1994).

Many stressors such as occupational, family and financial difficulties are considered normative life stressors (Pearlin, 1989; Wheaton, 1994). However, the amount and extent of exposure to stress vary across ethnic groups (Cervantes & Castro, 1985; Turner & Avison, 2003). In addition to normative life stressors, many Latinos with disabilities are exposed to non-normative chronic life stressors such as perceived discrimination associated with an ethnic minority status and disability (Beatty, 2006).

Other stressors may be more culturally specific, such as the stress resulting from being unable to define one's cultural identity. This phenomenon is known as acculturative stress and initial evidence appears to indicate that this type of stress has an important influence on the mental health of Latinos (Cervantes & Castro, 1985; Edwards & Romero, 2008). However, studies on acculturation and acculturative stress have produced mixed findings (Lara, Gamboa, Kahramanian, Morales, & Bautista, 2005). For example, some studies have indicated that acculturation among Latinos has a positive effect on health outcomes (Finch, Hummer, Reindl, & Vega, 2002; Hu & Covell, 1986) In contrast, several studies have found that acculturation has a negative effect on a number of health outcomes for Latinos including substance abuse (Vega & Gil, 1998), increased alcohol consumption and intimate partner violence (Caetano, Ramisetty-Mikler, Caetano Vaeth, & Harris, 2007), increased rates of cigarette smoking among pregnant women (Detjen, Nieto, Trentthiem-Dietz, Fleming, & Chasan-Taber, 2007), and decreased health as a result of change in dietary practices (Akresh, 2007).

The stress paradigm is useful to understand the complexity of these findings. For example, the higher prevalence rates of mental health disorders in U.S.-born Latinos compared to immigrants has been found to be associated with difficulties in defining one's cultural identity. Researchers consider that individuals experiencing acculturative stress and who are unable to define their

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cultural identity, may also experience limited social support networks and a reduced sense of belonging to a cultural group (Rogler, Cortes, & Malgady, 1991; Vega, Zimmerman, Gil, Warheit, & Apospori, 1993; Vega, 1998).

Community-Based Participatory Research. Community-based participatory research (CBPR) is characterized by active community involvement in the processes that shape the design and implementation of research (Fielden et al., 2007). According to CBPR principles, the identification of community health and mental health problems should result from a participatory process between researchers and key members of the community (O'Fallon & Dearry, 2002). Participatory approaches have been found to be effective in research with Latino populations because these approaches place an emphasis on identifying unique contextual stressors that affect this population such as fear of being disrespected by service providers, experiencing racial discrimination, or experiencing social isolation (Pantin et al., 2003).

This study is informed by the CBPR model proposed by Fraenkel (2006). This model is parsimonious and highlights the need for scientific rigor as well as strong collaborations with communities and research participants. Fraenkel's (2006) model consists of 8 sequential specific steps: (1) engagement with the community and formation of collaborative relationships, (2) intensive interviewing of potential participants and community leaders, (3) qualitative data analysis with members from the community, (4) creation of program formats and program manuals, (5) implementation of an experimental pilot study and session-by-session evaluation by participants, (6) interviewing participants regarding each cycle of the intervention, (7) testing for efficacy, and (8) adaptation to larger settings and dissemination.

This study will focus on achieving the first initial steps proposed by Fraenkel (2006). Findings from this study will be used to inform the additional steps of the model, which focus on developing a program of intervention services research aimed at addressing substance abuse in Latinos with disabilities.

CHAPTER III: RESEARCH DESIGN AND METHODOLOGY

Introduction

The purpose of this study was to obtain a detailed description of the life experiences of a group of Latinos with disabilities who have abused licit and/or illicit substances. This was accomplished by utilizing a method of data collection that provides participants with the opportunity to provide clear descriptions of their most relevant life experiences. Specifically, this investigation followed the principles of photovoice methodology to implement data collection procedures, as informed by Freire's theories on critical consciousness and pedagogy of the oppressed, feminist theory, and documentary photography (Freire, 1970; Wang & Burris, 1997; Wang, Burris, & Xiang, 1994). Data analysis was conducted according to the descriptive phenomenological tradition because the purpose of phenomenology is to describe experience as it is lived and understood by people (Porter, 1994, 1995).

Research participants were recruited in Los Angeles County, California, and they were invited to participate in three cycles of interviews. Seventeen focus groups were implemented with a range of 2 to 7 participants each. This study implemented recruitment and data collection procedures documented as effective by photovoice researchers (Wang and Burris 1997; Wang and Redwood-Jones, 2001).

The Photovoice Methodology

The photovoice methodology consists of providing participants with the opportunity to communicate their life experiences through visual images, while also promoting a process of empowerment with participants as they gain awareness of their experiences and reflect about alternatives to promote social change (Carlson, Engebretson, & Chamberlain, 2006). The photovoice methodology has been confirmed to be an effective method of data collection in studies with diverse and historically marginalized populations. To date, photovoice has been implemented with rural Chinese women (Wang & Burris, 1994; Wang, Burris, & Xiang, 1996), Appalachian children living in poverty (Ewald, 1985), Bosnian refugee youth (Berman, Ford-Bilboe, Moutrey, & Cekik, 2001), Latino men at risk for contracting HIV (Rhodes & Hergenrather, 2007), Latino immigrant workers (Gallo, 2002), tenants with disabilities (Woolrych, 2004), homeless women and men in Michigan (Wang, 2002), low-income elderly African-American women and homeless young African American women (Killion & Wang, 2000), male to female transgender (Hussey, 2006), Latino high-risk youth (Wilson, Dasho, Martin, Wallerstein, Wang, & Minkler, 2007), African American breast cancer survivors (Lopez, Eng, Randall-David, & Robinson, 2005), and older adults experiencing chronic pain (Baker & Wang, 2006).

Participatory and qualitative methodologies are effective alternatives to empower populations that have been overlooked in research because participants are approached as experts on their lives (Denzin, 2005). Foster-Fishman and collaborators (2005) suggested that participants are impacted in unique ways by the photovoice methodology because their role as photographers is followed by group dialogues that facilitate a process of critical analysis and consciousness. For example, after being exposed to the photovoice method, participants have expressed a higher sense of self-competence, critical awareness of their social ecology, and increased levels of social capital that have led to social and political action (Foster-Fishman et al., 2005).

Few studies have examined the ways in which critical consciousness can be promoted in participatory research with participants with disabilities (Carlson, Engebretson, & Chamberlain, 2006). Addressing this scientific question is of critical importance because research seems to indicate that photovoice methodologies can promote such consciousness by participants engaging in three levels of sequential reflexivity which are passive adaptation, emotional engagement, and cognitive-awakening (Carlson et al., 2006). Passive adaptation refers to a state of learned helplessness and placing blame on others. For example, participants finding themselves in an oppressive situation (e.g., perceived discrimination) may feel as though there is nothing they can do to change the situation. Emotional engagement consists of the manifestation of underlying emotions such as anger and sadness as well as questioning events rather than accepting them. For example, participants begin to think critically about their life experiences by asking themselves questions such as, "How do I feel about my disability?", "How do I explain these feelings?", "What do I want to do about my disability?" Finally, cognitive-awakening refers to participants engaging in critical thinking about their life experiences and oppressive situations. This experience may lead to an increased sense of empowerment (Carlson et al., 2006). Examples of insights reached at this level may be, "I feel this way about my disability because…," "What I can do to change my perception

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about my disability is....," What I can do about my perception of persons with disabilities is..." The sense of empowerment experienced by participants at this level of awareness can lead them to transform their insights into action, by changing their individual experiences as well as the immediate and larger community (Wang & Burris, 1997; Wang, Burris, & Xiang, 1994; Wang & Redwood-Jones, 2001).

The procedures associated with the photovoice methodology are particularly useful for the target population of this study. Specifically, because I was working with a population that is twice as likely to dropout out of high school when compared to their non-disabled counterparts (Grayson, 1998), the use of cameras minimized barriers associated with limited literacy by enabling participants to express their experiences without the need to read or write.

In summary, photovoice is a particularly empowering methodology for populations that have been historically disenfranchised. By placing cameras in the hands of participants, community members, practitioners, researchers, and policy makers can have a clear understanding of the most relevant life experiences described by participants (Wang & Burris, 1997; Wang, Burris, & Xiang, 1994). By collaborating with participants on dialogues that promote critical thinking and consciousness about their life experiences, the photovoice methodology fosters both individual and collective knowledge, facilitating social change at multiple levels (Wang, Burris, & Xiang, 1994).

Theoretical Foundations of the Photovoice Methodology

Photovoice is grounded in Freire's theories of critical consciousness and pedagogy of the oppressed, feminist theory, and photographic imagery. Contrary to the passive role usually assigned to research participants, Freire's (1970) pedagogy of the oppressed states that dialogue is imperative in order to co-create knowledge. Freire affirmed that in order for critical consciousness to occur, people in oppressed situations need to engage in dialogue and reflect on their life experiences as they see them through their own eyes, not through the eyes of an outsider. For example, although as a researcher I may view participants as oppressed by the larger socio-economic structures (e.g., health and economic disparities experienced by persons with disabilities), the subjective reality of participants may not reflect my perceptions of their experiences (i.e., participants not feeling oppressed).

Pedagogy of the Oppressed. The Brazilian adult educator Paulo Freire (1970) developed a culturally informed pedagogy aimed at promoting relevant learning experiences among underserved and disadvantaged populations. Specifically, Freire recognized that issues of power define social structures, overlooking the experiences of marginalized populations. Thus, he proposed for knowledge to be co-created with communities rather than educators adopting an "expert" stance. Such co-created knowledge should develop through the engagement of both the learner and the teacher in conversations aimed at promoting a process of critical thinking. In contrast to passive learning, this shifts the power dynamics from the teacher as an expert and the student as a passive learner, to a more egalitarian relationship in which both teachers and students become learners and co-creators of knowledge (Freire, 1970).

Based on his research findings, Freire (1970) proposed three levels of consciousness that ought to influence how reality is interpreted. The lowest level of consciousness is described as one in which people are trapped by assumptions of inherent inferiority and live within a culture of silent acceptance of the status quo. The manifestation of this level of consciousness ultimately results in attitudes of learned helplessness and behaviors of passive submission which systematically and reciprocally contribute to one's own oppression. At the second level of consciousness, although individuals perceive and interpret the social situation as problematic and characterized by social injustice, individuals often may continue to blame their peers for the social reality of their lives. Lastly, the final level refers to critical consciousness and it is described as the process in which individuals become aware that their own assumptions shape the interpretations of reality. This level of awareness serves as a vehicle to develop responsibility and accountability for choices and personal behaviors that can contribute to a process of structural change (Freire, 1970).

Through his work, Freire (1970) developed and implemented innovative methods that are widely used today in feminist-informed participatory research (Minkler & Wallerstein, 2003; Williams & Lykes, 2003). For example, he approached community settings by first establishing relationships through informal conversations with members of the community, while also remaining c

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carefully attentive to issues of culture. Freire's interests were to identify the ways in which individuals were impacted by their cultural contexts, as well as how cultural contexts were influenced by individuals. Freire considered that social change should be rooted in participants' capacity to generate in-depth discussions of their lived experiences. This approach could also empower people by allowing them to have an active role in any learning process aimed at promoting social and structural change. Freire referred to this reflexive process as *praxis* (Freire, 1970).

Freire's (1970) pedagogy of the oppressed and the methods developed by him have greatly influenced participatory and feminist-informed research approaches utilized in studies with underserved and marginalized groups (Minkler & Wallerstein, 2003; Wang & Burris, 1997). As Carlson, Engebretson, and Chamberlain (2006) state, "Critical consciousness appears to be the impetus for changing attitudes of personal responsibility and behaviors of participation based on the ability to perceive social reality as a consequence of individual choices" (p.838).

Feminist theory is also at the core of the photovoice methodology. Feminist scholars have highlighted the ways in which research agendas can be influenced by patriarchal structures that tend to overlook or ignore the experiences of minority groups, including the disability community (Wang & Burris, 1997). Thus, the photovoice method constitutes an alternative to promote empowerment with disenfranchised populations, particularly if target populations have limited opportunities to describe their most relevant life experiences.

Feminist Theory. Feminist ideologies have asserted that there is a need to address issues of power and privilege in society as directly related to gender (Walsh & Scheinkman, 1989). Specifically, feminist scholars have noted the imperativeness to take into consideration the ways in which patriarchal structures have historically shaped political and sociocultural contexts (Semmler & Williams, 2000). Thus, not taking into consideration issues of power associated with male privilege is a "decontextualized approach" (Vatcher & Bogo, 2001), which can ultimately result in women being blamed, pathologized, and excluded from having the opportunity to hold positions of power and leadership in society (Weingarten, 1998).

Feminist scholars have highlighted the need to remain attentive to the ways in which research and science may undermine the power of personal accounts of diverse life experiences as defined by individuals. As McDowell & Fang (2007) quote Smith (1999), "Research is one way of imperialism and colonization that has been and continues to be achieved by defining what is considered 'legitimate knowledge'" (p. 549).

Feminist-informed methods of inquiry privilege the lived experiences of participants (White & Epston,1990) by utilizing collaborative methods that highlight the importance of creating a learning context (Weingarten, 1998). In addition, feminist approaches challenge the notion that every person in any given social system has an equal voice, overlooking the consideration that power dynamics permanently influence the nature of people's participation in research studies (Weingarten, 1998). Thus, feminist-informed research approaches highlight the need for researchers to become aware of their power as scientists, as well as to underscore the need to co-create knowledge with participants. Following the tenets of feminist-informed research, the photovoice methodology aims to co-create knowledge with participants who also experience oppression from educational disparities. For example, by placing cameras into the hands of women living in a Chinese village, researchers were able to gather data on their experiences that would not have been possible otherwise as participants could not read or write (Wang & Burris, 1997; Wang, Burris, & Xiang, 1994). This experience was described by participants as empowering because through the utilization of photography they were able to share with others their knowledge and the complexities of the experiences that inform their lives (Wang et al., 1994).

Informed by feminist ideologies, Epston (1999) argues that collaborative research allows for alternative knowledge and gives voice and power to those who would not normally have so systematically and institutionally. Collaborative approaches also deconstruct the idea of researchers acting exclusively as observers and participant as passive subjects to be observed. According to Russell and Carey (2003) "...feminism is a privilege that brings responsibilities in relation to the ways in which I respond to other people who may not have had that privilege (p. 68)".

Photographic Imagery. Photographic imagery theory considers that participants can become social activists as they share with others their perceptions of their life experiences (Foster-Fishman et al., 2006). Specifically, by taking photos of relevant life experiences, participants convey multiple realities to researchers and members of the larger community with the expectation that those who are exposed to these images will be challenged to promote social change (Wang & Burris, 1997; Wang, Burris, Xiang, 1994).

This study integrated the photovoice methodology with the descriptive phenomenological tradition because the major goal of this investigation was to obtain a detailed description of the life experiences of a group of Latinos with disabilities who have abused licit and/or illicit substances. The integration of photovoice and descriptive phenomenology has been reported in the literature as particularly useful because the process of reflexivity promoted throughout the qualitative inquiry is enhanced through the process of gradual empowerment associated with photovoice procedures (Nowell et al., 2006).

Descriptive Phenomenology

Descriptive phenomenology has its roots in philosophical principles that emphasize the need to describe the experiences of people as lived and understood by them (Husserl, 1970). Descriptive phenomenology has evolved as a qualitative tradition that integrates philosophical principles that privilege human experience (Husserl. 1970), as well as a rigorous methodology that assists researchers to accurately describe the experiences that participants consider to be most relevant in their lives (Potter, 1994, 1995).

A central tenet of descriptive phenomenology is to promote a process of reflexivity with participants by inviting them to participate in multiple interviews (Porter, 1995). Multiple interviews offer participants the opportunity to gradually reflect on their experiences over extended periods of time, as well as to confirm or modify the initial input (Moustakas, 1994). Finally, descriptive phenomenology places great emphasis on monitoring and minimizing the researchers' biases that may distort the experiences shared by participants. By engaging in a process known as "bracketing," researchers engage in an intense process of reflexivity aimed at identifying the ways in which their own life experiences and life expectations may diminish their capacity to engage in the investigation with an open mind (Porter, 1994).

Site

The site for this research was Los Angeles County, California. The population of Los Angeles County is approximately 10 million, with more than 47% of its inhabitants identifying themselves as Hispanic or Latino. This figure is higher than the national Latino percentage in the U.S. of approximately 14% (U.S. Census Bureau, 2006). More than 12% of the Los Angeles County population 5 years of age and older has a disability (U.S. Census, 2006).

In an effort to gain access to this hard-to-reach population, I worked collaboratively with several trusted members of the Latino community in Los Angeles County. My research collaborators offered me full support to conduct this study by offering to facilitate recruitment, engagement, and data collection activities. In addition, they introduced me to key service providers in the community (e.g., Sunrise Counseling Community Center, Bienvenidos Children's Center, Homeboy Industries).

Community-Based Participatory Research: Establishing a Board

Following the tenets of community-based participatory research (CBPR), a community board was established to ensure the collaborative nature of this study (Berge, Mendenhall, & Doherty, 2010; Minkler & Wallerstein, 2003). Researchers have confirmed the importance of establishing and maintaining community boards in CBPR studies in an effort to build collaborative relationships characterized by trust and a commitment to mutual learning, which should ultimately lead to the benefit and empowerment of target populations and communities (Berge et al., 2010; Israei et al., 2005). Therefore, the purpose of establishing a community board was to: (a) develop a process by which community members could contribute to the advancement of knowledge, (b) establish trust with members of the community and research participants, (c) facilitate the recruitment, engagement and retention of the targeted sample, and (d) ensure that research findings accurately describe the life experiences of participants (Berge et al., 2010).

The community board consisted of three stakeholders with strong ties to the community. The board consisted of one Latina woman and two Latino men. All board members had over 45 years of combined experience working with the Latino community in Los Angeles in prevention and early intervention programs. The community board was key to facilitate recruitment, engagement and retention of participants. For example, I was introduced to religious leaders of churches who also played an instrumental role in recruitment and engagement activities. Community board members were particularly effective for addressing recruitment challenges. For example, when I conducted recruitment activities at a community center which offers services for disability and substance abuse, I was unable to successfully recruit any participants. In contrast, when I collaborated with one board member who volunteered to present the study with me to potential participants, I was able to successfully recruit 5 participants.

Furthermore, the community board played a key role in suggesting inclusion criteria of potential participants such as type of disability (i.e., physical), age range (i.e., over 18 and younger than 35 years of age), and substance abuse (i.e., past year versus past month). Effectively addressing issues of substance abuse in this study was of high relevance, particularly because some of the participants were receiving services which were contingent upon them no longer using licit and/or illicit substances. By participating in this study, they would in fact be disclosing their substance abuse. As such, the community board suggested to change the inclusion criteria to "past year," which increased the effectiveness of recruitment and engagement.

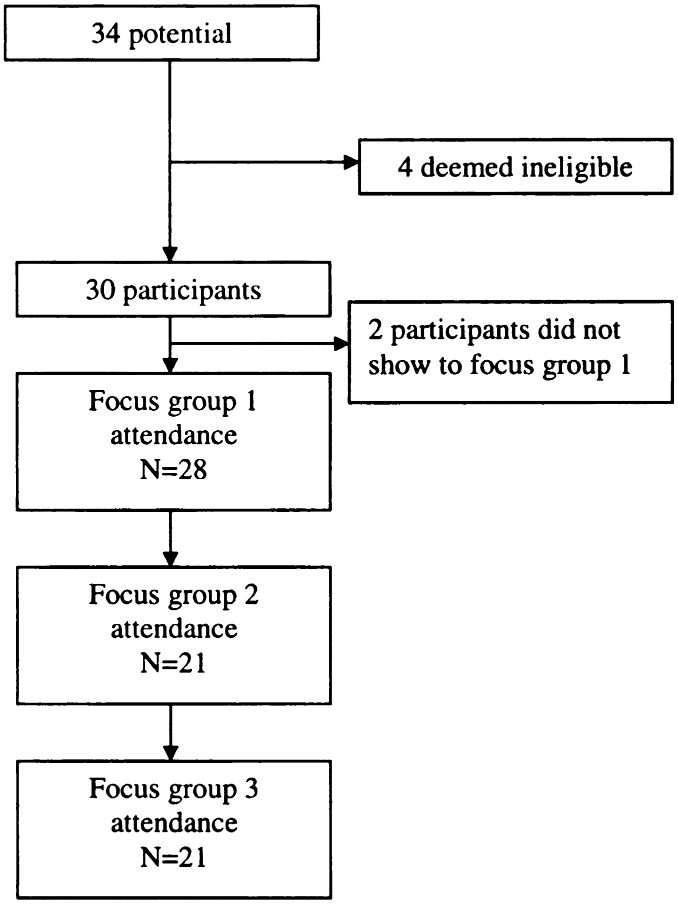
Finally, community board members had a key role in data analysis procedures. Specifically, I met with the community board after each iteration of analysis to obtain their feedback with respect to emerging findings. As I presented emerging data to board members, they offered relevant feedback and suggestions to ensure that the research protocol accurately explored the most relevant experiences commonly reported by Latinos who have abused substances.

Participants and Recruitment Procedures

Participants. For the purpose of this study, physical disability was defined as a physical limitation to perform normal and daily activities, with a minimum duration of at least 3 months (Russell, Turner, & Joiner, 2009; Turner et al., 2006). To be considered for the study, participants had to: (a) identify themselves as Latino or Hispanic, (b) identify themselves as having a physical disability, (c) be at least 18 years of age and younger than 35 years of age, (d) report recent use of licit or illicit substances as indicated by the National Survey on Drug Use and Health-past year Substance Use (SAMHSA, 2007) or the National Survey on Drug Use and Health-past year Binge Drinking (SAMHSA, 2007), and (e) sign a consent form expressing their willingness to participate in the study. Participants were excluded from this study if they did not meet any of the inclusion criteria or if they identified themselves as having a severe disability or an acute mental health disorder such as psychosis, dementia, or active suicidal ideation. War veterans were also excluded from the study because this population demands a well-specified research approach based on the intense life experiences they are likely to report (e.g., post-traumatic stress disorder). Participants were stratified by gender to ensure an equal number of both male and female participants. All participants received a $30 honorarium for each session they attended. This research protocol followed all recommendations established by the Michigan State University Institutional Review Board (IRB).

Although a sample of n=20 participants exceeds sampling requirements to ensure sufficient rigor in descriptive phenomenological research (Porter, 1994), the original target sample for this study was n=25 participants in order to compensate for attrition. However, based on the contextual challenges that I identified in the lives of participants that I initially recruited in this study, I oversampled by recruiting a total of n=34 potential participants. After accounting for inclusion criteria, a total of n=30 participants were enrolled in this study as n=4 were deemed ineligible. Two participants dropped out before interview I. One participant dropped out due to new employment and conflict of schedule and the second participant could not be reached to ascertain the reason for them not participating in the first group interview. Twenty-eight participants participated in the first round of focus group interviews, followed by 21 participants in each of the second and third round of focus group interviews. Table 1 provides an overview of participation rates for each round of focus group interviews.

Table 1. Participation rates at each interview level.



Sample Characteristics. A descriptive demographic analysis indicated that the mean age of the sample was 27.64 (SD=5.48) years and an equal distribution of women (n=14) and men (n=14) participated in the study. The majority of the participants were U.S.-born (82%). With respect to generational status, 10 participants (36%) identified themselves as first generation Latinos, followed by 9 second generation (32%), two third generation (7%), and 7 participants (25%) could not specify their generational status. Eighteen participants reported not having a high school diploma (65%), four reported having a high school diploma (14%), and 6 participants reported having achieved some college education (21%). Sixty-one percent of the participants reported English as their primary language, followed by Spanish (32%) and bilingual (7%). With regard to employment, 21% of participants reported being employed full-time, 4% part-time, 43% unemployed and looking for work, 21% unemployed and not looking for work, and 7% were unemployed because of their disability. Forty-three percent of participants made a combined household income of $10,000 or less, 18% made between $10,001 to $25,000, 14% made between $25,001 to $35,001, and 25% did not report their income. Table 2 provides an overview of the participants' demographic information.

Table2. Participants' demographic information

	Mean	Standard Deviation	Range
Age	27.64	5.48	19-35

N=28

	n	%		n	%
Gender			Educational attainment		
Female	14	50	Elementary school	18	65
Male	14	50	High school	4	14
Foreign-born	5	18	Some college	6	21
U.S.-born	23	82	Employment status		
Generational status			Full time	6	21
First generation	10	36	Part time	1	4
Second generation	9	32	Unemployed looking for work	12	43
Third generation	2	7	Unemployed not looking for work	6	21
Don't know	7	25	Unemployed due to disability	2	7
Primary language			Other	1	4
Spanish	9	32	Combined annual family income		
English	17	61	<$10,000	12	43
Both	2	7	$10,001-$25,000	5	18
			$25,001-$35,000	2	7
			>$35,001	2	7
			Don't know	7	25

With regard to disability, the mean age of onset for participants was 16.82 (SD=6.72) years of age. Twenty-one percent of participants reported receiving disability benefits. Furthermore, four participants reported visual impairment, three participants reported hearing impairment, and 21 participants reported mobility impairment, respectively. Of the 21 participants with mobility impairments, four participants utilized wheelchairs, two participants reported amputations, two participants reported limited arm movement, three participants reported limited leg movement, 6 participants reported difficulty lifting heavy objects, and 4 participants reported difficulty bending. Table 3 provides an overview of the disability demographics.

Table 3. Disability Demographics

	Mean	Standard Deviation	Range
Age of disability onset	16.82	6.72	11-35

	n	%
Receiving disability benefits	6	21
Types of disabilities		
Visual impairment	4	14
Hearing impairment	3	11
Use wheelchair	4	14
Amputation	2	7
Limited arm movement	2	7
Limited leg movement	3	11
Difficulty lifting heavy objects	6	21
Difficulty bending	4	15

With respect to past 30-day substance use, 10 participants reported using tobacco products (36%), followed by 8 participants reporting binge drinking (defined as 5 or more drinks for men and four or more drinks for women; 29%), 21% marijuana or hashish, 11% methamphetamine, and 7% heroin, respectively.

Cocaine, crack, PCP or angel dust, LSD or acid, inhalants, and benzodiazepines were each reported by 4% of participants.

With regard to past year use, 75% of participants reported binge drinking, followed by 64% tobacco products, 54% marijuana or hashish, 29% cocaine, 32% methamphetamine, 11% crack, 11% ecstasy, 7% other hallucinogens (e.g., mushrooms, mescaline), and 7% heroin or opiate, respectively. Inhalants, PCP or angel dust, LSD or acid, benzodiazepines and Vicodin were each reported by 4% of participants.

With respect to lifetime use, 86% reported marijuana or hashish, followed by 82% binge drinking, 75% tobacco products, 68% cocaine, 46% crack, 43% methamphetamine, 39% other hallucinogens, 32% PCP or angel dust, 32% ecstasy, 32% LSD or acid, 29% heroin or opiates, and 21% inhalants, respectively. Benzodiazepines and Vicodin were each reported by 3% of participants. Table 4 provides an overview of 30-day, past year, and lifetime substance use.

Table 4. Thirty-day, past year, and lifetime substance use.

	30-day use (%)	Past year (%)	Lifetime (%)
Binge Drinking	29	75	82
Tobacco	36	64	75
Marijuana	21	54	86
Methamphetamine	11	32	43
Heroin	7	7	29
Cocaine	4	29	68
Crack	4	11	46
PCP or angel dust	4	4	32
LSD or acid	4	4	32
Other hallucinogens	0	7	39
Inhalants	4	4	21
Benzodiazepines	4	4	4
Vicodine	0	4	4
Ecstasy	0	11	32

Recruitment Procedures. Following guidelines of previous photovoice studies, a total of n=30 participants were recruited for this study (Hussey, 2006; Killion & Wang, 2000). However, n=2 participants dropped out after initial recruitment and n=7 participants dropped out after interview I, which led to 21 participants completing all three interviews. Several strategies were utilized to recruit participants. First, fliers were distributed by key members of the community at sites frequently attended by Latinos such as churches, health care centers, and community centers. Fliers were also posted at center's which offered services to Latinos (e.g., Bienvenidos Children's Center, Homeboy Industries, Sunrise Community Counseling Center, etc.; see Appendix D).

Recruitment activities conducted in collaboration with the community board and key community members were the most effective methods to gain access to this population, confirming previous findings that indicate the key role that trusted members of the community have in the successful implementation of CBPR studies (Bamaca & Umana-Taylor, 2004; Marin & Marin, 1991). In addition to face-to-face recruitment, which I conducted in close collaboration with community board members, I relied on word-of-mouth and snowballing methods as additional recruitment strategies. These methods have been found effective with hard-to-reach populations and Latinos in particular (Bamaca & Umana-Taylor, 2004). As an incentive, participants were offered a $5 gift card for referrals of interested friends and neighbors, a strategy reported as useful in CBPR studies (Bamaca & Umana-Taylor, 2004).

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I also attended local churches that serve large segments of the Latino population in Los Angeles, including services in Spanish, and made public announcements about the study. Lastly, I attended a number of fairs, activities and events that are culturally relevant to the disability and Latino populations in Los Angeles to distribute fliers and inform potential participants about the study. A list of potential participants was compiled with contact information, including their name, email, phone number, home address, and best times to reach them.

Names and contact information of friends or relatives were also requested. This was particularly important for participants who did not have a telephone line or are recent immigrants. Potential participants were told that this information was gathered only to prevent losing their contact information in the case of relocation and that they could refuse to provide this information to me.

I followed up with potential participants to ensure that they met inclusion criteria. For those participants who did not have a phone, alternative methods of contacting the potential participants were used. For example, face-to-face contact was made by going to the centers they visited. In addition to completing screening procedures, dates and times were identified with participants for the implementation of the focus groups. A list was compiled with this information. Language of preference was also explored as participants had the option to participate in Spanish or English speaking focus groups. However, all focus groups were conducted in English.

Screening Measures

All participants were informed during screening procedures of the purpose of the study as well as the need to confirm their eligibility to participate. Participants completed two screening measures to confirm that they met inclusion criteria. Specifically, in addition to the aforementioned study requirements (i.e., Latino, disability), participants were screened based on the National Survey on Drug Use and Health—past year Substance Use (SAMHSA, 2007), and the National Survey on Drug Use and Health-past year-Binge Drinking (SAMHSA, 2007), both of which were included in the demographics sheet (Appendix F).

The National Survey on Drug Use and Health—past year Substance Use is an oral or paper and pencil instrument used to record data about participants' frequency of use of substances within the past one year. This instrument consists of 7-items measuring past year use of cigarette, marijuana or hashish, cocaine, crack, inhalants, heroin, hallucinogens, or other drugs. This instrument has been used with non-institutionalized civilians who are 12 years old or older (SAMHSA, 2007).

The National Survey on Drug Use and Health-past year-Binge Drinking (SAMHSA, 2007) is an oral or paper and pencil instrument used to record data about the frequency of binge drinking within the past year. This instrument consists of 1-item which reads, "During the past one year, on how many days did you have 5 or more drinks on the same occasion? By 'occasion,' we mean at the same time or within a couple of hours of each other." This instrument has been used with non-institutionalized civilians who are 12 years old or older (SAMHSA, 2007).

Although there are more precise methods to ascertain whether or not a person is using a substance (e.g., biological markers such as a urine sample), the implementation of such screening methods demand procedures that could not be accomplished in this exploratory study due to logistical limitations.

Procedures

A major goal of the photovoice methodology is to produce in-depth descriptions of the participants' life experiences, resulting from sharing diverse meanings associated with collected photographs (Wang & Redwood-Jones, 2001). To pursue this objective, this study consisted of three general cycles of photography and focus groups. A total of 17 focus groups interviews were conducted in this study. The same participants were interviewed in all the cycles. The first two cycles focused on promoting a process of reflexivity regarding the participants' life experiences. The last cycle focused on ensuring trustworthiness of the data by sharing with participants my descriptions of their life experiences (Guba & Lincoln, 1989). In addition to sharing emerging data with participants, Dr. Parra-Cardona reviewed samples of coded transcripts in an effort to increase trustworthiness of the data. Trustworthiness of the data was also increased by sharing coding iterations with the community board members. Data collection took place over the course of 20 weeks. All focus groups were implemented in a private room located at the participants' preferred site.

Group Composition. Both same and mixed-gender focus groups were implemented in the study. Mixed-gender groups may provide complementary insights that cannot be reached in a more homogenous group (Stewart et al., 2007). In addition, implementing gender homogeneous groups has the potential benefit of obtaining data that could not be obtained in a mixed group (e.g., participants' descriptions of male superiority; Bamaca & Umana-Taylor, 2004). This approach proved to be particularly helpful with women-only groups in this study, as Latina participants described in great detail their experiences with intimate partner violence (IPV).

Introductory Group Session. The first group session served as an introductory, joining, and training session. First, I described to participants the purpose of this study and its relevance. Because researchers have suggested that the initial group session is ideal for joining with participants and promoting a sense of group cohesion (Stewart et al., 2007), I shared with participants the fact that I am a Latino with a disability and clarified to them my motivation for conducting this study. I also obtained participants' consent to participate and explained in detail the goals and procedures of the study. I reminded participants that they could withdraw from the study at any time without penalty. Food was brought to each training session and all subsequent focus group interviews to further ensure the engagement and retention of participants (Bamaca & Umana-Taylor, 2004).

The training component of the first session focused on discussing with participants the benefits of using a camera in this type of research, the specifics about l

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about handling a camera, and ethics associated with this experience (Wang & Burris, 1997). In addition, participants were informed of how images can be a powerful tool to describe to the community, practitioners, researchers and policy makers their most relevant life experiences (Wang & Burris, 1997).

Training on handling the cameras helped participants to practice how to use the flash, how far in distance one stands to take the best picture, different angles, and how to protect the camera from damage from environmental factors such as water, sun, heat, and cold.

With respect to training on ethics, participants were introduced to the ethical mandates associated with this study. For example, they were trained in obtaining consents from individuals who were photographed, as well as considering provisions to ensure their safety and confidentiality (e.g., obtaining consent and assent forms). Because literacy problems are common in research with low-income Latino populations (Bamaca & Umana-Taylor, 2004), participants were trained on how to manage the consent process with individuals who experience literacy barriers. Specifically, a brief recruitment script was prepared to be used by participants and the consent form was written in lay terms (i.e., 4th grade level). Participants were instructed not to recruit war veterans or anyone who has a severe disability such as Alzheimer's disease or psychotic symptoms. All IRB recommendations were followed to ensure the protection of human subjects.

Each participant was given a single-use camera with flash to be used after the initial group session. Participants used their cameras by remaining attentive to the following questions: (a) can you please describe your life as a Latino with a disability?, (b) can you please describe your life as a Latino with a disability who has taken substances?, (c) can you please describe the strengths within your community in relation to disability?, and (d) what changes would you like to see in your community in relation to disability?

Participants were given two weeks after the first group session to take their pictures. At the end of this week, the cameras were collected for film processing. I arranged with each participant a time and date to collect the cameras in order to ensure the safety of the films. Because many of the collaborating centers were highly utilized by the participants, participants identified these centers as an ideal site for dropping off the cameras. In addition, I explored alternative options (e.g., picking camera up at home) with participants during the training session and ensured that such options ensured the safety of materials.

Cameras were collected and taken to a film-developing center for processing. Once processing was completed, I numbered each picture to correspond with the cycle and participant ID. I then returned the pictures to each participant at their desired location. Participants were given a week and asked to reflect on their pictures taken in order to prepare for the focus group interview. Each cycle was conducted approximately every four weeks to ensure adequate time for picture taking, film processing, and the implementation of the focus group interviews in which participants reflected on their photos as well as the experiences associated with collecting these images.

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All cameras and photos were numbered in order to ensure rigorous tracking and matching of photos to participants (Berkowitz & Nowell, 2003). This tracking process was implemented by utilizing the Photo Reflection Sheet (Appendix E), and a log of the cycle in which the film was taken which matched the photos with participants, the exposure and cycle numbers (e.g., #2), and the participant number.

Focus Groups. Prior to the implementation of each focus group interview, the participants and the researcher shared a meal together to promote group cohesion (Bamaca & Umana-Taylor, 2004). The first focus group had the goal of discussing with participants their life experiences based on the photos taken. Prior to the implementation of the focus group, all the consent forms from the participants, consent to publish the photos, and consent forms that participants obtained from photographed people were collected (Appendices A, B, C).

The focus group interviews lasted approximately two hours. During the first hour, each participant was given the opportunity to share with the group three photos and had approximately three to five minutes to discuss each photo. Once each member of the group had a chance to share their three photos, the group collectively decided on three photos that most accurately described their life experiences. This was accomplished through a voting process. The voting process consisted of each member of the focus group having a total of three votes. Thus, a group consisting of five members, for example, had a total of 15 votes. The three pictures receiving the most votes from the participants were selected. Life experiences associated with these pictures were discussed in-de

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depth during the second hour of the focus group. In order to avoid fatigue among participants, a brief 10-minute break with refreshments was offered to participants after selection of the most relevant pictures.

To start group discussions, procedures recommended by Wang and Redwood-Jones (2001) were followed. Thus, each photo was discussed using the mnemonic “SHOWeD”: “What do you See here? What is really Happening? How does this relate to your lives? Why does this problem or strength exist? What can you Do about it?” (p.562). Participants were each given a SHOWeD: Photo Reflection Sheet (Appendix E) in order to facilitate a critical reflection of the three pictures they chose to share in the focus group interview.

An interview guide was developed in order to ensure that the use of the mnemonic SHOWeD addressed the grand tour questions of this study (see Appendix G). Probes were used if participants did not address themes that were considered relevant to this investigation. These procedures were repeated in cycle two and modifications to the interview guide were made in order to further explore the life experiences that participants consider to be most relevant in their lives. I summarized the most relevant experiences prior to the implementation of focus groups in cycle three as the purpose of the last focus group was to ensure that I accurately described the reflections shared by participants in cycles one and two (Porter, 1995). As the photovoice and descriptive phenomenological methods indicate (Foster-Fishman et al., 2005; Porter, 1995), conversations of cycles two and three seemed to have a level of awareness characterized by

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increased reflexivity, which was initiated in the group discussions of the first cycle.

The third and final round of focus group interviews did not include a process of photo taking. Rather, the primary goal of the final round of focus groups was to ensure that my descriptions of the most relevant life experiences of participants were accurate. Descriptive phenomenology postulates that trustworthiness of the findings is ultimately rooted in whether or not the essence of phenomena as experienced by the participants of a study is reflected in the findings (Moustakas, 1994; Porter, 1995). Therefore, the purpose of this cycle of focus groups was to ensure that what I am reporting is in fact what participants are conveying.

Bracketing

Bracketing consists of identifying and setting aside preconceived ideas and biases in order to participate in the data collection and data analysis with an open mind (Porter, 1995). I conducted bracketing by identifying major themes associated with a literature review on the topic of the study of this investigation. I also wrote a personal narrative describing my personal experiences as a Latino with a disability in order to identify the biases and preconceived notions that I brought into the study. This narrative was also utilized prior to the final integration and write-up of the research findings.

Data Analysis

The audiotapes of the 17 focus groups were transcribed verbatim. Transcripts were reviewed for accuracy once transcription was completed. Two distinct processes of data analysis were used. First, I listened to audiotapes of the first cycle prior to preparing for the second round of focus groups. Thus, I was able to identify the most dominant themes addressed by participants. I then revised the interview guide of the second round of focus groups based on this content. I repeated these procedures prior to the final focus group. Finally, once all data was transcribed, a detailed analysis of life experiences and participants' intentions were conducted according to the phenomenological approach. NVivo qualitative software version 8 was used to complete all data analyses (QSRInternational, 2008).

The analysis of transcribed data followed a sequential process. First, each individual idea was coded as either life-world data or lived experience data (Porter, 1994; Porter, 1995). Life world data refers to data which describe factors in the participant's environment that influence their lived experience, but that are beyond the participants' control (Porter, 1995). For example, existing sociocultural and sociopolitical messages associated with Latinos with disabilities. These data were categorized into elements, descriptors, and features (Sharp, 2003).

Data related to lived experience refers to how participants make sense and interpret their experiences. Lived experience data identifies the participants' intentionality regarding specific life experiences (Porter, 1994). In order to arrive to the most relevant participants' intentions related to their life experiences, Porter (1994) recommends identifying individual intentions and integrating sets of

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common intentions by describing, comparing, and distinguishing each unit of analysis.

After identifying the most relevant life-world and lived experience data, and confirming with participants that such descriptions accurately describe their most relevant life experiences, a process of "filling out" was implemented (Porter, 1995). In descriptive phenomenology, this process refers to ensuring that final findings are not affected by the researcher's preconceived notions and ideas. I engaged in a process of "filling out" by presenting to participants the findings that I considered constitute the best descriptions of their life experiences. In addition, prior to writing the findings of this study, I read my personal statement and reflected on the ways in which my experiences as a Latino with a disability may have influenced my presentation of research findings. In addition, I received feedback from Dr. Parra-Cardona who reviewed the transcripts produced after each cycle of interviews. Finally, I shared with the community board iterations of the data analysis to obtain their feedback with regard to the data analysis.

Trustworthiness of the Data

Trustworthiness of the data refers to ensuring that research findings accurately describe the life experiences of participants, without distortion as a result of the researcher's biases (Guba & Lincoln, 1989). Trustworthiness of the data is established by credibility, transferability, and dependability (Guba & Lincoln, 1989). Keeping in mind that the original target sample size for this study was n=25, establishing trustworthiness of the data was particularly important in this research because the attrition rate was 16%. Therefore, it was essential to

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ensure that emerging findings accurately described the life experiences that were identified as most relevant by the research participants who completed all three rounds of interviews.

Credibility refers to ensuring that what I am reporting is in fact what participants are saying (Morrow, 2005). This was achieved through multiple data sharing methods. Specifically, participants were involved in every stage of this investigation and confirmed that my perceptions of their experiences are accurate. Credibility was strengthened through the focus groups of the third cycle and by sharing coded transcripts with community board members and with Dr. Parra-Cardona.

Transferability refers to "the degree of similarity between sending and receiving contexts" (Lincoln & Guba, 1989). This was accomplished by the very nature of the photovoice methodology (i.e., pictures describe the participants' contexts). In addition, group discussions had the purpose of ensuring that the multiple realities of participants are conveyed.

Dependability is the extent to which findings are reasonable as a result of implementing adequate methodology (Lincoln and Guba, 1985). To that end, I engaged in several conversations with Dr. Parra-Cardona and gave him copies of my transcripts and coding sheets. Furthermore, I engaged in several conversations with community board members and shared with them copies of coded sheets. In addition I kept audit trails throughout the implementation of the study to keep track of specific methodological decisions (Morrow, 2005).

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Lastly, I kept a journal to describe my feelings and experiences as I engaged in the different phases of this study. This journal served to help me to remain attentive to my biases throughout the implementation of the study (Morrow, 2005).

Ethical Considerations

Wang and Redwood-Jones (2004) have identified four major ethical considerations in conducting a photovoice study. These ethical considerations are: (a) intrusion into private space, (b) disclosure of embarrassing facts of individuals, (c) being placed in a false light by images, and (d) protection against the use of a person's likeness for commercial benefit.

Intrusion into private space refers to being photographed or having photos published for which the individual and/or participant did not give consent (Wang & Redwood-Jones, 2004). This issue was addressed in this study by the utilization of three consent forms: (a) consent from participants in the study, (b) consent from the subject being photographed and the participant as a photographer, and (c) a final consent at the end of each focus group from the participants, giving permission to publish the photos and utilize them to promote the goals of this investigation (Wang & Burris, 1994).

Participants may have disclosed embarrassing facts about an individual while taking photographs (Wang & Burris, 1994). For example, because the topic of interest in this study refers to Latinos with disabilities who have abused substances, we are dealing with multiple layers of stigma. Thus, a person who has a disability and has abused substances may have not wanted to disclose such information. Therefore, it was imperative for participants to receive consent from a person being photographed to verify that they provided consent to share such information. This was emphasized during the training session of the study. Participants were informed that any photos of a person without a consent form could not be shared during the focus group interview. In addition, participants were instructed to not take any photos of illegal activity or drug paraphernalia.

In addition, there was a potential for individuals who agreed to be photographed to be placed in a false light by images. In other words, participants of the study may have taken photos of participants being photographed in a position that does not represent the truth. For example, this occurs in the media with public figures where pictures and headlines are misleading. This risk, as Wang and Burris (2004) cite Gross, Katz, and Ruby (1988), refers to being "placed in a false light by images which distort the truth and create false impressions of one's intentions, character or actions" (p.11). Although I cannot say with great certainty that none of the participants photographed in the study were placed in a false light, methods aimed to prevent this from happening were implemented. First, the ethical considerations and importance of not placing individuals in a false light were emphasized during the training session. In addition, a consent form for participants being photographed aimed to prevent this from occurring.

Lastly, it is imperative that individuals who agree to be photographed are protected against the use of a person's likeness for commercial benefit. For instance, publishing a photo for profit would not be an ethical practice with the photovoice method. Therefore, each photographer was given a set of photos from each disposable camera they used. Because photovoice is a community based participatory research method which serves to create change in communities, policies, and the larger contexts, it was imperative that findings could be disseminated (Israel, Eng, Schulz, & Parker, 2005; Minkler, & Wallerstein, 2003), including photos. Researchers who have used this method have concluded that participants express feelings of appreciation and pride as their photos are displayed because the photos represent their reality (Wang & Burris, 2004). In fact, because it is a participatory research method, it is not uncommon for participants to be present during a research presentation in which the findings are disseminated to the general population, community members, and policy makers (Wang & Burris, 2004). It is for these reasons that a signed consent form at the end of each focus group from the participants was obtained. Such consent forms provided permission to publish the photos and utilize them to promote the goals of this investigation (Wang & Burris, 1994).

Although the use of focus groups and cameras as a method of collecting data can be a powerful tool and can be beneficial, it also carries risks (Stewart et al., 2007; Wang & Burris, 2004). Therefore, addressing every potential risk identified by the MSU IRB and NIH was critical in this study.

Confidentiality

The participants' privacy was protected according to Michigan State University IRB regulations. Only I and key community members who helped recruitment and engagement efforts were able to identify research participants.

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Pseudo-names and participant identification numbers were used in order to ensure the protection of the participants' identities. All audio recordings were kept in a locked filing cabinet located at my office at Behavioral Assessment Inc. in California. The office is secured and is locked during closed office hours. Furthermore, the building is closed by 7:00pm (PST), at which time a password is needed to enter the building and there is a camera installed in the elevator. All transcribed material was kept in a password-protected laptop computer. To further ensure confidentiality of participants, a National Institutes of Health Certificate of Confidentiality was obtained.

National Institutes of Health Certificate of Confidentiality. Prior to the implementation of this study and to further ensure confidentiality of participants, a National Institutes of Health (NIH) Certificate of Confidentiality (COC) was applied for and successfully obtained March 4, 2009. The COC aims to protect the privacy of research participants by withholding their identities from all persons not connected with this investigation. With this COC, the researcher cannot be forced to disclose information that may identify participants, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings. The researcher can use the Certificate to resist any demands for information that would identify participants, except as explained below.

The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation

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of federally funded projects or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA).

Participants were informed that a COC does not prevent participants or a member of their family from voluntarily releasing information about themselves or their involvement in this research. Participants were also informed that if an insurer, employer, or other person obtains their written consent to receive research information, then the researcher may not use the COC to withhold that information. In addition, participants were informed that the COC only protects against demands for information that may identify them as research participants. Therefore, if a participant's identity is known because of a photo (e.g., other community members recognize their photo), a COC may not offer protection. For example, if the photo is used in a presentation and identifies them as a participant in the study, then it may not be possible for the researcher to use the COC to protect other identifying information.

The Certificate of Confidentiality does not prevent the researcher from disclosing voluntarily, without participants' consent, information that would identify them as a participant in the research project under the following circumstances: child abuse, intent to hurt self and/or others. For example, instances that may be reported include photos which display child neglect in their homes (e.g., lack of clothing, food) and/or around drugs, and acts of violence, whether the perpetrator or victim. In addition, participants were informed that although the nature of this study is not to explore harm caused by others or participants, harm caused by anyone (e.g., threats of violence by others or participants) may be reported to the appropriate authorities, including police officials. Further, the researcher is not prevented from taking steps to ensure the safety and prevention of harm to participants or others if a participant takes a picture which depicts possible harm.

The COC does not represent an endorsement of the study by the Department of Health and Human Services or the National Institutes of Health.

Risks and Benefits to Participants

Some participants appeared to have experienced slight discomfort when they talked about issues that represented a challenge in their lives (e.g., stigma of having a disability, perceived discrimination). Incidents in which participants became visibly disturbed during the focus group, the focus group was stopped. For example, some participants cried while expressing the pain and despair experienced at the onset of their disability. I checked in with participants and informed them that they did not have to continue the focus group interview if they did not desire. All participants expressed a desire to continue the focus group interview as many described the process as therapeutic and provided an outlet for them to share their experience. However, I was prepared to arrange counseling referrals if requested by any participant. None of the participants requested such referrals. This occurred in approximately 7 out of 17 focus group interviews.

Participants were paid $30 for their participation in each session. Thus, each participant could earn up to $90 for his or her participation in the three cycles of the study, including the training session. Participation was voluntary and participants may have chosen not to participate at all, refused to participate in certain procedures or answer certain questions, or discontinued their participation at any time without penalty or loss of compensation.

In addition to the monetary compensation, participants appeared to gain insight about their experiences of having a disability and abused substances and increased their ability to think critically about their life experiences, including intentions and behaviors associated with social change or advocacy for the Latino disability community. Participants may have also experienced a sense of relief by having someone listen to them, as well as by sharing similar and contrasting experiences with other members of the community. Finally, findings from this study will constitute a relevant contribution to the scant literature on Latinos with disabilities who have abused substances.

CHAPTER IV: RESULTS

Throughout the process of analysis, I used the strategies of describing, comparing, distinguishing and inferring (Moustakas, 1994; Porter, 1994). This analytical process led to the identification of 309 original elements. Of these, 6 life-world features were identified: (a) being put down by my family, (b) being challenged by my community, (c) experiences with health and mental health providers and service professionals, (d) women experiencing exclusion and discrimination, (e) being supported by my family, and (f) being supported by my community. With regard to the participants' life experiences as Latinos with disabilities and drug abuse, 4 phenomena of the lived experienced were identified from 464 original intentions: (a) experiencing the struggle of living with my disability, (b) not giving up and wanting to change, (c) accepting and embracing my disability, and (d) wanting more understanding, help and increased awareness in the community (see appendices H and I for outlines of both life-world features and phenomena). Appendix J displays an overview of the research questions and both life-world and lived experience themes that emerged from the data. Next, I will describe the features of the life-world data.

FEATURES AND DESCRIPTORS OF THE LIFE-WORLD CONTEXT

Life-world context refers to the social ecology in which people are embedded (Moustakas, 1994: Porter, 1995). In contrast to lived experience data, which show participants' intentionality as they actively seek to impact their individual realities, life-world data refer to phenomena in the lives of participants for which they have limited or inexistent control. Participants of this study described the various ways in which their life-world context constitutes a significant challenge to their lives. For example, Latinos with disabilities who participated in this study described the ways in which their community has multiple challenges and barriers to their overall development. In addition, participants described family processes in which they felt as "being put down," which often led to emotions of pain and hurt for them. Participants also described significant negative interactions with health and mental health service providers. These interactions were characterized by experiencing multiple barriers when attempting to access services, which included not feeling respected nor supported by service providers, as well as service providers lacking cultural sensitivity. Finally, although this study was not aimed at conducting a separate analysis with regard to gender differences in the lives of Latinos with disabilities, the data indicated a number of descriptors only reported by women participants. Therefore, the feature referred as "Women experiencing exclusion and discrimination" refers to the experiences reported only by women participants. This feature contains the following descriptors: (a) programs of support are not designed for women, (b) substance abuse in women being overlooked, (c) they put men in jail, and (d) domestic Violence is pervasive but unacknowledged.

Participants also described the ways in which their community is supportive. For instance, participants described the ways in which they felt supported by their families through love and "being there for them." Participants also indicated the ways in which their community offers specific resources associated with outreach and engagement to the disability community, as well as recognition of the Latino culture. In the following sections, I will proceed to describe the life-world features described by Latinos with disabilities in this study.

BEING PUT DOWN BY MY FAMILY

Research participants described the ways in which their families have been barriers to their process of adaptation to disability as well as recovery from substance abuse. Participants described the following descriptors: (a) my family trying to help me, but in the wrong way, (b) not being able to ask my family for help, and (c) my family not trusting me.

My Family Trying To Help Me, But In the Wrong Way

Participants provided examples of the ways in which, although unintentional, their families were not helpful to them. One area, for example, refers to the ways in which family members were critical of their substance use. Although participants expressed understanding that the intentions of their families were to promote their substance abuse recovery, such intentions actually led to emotional distress, which increased the risk for relapse or continuing substance abuse. One participant elaborated on this issue:

> They have the best intentions for me, but they hardly ever express it in a positive way. So there is a lot of name calling and a lot of talking down to me. And they don't understand how bad that makes me feel and how much that is a trigger for me to use. I try to tell them, but they just get so caught up in what's going on that they don't see the overall picture and they just get really frustrated.

Participants also described not being accepted by their families and feeling "put down" by them through various forms of rejection, an experience that increased their risk for substance abuse or relapse. One participant shared how she felt hurt by her family:

> The kind of pain I endured was rejection from my family. A lot of negativity from my family and that always contributed to my drug use. Cause, well, fuck them if they're not going to accept me then I don't want to be accepted…It's really painful to not be able to be with your family or to not have your family accept you or love you.

Another participant shared his experience of being put down by his family:

> When my family puts me down, it's caused me so much pain. Just over the years, the relationship I have with my father has caused me so much grief and pain, just realizing that this man is…he has a lot of issues himself too. And it's always brought on this whole screw it attitude. If I can't have their acceptance or be loved, then who cares? That's just my way of thinking. And then I go and seek that love and comfort from things that aren't good for me like drugs, men, or anything just to feel accepted or loved.

Not Being Able To Ask My Family for Help

Latinos with disabilities described that one of the most difficult challenges for them is asking others for help, particularly because of past experiences in which they have reached out to family members for help and experienced rejection in return. One participant stated:

> Like for example, tomorrow I have an appointment right here at general hospital and it's stressful because I can't ask my family. Honestly, I don't want to ask them because I know the stupidity they are going to come out with. "Why don't you ask your other sister? Why don't you ask your friend?"

Similarly, another participant described how he was denied help from his family:

> Being able to help me out more. Instead of telling me, "Why don't you call your friends?" Or, "Why don't you call your little sister?" or "Why don't you call your brother?" Instead, like "OK, I'll go help you out." I wish they could be more supportive helping me…I need a ride to go to the damn market to buy some toilet paper, soap and stuff... I'm asking for a ride to go buy something to eat.

A common theme reported by participants refers to instances in which they would ask family members for help and family members would usually refer them to someone else. One participant shared:

> Just my family, when I ask them for a favor, just wishing that they wouldn't be like, "Why don't you ask so and so, or why don't you ask your friends, or why don't you ask your other brother?" I wish they wouldn't do that and be like, "You know what, I have nothing to do, cool." If they have something to do, just let me know instead of telling me to ask somebody else. I wish they could support me to take care of my things. It would be less stressful for me.

My Family Not Trusting Me

A significant challenge reported by participants refers to mistrust from their families, particularly as it refers to their efforts to stop substance abuse. One participant expressed:

> For me...the thing is I wish they would really just believe me. Cause right now that I'm staying away, I'm trying to tell them that I'm staying sober. They just don't believe me and it really bothers me. It really bothers me cause they don't know cause they're distanced from me...Especially, I'm trying to do my recovery over here for the simple fact that they've always put me down...I really want to prove them wrong by doing my recovery here. I just really wish they would believe me when I tell them. Cause they still stay putting me down. It's like, you don't know what I'm doing. They really don't believe me.

Participants expressed that one of the most difficult obstacles they face within the context of the family is a lack of understanding of their recovery efforts. Participants attributed this lack of understanding to the lack of knowledge with regards to substance abuse. One participant affirmed:

> I think they don't trust you, especially the Latino family. Even though they don't understand that we are not using and that we're staying clean. They think that you are going to be the same person. They don't have that knowledge. They're always going to judge you. Even though you are clean, they're always going to be saying, "Yeah, you were this, you were that." I think that's the hardest part. There's no trust.

Participants described how lack of trust from family members with regard to their commitment to recovery from substance abuse, represents an intense challenge to their process of recovery. One participant said:

> They think that because you've done it before, you're going to do it again. I stayed clean for like a year and a couple of months, and I relapsed. So they think it's a pattern. I'm doing Ok, but they're afraid I'll do it again, I'm going to relapse again. So they have that trust issue. I know I built that trust issue with them, but it's just that they don't trust me. Even though I have time clean, they don't trust me.

BEING CHALLENGED BY MY COMMUNITY

Participants described the ways in which their community context constitutes a significant challenge to their lives. Participants described these life-world features as "everyday occurrences" and expressed despair as these challenges seem impossible to overcome. For example, participants expressed issues of poverty, gangs, and high accessibility to drugs and alcohol as challenges that could never be resolved in their community. The theme, "Being challenged by my community," was defined through the following descriptors: (a) being impacted by poverty, violence, and gangs, (b) I'm invisible to others, and (c) drugs and alcohol all around me.

Being Impacted by Poverty, Violence and Gangs

Participants described their community as impoverished and lacking the necessary resources needed to flourish. One participant, for example, expressed, "We all live in different areas of LA, but you won't find none of us living in Beverly Hills. So our neighborhoods or where we grew up is pretty much just poverty."

Participants also expressed that issues related to poverty were not improving, and in some instances, were worsening. One participant affirmed, "I wish we weren't in such a debt [in the community]. I wish our community wasn't so poor. I don't know if it's the poverty or economy that contributes to Latinos using substances."

A constant reminder to participants with regard to poverty refers to the Electronic Benefits Transfer (EBT) signs advertised throughout their community. EBT is an electronic system that allows a recipient to authorize transfer of their government supplemental assistance benefits from a federal account to a retailer account to pay for products received. Participants expressed that the EBT signs are predominately displayed in Latino and Black communities. One participant indicated:

> And I notice that in barrios and hoods, the EBT stamp is on Pizza Huts...wherever there is a minority, like Latinos or African American communities, it's everywhere. It's in the smallest stores...it's in the Pizza Hut. Even in the Blockbuster, you can pay with your EBT card...It's like everywhere. But when you go to a different neighborhood with more Caucasians, you don't see these around...It kind of makes me feel like Latinos are poor.

Figure 1. Photo of Electronic Benefits Transfer sign representing poverty to participants.

A common contextual challenge experienced by participants refers to community violence. Community violence has been and continues to be a significant challenge to their overall well-being. For example, one participant mentioned, “People are killing innocent bystanders just doing drive-by shootings. The writing on the walls, some people are just trying to paint it and they’re getting shot thinking that they’re crossing them out.”

Participants described the ways in which they experience the death of friends and family members because of violence in the community. One participant, for example, expressed:

> I took pictures of where I live and what I’ve been exposed to and how one of my friends died. He was only 21 years old. And he just got shot in the day light right in the front. That’s really sad…people are shooting in the day now. They shoot at any time. And how he was so young and he was a victim of it…

Latinos with disabilities described how the violence in their community makes them feel as though they live in an uncivilized world. In addition, they expressed that most of this violence is directed at the men in the community. One participant said:

> It makes our community look really ghetto…like if we're not civilized. We're all killing each other and we are the same people. And I'm tired cause we as women, we lose our sons, fathers, brothers and husbands.

Figure 2. Photo of a cemetery representing the common reality of death and violence in the community.

Participants expressed the presence of gangs in their neighborhood as a significant challenge to their development. One participant described:

> Right here you see a youngster and an older fellow, they're gangsters…They're proud to be with it, you know? They do gang transactions with drugs and guns and everything. And they're just posted up on the block and they put in that work. By doing this, they're picking up other youngsters, male and female, who are lost or maybe they're privileged but they are looking for a thrill…It relates to our lives because

> they're everywhere. They are our fathers, mothers, brothers, sisters, aunts and uncles…the numbers just keep coming up, they're everywhere.

A permanent reminder to participants about gang presence refers to gang graffiti. One participant stated, "In my community there are always gang writings on the walls and you get tired of it."

Figure 3. Photo of gang graffiti representing the dominating presence of gangs in the community.

I am Invisible to Others

Participants shared the ways in which they felt invisible to others in the community. In particular, they expressed that the lack of accessibility for persons with disabilities constitutes a significant challenge in their lives.

Participants expressed that many locations throughout the community are not accessible for Latinos with disabilities. One important location for participants refers to homes in the community. However, participants expressed that due to the lack of accessibility in homes, the opportunities for social interaction were negatively impacted. One participant expressed:

> Like, for Mike to come over to my mom's house this weekend, he's not going to be able to go inside the house because we're not equipped. We don't have a ramp. There is two steps to get into the house and then there is another step. And the back porch has steps. But I still want him to come over, but he can't.

Participants expressed that although it was somewhat expected for homes of friends to not be accessible, it was a more difficult experience when it was the home of a relative. One participant, for example, mentioned:

> ...It's me going up at my auntie's house and there's only one stair. And there's a little ass curb too so I have to find a way of how to get back on there and how to get down without falling.

Participants expressed a lack of accessibility in the community for Latinos with disabilities. Of particular concern for participants were curbs in the community that constitute tremendous barriers to access. Participants reported that this lack of accessibility made them feel invisible to the community because their basic needs were not being met. One participant affirmed:

> There's only about 7 or 8 out of 20 blocks that people in wheelchairs, walkers or older people could go down because the other ones are sidewalks. They have big hills and the other ones are dangerous. I would like to see more accessible ramps for people in wheelchairs...not only for wheelchairs but for disabled people. And that they make our apartments a little more handicap accessible.

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Figure 4. Participant in wheelchair utilizing the escalator because there is no elevator for their use.

An additional area being negatively impacted by lack of accessibility refers to participants' high need of accessible public transportation. One participant expressed, "I got my struggles with access. ...It's bad. I mean it's bad." This lack of access is stressful and made participants feel invisible to the community. For example, one participant commented, "There's sometimes that I miss the bus cause only two people on a wheelchair can fit there, so, it's pretty stressful."

Latinos with disabilities also described the limitations of public transportation, particularly when critical routes for them were not offered. One participant shared, "I don't have access to services everywhere...I'm limited to places they take me. Like right there where I go to therapy...they can't take me. There's no bus to take me out there."

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Figure 5. Photo of bus routes representing public transportation.

Drugs and Alcohol All Around Me

Latinos with disabilities reflected on the effects of their community environment characterized by the high accessibility to both drugs and alcohol. One participant expressed, "Why does this problem exist? Because it's all over in our society, it's everywhere. It's on every street corner. Just call the *conecta* [connect to the drug dealer] and they'll bring it."

Participants indicated that methamphetamine was the illicit drug most widely abused and accessible in their community, with the exception of marijuana. Participants described the devastating effects methamphetamine had on their community and the attitude and behavioral changes of abusers. One participant shared her experience:

> It's like everybody…you knew everybody that was smoking meth. Instead of going out to a party or club and dancing, you go to a garage where

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> everybody is smoked out on meth. Everybody is like…you have one person looking out the window, the other one's looking through a TV monitor making sure cops ain't coming…

In addition to the high accessibility to illicit substances, participants also reported high accessibility with respect to alcohol. One participant stated:

> This is a picture of a market…It's like plastered in beer signs and pretty much just shoving it in your face. Advertising it in your face, just beer, you know? Excessively, just like, man there's even little neon signs just flashing…what's really happening here is that beer is being advertised excessively. It's just being pushed on you…To buy beer, beer, beer, you know what I'm saying? I see that there's just lots of times and places in the community that you're being tempted and pressured to drink or maybe even smoke or do drugs.

Similarly, another participant mentioned, "And this picture, it's just a picture of a liquor store and it just represents my community…And it's just like a temptation whenever I just go to the store."

Figure 6. Local convenience store with alcohol advertisement.

Being Discriminated Against As a Latino with a Disability

Participants shared the various ways in which they experience discrimination. Specifically, participants mentioned experiencing discrimination for being Latino, having a disability, and for abusing substances.

Being Latino. Participants expressed being discriminated against for being Latino. In particular, they shared that they would often be stereotyped as a gang member because of their appearance. One participant said:

> It sucked being discriminated against...I was 8 years blind already and I wanted to change my life so bad. And I got information about the Braille Institute. They were going to teach me how to walk with a cane, teach me how to use a computer, a bunch of things, right? And these people just judged me by my looks. They stopped me from getting this information.

In addition, participants shared the ways in which they have experienced discrimination when seeking employment opportunities. One participant affirmed:

> Out in the real world...outside of my community it was a real struggle for me to get a job. I could talk to you over the phone, but when they met me, it was, "You're Mr. Calderon?" Because of that Latino...the baggy jeans, the short hair...I think I dress neat. Just because I iron my clothes, I'm a gang member in society...and I'm Latino.

Similarly, another participant mentioned, "For myself, as a Latino...I've always had my head shaved or my hair cut low. And that's been associated with being a Latino gang member." Another participant shared her experience of being stereotyped as either promiscuous or a Latina gang member:

> Everybody thought I was a gangster and women would hold their purses...I think the stereotypes for Latina women...either we're whores or we're cholas [Latina female gang member]. But there's never an in-between. There can never be strong, good Latina women.

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Having a Disability. Participants talked about the ways in which they experience discrimination for having a disability by providing examples of discriminatory actions or messages from others. One participant expressed:

> They get mad when I try to get on the bus, but I can't cause my chair is too wide and I'm hitting the bars and all that. And so I tell them, "Ay relax dog. I'm in a wheelchair, you know? Come on ay." But, they're still talking shit.

Participants also discussed the stigma that is attached to having a disability, and how they perceive that disability is shunned by members of the community. One participant stated, "For a lot of people in the community...disability is shunned and we just get the doors closed on us." Another participant affirmed, "Labeling, I guess that's the stigma part. If you have a disability it's like, 'Well, you're not like us.'"

Participants reported experiencing discrimination in the work environment. One participant described a recent incident that occurred at his workplace:

> I didn't really know how to take it (experiencing discrimination). It was the first time that I had been called Cyclopes, or at least brought to my attention...It's kind of like, even if I did have a Cyclopes eye, I can get around and do what I do.

Participants expressed that a particularly stressful form of discrimination refers to discrimination from former friends. This often increased the feelings of isolation and challenged their self-esteem. Participants perceived that it was because of their disability that friends stopped talking to them. One participant stated, "A lot of people that I used to talk to before, they don't talk to me no more. And why, cause I'm in a wheelchair...It's just an accident, you know?"

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Substance Abuse. Participants described the ways in which they experience discrimination for using licit and/or illicit substances. Participants explained that it was common for non-abusers to think that they were "better" than them because they did not use. One participant expressed, "It's hard because people tend to think that they can disrespect you. People that don't use [drugs or alcohol] think they are better than you. They think you are worthless, that you're nothing."

Participants also indicated that substance abuse carried with it a stigma in the community. Participants explained that they would be labeled and judged for substance abuse. One participant mentioned:

> Well, the community is really aware. The people that live around you, they're really aware of who you are and what it is that you do. Even people who I don't know, somehow they know that I drink or that I use drugs. And it's kind of like I've been labeled this. And I just don't enjoy being judged or having people that don't even know me to have opinions about what they think my life is.

Of particular concern to participants was the stigma and label attached to their substance abuse because of a lack of empathy. Specifically, participants expressed that people lack an understanding with regard to their substance abuse because they overlook how contextual challenges, life experiences, and historical context are associated with the onset of substance abuse as well as relapse. One participant described this struggle:

> I know it's just a label when they say, "Them addicts, all they care about is getting high." And that's not true. They don't look at what affects us. They don't look at our consequences. They don't look at what's come before us. All they look at is just that label. And the label says a lot in one shot. Just being an addict mother with a disability says a lot. So I think it's more of a label than anything cause people don't look at the way we grow up or anything. Where we've grown up, or how? Cause they don't care…I think

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> they don't care. I mean for somebody to label us like that, that would be wrong, right?

EXPERIENCES WITH HEALTH AND MENTAL HEALTH PROFESSIONALS AND SERVICE PROVIDERS

Participants shared the ways in which they have had negative experiences with health and mental health professionals and service providers. Descriptors for this life-world context include: (a) not having access to mental health, (b) being stigmatized, and (c) being put down by service providers.

Not Having Access to Mental Health

Not having access to mental health care constitutes a significant challenge for Latinos with disabilities. One particular challenge with respect to access to mental health care refers to the lack of financial resources, and more specifically, lack of health insurance. One participant affirmed, "They ain't going to do nothing for free, you know? Anywhere you go, they want to see your MediCal, Medicare, or money. They won't do nothing for free."

Although the majority of participants were non-immigrant, U.S.-born citizens, a particularly relevant life-world descriptor with respect to access to health care for immigrant, foreign-born participants refers to documentation status. Specifically, undocumented participants in this study expressed that in addition to not having health insurance, many programs would not offer them help because of their documentation status. For example, one participant expressed, "There's not a lot of programs that will take me cause I'm a Latino and I don't have papers. So it's a lot harder for me."

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In addition to financial limitations, lacking health insurance, and documentation status, participants expressed that a significant barrier to access mental health resources refers to the lack of outreach and engagement initiatives from institutions. Participants expressed a strong desire to seek out mental health services, but did not do so because of the lack of outreach initiatives available to them. One participant shared:

> Nobody reached out to me and said, "What can we do to help you?"...And you're left to deal with it on your own, or you're left to find your own way to deal with it. And unfortunately for me, that was drugs and alcohol.

Stigma and Receiving Mental Health Services

Participants reported a fear of receiving mental health services because of the stigma attached to receiving services. Participants described their perception that a common stigma associated with mental health services is that these services are for "crazy people." For example, one participant expressed, "I think the stigma too, of you receiving mental health. I think the fact that, anybody find out that you're getting mental health, 'Man what's wrong with you? Are you crazy?'" Another participant commented:

> There is no funding or it's really taboo...People will tell you, "Oh what. Why? Are you crazy? What's wrong with you?"...So it's like, there is still a big stigma. It's a really big taboo subject when it comes down to it, when you say, "I'm on meds." You have to be bipolar cause that's the only thing they know. Or, you are schizo...that's how the community thinks.

Latinos with disabilities also expressed being taught at an early age that receiving mental health services means that you are "crazy." One participant explained:

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> It is taboo, in our community if you go to therapy, you're crazy. Something's wrong with you. Like when I told my baby's dad, when we were still together, "Oh, let's go to therapy", "Why? I'm not crazy. There's nothing wrong with me." But, for some reason we are taught at an early age, or it's programmed into our head, that if you go to some kind of therapy, you are nuts…There's something wrong with you.

Being Put Down By Service Providers

Participants overwhelmingly expressed the ways in which they have experienced being put down by service providers. These experiences led to feelings of mistrust and high reluctance to seek health and mental health services. One participant described his experience of going to the Welfare office, "I've gone to the Welfare and they're rude, evil, and they just bash you when you're trying to be nice. You come in with a smile on your face and they take it off quickly."

Participants described the ways in which they have been put down and discriminated against by service providers. For example, some participants expressed being accused of having children so that they could collect money from the government. One participant mentioned:

> It was when I first went in there…I remember hearing people, "Oh, she's just having more kids so that Welfare can give her more money." What the hell, you think $584…I'd rather get a job and get paid than get paid $584. I ain't having kids just so they can give me money…They don't give you anything, but yet you go and the workers act like they're giving you the money out of their wallet. It's hard…It's hard especially when you have kids and things cost so much. Diapers, a box of diapers is like 20 bucks. It's 88 diapers and they go threw them in two weeks.

Research participants also shared feeling put down by service providers because of not receiving vital information in a timely manner to promote their well-being. By not providing the necessary information, participants expressed feeling "h

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feeling “held back” by them. One participant described his experience with state rehabilitation counselors:

> Damn state rehab counselors. These people work and they even have a disability…and they act like if they are buying the things out of their own pocket. They won't help you get your things in time. They don't try to support you a lot and they judge you by how you look. Like I had a lot of problems with them too…my state rehab counselor held me back for so many months to get the tools that I need for my disability…a lot of information that is out there that us people with disabilities don't know nothing about.

Participants in this study expressed a sense of hope with respect to their successful adaptation to disability and overall recovery. However, participants mentioned that many service providers did not share the same level of hope. One participant explained feeling put down because her rehabilitation counselor informed her that she would not be able to walk in the future. One participant described:

> She put me down…I asked her, “OK Ms., since you've seen me walking and all that, what do you think? Am I going to be able to walk in the future all by myself?” And she told me, “By yourself, no.” And then I told her, “With a walker at least?” And then she told me, “No!” And then I asked her, “Why?” And she told me, “You can't keep your balance and when you do your turns, you pick up the walker.” And I asked her, “Isn't that why I'm here in therapy, so I can retrain to do all that?” I just left it like that, you know? That's fucked up. People shouldn't put you down.

Service Providers Lacking Cultural Sensitivity

According to participants, a particularly challenging life-world experience refers to working with service providers and professionals from different cultural backgrounds. Participants expressed a strong desire of having the experience of working with Latino professionals and service providers, yet there were only a handful. In addition, participants indicated perceiving those providers from different ethnic and racial backgrounds to lack cultural sensitivity toward them. For example, one participant expressed:

> That's what the first therapist told me...the fucked up thing is that all of them have been White, you know? The first therapist, when I tried to go back to get some therapy, they told me that I was too fat. That I was never going to walk. They told me the same thing that this therapist told me.

Participants described service providers as impersonal, despite the participants' hope for understanding and compassion. One participant stated, "More compassion, to understand that you just didn't relapse because you're this bad person, or judging you...No. Like, being more understanding."

Participants also expressed professionals and service providers lacking cultural sensitivity with regard to disability and substance abuse. One participant described his experience with a social worker:

> The thing that I would probably relay to them is them knowing substance abuse. Or them getting more educated in addiction and recovery...sometimes social workers could not relate or have no idea of what disability is about. Maybe having them be more aware of what disability and addiction is all about.

WOMEN EXPERIENCING EXCLUSION AND DISCRIMINATION

Although this study was not aimed at examining gender differences in the lives of Latinos with disabilities, women participants expressed important life-world experiences with regards to exclusion and discrimination that warrant special attention. Specifically, they reported the following unique descriptors: (a) programs of support are not designed for women, (b) substance abuse in women being overlooked, (c) they put men in jail, and (d) intimate partner violence is pervasive but overlooked.

Programs of Support Are Not Designed for Women

Women participants expressed that programs are not tailored to meet the specific needs of women in the community. Women participants expressed that their needs with regards to disability and substance abuse, differ from that of men in their community. One participant, for example, expressed, "I don't really feel support that is specifically designed for Latina women." Similarly, another participant expressed the lack of gender-responsive programs in her community. She expressed, "We don't really Have programs like this available to us. We need more promotions, advertisements, or referrals for these programs."

Participants shared the ways in which having programs of support specifically tailored to meet the needs of women could impact the community in a positive way. One participant expressed:

> There aren't programs to help us know that there are other women that are going through the same thing as us...so you think you're the only one and everything is going bad. There isn't that type of support where you know that other women can relate to your situation...That way women who have the same problem can give each other strength in overcoming it together.

Women Who Abuse Substances Being Overlooked

Latinas with disabilities expressed that because there is a lack of prevention and intervention programs specifically tailored to meet the needs of women with disabilities who abuse substances, there is a sense of invisibility regarding the unique challenges that Latinas with disabilities experience. One participant elaborated on this issue:

> The community ignores that women also go through problems. By not having the programs, they are saying that women don't go through these problems. So, just more outreach...That they offer these kinds of places

> so women could know that what they're going through…There's problems that everybody goes through. That it's OK to go and seek help and try to resolve them instead of just living with them and thinking it's just them.

Because of the lack of programs aimed at supporting Latina women who abuse substances, participants are not able to access these services in their own communities. One participant described this struggle:

> It would be nice if I didn't have to come all the way out here for an outpatient program. There definitely has to be more self help programs that are for women and free. Women have substance abuse too.

They Put Men In Jail

Women participants overwhelmingly expressed the disproportionate confinement of Latino men, which has impacted many of them. For example, one woman participant stated:

> Well right after we talked in our first interview, my man got locked up. It's just things you expect. I wasn't even surprised anymore when he went missing. And then I got the call that he was locked up. It was just like, "Oh, Ok. There he goes." We are used to it already…you don't even mourn for the fact that he's going to be in there for a while. You're just like, "Oh, alright."

Similarly, another participant mentioned, "I think the first time they get locked up you cry, you feel bad, you're like, 'Oh my God!' Then it's like, 'OK, he's gone. I know what to do.'"

Figure 7. Photo of Sherriff Department's bus transporting prisoners.

Women participants also described their community as one in which there are many single mothers. This, participants expressed, is attributed to the men leaving for no known reason, incarceration, and/or even death. Participants expressed that it is such a common experience, that they are no longer surprised when they experience this. One participant described her experience of men in the community:

> You're not surprised anymore when something happens to them. If you notice, in our community, there are a lot of single moms. There are a lot of single moms either because they're dead, they took off, they're in jail...it's sad because some of them don't get the opportunities because they don't know of the opportunities that are out there.

Intimate Partner Violence Is Pervasive But Unacknowledged

Women participants indicated that a significant challenge to their lives refers to intimate partner violence (IPV). In spite of the pervasiveness of IPV in the community, participants expressed that their community does not acknowledge or provide the context for having safe conversations on this issue. One participant affirmed:

> Your family just thinks, "Just deal with it. It's normal." Just, "who cares as long as he's the one that's providing." And you want to keep your family together, and for the sake of the kids. Even though it's a serious problem, they just minimize it because you don't talk about the family having all these problems…just deal with it. Who cares? It comes with the relationship, like if it's normal.

Another participant expressed how she feels like she has been "cast out" of her community and cannot talk about the IPV she experienced. She explained:

> Yeah, I feel like you've been cast out…you don't talk about what has happened. Like, my parents have no idea what I went through, but they know I went through it because I was in the hospital.

Women participants also indicated feeling that specific cultural expectations discourage Latina women from openly denouncing IPV in the Latino population. These cultural barriers lead women to experience hopelessness and despair. One participant affirmed:

> So that's one of the biggest barriers, how the culture perceives domestic violence…It's just something you don't do. You don't speak out. You don't ask for help. You don't go to classes. You don't talk about it. It's like a hush, hush according to the Mexican culture or being Latina.

Some women participants reported being IPV survivors. They identified substance abuse as an alternative to cope with traumatic IPV experiences. One participant expressed, "I started using drugs because of domestic violence. I could say that they helped me a lot." She went on to explain:

> But once I got off the drugs, emotionally and mentally I was not OK. Cause I never dealt with my issues. I always seemed to numb myself away with drugs. So when I stopped, I became too overwhelmed and I couldn't bear with my own feelings that I have never dealt with until now.

> So, the drugs, me living this life, it helped me. I never really looked at the way I was living while I was on drugs. It was like just helping cope with the domestic violence. I felt that that was a bigger problem.

Participants described the various ways in which they experienced IPV and the traumatic life experiences they endured. One participant shared:

> I've been damaged for life due to domestic violence and him being on drugs when he stabbed me. My hands are paralyzed, so is my left side cause I got stabbed on my inner left lung and my breast. So I have lost sensibility on my left breast and the side of my lung.

She went on to explain:

> And this is a picture of where I got stabbed. Cause he threw me down 7 steps, he stabbed me 38 times and he kicked me 4 times. I have defensive wounds. My left figure is damaged, it doesn't bend.

Figure 8. Photo of women's hand with scars from knife wounds having experienced intimate partner violence.

Women with disabilities also described the emotional and physical pain they endured due to IPV. One participant expressed, "It hurt me physically and mentally…But I proved him wrong that I would never go back and I'm not going to go back."

These participants also expressed that their children witnessed the situations in which they were victimized by their perpetrators. For example, one participant expressed, "My kids saw when he pretty much beat me up."

Participants were reluctant to discuss the ways in which their children witnessed episodes of violence. However, they described the significant emotional pain experienced because their children witnessed the violence. In addition, participants discussed how these experiences pushed them towards substance abuse. One participant expressed:

> My oldest witnessed some of the domestic violence that I've been through…he still has memories of the domestic violence which is one of the reasons why I started using substances. It's probably the only reason why I even used substances.

BEING SUPPORTED BY MY FAMILY

In contrast to the challenges that participants experience with their families, they also shared the ways in which they experience being supported by them. Because of this, participants reported feeling loved and encouraged by family members, which considerably increased their motivation to recover from substance abuse. More specifically, the following descriptors represent the ways in which participants felt supported: (a) my family being there for me and loving me, (b) my family not feeling sorry for me, and (c) my family giving me strength not to use drugs.

My Family Being There For Me and Loving Me

Participants expressed feeling supported by their families because they "were there for them" through various expressions of solidarity, love, and support. In spite of the fact that many participants have "burned bridges" because of their substance abuse behaviors, family members would still strive to support them. For example, one participant stated:

> How has my family supported me? Pretty much letting me stay at my mom's house even though she kicked me out before. I kind of burned her in different ways, taking stuff or money…she still took me back in her home and she still had love for me. She still fed me although I was messing up. I guess she just had that hope for me. I'm assuming she had it because she always accepted me back and never gave up on me…My family just being there for me and showing me love.

Family members assisting participants with their daily tasks constitute a significant source of support for participants. Specifically, they expressed the importance of feeling loved, humbled and were very grateful for their support. One participant expressed:

> My strength is my mom and my dad cause without them I wouldn't be anything. Thanks to God I have them both cause either my mom or my dad, in the morning whenever I need to wake up…as you guys know I have to wear a diaper, and they go change me and all that, you know? They take me a bath…they have to take a lot of shit cause of me, you know?

Participants reported that family encouragement through words served as a significant source of support. Believing in them and offering words of praise and encouragement proved to be a powerful motivator in working towards recovery goals. One participant described the power of his mother's words:

> You know, before…people used to say I was never going to become nothing in life…And I thank God for this beautiful lady who is my mom. Who always told me, "I believe in you mijo [my son]. You're going to

> become somebody. You're going to become somebody...watch, you are." My strength is my mom's words.

My Family Not Feeling Sorry For Me

Participants indicated how important it is for them for their families not feeling sorry for them. One participant commented:

> And even though it doesn't even really seem like support, man it's the best that they can do to support you because they've already tried to be gentle and tender and all that stuff. Then you just get that tough love.

Participants also expressed uncertainty as to whether their families understood the impact of not feeling sorry for them. One participant expressed:

> For me I thought, I'm blind in one eye, so mom you should move the furniture around to accommodate me. And that didn't happen. More or less my mom told me, "You know what, you just feel sorry for yourself and I'm not going to." I don't know if they even know that by them not feeling sorry for me, actually they support me.

My Family Giving Me Strength Not To Use Drugs

A salient theme expressed by participant refers to the ways in which their family served as a source of strength to remain free from drugs. For example, one participant expressed:

> I just don't feel like doing drugs in front of them. Not in front of them, but when they're right there and I go back and be all beamed up in front of them. Like at family parties and be all beamed up all on coke. I feel like they're looking at me, like they know. And my mom would kick my ass if she knows...But my family is the one that gave me the strength not to do drugs anymore.

Participants also described how being responsible for family members served as a motivation to stop abusing substances, particularly because other family members relied on them. One participant mentioned:

> My family helps me not to use drugs...My dad doesn't want me to get high. He's like, "well what if you go out there and get high and don't come

> back? What about the kids and what about me." So, he doesn't want me to get high.

BEING SUPPORTED BY MY COMMUNITY

In contrast to the contextual challenges reported by participants, they also elaborated on the various sources of support available to them in their communities.

People Understanding What I'm Going Through

Participants of this study described how members of the community who express an understanding of their experiences constitute a significant source of strength in their lives. This support allows them to feel as they are part of the community. One participant described, "Right there in my apartments, they understand that I have a disability…It's cool. They're cool and a lot of people understand me. They understand what I'm going through."

Participants further described the ways in which members of the community show them support. One participant affirmed, "Just by them expressing their friendliness and that they're there for you. That's how the community understands and is supportive…Just telling you, 'You could do it.'" In addition to friendliness and encouragement, participants described the ways in which they could find support for food and clothing in their communities. One participant expressed:

> Neighbors, people I see, people I meet…Those are my help. Yeah cause people that I know, they help me out…with clothing, they give me food, they talk to me and want to help me out like, "I've got a program for you." They understand my situation.

My Community Embracing My Culture

A common theme expressed by Latinos with disabilities refers to the ways in which they felt support from their community with regard to the open recognition and value of the Latino culture. For example, one participant mentioned, “In the community, you have the art work…Also through the neighborhood…through the neighborhood is about Brown Pride.”

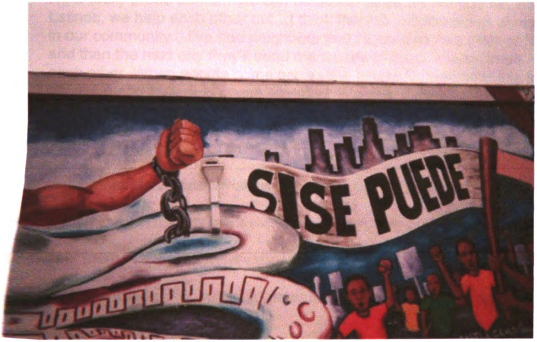

Figure 9. Photo of a mural on a neighborhood wall with the words “Si Se Puede” (It Can Be Done).

In addition to Latino cultural murals and artwork displayed throughout the community, participants expressed the importance of cultural fairs and activities held by and for the community. Such cultural events provided participants with the opportunity to reflect on their culture. One participant expressed, “They always have the big fairs and they make it seem like it's a Latino thing. And they do the dances, the Aztec dances and all that. And it's just refreshing."

Participants shared a strong sense of community cohesion with respect to the Latino culture. Participants expressed the collectivistic nature of the community which represents one key value of the Latino culture. One participant stated:

> For me, the Latino community, that's my community because I'm Latina. I'm a really proud Latina...we can be united when we need to be. As Latinos, we help each other out...I think there is still some sort of respect in our community...I've had neighbors that I'll send them a plate of food and then the next day they'll send me a plate of food. We are there for each other. When people come across the border, I remember this family moved in and they didn't have anything. We sent them clothes and shoes...we can be really united as a people when we want to be.

My Community Reaching Out To Me and Helping Me

Community resources constitute a critical source of support for Latinos with disabilities. As one participant expressed, "To know that there is that extra support out there, it's awesome, it's great." Knowing that there are systems of support facilitates the participants' engagement in community activities. One participant said:

> I'm starting to get a little more involved in the community and I think it's pushing us towards a more positive outlook to stay clean and sober. Really, it is because there is a lot of support. Like 5 years ago, there's a difference...So, now that I'm starting to see changes in the community and I see the community coming together a lot more now, that's what I see. Well, that's what I feel.

Participants also provided examples of the different types of support in the community they can reach out to. For example, one participant mentioned, "I think too, is an info line called 2-1-1 and they can answer anything...if you are homeless in the street and you need emergency food or shelter. I think that's just a good thing in my community." Similarly, another participant described how the community has reached out to her and has provided her with support:

> In the community, there is a resource center...They have free resources there like during Christmas and on Thanksgiving, they have free baskets. Resources that we have are strengths to the community as well as strengths for me.

Figure 10. Photo of a community center with the sign "Bienvenidos" (Welcome).

Summary of Life-World Context

Participants described the ways in which their communities constitute both a source of support as well as a challenge to their process of adaptation as individuals with disabilities. For example, participants identified poverty, violence and gangs as significant barriers to their lives. In addition, participants described in great detail the multiple levels of discrimination they experience as a result of being Latinos with disabilities who have abused substances.

Participants described how being *put down* by their family often times has

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led to decreased self-esteem, not feeling loved, unwanted, and relapse. Research participants also described negative *experiences with health and mental health providers and service professionals.* In particular, participants expressed a lack of trust and anger towards service providers because of experiences of *being put down* by them. Participants also described the struggle of not being able to be served by Latino professionals who would be likely to have an increased awareness of Latino cultural values and traditions. Furthermore, participants indicated how common it is for health and mental health professionals, as well as service providers to lack cultural sensitivity.

Women participants in this study expressed significant life-world experiences that warrant our attention. The feature, *women experiencing exclusion and discrimination*, emerged from the data as a result of the significant contextual challenges faced by women participants in this study. Women reported that a significant contextual challenge to their lives refers to *programs of support that are not designed for women,* including gender specific programs specifically tailored to meet their needs. In addition, women participants in this study described how Latino men are at risk of disproportionate confinement (*they put men in jail*), *as well as Latino men's increased risk for dying at a young age due to community violence.* Finally, women participants mentioned that *intimate partner violence (IPV) is pervasive but overlooked in the Latino community.* An inability to speak out or seek help for IPV because of cultural and community restraints, proved to be a significant barrier in the lives of women participants who are IPV survivors.

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Research participants also described the ways in which they experience *being supported by their communities.* Various forms of support include understanding what having a disability means to participants, recognizing the importance of culture through various art and cultural fairs, and offering support and resources such as prevention and intervention programs. Finally, participants expressed *being supported by their families*, which constitutes a significant source of strength to them. Participants' families showing *love and being there for them,* without *feeling sorry for them,* provided participants with a sense of self-worth and belonging that is critical for their process of recovery.

PHENOMENA, COMPONENT PHENOMENA, AND INTENTIONS

Lived experience data refers to phenomena describing intentionality. That is, life experiences that occur based on the individual intentions and proactive behaviors. For example, research participants uniformly reported an initial struggle as they experienced the conflict of having to find a new identity as individuals with a disability. As they tried to find their new identity, participants were likely to experience intense feelings of pain, sadness, and despair. Some participants openly shared feelings of no longer wanting to live. They also expressed the great desire of wanting those feelings to go away. In an effort to escape from those feelings, participants turned to licit and/or illicit substances.

Because of their drug use, participants expressed experiencing the loss of both their children and families, which often times perpetuated the abuse of substances. Although participants understood the need to discontinue their use of substances in an effort to reestablish relationships with their children and famil

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families, they would often resort to substances in an effort to numb distressing emotions. Participants described the emotional pain as if they were "drowning." To escape from these feelings, participants would turn to substance use, which in turn, would "intensify" their emotions and lead to increased substance abuse. Having gone through an initial phase of intense emotional distress and despair, participants reported that slowly, a desire to change would emerge. This desire for a new life would become so intense that it turned into their main motivation for change. Some participants attributed this desire to change as "coming from within," while others found that their children and families motivated them to change. Participants indicated that the strong desire for change led many to accept and embrace their new identity as a Latino with a disability.

Participants overwhelmingly expressed the great need for their community to be accountable for promoting social awareness with respect to disability and substance abuse. In addition, participants mentioned that in order to support their efforts for change, the community needed to be more proactive by offering more help and services.

Research participants described their experiences as Latinos with disabilities and substance abuse according to the following phenomena: (a) experiencing the struggle of living with my disability, (b) not giving up and wanting to change, (c) accepting and embracing my disability, and (d) wanting more help and increase awareness in the community.

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EXPERIENCING THE STRUGGLE OF LIVING WITH MY DISABILITY

The onset of disability brought to participants a wide range of emotions such as intense emotional pain, sadness, fear, anger, and despair. Component phenomena of experiencing the struggle of living with a disability included the following: (a) experiencing pain and sadness, (b) trying to escape and forget about my disability, and (c) feeling inferior to others.

Experiencing Pain and Sadness

Latinos with disabilities described in great detail the pain and sadness experienced in relation to their disability. Intentions reported by participants include: (a) crying about my life and wanting to die, and (b) experiencing despair when the feelings come back.

Crying about my life and wanting to die

Participants described the emotions they experienced at the onset of their disability. They indicated that a common experience referred to intense feelings of loss, sadness, and despair. For example, one participant expressed, "There are times when I stay in bed and cry about my life." Similarly, another participant shared the emotional pain and the everyday struggles he endured:

> You can either choose to stay there and think that it's going to be too hard or impossible, or you could just take all the pain and the suffering that is going to come with it and get up and just do. Like, I'm not going to lie...Everyday it's very painful. I cry every day.

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Participants also reported feeling depressed as a result of experiencing the loss associated with the disability. In particular, participants described the painful reality of waking up to a life of limited ability. Some participants openly shared feelings of no longer wanting to live. One participant expressed:

> For me, being in a wheelchair, it's been really hard, you know? I was really depressed...I wanted to die. I didn't want to face society. I didn't want to face people. I didn't want to see the things that they would say about me or the expression that I thought they would have about me. When I was in the hospital, I said, "God, please kill me!" And I know that's a bad way for me to think, but that's how I was feeling at that time. Cause come on, one day you're walking and then the next day you're not.

Another participant expressed the great desire to make the emotional pain disappear:

> I took a crescent wrench to my face one time and I slammed myself in the face with a crescent wrench about that big to see if I could break my bone...The doctor said that if I took another big blow to the face, that my eye could fall out because of the socket. The orbital socket is already broken, you could feel the damage. And I took a knife to my stomach one time and tried to stab myself and I couldn't really do it. I've done things...where it's like, I don't care if I get killed, you're doing me a favor.

This participant went on to share:

> I have to honestly say, I've tried to kill myself. What person in their right mind takes a knife to their stomach or takes a crescent wrench, and hits himself in the face? What sane person does that?

Participants also described taking lethal amounts of illicit substances because of the emotional pain they were experiencing. One participant affirmed, "I've chewed on a gram of meth just to see if I would OD [over dose] to take me out of my misery."

Latinos with disabilities indicated that one of the factors contributing to their depression was society's perception of disability. As a result, many participants expressed feeling ashamed of their disability which contributed to their depression. One participant described the shame he experienced:

> The reason I was depressed and miserable was because I was ashamed of myself. How am I going to face society when people have seen me walk one day, then the next day they see me in a wheelchair? How are they going to treat me? How are they going to be towards me?...And I really felt bad because of that.

The feelings of pain and sadness, combined with a sense of shame for having a disability, resulted in participants wanting to hide their disability because of the stigma attached to having a disability. One participant expressed:

> Naturally, when I first got my disability, I didn't want to hear nothing. But yet, I still went out there. I still went out into the streets 12 days after...I remember people looking at me like, "Damn!" They're not going to take away my eyesight and hide my face. Eventually, it got to me so much that I ended up hiding my face.

Experiencing despair when feelings come back

Participants described a cycle of emotions which was characterized by a sense of normalcy and acceptance, contrasting with a sense of despair when feelings of pain and sadness would return. Participants described feeling despair and confusion, and also at times experiencing more clarity and peace. One participant expressed:

> I think for me, wanting to die...it's just that you're so confused. You're so misinformed. You haven't been educated about your disability. You are looking at what it is right then and there. You're not looking at the possibilities. There's a lot though that comes out of it now that I get more clarity or hearing myself again. It's the easy way out. I've said already, die already, it's the easy way out. As opposed to, "what are you going to do about it?" I know for myself, I wouldn't allow anybody to talk to me like that. But at the same token it was like, nobody is going to hurt me but me. And I did it. And I think also, the drugs and meth itself does bring the emotions back. It's part of the meth itself along with your mental state of mind already that bring the pain back.

A challenge for many participants refers to experiencing despair when ce

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certain emotions returned. In particular, participants expressed wanting to use substances to cope with feelings of despair and profound sadness. One participant explained:

> Well, me when I'm not using, that's when I really feel depressed. There's days that I wake up and I just feel like laying there and crying in bed all day...All my feelings, they just come right back...that I hate to feel.

Trying to Escape and Forget About My Disability

Wanting to escape and forget the challenges resulting from having a disability was a common experience expressed by participants. Given the intense and various emotions experienced by participants with regard to disability, combined with the perceived shame and stigma of the larger societal context, participants indicated a desired to escape the reality of their disability. Intentions for the component phenomena "Trying to Escape and Forget about My Disability" include: (a) trying to put aside and forget that I have a disability, (b) turning to Drugs to escape my Disability and Depression, (c) losing my children to drugs, and (d) feeling inferior to others.

Trying to put aside and forget that I have a disability

Having experienced significant emotional pain, despair and marginalization from the community, participants expressed wanting to put aside and forget their disability in hopes of restoring some sense of normalcy in their lives. One participant described the great lengths to which he would go in an effort to forget about his disability:

> Having a physical disability...I would cut school just so I wouldn't get made fun of at school. So, people won't say, "Oh you're slow." So I turned to drugs when I would cut school to...I guess to forget that I have a

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> disability. But, in turn by me doing that, instead of rising above it, I ended up crashing like an airplane.

Participants also described the ways in which they would attempt to put their disability to the side. In an effort to "put their disability to the side," participants would sometimes engage in antisocial and illegal behaviors. Furthermore, participants whose disability wasn't so apparent (e.g., not using cane or wheelchair), expressed a desire to not inform others about their disability. One participant expressed:

> I hung out with a group of people which we would just go around and cause trouble and do drugs with other people. So, in my mind I was putting my disability to the side to show off somebody else who I really wasn't....Cause in my life, there's only a few people that know about the disabilities that I have. There's probably only like a handful of people that do know.

Turning to drugs to escape from my disability and mental health problems

As a result of dealing with the reality of disability, mental health problems were commonly reported by participants. In an effort to cope with distressing feelings, participants expressed the use of licit and illicit substances as a coping mechanism. One participant expressed, "My disability pushed me to use and I made the situation worse…it was because of my depression though which pushed me to use."

Participants explained substance abuse as a means to numb the emotional pain and suffering. One participant affirmed, "You want to get to that point where you're just numb. And you stay numb...and you stay numb. You isolate, you stay numb." Similarly, another participant explained, "That was like the best thing of using because all that feeling would just go away." Participants described how being alone would lead to depression, and depression would lead to increased substance abuse in an effort to numb the pain. One participant expressed:

> I just feel depressed when I'm alone. Depression just makes me want to use cause it makes me not feel anymore. Those feelings just go away. I won't feel anymore. I won't feel anything.

Similarly, another participant shared his strong desire to ease the pain by numbing his emotions through the use of illicit substances. He expressed.

> To suppress feelings…I feel pain, I don't want to feel this pain. Let me ease the pain with some drugs. Let me numb that pain, I don't want to feel that pain. So we put all these drugs in us and we don't feel anything.

Participants also shared feeling overwhelmed once they discontinued substance abuse and began to feel distressing emotions again. To cope with these feelings, they turned to drugs. One participant shared, "For me, it's emotions and feelings. When I feel like I start getting overwhelmed or even when I start feeling something, I tend to go to the drugs to numb my feelings away."

Participants also described in great detail feelings of low self-esteem and inadequacy because of their disability. Participants described wanting to be left alone and taking large quantities of illicit substances to placate undesired emotions. One participant mentioned:

> I would take enormous doses or use amounts like it was nothing…meth like it was nothing…And I would go overboard because of the fact that I was feeling depressed, miserable, inadequate, and I just wanted to be left alone, probably to die.

Losing my children to drugs

One of the most devastating life experiences expressed by participants referred to losing their children. Women participants in particular, described experiences of losing their children to the Department of Child and Family

Services (DCFS). The removal of their children primarily occurred because of the participants' substance abuse. One participant, expressed, "I was too into drugs…I lost all four of my kids to my sister for adoption." Participants described losing their children as paying the ultimate price for their substance abuse. One participant affirmed:

> Losing our kids is one of the great biggest challenges we have, to lose our kids. And to try and get them back is so hard…I wasn't grateful for what I had so I took advantage of it and I continued to use drugs and substances and I paid the great consequence which was losing my children.

Participants described losing custody of a child as an experience filled with grief, pain, sadness, and even comparable to death. One participant expressed, "Losing the kids, that just devastated us and it drowned us even more… it's the worst. It was like death, dying right there."

In addition to the pain associated with losing custody of a child, participants also expressed feeling ashamed and "like a failure." One participant described the experience of almost losing her daughter:

> When my child was in jeopardy of getting taken away, I felt ashamed of myself…I felt really scared and I felt like a failure. I accomplished so many things already and because I was being selfish and I wanted to smoke weed…I forgot about my daughter. I forgot about the most important thing to me.

Participants expressed that having their children removed from their home led to increased substance abuse. For example, one participant expressed, "My kids getting removed…Just getting them removed, the whole depression and everything just pushed me to want to use more."

Participants also commented that having their children removed afforded them more time to themselves. This time was spent on reflecting on some of the neg

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negative realities of their lives, including the fact that they no longer had their children. One participant shared, "We recently got our kids removed. So that was all my time. I use to be busy before with my kids. Now I had nothing to do, so that was the only thing there…eventually I turned to it (drugs)."

Participants expressed that having their children removed made life much more difficult for them and, in fact, increased their desire for substance use. One participant affirmed:

> That's what makes it harder for me. I just think it would be a lot easier if I did have my kids. Cause the reason why I started using more and more is because they were removed from me. I didn't have them. I didn't have anything to do. I had a lot of time on my hands and it just made me use more and more.

Figure 11. Picture of a playground representing participants' children.

Feeling Inferior To Others

One of the most challenging life experiences reported by participants refers to feeling inferior to others. Because of their level of ability and the messages received from the larger societal context, participants indicated feelings of inferiority whenever they compared themselves to their non-disabled counterparts. Participants described feeling disenfranchised and perceived themselves as *damaged goods.*

Seeing myself as damaged goods

Participants expressed the various ways in which they negatively perceived their disability. One particularly distressing perception referred to seeing themselves as damaged goods. One participant expressed:

> It's just society in general, if something's wrong with you they will pick you out. And that's what I mean by who is going to want you? As it is, I'm a drug addict, can't hold a job, I've got three kids. I have so much else going on and it's like, now with this disability. Who the hell wants me?

With respect to perceiving themselves as damaged goods, participants expressed the pain associated with realizing that there was nothing that could be done to reverse their disability. One participant indicated, "There's going to be some type of repercussion from your injury period. There is nothing that will heal us where we are going to be 100%. We're going to have limitations." Similarly, another participant described feeling inadequate, "We have physical scars that we can actually touch, not to mention feel. It's just that feeling of inadequacy."

Latinos with disabilities also expressed feeling inferior because they lack the necessary education needed to obtain a successful career. Many participants indicated not pursuing higher education or job skills training because they had to first deal with the emotional and physical pain of disability. One participant expressed:

> I've wasted all that time...Not getting well educated and learning about what's out there. The technology and everything is so advanced that sometimes you think you're not good enough or you just want to not even try because it seems so hard. Cause, "Where's your resume," you know? Like, you get it? Like, you're supposed to have a resume and be like the regular people out there when all along you've been with your disability and time just went by.

NOT GIVING UP AND WANTING TO CHANGE

In spite of the contextual challenges and emotionally painful life experiences expressed by Latinos with disabilities, participants expressed a strong desire for not giving up on life, as well as a strong desire to improve their quality of life. These experiences are described in the following component phenomena: (a) not giving up, and (b) finding a motivation to change.

Not Giving Up

Participants reported feelings of despair, anger and grief associated with having a disability. They also provided detailed descriptions about how substance abuse became an alternative to cope with a wide array of distressing feelings. However, as they gradually adapted to their new life with a disability, they expressed a strong desire to recover and regain control of their lives. Intentions for not giving up, which include the following: (a) getting up, fighting and deciding to get my life back, and (b) wanting to break the cycle.

Getting up, fighting and deciding to get my life back

Getting up and fighting is a unique experience for Latinos with disabilities which refers to their great desire to overcome adversity in their lives. Participants expressed that, despite the numerous contextual challenges they face, they are committed to overcoming such barriers. One participant described this desire:

> Strength is that we know about it, that it exists, and we're doing something about it. We know about places that offer help and we're seeking the help because we're admitting that we have a problem. And in order for our problem to be solved, we have to know and not be in denial. So our strength right now would be that...We're here attending and wanting to be better.

Participants also expressed that an important step in the struggle of getting up and fighting refers to the willingness of being open to different perspectives as well as the commitment to remain receptive to positive feedback. One participant affirmed:

> By allowing ourselves to be here...by still coming and allowing them [counselors] to tell us right from wrong. Even though they are just counselors and they're doing their job...I'm pretty sure they became counselors for some reason...So what they tell us, it's only for our own good...So I take up what they see in my problems. I guess criticism is a good thing from somebody that may have been through it already.

Participants identified hope as an important factor in their struggle to fight and overcome challenges in life. One participant commented:

> Obviously it's in us to want better. The cry for help, we know that somebody believes in us and it just makes us not give up on ourselves. That if we try, like I said, something good has to come out of all this badness. That's the way I see it. If we just try, one day everything is going to be better.

An important aspect for participants with regard to getting up and fighting refers to the strong desire of no longer wanting to abuse substances. In an effort to stop illicit and licit substance abuse, participants expressed the importance of staying engaged in prevention and intervention programs. One participant described their commitment to attending a substance abuse treatment program:

> I'm here every day early and everything, but this time I'm here because I want to be here. This time I'm here because I brought myself here. This time I'm here because I didn't wait for nobody to tell me where I had to go. I knew already what I had to do…I know what I have to do to make it right. And I'm here because I want to be here this time. The last time maybe I was here because they told me to come here to do this and to do that. This time I didn't wait for them to tell me anything, I came on self will. And that's the big difference this time. I try to keep my attendance because then I feel like if I miss one day, I feel like I miss a lot. This time I feel like I don't want to miss anything cause it's different, finally.

Wanting to break the cycle

Participants shared the various ways in which they experience daily triggers in their lives which drive them towards substance abuse. From the daily challenges of perceived discrimination and being put down by their families, to the feelings of despair and inferiority, participants expressed daily obstacles which led them towards substance abuse. For example, one participant expressed, "I keep saying I'm going to stop drinking, I'm going to stop drinking. And I keep going back to it. I keep going back to it. It's been a year in a wheelchair…" Participants expressed the great desire to stop abusing both licit and illicit substances. One particularly challenging dynamic for participants refers to family generational abuse of both licit and illicit substances. For example, one participant expressed, "It's like, everybody in my family uses and it just keeps going on from generation to generation."

Wanting to break the familial and transgenerational cycle of substance abuse was a significant motivation for participants. Participants expressed wanting to break the cycle for their families and children. One participant expressed, "My strength is to break the cycle in my family for myself and for my kids." Another participant described how her parents' drug use led her to begin using substances. In an effort to break the cycle of transgenerational family drug use, she maintains minimal contact with them. She explained:

> Yes, my mom is pretty much one of the people who really got me started on meth. She still uses to this day, she uses methamphetamine. My dad, he's an alcoholic. It's like, I go visit my mom or my mom comes visits me, and right away the first thing is, "Can you get me some shit?" So, that's why I try to stay away from them. That will be the best way to break the cycle.

One participant further elaborated on this issue:

> The ones I look at the most are my parents. I do not want to go the same way. My mom came to me offering me drugs. My dad comes to me and offers me a beer. I don't want to follow the same footsteps so I look at them and it really stops me a lot, to stop and think.

Given the pervasiveness of substance abuse and high accessibility to both licit and illicit substances in the community, coupled with family transgenerational substance abuse, participants expressed experiencing substance abuse as a "normal" part of life. In spite of this sense of normalcy, participants expressed a great desire to break the cycle. One participant expressed:

> I think we have to break those cycles because it happens over and over again. And I think it's up to one individual to say "No, it stops here"...I think we see something so much, so often, that we think it's normal. That this is the way we're going to be because this is the way our parents were. I think, you know how they say positive affirmations, once you say it enough times you believe it, I think it's the same thing with negative affirmations and negative things. And I think that if we think this is normal and we're learning to function in our dysfunction. And that's why things repeat. And

> it's like, we do it because we think…it's dysfunctional but we think that that's normal. So we learn to function in it. It's horrible, but a lot of us…right now we're trying to break that cycle by coming here…

Breaking the cycle was not only important for the participant to stop using, but also to model for their children a life without drugs. One participant explained:

> That's why I want to break the cycle. I want my kids to know that there doesn't have to be alcohol for a good time or they don't have to see mama smoking weed. That's why I want to change.

Similarly, another participant affirmed:

> That's the thing, we're shaping another life. We're shaping their course of life. And I have a boy and I know you have a boy too…It's up to us to build strong men and women and by giving them examples, by breaking the cycle. Because a lot of us F'd up because our parents messed up or because it was around us. If we did bad, the next generation is going to do worse.

Finding a Motivation to Change

Research participants described the experience of finding a motivation to change in an effort to improve their lives and the lives of others around them. Participants referred to two factors in respect to finding a motivation to change. First, participants described their desire to change as something that comes from within. That is, participants expressed a strong will and effort driven by self motivation to work towards change. In addition, a strong motivation to change refers to the participants' children. Specifically, participants described a strong motivation to change so that their children could live better lives than the ones they lived.

My strength comes from within

Participants in this study expressed that the strong desire to change comes from their own self will. For example, one participant expressed, "There's so m

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so many things that I can say, but my strength is myself. And I'm doing it for myself." Although participants acknowledged their own resiliency, participants found it difficult to express and were humbled by their own strength and resiliency. One participant expressed, "I know it's patting myself on my back, and don't take it wrong, but the strength comes from within."

Latinos with disabilities described working towards a better life, a life they described without drugs. One participant described:

> I'd have to say that my strength comes from me. Before when I was getting high, I didn't have any dreams. And now I'm learning there is a better way of living life. You don't have to be high or on drugs to cope with life or deal with life. No matter how you look at it, life is going to come and you just have to take it as it comes.

Figure 12. "My past, present and future". This photo displays the Los Angeles County Jail "Twin Towers" in the background, the participant's work place, and railroad tracks symbolizing the road to the future.

Wanting to change for my kids

Participants in this study expressed that their children constitute a strong motivation to discontinue substance use, work towards accepting their disability, and overcome contextual challenges. Participants expressed the pain associated with losing a child and wanting to have their children back in their lives. One participant indicated, "It just really hurts not to be able to be in my kid's life the way I want to. But I know I brought it upon myself. But I really want to change that now. Participants shared the ways in which they are working towards placing their children first in their lives through spending more time with them. One participant expressed:

> This one is with my son. Here in this picture, I see how I could really be a better person to myself and my son like in a healthy environment. And what's happening? I'm spending a Sunday at McDonald's with him.

Latinos with disabilities also described attending prevention and intervention programs in an effort to discontinue their substance use. Participants described that in addition to attending programs for their own well-being, participants aimed to complete a program for their children. One participant indicated:

> I don't have to be here, but I choose to continue coming. I could just stop coming if I want, but I feel like I need to care. I've gone through so much. I've put my kids through so much that I have to do it for me and for them.

Because some participants reported having lost custody of their children, they expressed a strong desire to regain legal custody. One participant expressed, "This one is of my kids. And because of my substance abuse, they got taken away from me and I'm here to make things right for them."

Participants further expressed that the responsibility of having to care for a child also motivated them to change, particularly because their children depended on them. Participants also expressed that if it wasn't for their children, their life wouldn't really matter with regard to being dead or alive. One participant commented:

> I guess if I didn't have a kid…if we wouldn't have someone to depend on us, we wouldn't care. If I go and die, I die. It's not like it matters…But there is someone that is going to miss me. If something happens to us, it affects someone else…So a sense of family or having children is a motivation…I need a stable place now because I have a little one with me. And it's different.

Although participants reported their efforts to break the cycle and a strong motivation to change, participants also reflected on negative family patterns. In particular, participants described the ways in which they repeated many negative attitudes and behaviors similar to that of their parents. Having recognized this, participants expressed that their children were their primary motivation for attending treatment programs. One participant affirmed:

> Everything I hated my mom for, I feel like I'm doing to them…because she was a drug addict and not giving a fuck about us. And the thing is I do care about my kids…that's the whole reason why I'm here.

Similarly, another participant expressed:

> I can't just sit there and smoke a joint or drink a beer. It's something that I don't want my kids to see anymore, something that I need to change for them. I want them to know that there doesn't have to be drugs in a home. There doesn't have to be alcohol in a home for a good time, for birthday parties, or baptisms and all that.

Participants described the importance of being a good example for their children. For instance, one participant expressed, "I want to be able to get my kids the power and the knowledge to know they could do it too. I want to be a

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good example for them." Similarly, another participant affirmed, "But now that I have a son, I can't do that anymore. It's hard, because I never thought about school. Now I think about these things because I have a son and because I have to make my life better for his life to be better."

Participants also described the importance of being strong despite adversity, particularly for their children. For many participants, having a perspective of overcoming challenges as opposed to giving up took several years. One participant expressed the importance of being strong and changing for their children:

> I have to be strong because I do have children. And...it's nice they can see that no matter what happens to you, you don't make excuses. You do what you have to do to get it done. That's the bottom line. But it took me a long time, four or five years to realize that.

My job, giving me a reason to live

Participants of this study described how their job constitutes a significant source of strength to their development as a Latino with a disability. Specifically, participants expressed how having a job not only provided them with financial resources, but more importantly, gave them a reason "to wake up" and "live for". One participant described the meaning of his job:

> To me, my job just doesn't pay my bills. It gives me something to wake up to. Something to get up, get my clothes ironed so the following day I could go to work. It just gives me something to wake up to. It just gives me something to live for, put it that way. And before this job...there wasn't anything to live for. I didn't care if I did or didn't die...It's just another day for me. Now it's not. Now it's like, I get up, make sure I get to work and make sure I get back from work. I say to myself... "I'm doing something for myself." And I love myself...Now I have a reason to live for.

Participants also mentioned that having a job gave them responsibility and an increased sense of accountability for their lives. Having responsibilities afforded them the opportunity to "get out of bed" and feel like a productive member of society. One participant expressed, "This job that I've got here…This job, this responsibility, it gets me up out of my bed and I'm going to do something."

Particularly important for participants was that having a job deterred them from a life of crime and illegal activities. Specifically, participants expressed that without a job, many of them would be forced into a life a selling drugs in order to have a source of income. One participant expressed:

> If it wasn't for this job, I could honestly say I would still have been out there selling dope... Now that I have this job, I'm responsible about a lot of things…I pay rent, I have my own apartment, I pay bills. And if it wasn't for this job, I don't know what I would be doing. I mean, I know exactly what I would be doing…selling drugs.

In addition, participants expressed how having formal employment constitutes a protective factor toward substance abuse. One participant mentioned:

> And in this picture, this is where it all goes down for me 8 to 10 hours a day. I'm happier in this room, than when I would isolate in my own room doing drugs. And this is where all the activity is for me today. And holding a job and being responsible with my co-workers to handle this office and manage this office is a strength that I'm going to be able to use and carry on with.

Finally, participants expressed how having a job provided them with the opportunity to no longer perceive their disability as a disadvantage. One participant affirmed:

> But now, I'm very fortunate to work here cause I don't see my disability as a disability or a disadvantage. When I speak out to the younger kids here who might be going through things that I've gone through…even without the disability, I like to think that it's like, "Hey, this guy has a disability. He's gone through something similar to what I've gone through in the past. If he

> can do it and he's got a disability, why can't I." I would hope that they see it like that.

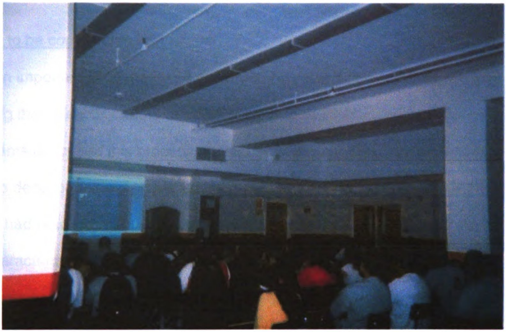

Figure 13. Photo of visually impaired participant presenting as part of his job in front of a large audience.

ACCEPTING AND EMBRACING MY DISABILITY

Participants reported a strong desire for change. For many participants, this strong desire to change led them to accept and embrace their disability. However, participants described this process as one that was both long and challenging.

Trying To Define My New Identity with a Disability

A unique life experience for Latinos with disabilities refers to the efforts in defining a new identity with a disability. Participants described the importance of being comfortable within their own bodies and wanting to be treated just like their non-disabled counterparts. In addition, participants reported on the importance of being "normal," just like their non-disabled counterparts. Intentions reported by participants include: (a) wanting to be comfortable with myself, and (b) wanting to be normal just like you.

Wanting to be comfortable with myself

An important life experience described by participants with regards to accepting their disability refers to feeling comfortable in their new bodies. Participants described this process as both slow and challenging. In addition, they also described this process as a circular process in which some days they felt they had reached a high level of comfort with themselves, and other days were characterized by feelings of distress and self-rejection. In addition, participants described that it was common to feel lost during this process. One participant explained:

> Yes, cause I'm a runner too just like her. I used to run away from everything and now it's like, I feel lost. I feel lost in this world cause I just don't know which way to run anymore cause I'm not trying to run back to that (drugs). And I just feel lost like I'm in this big ol' world where I'm lost now. I just want to be comfortable with who I am now.

Wanting to be normal just like you

Participants in this study indicated that a significant motivator for accepting and embracing their disability refers to the great desire of wanting to feel "normal" again. One participant explained what wanting to feel normal means to him:

> It's a feeling of not wanting to do anything. A feeling that you are not normal. A feeling that you don't belong. A feeling that everything is passing you by. A feeling of not being accepted. A feeling of wanting to be wanted. A feeling to be cared for. A feeling to be fixed. I want to be fixed, I want to be normal!

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Participants described that in an effort to reach a sense of normalcy, they would work to overcome any challenges they faced. One participant expressed:

> For me, I'm just willing to pay the price that I have to pay or do whatever I have to do in order to live a normal life…I'm tired of killing myself every time that I get high and I don't want to live like that. I see it as whatever price or whatever stairs I have to climb up in order to live normal…Bad situations that we're in, we have to turn them into good things to make our life good and for the well-being of people that are around us.

Experiencing a sense of normalcy served as a vehicle and strong motivational factor for participants to continue to work towards accepting their new identity as a Latino with a disability. One participant described his experience of what it is like to feel normal again and how that serves to keep him going:

> But I think for me, the more I get a taste of being myself again, being what I was before my disability, it makes me want to keep going. You feel so bad about not being you. And then when you do things that makes you feel normal, it's like that endorphin rush. You forget all about that, you know what I mean? I think for me, once I get a taste of being normal again.

Embracing (Learning How to Live) with my Disability

Latinos with disabilities in this study described the process of learning how to live with their disability. Although a challenging and difficult process, participants described their experiences of adapting to their disability and overcoming feelings of inferiority. Ultimately, some participants reported no longer seeing their disability as a disadvantage. Rather, they described perceiving their disability as a strength. Loving themselves, participants explained, allowed others to love them. Intentions reported by participants include:

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include: (a) adapting to my disability, (b) no longer seeing my disability as a disadvantage, and (c) learning to accept myself so others can accept me.

Adapting to my disability

Participants described stressful life experiences they endured while adjusting to their disability. One participant mentioned, “It was hard for me to even leave the house…I can’t do it! Poor me, somebody hold my hand. That was me!”

They also acknowledged the need to adapt to their disability and adjust to their new level of ability. Participants went on to explain that in “real life”, one must adapt to life’s challenges. One participant explained, “Real life is, something happens to you, you have to adapt. You have to get accustomed to your new way of being.”

Given their community context and in order to survive, participants expressed that adapting to life’s challenges has been something that they’ve had to do all of their lives. As such, adapting to their disability is just one more challenge for them to overcome. One participant stated:

> I have limitations, that’s all. I have to learn to work with them. I have to deal with them. I have to adapt. Being a Latino that’s been to prison, been out in the streets, been on drugs and alcohol, and made my life miserable…I’ve had to adapt always one way or another. I always had to adapt and this is just another thing that I adapted to. It’s not to say that I like it, it’s just that I’ve adapted to it…

Participants explained that adjusting to their disability is like learning how to do something all over again. One participant explained, “You have to be taught physically how to pick up the phone. You have to be taught how to dial what buttons. You have to be taught. And when something like a disability to oneself

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occurs, you need to be taught all over again." Another Latino with a disability compared this life experience to that of a child learning how to do something for the first time. They expressed:

> Something life changing is a disability. To be 30 and all of a sudden lose your eyesight, I would have to say that's traumatic...To be any age and lose a limb or lose an ability. You have to learn how to adapt, how to overcome. It's like being a kid again.

No longer seeing my disability as a disadvantage

In adapting and working towards embracing their disability, participants in this study described the process by which they no longer perceived their disability as a disadvantage, thereby embracing their disability. One participant stated, "And that's not the case today...I don't feel bad about my disability. The case is, I'm just like you. I can't work at the refineries anymore like I used to but I'm cool right here where I am today."

An important aspect of no longer seeing disability as a disadvantage refers to participants focusing on their level of ability and what it is they are able to accomplish in contrast to focusing on what they are not able to accomplish. One participant described a picture of himself and another person with a disability accomplishing a task. He expressed, "So that's what that picture represents. That two friends can actually do things together having disabilities."

Figure 14. Photo of a Latino in a wheelchair being pushed by a Latino who is visually impaired.

Learning to accept myself so others can accept me

Latinos with disabilities expressed that a milestone in their life experience refers to learning to accept their disability so that others would accept them. One participant describes the steps taken in an effort to work towards accepting themselves:

> Well, I think right now for me, me moving out is a sense of me not feeling sorry for myself. A sense of me doing for myself and, in turn, is showing everybody else.

Participants in this study described that once they achieved a level of acceptance and learned to embrace and love themselves, they became more open to receiving love and acceptance from others. Participants described this process as one in which they learned to embrace and look past their disability so that others could also do the same. One participant expressed:

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> Since 2004, November of 04 to now, for me to correct myself somewhat in order for someone to see past my disability…It's taken from 2004, November 2004 to now for me to have to work on myself in order for someone like her to be able to look past my disability.

Figure 15. "Learning to embrace my disability, so she can look past my disability."

Learning To Be Independent with my Disability

Participants overwhelmingly expressed that an important factor in working towards embracing their disability refers to having a sense of autonomy and independence. To facilitate this process, participants stressed the importance of not wanting others to feel sorry for them because of their limitations, and wanting others to recognize them as a person first rather than focusing primarily on their disability. In addition, participants indicated the importance of not wanting to completely depend on others to accomplish daily living tasks for them. By not de

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depending on others, participants were able to experience a restored sense of independence.

Not wanting people to feel sorry for me

A relevant life experience expressed by participants refers to wanting people to not feel sorry for them. Participants mentioned that receiving sympathetic messages from the community pushed them to experience further marginalization from their non-disabled counterparts. One participant explains, "I don't want nobody to feel sorry for me…I don't want nobody to feel sorry for me!"

Participants shared their experiences of people feeling sorry for them during the onset of their disability. For them, it was important to not receive pity because of their disability. One participant explained, "When I was first in a wheelchair, I didn't want pity from nobody!" Another participant shared a similar reaction, "if you start feeling sorry for me, what's going to happen? It's contagious…I'm going to start feeling sorry for myself."

Participants expressed that it is critical for people to acknowledge that they are not dead and only have limitations with regards to their ability. One participant stated:

> People put you down by feeling sorry for you for your disability, "Pobrecito mijo." They try to baby you…I don't like that…Why are you feeling sorry for me? Feel sorry if I'm dead or something, but I'm not dead yet, I'm still here. I'm still alive!

Not wanting to completely depend on others

A key life experience that Latinos with disabilities in this study reported refers to not wanting to completely depend on others. Not completely depending on others afforded participants the opportunity to have a sense of independence

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and solidarity. One participant mentioned, "Now, I like who I am today. I like the fact that I'm able to get up on my own, come to work, and get around. And I do it on my own." Participants also expressed the difficulties sometimes they encounter for wanting to accomplish tasks on their own. For example, one participant expressed, "The last time I tried to take the trash out I had two bags and I couldn't brake and I fell down sideways. But yeah, I pick myself up all the time and I do it myself." In spite of the difficult challenges experienced by participants in working towards independence, they expressed their strong desire to continue to strive and accomplish tasks on their own. One participant expressed:

> I do my laundry by myself. My mom gives me money, but I do my laundry by myself because I don't got a job yet. So, I wash my clothes and I do it by myself…I don't really like people helping me cause it feels, it makes me feel like I'm too useless.

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Figure 16. Participant doing his own laundry.

Particularly relevant to the lives of Latinos with disabilities with respect to not wanting to completely depend on others refers to acknowledging that others will not always be present to help participants. One participant shared:

> Yeah it is cause I don't always want to depend on someone or someone to help me out. I want to be able to do things on my own as much as I can because one day, that person might not be there and I'm not going to be able to get that help. So that's why I want to learn different ways to learn how to do the things that I need to do in order to get the things that I need.

One Latino with a disability summarized the importance of not wanting to completely depend on others and how critical this is for his process of growth, "So now its part of a growth process for me as a human being, as an individual, as a Latino, to be able to stand on my own two feet."

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Participants expressed the need for people to acknowledge them as individuals, rather than primarily focusing on their disability. Participants expressed that a common experience refers to people in the community focusing and acknowledging their disability first. Latinos with disabilities expressed that disability is one aspect of their identity and wanted people to first acknowledge them as a capable individuals. One participant expressed, “It’s more along the lines of people not looking at disability. I’d rather have someone look at me for something else, than somebody with a disability.”

WANTING MORE UNDERSTANDING, HELP, AND INCREASED AWARENESS IN THE COMMUNITY

Participants in this study expressed the need for increased awareness, outreach and engagement in the community with regard to disabilities and substance abuse. They also mentioned wanting more help from the community. These experiences are described in the following component phenomena: (a) wanting my family to be more supportive, (b) wanting better intimate relationships, and (c) wanting to experience understanding and solidarity from my community.

Wanting My Family to Be More Supportive

Having the support of family was extremely important for all participants in this study. For example, one participant expressed, “As far as my family, I do

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wish that they were more supportive." Participants affirmed that having family support was paramount in facilitating change and working towards improving their health and mental health. Of particular importance to participants in having their families' support was for family members to have a better understanding of their experience with respect to both disability and substance abuse, and wanting someone to be there for them during their efforts to stop abusing substances.

Wanting my family to understand

Participants in this study expressed wanting their families to develop a better understanding about disability. For example, when asked what they would make different in their family to better support them as a Latino with a disability, one participant expressed, "To understand my disability." Participants described how their families' lack of understanding was a factor that pushed them towards substance use. One participant commented, "I would get high because they don't understand what I've been through."

In addition to wanting their family to work towards a better understanding of what having a disability means, participants also expressed a great desire for families to have a better understanding of substance abuse. One participant expressed:

> They don't understand, and they expect so much from you. And they expect for you to go to a program and then you get cured...You have to look at it as a disability. This is going to be forever. Once you get a disability, you don't go back to work, you get disability. It doesn't go back to the way it used to be. That's how they have to actually look at it is a disability.

Participants also expressed a desire for their families to be supportive through increased physical and emotional closeness. Participants described feelin

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feeling distant from their families due to the disability as well as the effects of substance abuse. One participant described this experience:

> I would change the way that they are, so distant. Sometimes they don't even want to talk about it. In turn, I would want them to sit down and be hugging. Cause when you're going through all of this, you need a lot of hugs, affection, you just need understanding. And for them to be supportive in that sense, like emotional...going through the program...that's when you need the most understanding and be more compassionate and empathetic. Just by asking you even, "Oh, how are you doing"...instead of pretending that it's going to go away and it's something that you don't talk about.

Wanting someone to help me stop using

Participants indicated the importance of having support with regard to having someone assist them to stop abusing licit and/or illicit substances. One participant described how she would like for his family to attend substance abuse intervention classes with her:

> Going with you to your groups...It's like if we're sick or something, you break a leg. They have to go to the doctor with us. Somebody has to take us, right? And I figure, you have to want it...So as family, you have to make them understand that it's something that you need help with sometimes.

Participants also reflected on how fast substance abuse can develop as well as their hopes that somebody had intervened to help them stop their substance abuse. One participant described:

> It's a shame to me, when I just wake up months later when I start feeling bad about my drug use and I just reflect. When I'm on drugs, I like it but then there's that part of me that wishes I could get some help from my family or I could be saved, or that things don't have to be this way.

Wanting Better Intimate Relationships

Latinos with disabilities in this study indicated their desire to improve their intimate relationships. Participants expressed that this was a key factor in overcoming both contextual and personal challenges. They reported a strong desire to improve relationships with both their families and children.

Wanting a better relationship with my family

Latinos with disabilities described their strong desire to have better relationships with their families and for their families to be more united. Participants often expressed a perception that negative family relationships were associated with lack of education. One participant elaborated on this issue, "Its [family conflict] cause a lack of education…The only thing I wish I could do is for my family to be more united. But that's not going to happen for the same reasons…A lack of education, a lack of being civil with each other."

Participants also reflected on the fact that now that they are learning who they are, they want to improve the quality of relationships with their families. One participant described his desire to be closer to his family, as a result of learning about himself, "And now I'm learning about myself. And what I really want strongly is to come together with my family and make things work out."

Participants also mentioned that an important aspect to improving their relationship with their families refers to wanting to stop using licit and illicit substances. Participants acknowledged that substance abuse is a significant barrier to achieve emotional closeness with their families. One participant described her experience:

> What was I doing at that moment…just stuck on stupid, just drinking…Do I want to go back to that? Hell no. Do I want to go have a good time with my family or a good time with my friends? Hell yeah. So, that's what actually stops me from just over drinking and stuff like that.

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Participants compared their desire to build a stronger relationship with their families to that of rebuilding their individual foundation. One participant commented:

> We are all here to build our foundation back up. We all had our families, our kids, our jobs, and school...We're all here to get right...So, we're all here trying to rebuild our foundation with our families, our schools, and our friends because we all burned our bridges some way or another...I burned my bridges with my mom and my family. Little by little I'll restructure my foundation with them later on down the line. I don't plan for it to happen overnight.

Participants also expressed an understanding of the important role they play in establishing a better relationship with their families and acknowledged the ways in which they could facilitate change in their family system. Specifically, they mentioned that improving relationships with their families required participants to show more appreciation and to openly acknowledge the support from their families. One participant affirmed:

> And sometimes I think I'm ungrateful and I know I should appreciate them more. And I know sometimes, I shouldn't talk to my mom the way I talk to her...all the things she's done for me... And that's why I really appreciate my mom a lot, but I don't know how to show it to her...I think I am showing it by doing the things I'm doing now.

Participants reported a strong desire to improve the quality of communication with their families. By improving communication, they could also improve their family relationships. One participant elaborated on these issues:

> I've never really felt like I had a really close relationship with my mom or my dad...And I think that's really important because I think that reflects our relationship and our communication. I think that if we would've had more of a bond and would have been closer, that maybe things wouldn't have turned out the way they did for us.

Participants also described the challenges associated with learning to have productive conversations about difficult issues with their families. Because of this lack of ability, they considered that critical issues such as their substance abuse and disability were never openly discussed. One participant commented:

> I feel like at this age, my mom has tried so hard and sometimes it's not enough. It's not enough the effort that she puts out. It's not enough and I know that she's tired. I don't know if she feels the way I do or if she sees what I see, but I really think that our lack of communication and our lack of togetherness has been an underlying problem. It's not enough and I don't know how to express that to her and I don't want to bug her or make her feel bad for saying these things to her because I know that it will. I envy other people who have relationships with their parents and the parents are more supportive, and just having conversations with your parents. We talk, but it's not like we get into a deep conversation. Not a lot of things get said and I don't know if they ever will. Maybe we should go to therapy. I really want that bond and closeness with my family.

Wanting a better relationship with my kids

Participants expressed a strong desire to improve the quality of relationship with their children. They expressed how important their children are in their lives as well as their strong desire to improve their relationships with them. One participant stated:

> My kids are everything to me. My kids give me a reason to come to work. Give me the strength to come to work. Give me the strength to wake up every day and give me the strength to look forward to the weekend to see them. So that's why I'm doing this, I want to make it better with them.

An important component of wanting a better relationship with their kids refers to the need to stop abusing substances in order to fully enjoy the relationship with them. One participant expressed:

> Every time they're lying down, I take a picture of them. Sometimes they smile and sometimes they don't. They're the ones that motivate to not want to do drugs. I want to make our relationship better...I need to.

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Wanting To Experience Understanding and Solidarity from My Community

Participants overwhelmingly expressed a strong desire for their community to increase expressions of solidarity with regard to their life experiences. Of particular concern to participants was their desire for the community to work towards a better understanding of both substance abuse and disability issues. Participants also expressed the need for mental health professionals and service providers to become more accountable and responsive towards common challenges experienced by Latinos with disabilities. Finally, participants expressed a strong desire for their community to express accountability by promoting community-based prevention and intervention programs tailored to meet the specific needs of Latinos with disabilities and substance abuse.

Wanting people to understand addiction and disabilities

Participants expressed a strong desire for wanting people to better understand disability and addiction. For example, one Latino with a disability expressed, "I would really want more places out there so they could teach the community about people with disabilities."

Participants also provided examples of the ways in which people in the community do not understand their experience and how important it is to participants for people to work towards a better understanding. One participant shared:

> I just want people to be more understanding about us. There's some people who don't care that you're in a wheelchair...they'll go over you. Like a couple of days ago, I went to my homeboy's house. And I was getting on the bus and this jerk, he starts saying all kinds of things cause he wanted to get on the bus first. And the bus driver told him, "Hold on sir.

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> Let the wheelchair go in first." And he started talking shit. There should be more understanding people out there in this world.

Wanting mental health professionals to become accountable and "get it"

Research participants indicated a strong desire to seek out help with regards to their mental health. However, they also expressed the need for mental health professionals to work towards a better understanding of the multiple barriers and contextual challenges commonly experienced by Latinos with disabilities who abuse substances. One participant expressed:

> They right away come with the idea like, "Stop being selfish and thinking of yourself." They don't understand that it's kind of the opposite in our head. It's not because you're thinking you're selfish, it's because you're thinking (about your life)...because they come from a different world...healthy. They don't see it from our point of view...Look at what I'm going through...And they're not seeing it from our side...They come with expectations...not knowing that it's an everyday battle...I mean, you really want them to understand.

Participants described their frustration resulting from not being understood by mental health professionals and service providers. One participant elaborated on this issue:

> Some people cannot relate to you...I found myself with social workers that do not relate...And it takes my bigger end in having to understand that they don't understand. And by me understanding...I have to catch myself and just take a moment of silence and just be, "OK, well she doesn't understand"...It's kind of complicated but that's how I see it...just patience with social workers...I wish they understood more.

Wanting my community to become accountable

Participants expressed that a clear expression of the community's accountability towards the disability community, should be expressed through active efforts to promote an understanding in the general population in reference to what life is like to live with a disability. One participant commented:

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> Now that I have the knowledge through coming to the program, I could process it. Like I think about it and I just process it...To go where I'm at, you need the knowledge...and we need more knowledge in the community.

Another participant expressed:

> Promoting self improvement in schools or in jobs. Just promoting that attitude. Helping people to want more or to get more. Just opening up those minds, eyes, their views to want to get better...to let them know what's offered. To let them know that they can shoot for this, or this is open, or you can do this. This is how you can do it, whether it's college or work...Just letting the community and everyone know that whatever help is available or giving that help. Promoting it more as far as letting everyone know that there is help and here it is.

Participants in this study also indicated that communities need to work towards better informing people with disabilities about programs offered to meet their needs and life challenges. One participant expressed:

> Yeah, like my baby mama told me once they were selling apartments for guys with disabilities like me with a fake leg and it would be cheaper rent and stuff like that...One of my homeboys said, "There's a lot of programs out there for you." There's a lot of programs out there, but we don't know about them.

Another participant expressed:

> We don't know nothing about them. We don't know where to look or who to ask, stuff like that. So, some of us don't know about it. They should at least advertise it more often or something like that.

Participants expressed that their communities need to improve the dissemination of services for persons with disabilities. One participant explained, "I wish they could show more information for people with disabilities, or in the news." Similarly, another participant shared his experience of not having the information he needed with regards to disability and how he would like for the community to do more outreach:

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> I need help. I never knew about you guys. I never knew that this cane would help me get around easier. Or this computer will help me do things easier like read my mail and stuff like that. And it took this person a while to get me that information. And I wish that people could have given me that information right there and then.

Participants of this study explained the importance of having resources with respect to education on disability. Participants expressed concern with regard to the lack of education available for Latinos with disabilities. One participant shared:

> I think any type of injury, when its life changing you need some type of education. Whether it be self education or education on your injury, on your disability...Now you have a disability and its like, wait. Hold on now, what the hell do I do? Which way do I go? And we don't have that here.

Participants reflected on the potential consequences associated with lack of education with regard to disability. One participant mentioned:

> It's OK to tell people you are challenged and I think it needs to be addressed. Disabilities need to be addressed because there's people who go without help for years. And they end up dying or just stuck out there lost. It's been a challenge for me.

Summary: Life Experiences of Being a Latino with a Disability and Substance Abuse

Latinos with disabilities described the complexity of their life experiences. They reported the onset of their disability as characterized by feelings of intense despair, sadness and grief. In addition, participants expressed feeling inferior to others and perceiving themselves as "damaged goods." As a result, they turned to licit and/or illicit substances as a way to escape and cope with the feelings of despair and emotional pain, as well as to evade the loss they had to accept. Participants provided detailed narratives describing the negatives consequences of abusing substances, such as losing their parental rights. Furthermore, women partici

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participants described experiences of intimate partner violence, further illustrating the complexity of disability and substance abuse with regard to gender.

In spite of the intense emotional challenges associated with their disability, participants expressed a strong sense of resiliency by *not giving up and wanting to change*. They expressed *wanting to break the cycle* with respect to family generational substance abuse and reported that their strong motivation to change came from both their own will, as well as from finding inspiration in their children and wanting to offer them a better life.

Participants also expressed their commitment to work towards *accepting and embracing their disability*. In contrast to the initial feelings of despair at the onset of their disability, participants reported *no longer perceiving their disability as a disadvantage, rather as a strength* and motivational factor to succeed in life.

Research participants expressed the critical role that the community has in fostering a culture of understanding and solidarity towards individuals who have been impacted in their lives by disability and substance abuse. Participants also described the critical importance of experiencing support from their families and the community as they redefine their lives in the face of disability and substance abuse recovery. Of particular concern to participants was the lack of mental health professionals and service providers capable of fully understanding issues associated with disability and substance abuse. Finally, participants expressed a strong desire for professionals working with Latinos with disabilities and substance abuse to develop sound cultural competencies aimed at informing their work with these populations.

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CHAPTER V: DISCUSSION

Introduction

The main purpose of this study was to explore the experiences associated with disability and substance abuse as described by a group of young adult Latinos and Latinas. Specifically, participants described the contextual challenges that negatively impact their lives, as well as the changes they would like to see in their communities so they can become more supportive towards Latinos with disabilities who have abused substances. Participants also provided detailed descriptions of the protective factors that have helped them to gradually adapt to their disabilities and recover from substance abuse.

This study employed a qualitative research design which consisted of photovoice methodology with a descriptive phenomenological approach. The experiences shared by participants contribute to a better understanding of the lives of Latinos with disabilities who have abused substances. This knowledge can significantly inform research and clinical practice in the MFT field, as well as the development of relevant social policy on these issues.

Participants identified a number of contextual stressors which represent a challenge to their lives. For example, participants shared how they have been impacted by poverty, violence, gangs, and discrimination in their community. They also reported their perceptions of feeling invisible to others due to the lack of accessibility in the community. For example, participants shared the ways in which community curbs and transportation do not have adequate accessibility. The lack of accessibility with respect to transportation constitutes a significant

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contextual challenge and stressor for participants because this barrier prevents them from having access to community locations where they receive health or mental health services.

Participants also expressed that the high and easy accessibility to drugs and alcohol in the community represents a significant challenge to them because of the permanent risk for relapse. A particularly intense challenge for participants refers to experiences of discrimination in the community. Specifically, they described the various ways in which they experience perceived discrimination for being Latino, having a disability, and abusing substances. Participants also described the ways in which they were not supported or "put down" by their family. For example, because of the limitations to access public transportation on their own, participants often times face the need to request family members for transportation support to attend important appointments. However, participants reported that family members' refusal to provide such a support is common, particularly if family members do not trust that their desire to overcome substance abuse is genuine and sincere. Participants also described how family members, in an effort to help them recover from substance abuse, would approach participants in critical and unproductive ways.

A key contextual challenge reported by participants refers to negative experiences with respect to health, mental health and service providers. Particularly troublesome for participants was not having access to culturally competent health care and service providers. Thus, participants reported perceptions of being treated disrespectfully by service providers, which further

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increased their experiences of isolation resulting from the stigma associated with seeking mental health services.

Women participants expressed additional gender-specific stressors by describing unique experiences of exclusion and discrimination in the community. Specifically, women participants indicated a lack of culturally-informed services to meet the needs of women recovering from substance abuse, as well as the lack of resources to denounce and help them overcome intimate partner violence (IPV). Women participants also described the detrimental effects associated with the disproportionate incarceration of Latino men from their communities.

In contrast to these contextual challenges, participants shared the various ways in which they feel supported by both their community and family. For example, participants identified specific community resources aimed at supporting Latinos with disabilities, which included the recognition of Latino cultural values and traditions. Participants reported that these community resources help them to become more integrated in the community by reducing their sense of isolation.

With respect to family support, participants described specific ways in which their families provide them with love and support, which is particularly important as they recover from substance abuse. Participants expressed that one of the most beneficial ways of family support refers to family members not feeling sorry for them and supporting them to become independent and self-sufficient individuals, which in turn helps participants to focus on their own strengths.

Regarding life experiences associated with living with a disability, participants expressed the intense feelings of sadness, pain, hurt and despair associated with the onset of disability. Participants also described the intense struggle associated with feeling inferior to others, as well as the various ways in which they attempted to escape from their disability and mental health problems by recurring to licit and illicit substance abuse.

In contrast to experiences of pain and despair, participants reported a strong desire to overcome the challenges associated with their disability and substance abuse by "not giving up" and wanting to change. For example, they described how important it was to find precursors of resilience and change such as having a meaningful job or becoming aware of how important they are in their children's lives. Participants described the slow and painstaking process associated with accepting and embracing their disability. Specifically, they described having to face the need of defining a new identity as a Latino with a disability, learning to be independent with their disability, and embracing their disability as they worked to place a stronger emphasis on their strengths in contrast to their limitations. Participants expressed that it was particularly critical for their process of adaptation to achieve as much independence as possible, as well as being perceived by others as capable individuals.

Lastly, participants strongly agreed about the high need to increase awareness and accountability in the community towards Latinos with disabilities who have abused substances, which includes the need to ensure the cultural competence of health and mental health providers.

Re-integrating bracketed material with research findings is one of the most important final steps in the descriptive phenomenological approach (Porter, 1994). Thus, in the following sections, I will re-integrate bracketed material for both life-world and lived experience data. I will re-integrate bracketed material by examining current findings according to the theoretical framework of this study. Subsequent to re-integrating bracketed material, I will address clinical, research and policy implications with regard to Latinos with disabilities who have abused substances. In addition, I will discuss self-of-the-researcher issues that influenced the implementation of this study. I will finish this chapter by presenting limitations of the study and a conclusion.

Re-integrating Bracketed Material with Life-World Context Features

As described in Chapter I, bracketing is considered a key methodological step in phenomenological data analysis (Porter, 1995). Bracketing consists of identifying and working towards setting aside preconceived ideas and biases in an effort to participate in the data collection and data analysis with an open mind (Porter, 1995). Although a researcher can never fully put aside preconceived notions and biases, bracketing serves to ensure greater transparency of the biases which may potentially have influenced this study. Table 4 provides an overview of the life-world features and bracketed themes with respect to life-world context.

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Table 4. Comparison of life-world features and bracketed themes

Life-World Features	Bracketed Themes
Being Challenged by my Community	Existing Research on Latinos with Disabilities and Substance Abuse, Ecodevelopmental Framework, Stress Paradigm, Pedagogy of the Oppressed and Feminist Theory
Being Put Down by my Family	Existing Research on Latinos with Disabilities and Substance Abuse, Ecodevelopmental Framework, Stress Paradigm, Pedagogy of the Oppressed and Feminist Theory
Experiences with Health and Mental Health Professionals and Service Providers	Existing Research on Latinos with Disabilities and Substance Abuse, Ecodevelopmental Framework
Women Experiencing Exclusion and Discrimination	Existing Research on Latinos with Disabilities and Substance Abuse, Feminist Theory, Ecodevelopmental Framework, Stress Paradigm, Pedagogy of the Oppressed
Being Supported by my Community	Ecodevelopmental Framework
Being Supported by my Family	Ecodevelopmental Framework

In the following sections, I will analyze each of the life-world features according to the bracketed themes associated with each specific feature. Not all themes (e.g., Ecodevelopmental framework, Feminist theory, etc.) are developed for each feature, only the ones that were considered to be most relevant to each feature.

Being Challenged by my Community

Ecodevelopmental framework. The ecodevelopmental framework (Szapocznik & Coastworth, 1999) provides a foundation for identifying salient risk factors at multiple levels that negatively impact the lives of Latinos with disabilities. Risk factors can be identified in the various systems of the participants' ecology such as family of origin and the larger community context. In this study, the most deleterious community challenges identified by participants referred to being impacted by poverty, community violence, high availability of alcohol and drugs in the community, lack of community support towards individuals with disabilities, and various forms of perceived discrimination.

<u>Stress paradigm</u>. The relationship between psychosocial stress and the overall health of Latinos continues to be of critical relevance and interest to scholars (Cervantes & Castro, 1985; Padilla, Cervantes, Maldonado, & Garcia, 1988; Finch, Hummer, Kol, & Vega, 2001). The stress paradigm postulates that stressful life events (e.g., discrimination) are associated with increased psychological and behavioral problems such as substance abuse and mental health (Pearlin, 1989; Wheaton, 1994).

The stress paradigm was helpful for the identification of key stressors expressed by participants. In addition to normative life stressors (e.g., work), Latinos with disabilities identified a significant number of non-normative chronic life stressors such as perceived discrimination and lack of accessibility, which prevented participants from being able to independently access the resources they need to adapt to their disability and recover from substance abuse (Beatty, 2006).

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Pedagogy of the oppressed and feminist theory. The methodology implemented in this study was informed by the work of Paulo Freire (1970). By reflecting on their individual experiences, participants co-created a learning experience with other Latinos with disabilities. This approach in research also goes in line with participatory tenets of Feminist-informed research (Keeling & Bermudez, 2006; White & Epston, 1990). Thus, in contrast to engaging in a passive learning experience, the approach utilized in this investigation aimed at shifting the power dynamics from the researcher as an expert and the participant as a passive learner, to a more egalitarian relationship in which both researchers and participants become learners and co-creators of knowledge (Freire, 1970; Keeling & Bermudez, 2006).

Freire (1970) proposed three levels of consciousness that ought to influence how reality is interpreted. The lowest level of consciousness is described as one in which people are trapped by assumptions of inherent inferiority and live within a culture of silent acceptance of the status quo. The manifestation of this level of consciousness ultimately results in attitudes of learned helplessness and behaviors of passive submission which systematically and reciprocally contribute to one's own oppression. At the second level of consciousness, although individuals perceive and interpret the social situation as problematic and characterized by social injustice, individuals often may continue to blame others for the social reality of their lives. Lastly, the final level refers to critical consciousness and it is described as the process by which individuals become aware that their own assumptions shape their interpretations of reality.

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This level of awareness serves as a vehicle to develop responsibility and accountability for choices and personal behaviors that can contribute to a process of structural change (Freire, 1970). Participants in this study expressed increased insight regarding their life experiences as a result of participating in sequential interviews. This was evident during the third round of focus group interviews which served to increase trustworthiness of the data. For example, one participant described after the third interview, "It's like a reflection, like seeing a reflection…We said all that? Wow…and it's hard to hear it. So I'm just processing it."

Similarly, another participant shared feeling grateful because participating in the study allowed her to process the core issues associated with her disability and substance abuse:

> I think that's why it's good that you have this research. So you could do more research on getting to the core…I'm just grateful that you came into my life and that you're here doing this research because it's allowing me to reflect on really what's the issue.

Additional methods developed by Freire (1970), which go in line with Feminist-informed research (White & Epston, 1990), were implemented in this study to ensure its participatory approach (Minkler & Wallerstein, 2003; Williams & Lykes, 2003). For example, I initially engaged the community by establishing relationships through informal conversations with members of the community, while also remaining carefully attentive to issues of culture. As I implemented the photovoice and qualitative methods, I kept a diary in order to ensure that my

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biases and preconceived notions did not interfere with the process of data collection.

Research on Latinos with disabilities and substance abuse. Participants indicated the various ways in which they experience challenges in their communities. One key finding refers to challenges associated with poverty and violence. These findings confirm the negative effects of community violence and poverty previously reported in the literature. Specifically, research has demonstrated that contextual challenges such as family socioeconomic status and neighborhood residential instability constitute risk factors that can have negative effects on behavior and mental health such as increased risk for substance use disorders and co-morbid behaviors (Buu et al., 2009; Catalano & Hawkins, 1996). Furthermore, this study reflects demographic trends of persons with disabilities. Specifically, persons with disabilities are more likely to live in poverty with a 20% poverty rate compared to 7.7% for the non-disabled population, are more likely to be unemployed, have significantly lower median household incomes compared to their Euro-American counterparts ($37,781 compared to $52,423), and are more likely to have lower education levels (two in five Latinos age 25 and older have not graduated from high school; Marotta & Garcia, 2003; U.S. Census Bureau, 2005, 2007).

The exposure to stigma and various forms of discrimination, commonly experienced by persons with disabilities, places this population at high risk for experiencing alienation and social isolation (Hargreaves, 2000; Susman, 1994). A key finding in this study refers to participants' experiences of perceived discrimination. This finding confirms previous research suggesting that the current sociopolitical and anti-immigration climate in the U.S. poses serious challenges for the well-being of Latinos, particularly if they are first-generation and undocumented immigrants (Berk, Schur, Chavez, & Frankel, 2000; Derose, Escarse, & Lurle, 2007).

In addition to experiencing discrimination due to their ethnic minority status, participants described experiencing discrimination because of their disability. This finding confirms previous studies suggesting that Latinos with disabilities face unique challenges in the United States because they may be discriminated against based on both their ethnicity and the stigma associated with disability (Finley, 1998, Gayman, Turner, & Cui, 2008). Researchers have confirmed that coping with the stigma associated with having a disability is often times a much more challenging experience than dealing with the disability itself (Austin, MacLeod, Dunn, Shen, & Perkins, 2004). Present findings justify the need to extend the current literature on discrimination experienced by Latino populations because few studies have carefully examined the devastating effects of discrimination on Latinos with disabilities.

Participants also expressed experiencing stigma because of substance abuse. These findings confirm previous research indicating that Latinos with disabilities are further stigmatized when issues of substance abuse are present (Koch, Nelipovich, & Sneed, 2002). Particularly challenging to participants was being perceived by others as “less than” and lacking the accountability and

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commitment to overcome substance abuse. Thus, current findings confirm previous studies indicating that people who abuse substances are at increased risk of being labeled as morally flawed or lacking will power (Urbanoski, Cairney, Bassani, & Rush, 2008). Unfortunately, limited research exists aimed at carefully examining experiences of stigma and discrimination in Latinos with disabilities who abuse substances (Gayman et al., 2008; Turner et al., 2006).

Being Put Down by my Family

Ecodevelopmental framework. The ecodevelopmental framework (Szapocznik & Coatsworth, 1999) was helpful to identify risk factors at the family level particularly as it refers to the diverse nature of daily interactions and patterns of family communication. For example, participants shared the counterproductive ways in which families attempted to intervene with respect to participants' substance abuse. Although participants acknowledged the purpose of their families' attempts to help them stop substance abuse (e.g., being told how to behave to prevent relapse), participants perceived such help as "going about it the wrong way." Thus, family pressure rather than protecting participants from substance abuse, could turn into a risk factor for relapse if the interaction with close relatives was conflictual. Based on present findings, there is a need to carefully analyze the ways in which family factors such as family dynamics, family structure, and communication constitute barriers to the successful adaptation to disability and recovery from substance abuse. Given that all family members must adapt to the onset of disability, this line of research has the potential to highlight risk and protective factors associated with disability,

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particularly as it refers to the impact of disability on children's development (Gorman, Fitzgerald, & Blow, 2010).

Stress paradigm. The stress paradigm (Pearlin, 1989; Wheaton, 1994) was also helpful to identify key stressors within the family context. In addition to the stress created by the multiple contextual challenges at the community level, participants indicated the ways in which families putting them down created additional stressors. For example, mistrust from family members, not being able to reach out to family in time of need, and receiving critical messages from family members constitute additional stressors reported by participants in this study. Research has highlighted the ways in which negative interactions in substance abusing families can further be exacerbated by experiences of distress, as well as a lack of family cohesion (Loukas, Piejak, Bingham, Fitzgerald, & Zucker, 2001).

Pedagogy of the oppressed and feminist theory. Pedagogy of the oppressed (Freire, 1970) was helpful in understanding maladaptive systemic patterns of interaction between participants and their families. Participants constantly expressed families' lack of knowledge and understanding with regard to disability and substance abuse as a significant contextual challenge. Families lacking an increased level of consciousness with regard to disability and substance abuse often perpetuated a counterproductive family interaction cycle because participants experienced a lack of understanding and support from their families. Finally, participants reported the detrimental effect of family members adopting a position of superiority by communicating or engaging in behaviors in

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which they took the expert stance. Although participants recognized the role of their denial associated with their own substance abuse problems, they also expressed that a stance of superiority and critical judgment adopted by family members was not beneficial to their process of adaptation to disability, nor their recovery from substance abuse. According to Feminist theory (Kim, 2001), embracing a collaborative stance with individuals who experience intense life challenges, including systematic exclusion and discrimination, is a critical factor leading to experiences of empowerment and recovery.

Research on Latinos with disabilities and substance abuse. Latinos with disabilities reported that one of the most significant contextual challenges refers to being put down by their families. "Being put down" by family members is a particularly relevant finding because of the cultural value and high importance that Latinos place on family. Specifically, *familismo* refers to one's dedication and commitment to the family (Falicov, 1998). It has been noted that this cultural value may act as an important protective factor in the lives of Latinos (Parra-Cardona, Bulock, Imig, Villlarruel, & Gold, 2006). Given the significant value of family in the Latino culture, additional research is needed to clearly identify the ways in which lack of family support and family criticism is associated with increased risk for substance abuse, particularly as it refers to Latinos with disabilities.

Experiences with Health and Mental Health Professionals and Service Providers

Ecodevelopmental framework. The ecodevelopmental framework (Szapocznik & Coatsworth, 1999) was helpful for the identification of risk factors expressed by participants with respect to the critical role of health and mental health professionals and service providers. For example, participants expressed how the lack of culturally competent service providers led them to experience discrimination when attempting to access the services they needed, which also led them to distrust institutions. Based on these experiences, participants reported reluctance to seek the services they need and some participants even reported their decision to stop seeking support services altogether.

Research on Latinos with disabilities and substance abuse. Participants shared the ways in which access to health and mental health care is lacking in their communities. Barriers to accessing health and mental health care constitute a significant challenge to participants. These findings confirm previous research highlighting that multiple contextual barriers such as economic problems, language difficulties, and discrimination may prevent Latinos from accessing mental health services (Castro et al., 2004).

Current findings also indicate that an additional barrier with respect to access to health care refers to participants lacking sufficient financial resources and/or health insurance. In spite of the fact that Latinos currently are the largest ethnic minority group in the U.S. and constitute 14% of the total U.S. population, they represent 30% of those who lack health insurance (Marotta & Garcia, 2003; U.S. Census Bureau, 2007). Thus, Latinos are underrepresented as recipients of general health and mental health services (Cervantes & Acosta, 1992; Vega et al., 2007).

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Participants also identified perceived discrimination from professionals and service providers as a significant contextual challenge that negatively impacted their lives. These findings reflect previous studies suggesting that perceived discrimination is a critical barrier that prevents Latinos from accessing and receiving culturally appropriate mental health services (Berk, Schur, Chavez, & Frankel, 2000; Derose, Escarse, & Lurle, 2007; Williams, Neighbors, & Jackson, 2003). However, limited studies have been conducted to examine the prevalence of perceived discrimination from health professionals and service providers in the Latino disability population. This study contributes to the literature by providing in-depth descriptions of experiences of perceived discrimination as reported by a group of Latinos with disabilities.

Present findings also illustrate structural barriers that undermine the cultural relevance of services being offered in the community. For example, participants reported the lack of service providers who are of Latino-origin, or at the very least knowledgeable of the Latino culture. Therefore, participants described mental health and service providers as emotionally distant and lacking empathy. These findings coincide with previous studies highlighting the importance of service providers being aware of the importance of key Latino cultural values such as the importance of establishing close interpersonal relationships (i.e., personalism), as well as informing relationships according to appropriate deference (i.e., respect) (Falicov, 1998).

Women Experiencing Exclusion and Discrimination

Feminist theory. Feminist theory is particularly helpful to understand the experiences of Latina women with disabilities who abuse substances. Feminist ideologies have asserted the need to address issues of power and privilege in society as directly related to gender (Walsh & Scheinkman, 1989). Specifically, feminist scholars have noted the imperativeness to take into consideration the ways in which patriarchal structures have historically shaped political and sociocultural contexts (Semmler & Williams, 2000). By not adopting a feminist-informed stance when evaluating specific phenomena such as intimate partner violence (IPV), there is a risk for understanding this societal problem from a perspective in which women are blamed, pathologized, and excluded from society (Weingarten, 1998; Vatcher & Bogo, 2001).

Ecodevelopmental framework. In the current study, women participants agreed about the lack of programs tailored to meet their specific needs. This finding is particularly troublesome when considering issues of IPV because although participants reported the pervasiveness of domestic violence, they also described how family structures and cultural mandates, as well as lack of culturally sensitive IPV services, prevent them from denouncing abuse and violence as well as their initial desire to seek help. These findings confirm previous studies indicating the lack of gender-informed interventions aimed at addressing health and mental health problems commonly experienced by Latinas (Amaro, Larson, Zhang, Acevedo, Dai, & Matsumoto, 2007). This study also contributes to the current literature by providing detailed empirical data illustrating the particularly deleterious effects of exclusion experienced by Latinas with disabilities who have abused substances and who have been exposed to IPV.

Stress paradigm. The stress paradigm is helpful in conceptualizing additional stressors experienced by women as a result of unique contextual challenges that they face in their lives. Relative to their men counterparts, women experience additional stressors that reflect gender differences. For example, women participants of this study described the ways in which they experience exclusion from prevention intervention programs. In spite of the fact that women participants expressed a strong desire to address the maladaptive behaviors that were both influencing and influenced by stressors, women were not supported by their community (e.g., overlooking IPV, lack of gender-specific prevention interventions, overlooking substance abuse in women). This, in turn, added additional stressors to women participants.

Pedagogy of the oppressed. Women participants in this study reported increased critical consciousness as a result of participating in the group interviews. Specifically, they expressed that the interviews allowed them to carefully consider over time what it means to be a Latina with a disability, what are the unique stressors that they face, as well as what are the unique structural challenges that they face in their daily lives. For example, as women described their struggles with issues of IPV, they reported an awareness that IPV should not be normalized and that specific cultural values (e.g., the need to preserve the family), as well as oppressive societal structures (e.g., lack of culturally competent IPV service providers), determine the likelihood for them to reach out for help to their families and institutions.

Research on Latinas with disabilities and substance abuse. Women participants indicated the ways in which the community overlooks substance abuse in women. A limited number of evidence-based interventions have been culturally adapted to address substance abuse in Latino populations (Castro, Barrera, & Martinez, 2004), and even fewer gender-specific interventions exist for Latina women (Amaro et al., 2007). This is a key finding given that previous research indicates the underutilization of substance abuse treatment by Latina women (Zemore, Mulia, Ye, Borges, & Greenfield, 2009). Based on present findings, it is plausible that the underutilization of treatment services by Latinas refers to the fact that Latinas do not perceive such services to be culturally relevant and potentially useful to address their life difficulties (e.g., cultural pressure for Latina women to remain in a submissive role). Furthermore, lines of research aimed at developing a better understanding of substance abuse in women are needed, as research has indicated that women's substance use problems are more correlated to mental health problems, family conflict, and offspring behavioral problems, relative to their men counterparts (Nolen-Hoeksema, Wong, Fitzgerald, & Zucker, 2006).

Another key finding from this study refers to the importance of fully understanding the co-occurrence of IPV, disability, and substance abuse. The Centers for Disease Control and Prevention has identified IPV research in the Latina community as a priority, particularly because most research on IPV has been limited to Euro-American women (Klevens, 2007). However, despite the frequent occurrence of IPV in the Latino community (Ingram, 2007; Tjaden & Thoennes, 2000), no studies have been undertaken to study the specific dynamics associated with IPV among Latinas with disabilities who have abused substances. Additional research focused on this area of inquiry is clearly needed based on present findings.

Being Supported by my Community

Ecodevelopmental framework. The ecodevelopmental framework (Szapocznik & Coatsworth, 1999) allows for the identification of protective factors that have a direct or indirect influence in the lives of participants. In this study, participants expressed receiving community support through specific expressions of outreach and engagement in their community. For example, participants of this study described how members of the community who express an understanding of their experiences constitute a significant source of strength in their lives, particularly because this support allows them to feel more included in the community. Furthermore, community resources constitute a critical source of support for Latinos with disabilities because by knowing that there are systems of support available to them, participants can more easily engage in key community activities that help them in their process of adaptation to disability and recovery from substance abuse.

In addition, participants expressed that the community embracing the Latino culture constitutes a protective factor. Specific examples by which participants considered that the Latino culture was recognized and valued in their community referred to the open recognition and value of the Latino culture. Examples of the ways in which their community valued their culture refer to cultural fairs and dances (e.g., Aztec dancers), as well as cultural murals depicting empowering messages (e.g., “Si se puede”).

Being Supported by my Family

Ecodevelopmental framework. Participants expressed feeling loved and supported by their families, which represents a critical motivation as they embraced their adaptation to their disability and substance abuse recovery. This finding confirms previous studies indicating that the family system is one of the most important systems for reducing and preventing substance abuse in Latino populations (Szapocznik, Hervis, & Schwartz, 2003).

A key finding in this study refers to participants feeling supported as a result of family “not feeling sorry” for them. By not feeling sorry for them, their families empowered participants to focus on their strengths, made them feel important in the family, and reassured their sense of belonging. All these factors encouraged participants to accept their disability, moving them away from experiences of despair such as feeling sorry for themselves. According to Admi and Shaham (2007), “There is a reciprocal relationship between the stigmatized person and the stigmatizing surroundings, creating a cycle in which people with a chronic disease are affected by the reactions of their surroundings, interpret these reactions, and decide if they will conceal or expose their illness” (p.1178). Participants expressed that by family members not feeling sorry for them, they provided participants with a context in which they felt an increased sense of "normalcy."

Re-integrating Bracketed Material with Experiences of Being a Latino with a Disability and Substance Abuse

Consistent with the process of re-integrating bracketed material with life-world context features, I integrated bracketed material in the process of analysis for lived experiences of being a Latino with a disability and substance abuse. Table 5 illustrates the comparison between phenomena related to the experience of being a Latino with a disability and substance abuse.

Table 5. Comparison of the phenomena to bracketed themes

Phenomena	Bracketed Themes
Experiencing The Struggle of Living with my Disability	Existing Research on Latinos with Disabilities and Substance Abuse, Ecodevelopmental theory, Stress Paradigm, Pedagogy of the Oppressed
Not Giving Up and Wanting To Change	Existing Research on Latinos with Disabilities and Substance Abuse, Feminist Theory
Accepting and Embracing my Disability	Pedagogy of the Oppressed
Wanting More Help and Increased Awareness in the Community	Existing Research on Latinos with Disabilities and Substance Abuse

Experiencing the Struggle of Living with my Disability

Ecodevelopmental framework. The ecodevelopmental framework is a relevant model to understand the struggles associated with living with a disability (Szapocznik & Coatsworth, 1999). For example, the capacity to adapt to a disability heavily depends on the type of social and contextual resources available to support individuals with disabilities, as well as the type and intensity of contextual factors that constitute barriers to the process of adaptation to living with a disability. Current findings confirm previous scholarship indicating the critical role that institutional and social support networks have in the process of adapting to a disability (Livneh, 2009a). For example, participants in this study shared feelings of emotional pain and despair related to having a disability, which were intensified by the lack of community resources aimed at helping them cope more effectively with learning how to live with their disability. Participants also reported a sense of isolation whenever family members and immediate social networks were not supportive towards their life struggles.

Stress paradigm. As described by participants, the onset of a disability comes with a significant amount of new and intense stressors that individuals have never experienced before in their lives. For example, participants shared the ways in which they struggled with the distress of coping with the reality that they would never walk again, see, or have the level of independence that they desired to have in their daily lives. These findings confirm the importance of fully understanding the nature and intensity of stressors experienced by individuals with disabilities, particularly in the early stages of accepting and learning to live with a disability (Livneh, 2009a; 2009b). The stress paradigm is a relevant and useful theory to examine present findings, particularly because it is of critical importance to examine how the lives of participants have been negatively impacted by specific stressors at various stages of their disability (Gayman, 2008; Livneh, 2009b)

Pedagogy of the oppressed. Research participants reported experiencing various forms of discrimination, exclusion, and isolation associated with their disability and substance abuse. Understanding the life experiences of participants according to the role of oppressive experiences in their lives, particularly as it refers to maladaptive behaviors and mental health problems, prevents researchers and service providers from adopting a narrow perspective in which an understanding of the role that the larger context plays in the participants' life struggles is absent (Pantin, Schwartz, Prado et al., 2004; Pantin, Schwartz, Sullivan et al., 2003). For instance, participants shared various life situations in which they experienced shame, stigma, and discrimination by others. These oppressive experiences have deleterious effects on individuals with disabilities, particularly because overt and covert expressions of exclusion (e.g., you don't have a place in this society because you have a disability), may result in internalized feelings of inferiority (e.g., I am less than). An individual exposed to these experiences may turn to maladaptive practices such as substance abuse, to escape from the feelings of despair associated with this oppressive cycle. Thus, understanding substance abuse also as an alternative to cope with social exclusion and alienation may maximize the impact of interventions that would otherwise focus exclusively on promoting individual accountability for addictive behaviors.

Research on Latinos with Disabilities and Substance Abuse. Current findings demonstrate the high likelihood for the co-occurrence of experiencing a disability and substance abuse. These findings also confirm previous research indicating that Latinos are disproportionately affected by substance abuse (Vega & Gil, 1998; Warner, Valdez, Vega, De La Rosa, Turner, & Canino, 2006). Latinos are also more likely to experience negative health and social consequences from substance abuse than their Euro-American counterparts (Caetano & Clark, 1998; Castro et al., 2006). Research in the general population indicates that there are significant differences in the prevalence of substance abuse and dependence rates among persons with disabilities when compared to persons without disabilities (Brucker, 2007). Specifically, individuals with a physical disability have reported higher rates of alcohol dependence, illicit drug abuse, and illicit drug dependence than their counterparts. Turner and colleagues (2006) found that approximately 40% of their research participants with a physical disability met the criteria for a psychiatric or substance abuse disorder. Furthermore, compared to Euro-Americans and African Americans, Latinos with disabilities report higher rates of psychiatric (Kemp, Krause, & Adkins, 1999; Turner et al., 2006) and substance abuse disorders (Turner et al., 2006). Although few studies have examined prevalence rates of substance abuse in Latinos with disabilities, there is a dearth of studies aimed at exploring in depth the co-occurrence of disability and substance abuse in this population. This study contributes to addressing this gap in knowledge and research.

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Not Giving Up and Wanting To Change

Feminist theory. Feminist theory is particularly helpful to understand the experiences of Latinos with disabilities, particularly as it relates to resiliency and the ways in which participants expressed determination in overcoming oppressive contexts. Feminist ideologies have asserted the importance of establishing and maintaining intimate human relationships characterized by equality, love and support (Walsh & Scheinkman, 1989). Participants in this study indicated the ways in which establishing and maintaining these types of relationships was a driving force for them to overcome adversity in their lives. For example, a clear motivational factor for “not giving up” and remain committed to change referred to thinking about how important they are in their children’s lives. Thus, participants expressed a strong desire to correct maladaptive behaviors (e.g., substance abuse) in order to be responsible parents and ensure the well-being of their children. In spite of this desire and motivation to change, however, participants experienced a significant amount of contextual challenges that constitute intense barriers to them. Feminist scholars have noted the imperativeness to take into consideration the ways in which patriarchal structures have shaped oppressive contexts for many segments of the population (Semmler & Williams, 2000). As such, a feminist-informed stance promotes the understanding of these phenomena from a perspective in which participants are not blamed nor pathologized (Weingarten, 1998; Vatcher & Bogo, 2001).

Research on Latinos with disabilities and substance abuse. A key finding in this study refers to the fact that participants identified having a job and a career as key motivators to overcome the adversity associated with having a disability and substance abuse. Unfortunately, Latinos with disabilities are likely to experience clear barriers in their efforts to develop a formal productive life. Specifically, when examining the socio-demographic characteristics of the disability population in the U.S., persons with disabilities are less likely to complete higher levels of education, and are more likely to be unemployed (Turner & Turner, 2004; U.S. Census, 2005). Taken into consideration that Latinos continue to be among the ethnic groups with lower rates of education and training completion in the country (Turner & Turner, 2004; U.S. Census, 2005), Latinos with disabilities who have abused substances are likely to experience important barriers when attempting to find opportunities for professional development. Participants in this study described how important it was for their process of recovery to experience that they have rewarding professional lives. Thus, a lack of opportunities for professional development through established employment is likely to have deleterious effects for this population.

Accepting and Embracing my Disability

Pedagogy of the oppressed. Participants reported how critical it was to their process of adaptation to their disability to challenge societal messages depicting individuals with disabilities as “abnormal” or “defective.” As a result of recognizing the oppressive nature of various societal messages associated with disability, participants were able to gradually embrace a process of accepting their disability, feel comfortable with their new identity as individuals with a disability, and learn to adapt their lives accordingly. In fact, participants expressed how critical it was for them to "no longer see their disability as a disadvantage." These findings strongly confirmed key premises of the pedagogy of the oppressed as outlined by Freire (1970), particularly as it refers to the importance of calling into question oppressive societal messages (e.g., disability is defective and ruins an individual's life), as well as expanding subjugated knowledge and experience. For example, participants in this study reflected on how they learned to accept themselves and even stopped seeing their disability as a disadvantage.

Pedagogy of the oppressed (Freire, 1970) is helpful to overcome oppressive ideologies and challenges the notion that individuals with disabilities are "broken." Yet, this requires a process of working from the lowest level of consciousness (i.e., learned helplessness) to critical consciousness in which participants expressed awareness that their own assumptions shape their interpretations of reality and develop responsibility and accountability for choices and personal behaviors that can contribute to a process of structural change (Freire, 1970). As such, participants in this study displayed a remarkable amount of strength, resilience and an increased level of consciousness. Despite the numerous contextual challenges and the pain and despair associated with the onset of their disabilities, participants also highlighted the ways in which they fought and worked towards accepting and embracing their disability, thereby highlighting an increased level of consciousness with respect to their disability.

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Wanting More Help and Increased Awareness in the Community

Research on Latinos with disabilities and substance abuse. Participants in this study expressed their desire to see an increased number of resources in their communities aimed at supporting Latinos with disabilities. According to participants, the existence of such resources would constitute a concrete expression of accountability from their communities towards this population. For example, participants expressed the great need for culturally informed mental health interventions aimed at supporting Latinos throughout their process of adaptation to disabilities, particularly if there is co-occurrence of substance abuse. The limited exposure of Latinos to culturally informed prevention and clinical interventions has been documented in the literature, particularly as it refers to the limited number of evidence-based interventions that have been informed according to Latino cultural values and traditions (Castro, Barrera, & Martinez, 2004).

Mental health disparities in the Latino population are associated with specific barriers such as economic problems, language barriers, and discrimination (Castro et al., 2004; Chen & Rizzo, 2010). In addition to these factors, present findings indicate that the mental health disparities experienced by the participants in this study may be increased due to unique challenges commonly associated with disability and substance abuse. For example, participants expressed their desire for service professionals to fully understand the complex dynamics associated with substance abuse, particularly when the person in recovery has been exposed to intense stigma and isolation, as it is frequently the case with persons with disabilities.

Finally, although the need to address the disparities experienced by Latinos who abuse drugs has been frequently recognized by major federal agencies (NIDA, 2005; SAMHSA, 2005), present findings indicate that Latinos with disabilities who have abused substances continue to be an overlooked population in health disparities research based on the limited number of interventions and policies especially designed to address their needs.

Clinical Implications

Sensitivity towards disability and substance abuse. Present findings provide relevant data to inform marriage and family therapy practice with Latinos with disabilities who have abused substances. First, participants identified several contextual challenges that constitute significant barriers to their lives such as poverty, violence, and high accessibility to both licit and illicit drugs. In addition, participants reported experiencing discrimination, not being supported by their families, as well as inadequate cultural sensitivity from health and mental health and service providers. Thus, it is imperative for family therapists to explore the extent to which the life challenges reported by participants in this study resemble risk factors in the lives of their clients, particularly because these contextual challenges can constitute clear barriers to the therapeutic process.

Participants reported the damaging effect of feeling invisible in their communities as a result of lack of adequate supports to help them cope with their disabilities and substance abuse. Therefore, family therapists should be attentive to the risk of duplicating this experience of invisibility in the therapeutic relationship, particularly if they overlook or minimize the struggles commonly experienced by the population under study. Finally, reducing the sense of invisibility should not be limited to verbal interventions, as it is critical to ensure that clinical environments offer the necessary accessibility to clients with disabilities (e.g., access to elevators, accessible curbs, transportation, etc.).

Issues of engagement in family therapy. A critical implication from present findings refers to the importance of successfully engaging Latinos with disabilities in the process of therapy. Participants indicated the various ways in which they perceived service providers lacking cultural sensitivity, lack of culturally experienced health professionals of the same ethnic background, stigma in receiving mental health services, and feeling "put down" by service providers. In addition, participants expressed wanting to experience more specific outreach and engagement efforts from health and mental health service providers. As such, it is of critical importance for family therapists to explore with clients previous negative experiences with health, mental health, and service providers. The need for ensuring a successful engagement in the therapeutic process is particularly relevant based on the lack of training policies and practices in the marriage and family therapy field with regard to cultural competence towards the Latino disability population.

Individual Accountability, Familial Risk Factors, and Clinical Psychopathology. Although limited data were collected in this study to address issues of individual accountability as related to substance abuse behavior, a key area of clinical intervention refers to the need to encourage clients to engage in a process of assuming personal responsibility and introspection with regard to their substance abuse, within a non-judgmental and collaborative framework. In fact, there is vast literature in the substance abuse field indicating that the path to recovery can be significantly obstructed if the individual abusing substances avoids assuming full responsibility for individual addictive behaviors (Henningfield, Santora, & Bickel, 2007). In addition, family dynamics can perpetuate substance abuse if family members cover up or enable abusive behaviors (Szapocznik, Hervis, & Schwartz, 2003). Finally, it is important to consider that individuals experiencing various ranges of individual psychopathology are at an increased risk for substance abuse (Miller, Rathus, & Linchan, 2008).

Although the present study contributes to the existing literature by giving voice to participants who are engaged in the process of recovery, clinicians must be fully familiar with the broad literature associated with substance abuse, individual accountability, familial risk factors, and psychopathology. However, present findings indicate the importance of addressing these issues according to a thorough awareness of the multiple contextual challenges faced by this population. For instance, participants shared that one of the most significant challenges they faced referred to the shame, stigma, and discrimination resulting from their substance abuse. Therefore, it is critical for family therapists to avoid adopting a stance of superiority towards their clients, resembling the ways in which participants have felt being “put down” by others. Thus, clinicians should constantly remain aware of the challenges associated with addressing three marginalized identities commonly expressed by participants in this study, which refer to being an ethnic minority, as well as an individual with a disability who has abused substances.

Risk for suicidal ideation. Participants in this study expressed feelings of pain and despair, particularly at the onset of their disability. In particular, the phenomena, "Experiencing the Struggle of Living with My Disability," highlights the various ways in which participants experienced mental health problems characterized by various narratives of despair, not finding a meaning in life, and active suicidal ideation. Therefore, a key clinical implication from this study refers to the high need to assess Latinos with disabilities for risk of suicide, particularly if there is a co-occurrence of disability and substance abuse. Research has suggested that persons with physical disabilities are at an increased risk of suicide, relative to their non-disabled counterparts (Russell, Turner, & Joiner, 2009). Therefore, although it is expected that family therapists should assess for both suicidal ideation and substance abuse for all clients in general, suicide screening and continuous monitoring is particularly critical with this population based on the numerous and intense contextual stressors that participants in this study continuously reported as associated with potential risk for suicide. For example, participants expressed how the sense of despair associated with a disability is particularly intense when individuals experience intense struggles with their initial experiences of loss and despair. Therefore, careful screening and

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monitoring of risk for suicide should be a constant practice throughout the process of therapy.

Informing therapy according to advocacy approaches. Present findings confirm the deleterious effects of stigma and discrimination among Latinos with disabilities who have abused substances. In particular, the life-world context data, "Being Challenged by My Community", "Experiences with Health and Mental Health Professionals," as well as the phenomena data, "Wanting More Understanding, Help, and Increased Awareness in the Community," highlight the various ways in which participants experience stigma, discrimination, and structural exclusion. In addition, participants' intentions identified in the lived experience data provide strong evidence regarding their strong desire for increased systems of support in the community. Based on these findings, clinicians should inform family therapy approaches according to theories such as pedagogy of the oppressed (Freire, 1970), as mental health problems such as depression and anxiety, may be strongly influenced by diverse experiences of social exclusion and alienation. To challenge these deleterious effects, family therapists should inform their clinical interventions according to advocacy approaches aimed at empowering clients in their daily lives in order to reduce the effects of structural oppression. For instance, family therapists should recognize that providing members of marginalized populations with the necessary means to reduce their experience of isolation (e.g., access to job training, culturally sensitive services for persons with disabilities) can be as effective as traditional ment

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Informing therapy according to strength-based perspectives. Present findings highlight the need to remain attentive to the protective factors in the lives of participants, including their remarkable sense of resilience. For example, participants in this study indicated the ways in which they felt supported by their community and family members. Participants also identified their jobs as an important precursor of change and recovery. Finally, participants provided detailed testimonies of resilience as evidenced by their strong desire to change in the face of adversity, as well as their strong desire to succeed in life by considering how important they are in their children's lives. As participants expressed, it was key for them for people to "not feel sorry" for them and encourage them to embrace their strengths. This reflection should constantly inform the clinical approaches adopted by family therapists committed to supporting this population.

The need for interdisciplinary clinical interventions. Findings from this study indicate the complexities involved when exploring substance abuse in Latinos with disabilities. The complex life experiences and challenges reported by participants confirm the conclusions reported by the NIDA Prevention Research Work Group (2009) highlighting the necessity of adopting cross-disciplinary approaches for the prevention and treatment of substance abuse. Such a cross-disciplinary approach should also inform clinical practice in the substance abuse field, particularly as it refers to clinical work with Latinos with disabilities and substance abuse. Furthermore, although well-established evidence-based interventions have been developed in the MFT field to serve families with youth who abuse substances, "The development of the subspecialty of family-based treatment for adult drug abuse is unfortunately limited" (Rowe & Liddle, 2002, p. 70). This particularly applies to family-based treatment for minority adult populations, including Latinos with disabilities.

Present findings expand the understanding of critical risk and protective factors associated with the etiology and recovery of substance abuse among Latinos with disabilities. However, in order to effectively support Latinos with disabilities who have abused substances, family therapists must recognize that support for recovery should be informed according to interdisciplinary efforts. Thus, relying exclusively on family therapy approaches is likely to be insufficient particularly if substance abuse is chronic or has developed into substance dependence. If such is the situation, family therapists should propose to clients an interdisciplinary treatment approach (e.g., psychiatry, chemical dependency treatment, etc.), rather than relying exclusively on family therapy interventions. Equally important is for family therapists to recognize the positive impact that alternative approaches (e.g., recovery groups) can have when issues of individual denial or lack of accountability towards substance abuse are present. Taking a cross-disciplinary approach (e.g., rehabilitation counselor, MFT, psychiatrist, etc.) could prove more effective in reducing and preventing substance abuse in Latinos with disabilities.

Future Research

The family therapy literature focusing on disabilities and substance abuse continues to be scarce. Family therapy research focused on substance abuse in the disability context remains in its infancy, particularly as it refers to Latinos with disabilities. The need for research exploring the co-occurrence of substance abuse and disability is greatly needed, particularly because the presence of a disability can significantly increase the probability of substance abuse and dependence (Brucker, 2007). For example, it is estimated that nearly 4 out of 10 persons with physical disabilities meet the criteria of psychiatric or substance abuse disorder (Brucker, 2007; Turner, Lloyd, & Taylor, 2006).

In addition, there continues to be a high need for research aimed at culturally adapting evidence-based interventions focused on substance abuse prevention in the Latino disability population. In concurrence with present findings, drug abuse prevention and intervention programs are less accessible to persons with disabilities, relative to their non-disabled counterparts (Boros, 1989).

This research contributes to the existing scholarship because it demonstrates the importance of informing interventions according to the most relevant life experiences of potential recipients of such interventions (Brucker, 2007). Present findings illustrate that a disability can place an individual at greater risk for problems associated with substance abuse. However, little is known about the patterns of substance use, abuse, and dependence among Latinos with disabilities. Implementing these lines of research is critical for the development of culturally appropriate interventions for Latinos with disabilities and substance abuse. In addition, future lines of research should be informed according to an understanding of the effects associated with having a disability, being an ethnic minority, and being exposed to the stigma associated with disability and substance abuse.

Present findings confirm the need for further research aimed at more clearly understanding stigma in the context of multiple marginalized identities. The effects of stigma and discrimination on substance abuse and mental health problems are not well understood (Corrigan & Watson, 2007). Thus, new lines of research are needed aimed at reaching a better understanding of the effects of stigma and problematic behaviors such as substance abuse and mental health problems in the Latino disability population.

A critical area of future research refers to studies aimed at exploring the ways in which individuals can successfully adapt to having a disability while also recovering from substance abuse. Participants in this study identified several strengths in various levels of their ecology which were associated with their processes of adaptation to disability and their substance abuse recovery. Thus, additional studies are warranted to clarify what are the most relevant precursors to their process of recovery (Beatty, 2003; Turner et al., 2006).

Present findings indicate that it is imperative to reach a better understanding of intimate partner violence (IPV) in the Latino disability population. Given the intense challenges reported by Latina participants in this study, it is necessary to understand the increased risk for exposure to IPV that

Latinas with disabilities experience. Currently, there is a dearth of studies focused on Latinas with disabilities who are also IPV survivors.

Finally, it is important to implement future lines of research aimed at examining the similarities and differences of life experiences among women and men in an effort to develop gender responsive interventions. Participants in this study clearly indicated their perception that substance abuse among Latina women with disabilities has been overlooked in service delivery as they could not identify interventions especially tailored to meet their needs.

Public Policy Implications

Findings of this study have relevant policy implications. With the passage of Public Law 104-121, the Contract with American Advancement Act of 1996, individuals who had a disability due to licit or illicit substance abuse and who were receiving Supplemental Security Income (SSI) were no longer eligible to receive such benefits. Included in these benefits was Medicaid, which meant that this population was also no longer insured. Prior to the implementation of the Contract with American Advancement Act of 1996, approximately one-quarter of a million U.S. citizens were receiving benefits from the Social Security Administration, at least partially due to diagnosis of substance abuse (Brucker, 2007). With the implementation of this act, persons with disabilities with dual diagnosis were left uninsured and without access to appropriate mental health care. Furthermore, persons with disabilities who had SSI benefits did not seek out services due to fear of losing benefits (Hanrahan, Luchins, Cloniger, & Swartz, 2004).

Findings from this study indicate a high need for legislation aimed at ensuring substance abuse and mental health services for the Latino disability population. Participants expressed a strong desire to seek out substance abuse and mental health services, yet encountered numerous obstacles including lack of insurance and financial resources. Given the high cost to society associated with substance abuse and mental health problems, it is relevant to further explore the effects of current public policy on the morbidity and mortality associated with substance abuse in the Latino disability population.

Research participants also expressed that a significant contextual challenge in their lives refers to the widespread presence of alcohol advertisements in their communities. According to them, this disproportionate advertisement takes place predominately in ethnic minority and impoverished communities. These advertisements served as an important barrier to participants' recovery efforts from substance abuse because of the higher risk for relapse associated with easy accessibility to licit substances. Therefore, more policy research is needed with respect to the effects of high exposure to alcohol and tobacco advertisement as it refers to the Latino disability population.

Self-of-the-Researcher

My personal life experiences as a Latino with a disability have afforded me the opportunity to resonate and empathize with participants as they described their life experiences. I consider this to be a strength given that the researcher is considered to be the instrument by which data is collected in a qualitative research design. Being a Latino with a disability can also serve as a barrier as my preconceived ideas about what it means to be a Latino with a disability and my life experiences influence the research process. As such, one of the key factors to reach increased awareness of self-of-the-researcher issues consisted of completing a personal narrative prior to engaging in data collection activities. Accomplishing this task provided me with the opportunity to become more aware of the biases that I brought into this research study.

In reflecting about my own personal life experiences, I really resonated with participants as they described the intense feelings of despair during the onset of disability. The experience of feeling "less than" and that "others don't understand" was something that I remember quit distinctly. In spite of being able to empathize with participants, I also found myself reactive at times particularly when participants were describing negative attitudes towards having a disability. During this time, I found myself leaving the interviews with reactivity, especially because I wanted participants to have a more positive perspective on disability. More specifically, I wanted participants to focus more on their strengths and the factors associated with resiliency and how it was that they were able to overcome contextual challenges. During this time, I found having conversations with Dr. Parra-Cardona to be helpful in processing this reactivity. For example, I had a conversation with Dr. Parra-Cardona explaining my reactivity with the fact that participants were really focused on the contextual challenges they were experiencing and the negative attitudes with regard to disability. He helped me process this by highlighting that despite these challenges, participants were showing up to the focus group interviews to share their stories, which alone constitutes a strength. This helped me to refocus subsequent interviews by asking participants, "Despite these contextual challenges and difficulties experienced, how are you able to overcome them? Where does this strength to persevere come from?" This, in turn, helped guide the interviews to highlight the various strengths the participants have and answer a critical research question, "Can you describe the strengths within your community in reference to the disability community?"

Another area in which I had to address self-of-the-researcher issues referred to participants forgetting or losing cameras. My initial response consisted of feeling frustration and anger. During that time, I realized that I was only thinking about myself and the fact that I had a dissertation to finish. I was placing my needs first, without taking into consideration the life experiences of participants. I was repeating the same pattern of alienation that participants were describing in reference to how they feel with regard to the larger and oppressive contexts, which have hurt them in various ways. It was during each interview process, however, that I clearly understood how participants could forget or lose cameras. All the pain, such as experiences of being put down by others and experiencing having their children removed from their custody were intense challenges that prevent them from fully considering "my research needs." Participants had so much going on in their lives, and I now invited them to participate in a study. It was only after listening to their stories, that I clearly understood how easy it could be to forget or misplace a camera if I was the one experiencing those intense challenges.

Because participants would at times misplace or forget to bring their cameras to a predetermined time and location, I had to meet some of them at their homes to retrieve the cameras. I experienced fear, anger, and frustration whenever I faced this type of situation. Although I grew up in a *barrio* (neighborhood), I understand that each barrio has its own rules. As such, going into neighborhoods such as South Central, Watts, and East Los Angeles evoked emotions of fear and anger, particularly because I was concerned about my safety. At times, I would drive down streets and see groups of young men "hanging out" on a corner block and I felt vulnerable being in an unfamiliar vehicle to them and driving in an unfamiliar area. Because my front windows were tinted, I would roll down my windows so that they could have a clear view of me and not mistake me as an enemy. My goal was to abide by the golden street rule, which is to not disrespect. In the end, I realized that although this was something I once experienced growing up, I now have the privilege of no longer having to experience it. And even though I had to experience it for a few minutes, this is an extremely intense contextual challenge that participants experience on a daily basis.

I also struggled with feelings of guilt. Listening to participants' stories brought to my attention the privilege I have due to my advanced education. Given my multiple identities, it is easy to put my marginalized identities at the forefront of my identity. That is, being Latino and having a disability. In contrast, it is more difficult to place my privileged identities first; being educated, male, and having light skin. Therefore, listening to participants' stories helped me to see the privileges I carry through my multiple identities. Furthermore, I had feelings of guilt because I have to accept that many of these participants may never have the opportunity to pursue higher education. For me, pursing a higher education was paramount in overcoming the negative ideologies I once had about my disability. Having an education provided for me doors of opportunity that I would have never imagined possible. And, as participants expressed, these doors of opportunity have, for the most part, been closed for them by structures of historical oppression and exclusion.

At the beginning of this research project, I also experienced feelings of guilt because of the fact that this was a "research study." There were times when participants would cry in sharing their stories and the pain they were experiencing was very clear. During those times, I wanted to take my research hat off, and put on my therapist hat, in an effort to help them process some of what they were experiencing. In the end, however, participants expressed a great deal of gratitude for being able to share their story and have someone listen to them. Some had never had this experience in their lives. For example, one participant shared, "This is a healing thing for me…I've never sat down with individuals with disabilities and straight up asked, 'How do you do it?'" Participants also described to me how the research process was therapeutic for them. For example, one participant expressed:

> This is therapeutic for me. When I leave, I feel like I've let go of some side…questions that you don't think about. I think it's pretty intense. Cause drug counselors, they usually don't relate to disabilities and what disabilities are linked up to emotionally. So I think this is a very good thing for all of us, for whoever joined. And for whoever didn't, I think that's very unfortunate for them.

In spite of the anxiety and frustrations experienced through this research, I wouldn't have it any other way. I love having the power of working towards giving voice to populations that have historically been overlooked and underresearched in academia, in an effort to empower them. Although it would have been much easier to collect data within the context of a university, the satisfaction and fulfillment that I experienced during this research process could have never been achieved through such methods.

Clinical Implications

Sensitivity towards disability and substance abuse. Present findings provide relevant data to inform marriage and family therapy practice with Latinos with disabilities who have abused substances. First, participants identified several contextual challenges that constitute significant barriers to their lives such as poverty, violence, and high accessibility to both licit and illicit drugs. In addition, participants reported experiencing discrimination, not being supported by their families, as well as inadequate cultural sensitivity from health and mental health and service providers. Thus, it is imperative for family therapists to explore the extent to which the life challenges reported by participants in this study resemble risk factors in the lives of their clients, particularly because these contextual challenges can constitute clear barriers to the therapeutic process.

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Informing therapy according to advocacy approaches. Present findings confirm the deleterious effects of stigma and discrimination among Latinos with disabilities who have abused substances. In particular, the life-world context data, "Being Challenged by My Community", "Experiences with Health and Mental Health Professionals," as well as the phenomena data, "Wanting More Understanding, Help, and Increased Awareness in the Community," highlight the various ways in which participants experience stigma, discrimination, and structural exclusion. In addition, participants' intentions identified in the lived experience data provide strong evidence regarding their strong desire for increased systems of support in the community. Based on these findings, clinicians should inform family therapy approaches according to theories such as pedagogy of the oppressed (Freire, 1970), as mental health problems such as depression and anxiety, may be strongly influenced by diverse experiences of social exclusion and alienation. To challenge these deleterious effects, family therapists should inform their clinical interventions according to advocacy approaches aimed at empowering clients in their daily lives in order to reduce the effects of structural oppression. For instance, family therapists should recognize that providing members of marginalized populations with the necessary means to reduce their experience of isolation (e.g., access to job training, culturally sensitive services for persons with disabilities) can be as effective as traditional mental health interventions aimed at reducing depressive or anxious symptomatology (Sullivan, 2003).

Informing therapy according to strength-based perspectives. Present findings highlight the need to remain attentive to the protective factors in the lives of participants, including their remarkable sense of resilience. For example, participants in this study indicated the ways in which they felt supported by their community and family members. Participants also identified their jobs as an important precursor of change and recovery. Finally, participants provided detailed testimonies of resilience as evidenced by their strong desire to change in the face of adversity, as well as their strong desire to succeed in life by considering how important they are in their children's lives. As participants expressed, it was key for them for people to "not feel sorry" for them and encourage them to embrace their strengths. This reflection should constantly inform the clinical approaches adopted by family therapists committed to supporting this population.

The need for interdisciplinary clinical interventions. Findings from this study indicate the complexities involved when exploring substance abuse in Latinos with disabilities. The complex life experiences and challenges reported by participants confirm the conclusions reported by the NIDA Prevention Research Work Group (2009) highlighting the necessity of adopting cross-disciplinary approaches for the prevention and treatment of substance abuse. Such a cross-disciplinary approach should also inform clinical practice in the substance abuse field, particularly as it refers to clinical work with Latinos with disabilities and substance abuse. Furthermore, although well-established evidence-based interventions have been developed in the MFT field to serve families with youth who abuse substances, "The development of the subspecialty of family-based treatment for adult drug abuse is unfortunately limited" (Rowe & Liddle, 2002, p. 70). This particularly applies to family-based treatment for minority adult populations, including Latinos with disabilities.

Present findings expand the understanding of critical risk and protective factors associated with the etiology and recovery of substance abuse among Latinos with disabilities. However, in order to effectively support Latinos with disabilities who have abused substances, family therapists must recognize that support for recovery should be informed according to interdisciplinary efforts. Thus, relying exclusively on family therapy approaches is likely to be insufficient particularly if substance abuse is chronic or has developed into substance dependence. If such is the situation, family therapists should propose to clients an interdisciplinary treatment approach (e.g., psychiatry, chemical dependency treatment, etc.), rather than relying exclusively on family therapy interventions. Equally important is for family therapists to recognize the positive impact that alternative approaches (e.g., recovery groups) can have when issues of individual denial or lack of accountability towards substance abuse are present. Taking a cross-disciplinary approach (e.g., rehabilitation counselor, MFT, psychiatrist, etc.) could prove more effective in reducing and preventing substance abuse in Latinos with disabilities.

Future Research

The family therapy literature focusing on disabilities and substance abuse continues to be scarce. Family therapy research focused on substance abuse in the disability context remains in its infancy, particularly as it refers to Latinos with disabilities. The need for research exploring the co-occurrence of substance abuse and disability is greatly needed, particularly because the presence of a disability can significantly increase the probability of substance abuse and dependence (Brucker, 2007). For example, it is estimated that nearly 4 out of 10 persons with physical disabilities meet the criteria of psychiatric or substance abuse disorder (Brucker, 2007; Turner, Lloyd, & Taylor, 2006).

In addition, there continues to be a high need for research aimed at culturally adapting evidence-based interventions focused on substance abuse prevention in the Latino disability population. In concurrence with present findings, drug abuse prevention and intervention programs are less accessible to persons with disabilities, relative to their non-disabled counterparts (Boros, 1989).

This research contributes to the existing scholarship because it demonstrates the importance of informing interventions according to the most relevant life experiences of potential recipients of such interventions (Brucker, 2007). Present findings illustrate that a disability can place an individual at greater risk for problems associated with substance abuse. However, little is known about the patterns of substance use, abuse, and dependence among Latinos with disabilities. Implementing these lines of research is critical for the development of culturally appropriate interventions for Latinos with disabilities and substance abuse. In addition, future lines of research should be informed according to an understanding of the effects associated with having a disability, being an ethnic minority, and being exposed to the stigma associated with disability and substance abuse.

Present findings confirm the need for further research aimed at more clearly understanding stigma in the context of multiple marginalized identities. The effects of stigma and discrimination on substance abuse and mental health problems are not well understood (Corrigan & Watson, 2007). Thus, new lines of research are needed aimed at reaching a better understanding of the effects of stigma and problematic behaviors such as substance abuse and mental health problems in the Latino disability population.

A critical area of future research refers to studies aimed at exploring the ways in which individuals can successfully adapt to having a disability while also recovering from substance abuse. Participants in this study identified several strengths in various levels of their ecology which were associated with their processes of adaptation to disability and their substance abuse recovery. Thus, additional studies are warranted to clarify what are the most relevant precursors to their process of recovery (Beatty, 2003; Turner et al., 2006).

Present findings indicate that it is imperative to reach a better understanding of intimate partner violence (IPV) in the Latino disability population. Given the intense challenges reported by Latina participants in this study, it is necessary to understand the increased risk for exposure to IPV that

Latinas with disabilities experience. Currently, there is a dearth of studies focused on Latinas with disabilities who are also IPV survivors.

Finally, it is important to implement future lines of research aimed at examining the similarities and differences of life experiences among women and men in an effort to develop gender responsive interventions. Participants in this study clearly indicated their perception that substance abuse among Latina women with disabilities has been overlooked in service delivery as they could not identify interventions especially tailored to meet their needs.

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Findings from this study indicate a high need for legislation aimed at ensuring substance abuse and mental health services for the Latino disability population. Participants expressed a strong desire to seek out substance abuse and mental health services, yet encountered numerous obstacles including lack of insurance and financial resources. Given the high cost to society associated with substance abuse and mental health problems, it is relevant to further explore the effects of current public policy on the morbidity and mortality associated with substance abuse in the Latino disability population.

Research participants also expressed that a significant contextual challenge in their lives refers to the widespread presence of alcohol advertisements in their communities. According to them, this disproportionate advertisement takes place predominately in ethnic minority and impoverished communities. These advertisements served as an important barrier to participants' recovery efforts from substance abuse because of the higher risk for relapse associated with easy accessibility to licit substances. Therefore, more policy research is needed with respect to the effects of high exposure to alcohol and tobacco advertisement as it refers to the Latino disability population.

Conclusion

There is a great need for substance abuse and mental health research focused on the disability population (Hanrahan et al., 2004). Existing interventions for substance abuse do not adequately address the complexities associated with the co-occurrence of substance abuse and disability (Bachman, Drainoni, & Tobias, 2004).

This study provides relevant qualitative data describing various strengths and challenges with regard to disability and substance abuse experienced by a group of Latino adults. These findings can assist family therapy researchers and clinicians to better understand the life experiences of the population under study.

This study also contributes to building a larger body of knowledge on risk and protective factors associated with Latinos with disabilities who have abused substances. The ultimate goal of this line of research should be to culturally inform research, clinical practice, and public policy aimed at addressing the needs of this population.

In summary, it is my hope that through this study, I was successful at highlighting the ways in which Latinos with disabilities experience intense contextual challenges. As one participant expressed, "...They don't look at what affects us." In addition, it is my hope that I have identified the protective factors and resiliency operating in the lives of Latinos with disabilities. One participant stated, "I have limitations, that's all. I have to learn to work with them. I have to deal with them. I have to adapt." Working towards a better understanding of both risk and protective factors operating in the lives of Latinos with disabilities could serve to reduce and ultimately eliminate the health disparities experienced by this highly overlooked and underresearched population.

Appendix A: Consent Form to Participate in the Study

Through The Eyes of Latinos/as with Physical Disabilities who currently Abuse Substances: A Photovoice Study

What we are doing:

We are conducting a research study that will help us understand the experiences of Latinos/as with physical disabilities who currently abuse substances. The purpose of this research is to learn about your perceptions and experiences about strengths and challenges of having a disability. We expect to obtain this information by asking those who show an interest in participating in this study to take pictures of their experiences and share their photos with other participants in a two hour focus group interview. Mr. David Cordova will conduct all the focus group interviews. You may decide not to participate in the study or not answer any of the questions. Each focus group interview will be tape recorded and later transcribed and later studied by the research team. To be considered for the study, you must: (a) identify yourself as Latino/a or Hispanic, (b) identify yourself as having a physical disability, (c) have answered yes to past year substance use or binge drinking questionnaire, (d) be at least 18 years of age, and (e) show an interest in participating in the study.

Who is in charge?

The people in charge of this study are Dr. José Rubén Parra-Cardona and Mr. David Cordova of Michigan State University. Mr. Cordova may be reached at (310) 487-8018 or cordovad@msu.edu , and Dr. Parra at (517) 432-2269 or parraca1@msu.edu .

What will happen?

1. You will participate in a Photovoice study in which you will be asked to take pictures of your experiences over the course of a week with a disposable camera, based on the following questions: (a) Can you please describe to me your life as a Latino/a with a disability, (b) Can you please describe to me your life as a Latino/a with a disability who is currently taking substances, (b) Can you please describe to me the strengths in your community related to your disability, and (c) what would you like to see changed in your community related to your disability.
2. The study involves two cycles of photo taking and three focus group interviews over the course of approximately 9 weeks. The focus group interviews will be audiotape recorded, last approximately two hours each and the nature of these group interviews will be to discuss the photographs. The final focus group will not involve discussion of photographs, rather will focus on ensuring that what I am reporting in the research findings is in fact what you are saying.
3. You will be paid $30.00 for your participation in each focus group.
4. Participation is voluntary, you may choose not to participate at all, or you may refuse to participate in certain procedures, or answer certain questions, or discontinue your participation at any time without penalty or loss of benefits.

Why the study is being done?

We want to better understand the experiences of Latinos/as with disabilities who are currently abusing substances in order to offer better services. Your feedback will be very important because we will have a better idea of the challenges you experience. In addition, we will be clearer about the experiences in your community and what you see as strengths as well what needs to change in your neighborhood. We want to know your experiences and perceptions about how you understand disability and substance abuse.

Confidentiality:

Your privacy will be protected to the maximum extent allowable by law. Because Photovoice requires you to take photos of your experiences, as well as disseminate photos to increase awareness of your experiences, your photo may be identified particularly if someone from the community is the photo participant. Mr. Cordova will listen to the audiotapes and know the answers to the questions. If the study is published, there will be no personal identifying information reported.

Certificate of Confidentiality

To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, the researchers cannot be forced to disclose information that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of federally funded projects or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA).

You should understand that a Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person obtains your written consent to receive research information, then the researchers may not use the Certificate to withhold that information. In addition, the Certificate of Confidentiality only protects against demands for information that may identify you as a participant. Therefore, if your identity as a participant is known because of a photo (e.g., other community members recognize your photo), a Certificate of Confidentiality may not offer protection. For example, if the photo is used in a presentation and identifies you as a participant in the study, then it may not be possible for us to use the Certificate of Confidentiality to protect other identifying information.

The Certificate of Confidentiality does not prevent the researchers from disclosing voluntarily, without your consent, information that would identify you as a participant in the research project under the following circumstances: child abuse, intent to hurt self and/or others. For example, instances that may be reported include photos which display child neglect in their homes (e.g., lack of clothing, food) and/or around drugs, and acts of violence, whether the perpetrator or victim. In addition, please be aware that although the nature of this study is not to explore harm caused by others or yourself, harm caused by anyone (e.g., threats of violence by others or yourself) may be reported to the appropriate authorities, including police officials. Further, we as researchers are not prevented from taking steps to ensure the safety and prevent harm to participants or others if a person takes a picture which depicts possible harm.

Please note that this Certificate of Confidentiality does not represent an endorsement of the study by the Department of Health and Human Services or the National Institutes of Health.

Risks and Benefits:

The principal risk of Photovoice is the risk of incrimination. This means that because this research involves the taking of photographs, there is the potential that a photo may be taken which places a person or building at risk to be accused of or present proof of a crime or fault. Photos which place an individual engaged in any illegal activity (e.g., using illegal drugs) will not be used for this study. In addition, because you may take photos of other people and businesses, there is a risk that you may potentially be in danger particularly if that individual or business does not want to be photographed. Photos will not be discussed in the focus group without a signed acknowledgement and release consent form from the person or business you have photographed.

You may experience slight discomfort if you talk about issues that represent a challenge in your community and development (e.g., discrimination, stigma of having a disability). If you become visibly disturbed during the focus group, the interview will be stopped. Mr. Cordova will offer counseling referrals if any follow-up services are required.

You may gain insight about your experiences of living with a disability, and may experience a sense of relief by having someone listen to your stories. Further, this information will be used in an effort to better understand the life experiences of Latinas/os with disabilities.

If I have a question:

If you have any concerns or questions about this research study, such as scientific issues, how to do any part of it, or if you believe you have been harmed because of the research, please contact the researcher, Mr. Cordova (310) 487-8018, corodvad@msu.edu , or Dr. José Rubén Parra-Cardona (517) 432-2269, parraca1@msu.edu , or write to 291 South La Cienega Suite 308, Beverly Hills, CA 90211.

If you have any questions or concerns about your role and rights as a research participant, or would like to register a complaint about this research study, you may contact, anonymously if you wish, MSU's Human Research Protection Programs, at 517-355-2180, FAX 517-432-4503, or e-mail irb@msu.edu, or regular mail at: 202 Olds Hall, MSU, East Lansing, MI 48824.

Mr. Cordova has read this form out loud. He has answered our questions. I, as a participant, have a copy of this form.

To agree to be a part of this research study, initial the boxes below and sign.

☐ I voluntarily agree to participate in this study

☐ I will be paid $30.00 for each focus group interview I participate in.

☐ I give permission to be audio taped during the focus group interview.

Signature of Participant Date

Appendix B: Photo Release Form

Introduction:
This Photovoice project is being conducted on behalf of researchers at Michigan State University to give individuals an opportunity to describe their life experiences, and identify strengths and concerns of the community. The findings of this research will be used to better understand and offer better services to Latinas/os with disabilities

This project is focused on members of the community taking photographs, sharing stories and identifying issues to educate others about Latinas/os with disabilities. Some of the photographs may include images of people. If you are asked to have your photograph taken as part of the project and agree to do so, please read the following:

What is the purpose of the photographs?
Your photograph(s) may be used by this Photovoice Project to accomplish two goals: to identify issues or concerns for members of the community involved in this Photovoice project and to initiate social change through exhibits, presentations and publications.

What will happen?

1. Your participation will take less than ten minutes. During this time, the photographer(s) may take pictures that contain images of you. This project is confidential. Your name or any other identifying information will not be known or listed with photographs and reports. It is good to remember that despite efforts to maintain confidentiality, there is always the chance that someone may recognize you in the photographs.
2. Participation is voluntary, you may choose not to participate at all, or you may refuse to participate in certain procedures, or answer certain questions, or discontinue your participation at any time without penalty or loss of benefits.

What happens to the photographs?
Photographs become the property of the researchers of this Photovoice project and may be used in exhibits, presentations and publications. All photographs and information will be maintained in a confidential manner. Data will be stored in computers that are password protected and all data will be secured in a locked storage file.

Who is in charge?
The people in charge of this study are Dr. José Rubén Parra-Cardona and Mr. David Cordova of Michigan State University. Mr. Cordova may be reached at (310) 487-8018 or cordovad@msu.edu , and Dr. Parra at (517) 432-2269 or parraca1@msu.edu .

Confidentiality:
Your privacy will be protected to the maximum extent allowable by law. Because Photovoice requires photo taking of experiences, as well as the dissemination of photos to increase awareness of the photographers experiences, your photo may be identified particularly if someone from the community is the photographer or participant. The

research team will use these photos for the analysis of the study. If the study is published, there will be no personal identifying information reported.

Certificate of Confidentiality

To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, the researchers cannot be forced to disclose information that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of Federally funded projects or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA).

You should understand that a Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person obtains your written consent to receive research information, then the researchers may not use the Certificate to withhold that information.

The Certificate of Confidentiality does not prevent the researchers from disclosing voluntarily, without your consent, information that would identify you as a participant in the research project under the following circumstances: child abuse, intent to hurt self and/or others.

Risks and Benefits:

The principal risk of Photovoice is the risk of incrimination. This means that because this research involves the taking of photographs, there is the potential that a photo may be taken which places a person or building at risk to be accused of or present proof of a crime or fault. Photos which place an individual engaged in any illegal activity (e.g., using illegal substances) will not be used for this study. Another potential risk of being photographed in this Photovoice study includes the disclosure of embarrassing facts. For example, a picture may reveal your disability status and/or sexual orientation, which you may not want to disclose. In addition, there is also the risk of being placed in a false light by images. This refers to the picture not representing who you or your business is. For example, because this study requires the taking of photos and discussion of those photos, the photographer may have a different opinion of what the photos mean or represent. Finally, you may experience slight discomfort if you give permission to have a photo taken of yourself that represents a challenge to your community and development (e.g., discrimination, stigma of having a disability). In an effort to prevent this from happening, no photos will be used if we do not have your permission to have your photo taken or to be published for the purposes of this study.

The information gathered from this study will be used to better understand the life experiences of Latinas/os with disabilities in an effort to develop better services.

If I have a question:
If you have any questions about this study, please contact one of the investigators, Mr. Cordova (310) 487-8018, corodvad@msu.edu , or Dr. José Rubén Parra-Cardona (517) 432-2269, parraca1@msu.edu , or write to 291 South La Cienega Suite 308, Beverly Hills, CA 90211

Agreement statement: By signing this consent form, I agree to voluntarily have my photograph or my child's photograph taken. I also understand and agree that unless otherwise notified in writing, the researchers of this Photovoice project assumes that permission is granted to use my photograph(s) for public exhibits, presentations, publications and/or other educational purposes and that no identifying information will be used. If the individual being photographed is a minor, parental permission must be provided below.

Print Parent/Guardian's Name

____

Parent/Guardian's Signature ____________________________Date

____

Print Youth's
Name____

Youth's
Signature___________________________________Date______________

Or

Print Adult Participant's Name

____

____
Signature of Participant Date

Photographer's ID ____

Appendix C: Consent Form for Photographs to be Published

Through The Eyes of Latinos/as with Physical Disabilities who currently Abuse Substances: A Photovoice Study

What we are doing:

We are conducting a research study that will help us understand the experiences of Latinos/as with physical disabilities who currently abuse substances. The purpose of this research is to learn about your perceptions and experiences about strengths and challenges of having a disability. We expect to obtain this information by asking those who show an interest in participating in this study to take pictures of their experiences and share their photos with other participants in a two-hour focus group interview. Mr. David Cordova will conduct all the focus group interviews. You may decide not to participate in the study or not answer any of the questions. Each focus group interview will be tape recorded and later transcribed and later studied by the research team. To be considered for the study, you must: (a) identify yourself as Latino/a or Hispanic, (b) identify yourself as having a physical disability, (c) have answered yes to past year substance use or binge drinking questionnaire, (d) be at least 18 years of age, and (e) show an interest in participating in the study.

Who is in charge?

The people in charge of this study are Dr. José Rubén Parra-Cardona and Mr. David Cordova of Michigan State University. Mr. Cordova may be reached at (310) 487-8018 or cordovad@msu.edu , and Dr. Parra at (517) 432-2269 or parraca1@msu.edu .

What will happen?

1. You will participant in a Photovoice study in which you will be asked to take pictures of your experiences over the course of a week with a disposable camera, based on the following questions: (a) Can you please describe to me your life as a Latino/a with a disability, (b) Can you please describe to me your life as a Latino/a with a disability who is currently taking substances, (b) Can you describe some of the strengths in your community related to your disability, and (c) what would you like to see changed in your community related to your disability.
2. The study involves two cycles of photo taking and three focus group interviews over the course of approximately 9 weeks. The focus group interviews will be audiotape recorded, last approximately two hours each and the nature of these group interviews will be to discuss the photographs. The final focus group will not involve discussion of photographs, rather will focus on ensuring that what I am reporting in the research findings is in fact what you are saying.
3. You will be asked for permission to have these photos published for the purposes of this study.
4. Two sets of photos will be developed. One set belongs to you, while the second set of photos belongs to the investigators of this research to be published and/or used for the purposes of the study.
5. You will be paid $30.00 for your participation in each focus group.

6. Participation is voluntary, you may choose not to participate at all, or you may refuse to participate in certain procedures, or answer certain questions, or discontinue your participation at any time without penalty or loss of benefits.

Why the study is being done?
We want to better understand the experiences of Latinos/as with disabilities who are currently taking substances in order to offer better services. Your feedback will be very important because we will have a better idea of the challenges you experience. In addition, we will be clearer about the experiences in your community and what you see as strengths as well what needs to change in your neighborhood. We want to know your experiences and perceptions about how you understand disability and substance abuse.

Confidentiality:
Your privacy will be protected to the maximum extent allowable by law. Because Photovoice requires you to take photos of your experiences, as well as disseminate photos to increase awareness of your experiences, your photo may be identified particularly if someone from the community is the photo participant. Mr. Cordova will listen to the audiotapes and know the answers to the questions. If the study is published, there will be no personal identifying information reported.

Certificate of Confidentiality
To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, the researchers cannot be forced to disclose information that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of Federally funded projects or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA).

You should understand that a Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person obtains your written consent to receive research information, then the researchers may not use the Certificate to withhold that information. In addition, the Certificate of Confidentiality only protects against demands for information that may identify you as a participant. Therefore, if your identity as a participant is known because of a photo (e.g., other community members recognize your photo), a Certificate of Confidentiality may not offer protection. For example, if the photo is used in a presentation and identifies you as a participant in the study, then it may not be possible for us to use the Certificate of Confidentiality to protect other identifying information.

The Certificate of Confidentiality does not prevent the researchers from disclosing voluntarily, without your consent, information that would identify you as a participant in the research project under the following circumstances: child abuse, intent to hurt self and/or others. For example, instances that may be reported include photos which display child neglect in their homes (e.g., lack of clothing, food) and/or around drugs, and acts of violence, whether the perpetrator or victim. In addition, please be aware that although the nature of this study is not to explore harm caused by others or yourself, harm caused by anyone (e.g., threats of violence by others or yourself) may be reported to the appropriate authorities, including police officials. Further, we as researchers are not prevented from taking steps to ensure the safety and prevent harm to participants or others if a person takes a picture which depicts possible harm.

Please note that this Certificate of Confidentiality does not represent an endorsement of the study by the Department of Health and Human Services or the National Institutes of Health.

Risks and Benefits:

The principal risk of Photovoice is the risk of incrimination. Photos which place an individual engaging in any illegal activity (e.g., using illegal substances) will not be used for this study. You may experience slight discomfort if you talk about issues that represent a challenge in your community and development (e.g., discrimination, stigma of having a disability). If you become visibly disturbed during the focus group, the interview will be stopped. Mr. Cordova will offer counseling referrals if any follow-up services are required.

You may gain insight about your experiences of living with a disability, and may experience a sense of relief by having someone listen to your stories. Further, this information will be used in an effort to better understand the life experiences of Latinas/os with disabilities.

If I have a question:

If you have any concerns or questions about this research study, such as scientific issues, how to do any part of it, or if you believe you have been harmed because of the research, please contact the researcher, Mr. Cordova (310) 487-8018, corodvad@msu.edu , or Dr. José Rubén Parra-Cardona (517) 432-2269, parraca1@msu.edu , or write to 291 South La Cienega Suite 308, Beverly Hills, CA 90211.

If you have any questions or concerns about your role and rights as a research participant, or would like to register a complaint about this research study, you may contact, anonymously if you wish, MSU's Human Research Protection Programs, at 517-355-2180, FAX 517-432-4503, or e-mail irb@msu.edu, or regular mail at: 202 Olds Hall, MSU, East Lansing, MI 48824.

Mr. Cordova has read this form out loud. He has answered our questions. I, as a participant, have a copy of this form.

To agree to be a part of this research study and give permission to have my photos published, initial the boxes below and sign.

☐ I voluntarily agree to participate in this study

☐ I give permission to have my photos published for the purposes of this study.

☐ I have received a copy of all of the photos I have taken as a photographer in this study.

____

Signature of Participant Date

Appendix D: Participant Recruitment Flier

Latinos with Disabilities: A Health Study
We would like to hear your voices!

Researchers from Michigan State University would like to invite you to participate in a Photovoice research study in which you will take photos of your experiences. In addition, you will be asked to participate in a series of focus group discussions about your photos related to your experiences as a Latino/a with a disability. These group interviews are part of a research study that will help us understand your experiences. Further, your input will help us to better understand some of the challenges and strengths that you find in your community.
These small group discussions will help us understand:

- What is your life like as a Latino/a with a disability
- What are the strengths of your community
- What would you like to see different in your community

Benefits of participation include:
- Your voice will be heard
- Gain insight about your experiences in your community

- ❖ Your participation in this Photovoice research project and group interviews are entirely voluntary and you will not be required to talk about any issues you do not want to discuss.
- ❖ Your participation in these discussions can be stopped at any time without penalty.
- ❖ We will ensure that the information you provide along with your identity will remain confidential.

To learn more about your opportunity to attend a discussion session, please contact Mr. David Córdova at 310-487-8018 or 310-652-7619 or cordovad@msu.edu,

Your participation is the key  to understanding your experiences!

Nos gustaría escuchar sus voces!

Latinos con Incapacidades: Un Estudio de Salud

Investigadores de la Universidad del Estado de Michigan quisieran invitarlo a tomar parte en un estudio de investigación de 'Photovoice' en el que usted tomará fotos de sus experiencias. Además, le pedirán participar en una serie de discusiones sobre sus fotos relacionadas con sus experiencias como Latino/a con una incapacitacion. Estas entrevistas serán en grupo y forman parte de un estudio de investigación que nos ayudará a comprende sus experiencias como Latino/a con una incapacitación. Además, con su participacion nos ayudará a comprender mejor algunos de los retos y las fortalezas que se encuentran en al comunidad Latina.

Estos pequeños grupos de discusión nos ayuda a entender:

- ¿Como es su vida como un latino / a con una incapacidad?
- ¿Cuáles son las fortalezas de su comunidad?
- ¿Qué le gustaría ver diferente en su comunidad?

Beneficios de su participación:

Su voz es escuchada

Conocimiento de sus experiencias en su comunidad

- Su participación en este proyecto de investigación en "Photovoice" y entrevistas de grupo son completamente voluntario y no se le requiere hablar de temas que no quiere discutir.
- Su participación en esta discusión puede terminar a cualquier tiempo sin penalidad
- Aseguraremos que la información que nos proporcionaron y su identidad será mantenida confidencialmente.

Para mas información por favor póngase en contacto con el Sr. David Córdova 310-487-8018 o 310-652-7619 o cordovad@msu.edu

Su participación es la llave  para mejor entender las experiencias de Latinos viviendo con una incapacitación.

Appendix E: Photo Reflection Sheet

SHOWeD (Wang & Redwood Jones, 2004): Photo Reflection

Participant Name:

Participant #:
Week #
Exposure#:

What do you See here?

What is really Happening?

How does this relate to Our lives?

Why does this problem or strength exist?

What can we Do about it?

Appendix F: Demographics

Identification #: ☐☐-☐☐-☐☐
ID Group Cycle

Date: ____________________

Instructions:

This survey asks questions about you, your thoughts and feelings. We greatly value your input and by completing this survey you will be helping us to learn more about how to provide culturally appropriate services.

For each item check the box that best fits with how you feel about the question. Remember this is not a test, just answer the questions to the best of your abilities. Simply respond as truthfully as you can.

YOUR RESPONSES ARE CONFIDENTIAL

TELL US ABOUT YOU . . . .

SECTION A: ***Demographic Information***
Please place a X or fill in the blank that best describes you

1. **How would you describe yourself?** ☐ Male ☐ Female

2. **When were you born?** ___ ___ / ___ ___ / ___ ___
Month Day Year

3. **Where you live now, who lives with you?** *(mark all that apply)*
☐ Mother
☐ Father
☐ Sister/s
☐ Brother/s
☐ Foster Mother
☐ Foster Father
☐ Stepmother
☐ Stepfather
☐ Grandparent
☐ Other adults
☐ Other children

4. **What is your marital status?**
☐ Single
☐ Married
☐ Separated
☐ Widowed
☐ Divorced
☐ Living with someone (partner, boyfriend, girl friend)
☐ Other: Specify ____________________

5. **How many persons live in your home** *(including yourself)***?** __________

6. **Were you born in the United States?** ☐ Yes ☐ No

6a. **If NO, how many years have you been in this Country?** __________

7. **Are you:**
☐ 1st generation
☐ 2nd generation
☐ 3rd generation
☐ Don't know
☐ Other, Born in__________

Identification #: ☐☐-☐☐-☐☐
ID Group Cycle

8. What is the primary language spoken in your home?
☐ English ☐ Spanish Other:________________

9. Are you Hispanic / Latino? ☐ Yes ☐ No

9a. How would you best describe yourself? (*Circle all that apply.*)

a	White / Anglo Saxon
b	Black or African American (non Hispanic)
c	Asian / Asian American
d	American Indian or Alaskan Native
e	Hispanic/Latino
f	Mexican/Mexican American/Chicano
g	Central American (specify country: ____________)
h	South American (specify country: ____________)
i	Puerto Rican
j	Cuban
k	Other: specify ____________________

10. Do you have a disability?
☐ yes ☐ no

10a. If yes, what is your disability?____
____

10b. How old were you when you were diagnosed as having a disability?____
____

10c. Are you currently recieving disability benifits?
☐ yes ☐ no

10d. Are you currently receiving any benefits? Please explain.____
____

11. What is the highest level of education (the last grade) **you have finished, whether or not you received a degree? (01=1st grade, 12=12th grade, 13=college freshman, 16=college completion)**
☐ ☐ Level in years

Identification #: ☐☐-☐☐-☐☐
ID Group Cycle

12. **If less than 12 years (12th grade) of education, do you have a GED (Graduate Equivalent Diploma)?**
☐ Yes ☐ No

13. **What is your current employment status?**
- ☐ Employed full time
- ☐ Employed part time
- ☐ Unemployed, looking for work
- ☐ Unemployed, not looking for work
- ☐ Unemployed, disabled
- ☐ Unemployed, retired
- ☐ Other:____________

14. **Think about the household members that live with you right now. About how much income did the whole household have in the past year? Please include wages or pay from jobs before taxes. Please also include child support, and/or cash payments from the government (for example, welfare, SSI, or unemployment insurance).**
- ☐ 0-$5,000
- ☐ $5,001-$10,000
- ☐ $10,001-$15,000
- ☐ $15,001-$20,000
- ☐ $20,001-$25,000
- ☐ $25,001-$30,000
- ☐ $30,001-$35,000
- ☐ $35,001-$40,000
- ☐ $40,001-$45,000
- ☐ $Over 45,001

15. **What is your religion?**
- ☐ Catholic
- ☐ Jewish
- ☐ Jehovah's Witness
- ☐ Muslim
- ☐ Christian
- ☐ Protestant
- ☐ Baptist
- ☐ Other:______________________

16. **During the past 30 days, have you used any of the following?**

a.	Tobacco	☐ Yes	☐ No	Number of times _______
b.	Marijuana or hashish	☐ Yes	☐ No	Number of times _______
c.	Cocaine	☐ Yes	☐ No	Number of times _______
d.	Crack	☐ Yes	☐ No	Number of times _______
e.	Heroin or Opiate	☐ Yes	☐ No	Number of times _______
f.	PCP or Angel Dust	☐ Yes	☐ No	Number of times _______

Identification #: ☐☐-☐☐-☐☐
ID Group Cycle

16. During the past 30 days, have you used any of the following? (Cont.)

g. Ecstasy ☐ Yes ☐ No Number of times _______

h. LSD or Acid ☐ Yes ☐ No Number of times _______

i. Other Hallucinogens

(e.g., mushrooms, mescaline) ☐ Yes ☐ No Number of times _______

j. Inhalants (e.g., glue, paint) ☐ Yes ☐ No Number of times _______

k. Any other drug not listed ☐ Yes ☐ No Number of times _______

specify____

17. During the past one year, have you used any of the following?

a. Tobacco ☐ Yes ☐ No Number of times _______

b. Marijuana or hashish ☐ Yes ☐ No Number of times _______

c. Cocaine ☐ Yes ☐ No Number of times _______

d. Crack ☐ Yes ☐ No Number of times _______

e. Heroin or Opiate ☐ Yes ☐ No Number of times _______

f. PCP or Angel Dust ☐ Yes ☐ No Number of times _______

g. Ecstasy ☐ Yes ☐ No Number of times _______

h. LSD or Acid ☐ Yes ☐ No Number of times _______

i. Other Hallucinogens

(e.g., mushrooms, mescaline) ☐ Yes ☐ No Number of times _______

j. Inhalants (e.g., glue, paint) ☐ Yes ☐ No Number of times _______

k. Any other drug not listed ☐ Yes ☐ No Number of times _______

Identification #: ☐☐-☐☐-☐☐

ID Group Cycle

17. During the past one year, have you used any of the following?

(Cont.)

specify____

18. In your lifetime, have you used any of the following?

a. Tobacco ☐ Yes ☐ No Number of times _______

b. Marijuana or hashish ☐ Yes ☐ No Number of times _______

c. Cocaine ☐ Yes ☐ No Number of times _______

d. Crack ☐ Yes ☐ No Number of times _______

e. Heroin or Opiate ☐ Yes ☐ No Number of times _______

f. PCP or Angel Dust ☐ Yes ☐ No Number of times _______

g. Ecstasy ☐ Yes ☐ No Number of times _______

h. LSD or Acid ☐ Yes ☐ No Number of times _______

i. Other Hallucinogens

(e.g., mushrooms, mescaline) ☐ Yes ☐ No Number of times _______

j. Inhalants (e.g., glue, paint) ☐ Yes ☐ No Number of times _______

k. Any other drug not listed ☐ Yes ☐ No Number of times _______

specify____

19. During the past 30 days, have you had five (men)/ four (women) or more drinks on the same occasion? By “occasion,” we mean at the same time or within a couple of hours of each other.

☐ Yes ☐ No Number of times _______

Identification #: ☐☐-☐☐-☐☐
ID Group Cycle

20. **During the past one year, have you had five (men)/ four (women) or more drinks on the same occasion? By "occasion," we mean at the same time or within a couple of hours of each other.**

☐ Yes ☐ No Number of times _______

21. **In your lifetime, have you had five (men)/ four (women) or more drinks on the same occasion? By "occasion," we mean at the same time or within a couple of hours of each other.**

☐ Yes ☐ No Number of times _______

Appendix G: Interview Guide

INTERVIEW GUIDE

I thank you for your participation in this group interview. I want to learn more about your experiences as a Latina/o with a disability and about the strengths in your community as well as what needs to change in relation to your disability. Your responses will help me understand what it means to be a Latina/o and have a disability and what are the ways in which I can support you and other Latinas/os with disabilities.

I am really interested in your personal experiences and in any thoughts and feelings that you experience related to being a Latina/o and having a disability. There are no right or wrong answers because all your experiences are really important to me. As I mentioned to you before, you have the right to stop this interview at any time if you feel like doing so or you can skip any question that you don't want to answer for any reason. Please ask me if you are confused about any questions I ask you.

Grand Tour Question #1

Please describe to me your life as a Latino/a with a disability

Probes:

- Do you consider yourself to have a disability? How important is disability to your identity?
- If you had to describe to someone what your life is like as a Latino with a disability, what would you say?
- What are your strengths as a Latino with a disability?
- What do you find most difficult as a Latino with a disability?

Grand Tour Question #2

Please describe to me your life as a Latino/a with a disability who currently takes substances?

Probes:

- When do you find yourself most wanting to use the substances? Please explain
- Are there some days that you feel like using more than others? What is going on those days?
- Up until the point you are about to use the substance, what are you thinking/feeling?
- Where are you at when you use substances?
- Are you alone or with other people? Please describe the setting.
- How do your family, peers, work/school, community/culture, and social policy push you towards or away from using substances?
- What is the significance of identifying as a Latino to your taking substances?
- As a Latino with a disability, what challenges have you experienced which drive you towards wanting to use substances?
- As a Latino with a disability, what sources of support do you have access to that prevent you from wanting to use substances?

Grand Tour Question #3

Can you describe the strengths within your community?

Probes:

- How does your community support you as a Latino with a disability (e.g., appropriate and accessible services)?
- How does your community support your ethnic culture (e.g., values, beliefs, language)?
- Tell me about who or what has helped you the most in your life as a Latino with a disability? Describe to me how they have helped you?
- As a Latino with a disability, can you please describe to me how your family has supported you?
- As a Latino with a disability, can you please describe to me how your work/school has supported you?
- As a Latino with a disability, can you please describe to me how your friends/peers have supported you?
- As a Latino with a disability, can you describe to me how current social policy has supported you?

Grand Tour Question #4

What changes would I like to see in my community in order to better serve the disability community?

Probes:

- What would you say is the biggest obstacle as a Latino with a disability?
- What concerns you the most in your community as a Latino with a disability?
- Tell me about changes or things that you would make different in your community as a Latino with a disability?

- Would you change anything in your family to better support you as a Latino with a disability?
- Would you change anything in your peer/friend relationship to better support you as a Latino with a disability?
- Would you change anything in your work/school environment to better support you as a Latino with a disability?
- Would you change anything in regards to social policy to better support you as a Latino with a disability?

Grand Tour Question #5

Please talk about any issues that I did not addressed and that you consider are important in describing your experiences as a Latino with a disability?

Appendix H: Emergent Features of Life-World Context

First draft

1. Community is the biggest challenge of my life
    - Our neighborhoods are poor.
    - There is a lot of community violence.
    - Gangs in the community.
    - Accessibility for persons with disabilities is a challenge.
    - Drugs are everywhere in our community.
    - Alcohol is easily accessible.
2. Judging Me by My Looks
    - Discrimination for Being Latino
    - Discrimination for having a disability
    - Discrimination for Substance Use
    - Discrimination against women
3. Transportation and Disability
    - Only two people with wheelchairs can fit
    - My biggest challenge
    - Not Accurate
    - Not Dependable
    - Both a Strength and A Challenge
    - Brings Me To Work
    - Is Expensive
4. My Community is Supportive
    - My Job, Now I have a reason to live for
    - People understand what I'm going through
    - My Community supports my culture
    - Murals

I Get support from my neighbors

There are a lot of Latinos in my community

Community centers offer a lot of help

5. Churches are a positive thing in the community

    Father Greg Boyle is a Father I never had

    Church Saved Me

    God is my strength

    Religion is my strength

    Good Christian Homes

6. Family Supports you

    Family Being There for me and showing me love

    Family doesn't feel sorry for me

    My strength is my mom's words

    My mom and dad have been there for me

    Gave me strength not to use drugs

7. Family putting me down to the point of wanting to use again

    They just talk really bad towards me and towards my addiction

    They have the best intentions for me, but hardly express it in a positive way.

    I can't ask my family for help.

    My Family Does not trust me

8. Health, Mental Health, and Service Providers

    Not Having Access to Mental Health

    Community Stigma and Mental Health Services

    Welfare Reps put you down

    State Rehab Counselors put you down

    Social workers put you down

    Mistrust towards doctors

Physical therapist putting me down

Need more training on substance abuse and disability

Professionals from different ethnic backgrounds

9. Women and Disparities

No programs designed specifically for women

Society doesn’t acknowledge substance abuse in women

Emergent Features Of Life-World Context

Second draft

1. Community is the biggest challenge of my life
    - A. Poverty, Violence and Gangs
    - B. A lack of accessibility for persons with disabilities.
    - C. Drugs and alcohol are everywhere in our community.
    - D. Discrimination: Being Latino, having a disability, abusing substances, and being a woman.
2. Transportation and Disability
    - A. Accessibility is a challenge.
    - B. Both Strength and a Challenge
3. My Community is Supportive
    - A. My Job, now I have a reason to live for
    - B. People understand what I'm going through
    - C. My Community supports my culture
    - D. Community centers offer a lot of help
4. Churches are a positive thing in the community
    - A. Father Greg Boyle is a Father I never had
    - B. Religion is my strength
    - C. Church Prevents Substance Use
5. Family supports you
    - A. Family Being there for me and showing me love
    - B. Family doesn't feel sorry for me
    - C. Gave me strength not to use drugs
6. Family putting me down to the point of wanting to use again
    - A. They have the best intentions for me, but hardly express it in a positive way.

    - B. I can't ask my family for help.
    - C. My Family Does not trust me

7. Health, Mental Health, and Service Providers
    - A. Not Having Access to Mental Health
    - B. Community Stigma and Mental Health Services
    - C. Being Put Down By Health and Mental Health Professionals and Service Providers
    - D. Mistrust towards doctors
    - E. Lack of Culturally Appropriate Services

8. Women and Disparities
    - A. No programs designed specifically for women
    - B. Society doesn't acknowledge substance abuse in women
    - C. Our Men are institutionalized
    - D. Domestic Violence

Emergent Features of Life-World Context

Third draft

1. Community is the biggest challenge of my life
    - A. Poverty, Violence and Gangs
    - B. Experiencing a lack of accessibility for persons with disabilities.
    - C. There are drugs and alcohol are everywhere in our community.
    - D. Discriminated against: Being Latino, having a disability, abusing substances, and being a woman.
    - E. Transportation as a person with a disability is challenging.
2. My Community is Supportive
    - A. My Job, now I have a reason to live for
    - B. People understand what I'm going through
    - C. My Community supports my culture
    - D. Community centers and programs offer a lot of help
    - E. Churches help prevent substance abuse
3. My family supports me
    - A. Family Being there for me and showing me love
    - B. My family doesn't feel sorry for me
    - C. Gave me strength not to use drugs
4. Family putting me down to the point of wanting to use again
    - A. They have the best intentions for me, but hardly express it in a positive way.
    - B. I can't ask my family for help.
    - C. My Family Does not trust me
5. Health, Mental Health, and Service Providers
    - A. Not Having Access to Mental Health
    - B. Community Stigma and Mental Health Services

    C. Being Put Down By Health and Mental Health Professionals and Service Providers

    D. Mistrust towards doctors

    E. Lack of Culturally Appropriate Services

6. Women and Disparities

    A. No programs designed specifically for women

    B. Society doesn't acknowledge substance abuse in women

    C. Our Men are institutionalized

    D. Domestic Violence

FEATURES AND DESCRIPTORS OF THE LIFE-WORLD CONTEXT

1. BEING CHALLENGED BY MY COMMUNITY
    - A. Being impacted by poverty, violence and gangs
    - B. I'm invisible to others
    - C. Drugs and alcohol all around me
    - D. Being discriminated against: as a Latino with a disability
2. BEING PUT DOWN BY MY FAMILY
    - A. My family trying to help me but in the wrong way
    - B. Not being able to ask my family for help.
    - C. My family not trusting me
3. EXPERIENCES WITH HEALTH AND MENTAL HEALTH PROFESSIONALS AND SERVICE PROVIDERS
    - A. Not having access to mental health
    - B. Being stigmatized for receiving mental health services
    - C. Being put down by service providers
    - D. Service providers lacking cultural sensitivity
4. WOMEN EXPERIENCING EXCLUSION AND DISCRIMINATION
    - A. Programs of support are not designed for women
    - B. Substance abuse in women being overlooked
    - C. They put men in jail
    - D. Intimate partner violence is pervasive but unacknowledged
5. BEING SUPPORTED BY MY COMMUNITY
    - A. People understanding what I'm going through
    - B. My community embracing my culture
    - C. My community reaching out to me and helping me
6. BEING SUPPORTED BY MY FAMILY
    - A. My family being there for me and loving me

B. My family not feeling sorry for me

C. My family giving me strength not to use drugs

Appendix I: Emergent Phenomena
EMERGENT PHENOMENA

First draft

1. Drugs and Alcohol

Wanting the pain to go away
To forget that I have a disability
Putting my disability to the side
The Feelings come back when you're not high
Turning to drugs as a way of escaping my disability

2. Having DCFS in my life

Using Drugs got my children taken away
Getting my kids taken away is one of the greatest challenges in my life
It devastated us, it drowned us even more
Turning to drugs

3. Domestic Violence

Experiencing Domestic Violence
Putting me down
My kids witnessed everything

4. Disability and Stress

Crying about my life
Waiting on transportation is really stressful
Who is going to Want Me Like This?

5. Wanting to change for my kids

Wanting to be a good example for my kids
Wanting to break the cycle

6. I'm damaged goods, is how I feel

Wanting to hide my disability
Who wants me with a disability?

7. Adjusting and learning how to live with my disability

Learning how to get around
Relying on my other senses
Learning to accept myself
Accepting my disability so others can accept me
Letting all that anger and hate out
Not caring anymore about what people think about my disability
Not Letting Our Disability Stop Us
No Longer Seeing My Disability as a Disadvantage
There's nothing I can do about my disability
Trying to have a positive mental attitude
Looking Beyond Disability
My disability is my strength

8. Living in poverty

Can't leave the house without my EBT card
Experiencing a struggle
Experiencing Not Having Health Care
Experiencing Not Being Able To Provide for Your Kids

9. Being depressed

Wanting to die
Talking down about myself
The depression sits in
Depression because of what people would think of me
Shutting people out
That's when my drug addiction was at its worst

10. Experiences of disability

Experiencing Difficulties of Limitations
Not having that many friends

Life in a wheelchair is a lot more harder
Using my hands to feel around

11. Not Wanting to Depend on Other people

Wanting to do it myself

12. Not knowing who I am

Wanting to be comfortable with myself
Wanting to be just like you
Wanting to be normal

13. Not Wanting Them to Feel Sorry For Me

Me as a person first

14. Not Wanting To Give Up

We're here attending and wanting to do better
Never losing hope
Not wanting to use drugs anymore
Getting up and doing something
My Strength comes from within

15. Wanting a better environment

Wanting a better relationship with my family
Wanting a better relationship with my kids

16. Wanting help

Wanting family therapy
Wanting someone to help me stop using

17. Wanting More Accessibility

Financially

18. Wanting More Awareness in the Community about Disability

19. Wanting More Awareness in the Community about Drugs

20. Wanting More Information about Mental Health

21. Wanting More Information about Resources

Programs available for persons with disabilities and substance abuse

22. Wanting My Family to Be More Supportive

Wanting my family to understand

23. Wanting More Education

EMERGENT PHENOMENA

Second draft

1. DISABILITY, DRUGS AND ALCOHOL

A. Pain and Sadness

Wanting the pain to go away
The Feelings come back when you're not high

B. Forgetting

To forget that I have a disability
Putting my disability to the side
Turning to drugs as a way of escaping my disability

2. DISABILITY, SUBSTANCE ABUSE AND WOMEN: DCFS AND DOMESTIC VIOLENCE

A. Having DCFS in my life

Using Drugs got my children taken away
Getting my kids taken away is one of the greatest challenges in my life
It devastated us, it drowned us even more
Turning to drugs

B. Domestic Violence

Experiencing Domestic Violence
Putting me down
My kids witnessed everything

3. FEELING INFERIOR

A. Damaged Goods

I'm damaged goods, is how I feel
Who is going to Want Me Like This?
Who wants me with a disability?

B. Wanting To Hide

Wanting to hide my disability

Crying about my life

C. Being Depressed
Wanting to die
Talking down about myself
Depression because of what people would think of me
Shutting people out
That's when my drug addiction was at its worst

4. NOT GIVING UP AND WANTING TO CHANGE

A. Not Giving Up
We're here attending and wanting to do better
Never losing hope
Not wanting to use drugs anymore
Getting up and doing something
My Strength comes from within

B. Wanting to change
Wanting to change for my kids
Wanting to break the cycle

5. ADJUSTING, ACCEPTING AND LEARNING HOW TO LIVE WITH MY DISABILITY

A. Not Knowing Who I Am
Wanting to be comfortable with myself
Wanting to be just like you
Wanting to be normal

B. Adjusting
Learning how to get around
Relying on my other senses
Trying to have a positive mental attitude

C. Accepting
Learning to accept myself
Accepting my disability so others can accept me
Letting all that anger and hate out
Not caring anymore about what people think about my disability
There's nothing I can do about my disability

D. My Strength

Not Letting Our Disability Stop Us
No Longer Seeing My Disability as a Disadvantage
Looking Beyond Disability
My disability is my strength

6. LIVING IN POVERTY

A. Can't leave the house without my EBT card
B. Experiencing a struggle
C. Experiencing Not Having Health Care
D. Experiencing Not Being Able To Provide for Your Kids

7. EXPERIENCES OF DISABILITY

A. Experiencing Difficulties with Regards to Limitations

Life in a wheelchair is a lot harder
Using my hands to feel around

B. Feeling lonely

Not having that many friends

C. Not Wanting to Depend on Other people

Wanting to do it myself .

D. Not Wanting Them to Feel Sorry For Me

Me as a person first

8. WANTING SUPPORT AND IMPROVED RELATIONSHIPS

A. Wanting My Family to Be More Supportive

Wanting my family to understand
Wanting someone to help me stop using

B. **Wanting A Better Relationship**

Wanting a better relationship with my family
Wanting a better relationship with my kids

9. WANTING MORE HELP AND INCREASED AWARENESS IN THE COMMUNITY

A. Disability

- A lot of people don’t know about disability

B. Drugs

- Wanting them to know that addiction is forever

C. Mental Health

- I’ve never been taught to do that (talk about my feelings)
- Nobody ever reached out to me
- Wanting family therapy

D. Resources

- Programs available for persons with disabilities and substance abuse
- Education
- Accessibility

EMERGENT PHENOMENA

Third draft

1. DISABILITY, DRUGS AND ALCOHOL

A. Experiencing Pain and Sadness
- Wanting the pain to go away
- The Feelings come back when you're not high

B. Wanting to Escape and Forget About My Disability
- To forget that I have a disability
- Putting my disability to the side
- Turning to drugs as a way of escaping my disability

2. DISABILITY, SUBSTANCE ABUSE AND WOMEN: DCFS AND DOMESTIC VIOLENCE

A. Having DCFS in my life
- Using Drugs got my children taken away
- Getting my kids taken away is one of the greatest challenges in my life
- It devastated us, it drowned us even more
- Turning to drugs

B. Domestic Violence
- Experiencing Domestic Violence
- My kids witnessed everything

3. FEELING INFERIOR TO OTHERS

A. Damaged Goods
- I'm damaged goods, is how I feel
- Who is going to Want Me With a Disability?

C. Being Depressed and Wanting To Hide
- Wanting To Hide
- Crying About My Life
- Feeling Lonely
- Wanting to Die
- Talking down about myself
- Depression because of what people would think of me
- Shutting people out

That's when my drug addiction was at its worst

4. NOT GIVING UP AND WANTING TO CHANGE

A. Not Giving Up

We're here attending and wanting to do better
Never losing hope
Not wanting to use drugs anymore
Getting up and doing something
My Strength comes from within

B. Wanting to change

Wanting to change for my kids
Wanting to break the cycle

5. ADJUSTING, ACCEPTING AND LEARNING HOW TO LIVE WITH MY DISABILITY

A. Not Knowing Who I Am

Wanting to be comfortable with myself
Wanting to be just like you
Wanting to be normal

B. Adjusting

Learning how to get around
Relying on my other senses
Trying to have a positive mental attitude

C. Accepting

Learning to accept myself
Accepting my disability so others can accept me
Letting all that anger and hate out
Not caring anymore about what people think about my disability
Accepting there's nothing I can do about my disability

D. My Strength

Not Letting Our Disability Stop Us
No Longer Seeing My Disability as a Disadvantage
Looking Beyond Disability
My disability is my strength

6. LIFE IS A LITTLE MORE DIFFICULT…BUT I DON'T WANT TO DEPEND ON OTHERS AND I DON'T WANT THEM FEELING SORRY FOR ME

A. Experiencing Difficulties with Regards to Limitations

Life in a wheelchair is a lot harder
Using my hands to feel around

B. Not Wanting to Depend on Other people

Wanting to do it myself .

C. Not Wanting Them to Feel Sorry For Me

Me as a person first

7. WANTING SUPPORT AND IMPROVED RELATIONSHIPS

A. Wanting My Family to Be More Supportive

Wanting my family to understand
Wanting someone to help me stop using

B. **Wanting A Better Relationship**

Wanting a better relationship with my family
Wanting a better relationship with my kids

8. WANTING MORE HELP AND INCREASED AWARENESS IN THE COMMUNITY

A. Disability

A lot of people don't know about disability

B. Drugs

Wanting them to know that addiction is forever

C. Mental Health

I've never been taught to do that (talk about my feelings)
Nobody ever reached out to me
Wanting family therapy

D. Resources

Wanting more programs for persons with disabilities and substance abuse
Wanting more education for the Latino community
Wanting more accessibility to services

Fo

1.

EMERGENT PHENOMENA

Fourth draft

1. EXPERIENCING THE STRUGGLE OF LIVING WITH MY DISABILITY

A. Experiencing Pain and Sadness

Wanting the pain to go away
Experiencing despair when feelings come back

B. Trying to Escape and Forget About My Disability

Trying to forget that I have a disability
Trying to put my disability to the side
Turning to drugs to escape from my disability

2. LOSING MY LIFE BECAUSE OF MY DISABILITY

A. Losing my Loved Ones

Losing my children to drugs
Losing my family to drugs

B. Domestic Violence

Experiencing Domestic Violence
My kids witnessed everything

3. FEELING INFERIOR TO OTHERS

A. Seeing myself as Damaged Goods

Experiencing I'm a damaged goods
Seeing myself as unlovable

C. Experiencing Depression and Wanting to Hide

Crying About My Life
Wanting To Hide

4. NOT GIVING UP AND WANTING TO CHANGE

A. Not Giving Up

Getting up and fighting

Wanting to break the cycle

B. Finding a Motivation to Change
My strength comes from within
Wanting to change for my kids

5. ACCEPTING AND EMBRACING MY DISABILITY

A. Accepting my Loss Due to my Disability
Wanting to be comfortable with myself
Wanting to be just like you
Wanting to be normal

B. Accepting my Disability
Learning to accept myself so others can accept me
Not depending on what people think about my disability

C. Embracing (Learning how to live) with my Disability
Adjusting to my disability
No longer seeing my disability as a disadvantage

6. LEARNING TO BE INDEPENDENT WITH MY DISABILITY

A. Experiencing Difficulties with Regards to Limitations
Life in a wheelchair is a lot harder
Using my hands to feel around

B. Learning to be Independent
Not wanting people to feel sorry for me
Not wanting to completely depend on others
Me as a person first

7. WANTING MORE HELP AND INCREASED AWARENESS IN THE COMMUNITY

A. Wanting My Family to Be More Supportive
Wanting my family to understand
Wanting someone to help me stop using

B. **Wanting Better Intimate Relationships**

Wanting a better relationship with my family
Wanting a better relationship with my kids

C. Wanting to Experience Understanding and Solidarity from my Community

Wanting people to understand addiction and disabilities
Wanting mental health professionals to become accountable and"get it"
Wanting my community to become accountable

PHENOMENA, COMPONENT PHENOMENA, AND INTENTIONS

1. EXPERIENCING THE STRUGGLE OF LIVING WITH MY DISABILITY

A. Experiencing Pain and Sadness
Crying about my life and wanting to die
Experiencing despair when feelings come back

B. Trying to Escape and Forget About My Disability
Trying to put aside and forget that I have a disability
Turning to drugs to escape from my disability and mental health problems
Losing my children to drugs

C. Feeling Inferior to Others
Seeing myself as damaged goods

2. NOT GIVING UP AND WANTING TO CHANGE

A. Not Giving Up
Getting up, fighting and deciding to get my life back
Wanting to break the cycle

B. Finding a Motivation to Change
My strength comes from within
Wanting to change for my kids
My job, giving me a reason to live

3. ACCEPTING AND EMBRACING MY DISABILITY

A. Trying to Define my New Identity with a Disability
Wanting to be comfortable with myself
Wanting to be normal just like you

B. Embracing (Learning How to Live) With my Disability
Adapting to my disability
No longer seeing my disability as a disadvantage
Learning to accept myself so others can accept me

C. Learning to be Independent with my Disability
Not wanting people to feel sorry for me
Not wanting to completely depend on others
Me as a person first

4. WANTING MORE UNDERSTANDING, HELP AND INCREASED AWARENESS IN THE COMMUNITY

A. Wanting My Family to Be More Supportive

Wanting my family to understand
Wanting someone to help me stop using

B. Wanting Better Intimate Relationships

Wanting a better relationship with my family
Wanting a better relationship with my kids

C. Wanting to Experience Understanding and Solidarity from my Community

Wanting people to understand addiction and disabilities
Wanting mental health professionals to become accountable and "get it"
Wanting my community to become accountable

Appendix J: Research Questions and Themes

Research Questions	Features and Phenomena	Descriptors and Component Phenomena	Intentions
What are the life experiences of Latinos with disabilities who abuse substances?	Experiencing the Struggle of Living with my Disability	Experiencing Pain and Sadness	1. Crying about my life and wanting to die 2. Experiencing despair when feelings come back
		Trying to Escape and Forget About My Disability	1. Trying to put aside and forget that I have a disability 2. Turning to drugs to escape from my disability and mental health problems 3. Losing my Children to Drugs
		Feeling Inferior to Others	1. Seeing myself as damaged goods
	Not Giving Up and Wanting To Change	Not Giving Up	1. Getting up, fighting and deciding to get my life back 2. Wanting to break the cycle
		Finding a Motivation to Change	1. My strength comes from within 2. Wanting to change for my kids 3. My job, giving me a reason to live
	Accepting and Embracing my Disability	Trying to define my new identity with a disability	1. Wanting to be comfortable with myself 2. Wanting to be normal

			just like you
		Embracing (Learning How to Live) With my Disability	1. Adapting to my disability 2. No longer seeing my disability as a disadvantage 3. Learning to accept myself so others can accept me
		Learning to be independent with my disability	1. Not Wanting People to Feel Sorry For Me 2. Not Wanting to Completely Depend on Others 3. Me as a person first
	Wanting More Help and Increased Awareness in the Community	Wanting My Family to Be More Supportive	1. Wanting my family to understand 2. Wanting someone to help me stop using
		Wanting Better Intimate Relationships	1. Wanting a better relationship with my family 2. Wanting a better relationship with my kids
		Wanting to experience understanding and solidarity from my community	1. Wanting people to understand addiction and disabilities 2. Wanting mental health professionals to become accountable and "get it" 3. Wanting my community to become accountable

Substance abuse in

What are the risk factors in the lives of Latinos with Disabilities who abuse substances?	Being Challenged by my Community	Being impacted by poverty, violence and gangs I'm invisible to others Drugs and alcohol all around me Being discriminated against: as a Latino with a disability	
	Being Put Down by my Family	My family trying to help me but in the wrong way Not being able to ask my family for help. My family not trusting me	
	Experiences with Health and Mental Health Professionals and Service Providers	Not having access to mental health Being stigmatized for receiving mental health services Being put down by service providers Service providers lacking cultural sensitivity	
	Women Experiencing Exclusion and Discrimination	Programs of support are not designed for women Substance abuse in	

		women being overlooked They put men in jail Intimate partner violence is pervasive but unacknowledged	
What are the protective factors in the lives of Latinos with Disabilities who abuse substances	Being Supported by my Family	My family being there for me and loving me My family not feeling sorry for me My family giving me strength not to use drugs	
	Being Supported by my Community	People understanding what I'm going through My community embracing my culture My community reaching out to me and helping me	

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