2022

Iris Clubhouse: Experiences of Community Integration

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Iris Clubhouse: Experiences of Community Integration

by

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An Independent Study

Submitted to the Graduate Faculty

of the

University of North Dakota

in partial fulfillment of the requirements

for the degree of

Occupational Therapy Doctorate

University of North Dakota, 2022

APPROVAL

This independent study, submitted by Rebecca Reeves in partial fulfillment of the requirement for the Degree of Occupational Therapy Doctorate from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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April 8, 2022

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PERMISISON

Title: Iris Clubhouse: Experiences of Community Integration

Department: Occupational Therapy

Degree: Occupational Therapy Doctorate

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Rebecca Reeves

Rebecca Reeves

April 12th, 2022

Date

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ACKNOWLEDGEMENTS

I would like to acknowledge and give a sincere thank you to my advisor Dr. Nicole Harris who made this work possible. Her guidance and advice carried me through all the stages of writing this independent study. I would also like to thank Dr. Marilyn Klug who gave her advice on how to structure and implement this research. Additionally, I would like to thank my classmates for providing me support. Furthermore, I would like to give special thanks to my husband and my family who gave me an endless amount of emotional support, thank you for believing in me. Lastly, this work would not have been possible if it wasn't for the support of Iris Clubhouse, in particular my mentor Dan Odell and all the members that contributed to this study. Thank you for sharing your stories with me.

ABSTRACT

The lived experience of community integration for those living with a serious mental illness (SMI) who are members of an unaccredited Clubhouse is an under investigated topic. The goal of this study is to better understand this phenomenon to inform the development of efficient and effective community integration programming for a local Clubhouse who is working toward becoming accredited. 15 active and inactive members of a local Clubhouse participated in a semi-structured interview to discuss their experiences of community integration while living with an SMI. The interviews were analyzed using a hermeneutic phenomenological approach (Dibley et al., 2020). Seven themes were identified: (1) Traumatic life events influence function; (2) community integration is desired by the majority despite social barriers; (3) employment is desired by majority despite barriers; (4) education is valued but is currently unachievable by most (5) disability benefits and housing experiences; (6) experiences of mental illness; and (7) clubhouse benefits reduce barriers to participation. Findings showed that people with an SMI have a desire to integrate within their communities but experience many barriers to successfully do so. Clubhouses can positively influence these barriers and shift the dynamic of community integration in a healthy way. Further research is needed to examine how co-occurring intellectual and learning disabilities impact community integration for this population. It will also be important to examine how Clubhouse programming can meet the needs of members who experience physical dysfunctions as well.

CHAPTER I

INTRODUCTION

Serious mental illness (SMI) is increasing among adults in the United States (Substance Abuse and Mental Health Services Administration, [SAMHSA], 2020b). Currently, one in 20 adults live with an SMI (SAMHSA, 2021). The statistics are comparable in Wyoming, the location of this study, where one and 24 people experience an SMI (SAMSHA, 2020b). SMI is defined as the inability to engage in one or more everyday activities due to the significant deterioration of function caused by a mental, emotional, or behavioral disorder (U.S. Department of Health and Human Services, 2022). According to the Commission on Accreditation of Rehabilitation Facilities (CARF), community integration is important for all people to live meaningful and balanced lives (CARF International, 2022). CARF defines community integration as the ability of all persons to be able to participate in their communities in the areas of employment, socialization, and personal interests (CARF International, 2022).

Those with an SMI experience several barriers in carrying out the major life activities that result in community integration. This is due to the functional impairments caused by their illness and the accompanying social, structural, and economic disadvantages that they incur. (CARF International, 2022; Hanisch et al., 2015). These barriers may include health problems related to medications, psychiatric symptoms, and cognitive impairments. These experiences interfere with their ability to stay employed, socialize with others, and pursue personal interests (Carolan et al., 2011; Hanisch et al., 2015; Sanchez et al., 2019). Self-stigma and stigma from others can also affect these areas of community integration. This is because one may engage in avoidance behaviors to prevent harm that the stigma may cause (Bromley, et al., 2013; Gumber & Stein, 2018). Additionally, there are social and structural barriers that this population faces

that interfere with the ability to engage in community integration. These may include unequal access to housing, education, or a lack of opportunities for socialization. (Hanisch et al., 2015).

The National Alliance of Mental Illness (NAMI) reports that 65% of those experiencing an SMI can and do live a life of recovery (Davidson & Ponte, 2021). To be in recovery means that a person can live a meaningful and purposeful life despite the challenges that living with an SMI brings. One of the cornerstones of recovery is community and is defined by SAMSHA (2012) as "relationships and social networks that provide support, friendship, love and hope" (p. 3). A mental health movement called Clubhouse International works to improve community integration by offering a supportive recovery community. Clubhouse International consists of a network of Clubhouses around the United States. Their mission is to reduce social and economic isolation for those with an SMI (Clubhouse International, 2021).

Clubhouse International encourages Clubhouses to become accredited. For a Clubhouse to be eligible for accreditation they must meet certain standards set forth by Clubhouse international that are aimed to reduce social economic isolation for its members. The major standards to be met include the Clubhouse offering transitional or supported employment options as well as opportunities for supported education. Other standards include voluntary membership, relationships that are collaborative between staff and members, a Clubhouse space that is separate from any institutionalized programs, a work-ordered day that encourages members to be a part of all aspects of running a Clubhouse, and a commitment by the Clubhouse to provide local support services and housing opportunities.

While the literature demonstrates that positive outcomes can be achieved for those living with an SMI who are members of an accredited Clubhouse, there is little evidence that considers the experiences of members who are part of an unaccredited Clubhouse. Thus, this independent

study will address how the lived experience of SMI affects community integration for those who are members of an unaccredited Clubhouse. The aim of this study is to gather in depth information about the experiences of community integration for members of a newly formed Clubhouse to guide program development for accreditation. To gain this knowledge of community integration for those living with an SMI a qualitative study was developed. Within this study a semi-structured interview was created to capture the lived experience of community integration for 15 members at a local Clubhouse. Questions were asked surrounding five themes: person factors, habituation, mental health context, community/social integration, and employment.

Three models were used to guide the development and implementation of this study. The Model of Human Occupation, The Clubhouse Model, and The Recovery Model. Each of these models are relevant to this research study as they all have a focus on enabling participation in everyday activities.

There are five chapters within this independent study. Chapter I Introduction offers an introductory view of the independent study. It describes the problem and solution of the phenomenon being studied in addition to the overall purpose of the study. Key terms that are used throughout the study are listed. Chapter II Literature Review provides an in-depth review of both the barriers and supports in the primary areas of community integration: employment, socialization, and personal interests. Chapter III Methodology provides an overview of the literary and theoretical supports for the study in addition to the study design and sample, instrumentation, and ethical considerations. Chapter IV Results discusses the primary themes that were created post analysis of the interviews. Lastly, Chapter V discusses key findings, conclusions, and future recommendations for research.

Key Terms

A list of key terms has been created for the reader to have a direct understanding of the information within this study.

Clubhouse – A place for people with an SMI to go and participate in a structured day that simulates a working environment. Clubhouses have a mission to end social and economic isolation for their members (Clubhouse International, 2021).

Community Integration – The Commission on Accreditation of Rehabilitation Facilities (CARF) defines community integration as the ability of all persons to be able to participate in their communities in the areas of employment, socialization, and personal interests (CARF International, 2022).

Environment – The environmental context discussed within this study includes both the physical environment and the social environment.

Habituation – The patterns and routines that a person's actions demonstrate. These patterns and routines are shaped by habits and roles. Habits and roles are then influenced by a person's context and environment (O'Brien, 2017).

Mental Health Context – Refers to the supporting information needed to better understand one's mental illness. This includes what the mental illness is, when it was diagnosed, and what it felt like to be diagnosed.

Occupations – "The meaningful, necessary, and familiar activities of everyday life" (AOTA, 2016, pg. 1).

Performance Capacity - Performance capacity, or the skills and abilities that enable people to perform their occupations (Kielhofner & Brooke, 1980).

Person Factors – This refers to the members' values and beliefs and was used to initiate the interviews to establish rapport and to get to know members on a more personal level.

Recovery – When a person engages in change behavior to positively impact their health and wellbeing while being self-motivated to maximize their potential in life (SAMSHA, 2012).

Serious Mental Illness (SMI) – SMI is defined as the inability to engage in one or more everyday activities due to the significant deterioration of function caused by a mental, emotional, or behavioral disorder (U.S. Department of Health and Human Services, 2022).

Socialization – Refers to the act of conversing and engaging with other people in the community.

Volition - Why people choose the occupations that they do (Kielhofner & Brooke, 1980).

CHAPTER II

LITERATURE REVIEW

Serious mental illness (SMI) is increasing among adults in the United States (Substance Abuse and Mental Health Services Administration, [SAMHSA] (2020a). Currently, one in 20 adults live with an SMI (SAMHSA, 2021). The statistics are comparable in Wyoming, the location of this study, where one in 24 people experience an SMI (SAMSHA, 2020b). SMI is defined as the inability to engage in one or more everyday activities due to the significant deterioration of function caused by a mental, emotional, or behavioral disorder (U.S. Department of Health and Human Services, 2022). According to the Commission on Accreditation of Rehabilitation Facilities (CARF), community integration is important for all people to live meaningful and balanced lives (CARF International, 2022). However, those with an SMI experience several barriers in carrying out the major life activities that result in community integration. This is due to the functional impairments caused by their illness and the accompanying social, structural, and economic disadvantages that they incur. (CARF International, 2022; Hanisch et al., 2015).

Clubhouse International is a network of non-profit organizations dedicated to removing the barriers that people with an SMI experience. Accredited Clubhouses support this population in all areas of community integration: employment, socialization, and personal interests. They do this by providing a place for people to participate in what they coin as a work-ordered-day. This work-ordered day consists of meaningful and purposeful tasks aimed at reducing the economic and social barriers that those with an SMI face (Clubhouse International, 2021). In addition, they provide supported employment and support for educational pursuits for their members.

The following sections are aligned according to CARF's definition of community integration: the ability for any person regardless of disability to be able to participate in employment, socialization, and personal interests (CARF International, 2022). All studies within this review involve Clubhouses that are accredited.

Barriers

There are several barriers to community integration that are experienced by a person living with an SMI. Many of these barriers are outside of the person's control. One of these uncontrollable barriers includes a person's cognitive abilities that are affected by the illness (Coniglio et al., 2012). Others include health problems related to medications, symptoms of the illness itself, relapse from not taking medication regularly, being on disability, inaccessible housing, and lack of family support (Hanisch et al., 2015).All these uncontrollable barriers result in compounded social and economic disadvantages (Gallagher et al., 2015; Hanisch et al., 2015). These barriers can be categorized into the areas of employment, socialization, and personal interests.

Employment

There are many factors reported in the literature that result in a person with an SMI unable to find or keep employment. A study completed in 2010 shows that people with an SMI have lower employment rates than the rest of the population and that those who are over the age of 49 are less likely to pursue employment altogether (Luciano & Meara, 2014). Age as a barrier for employment for those experiencing an SMI is also supported by a 2017 study exploring how distinct stages of life impacted community participation (Thomas et al., 2017).

In addition to age as a barrier, people with an SMI may have differing cognitive abilities and may process things at a slower pace than their neuro-typical peers. For example, one

participant in a qualitative study about peer-support explains how hard employment was because they were “too slow” (Coniglio et al., 2012, p. 157). Factors such as health problems related to medication, mental illness, and relapse are additional barriers that this population experiences (Hanisch et al., 2015). These factors make it hard to keep a job due to the unpredictable nature of the barriers. Due to this, a lack of work experience or gaps in employment may further compound the difficulties in finding a job (Hanisch et al., 2015). One of the most frequently reported barriers in the study completed by Hanisch et al., (2015), surrounded the understanding of the application process and the development of a resume. Additionally, this study also shows that social and structural disadvantages affect employment for this population. This may be things like unequal access to education, housing, healthcare, or a lack of family support.

It is also worthy to note that successful employment can contribute to positive role identification for some people, but it may also be a source of contentment for others. Some of the drawbacks to being actively employed reported by subjects in a narrative study by Saavedra et al., (2016), included having employment that was not meaningful, having less free time to enjoy meaningful and purposeful activities, and the outlook that unemployment was temporary and sometimes needed to better one’s mental health situation. This suggests that there are some people who choose not to work and are able to live a purposeful and meaningful life without employment. Overall, this study highlights the importance of considering a person’s culture and lived experience of mental illness and employment (Saavedra et al., 2016). Another barrier commonly experienced by those with an SMI is the ability to socially integrate into the community.

Socialization

To be able to connect and contribute to others helps one develop a sense of belonging and is beneficial to one's health (Hammel, 2014). However, when a person lives with an SMI, social skills and everyday interactions may become difficult. How one views their ability to socialize with others will inherently affect how well they are able to perform socially (Sanchez et al., 2019). In other words, perceived social effectiveness is important regarding community integration. Barriers to social effectiveness include psychiatric symptoms, cognitive impairment, insight into one's mental illness, and self-stigma (Sanchez et al., 2019).

The culture of the western world thrives off the ability to communicate and be social. Thus, it is critical to have the basic social skills to interact with others. Whether one is going to the grocery store, visiting the doctor, or using public transportation, socialization is a part of these everyday experiences. However, the stigma of having a mental illness makes it hard to socialize (Bromley et al., 2013). Those living with an SMI have reported experiencing low self-esteem and stigma in social situations (Gumber & Stein, 2018). In one study that specifically looked at the lived experience of those with SMI and how they viewed community integration, they found that many participants often avoid mainstream community integration to avoid stigma related to their mental illness. In doing so they were able to protect their self-esteem and view of self (Bromley et al., 2013).

Additionally, the social context in which people live may impact one's views of oneself and the resulting perceived social effectiveness one has. Being in the world can mean different things whether one is a doctor or whether one is a janitor. The social groups to which one belongs influences what one does and how one fits into the world, and this impacts a person's overall health and well-being (Gallagher et al., 2015). Many people experience socialization and develop social identities through employment, and due to this population's low employment rate,

this can be a barrier to socialization as well (Hanisch et al., 2017; Saavedra et al., 2016). To further compound the situation, not having a social network or a place to go are common experiences for those living with an SMI (Coniglio et al., 2012). This is demonstrated in a study by Bromley et al. (2013) where the experiences of community integration by those who had an SMI were often described in the context of where they received mental health support services. The ability to pursue and engage in personal interests is another important aspect of community integration that may be impacted for those living with an SMI.

Personal Interests

SAMSHA (2016) describes the eight dimensions of wellness and the importance of these dimensions being in balance of one another to achieve optimal health in one's life. Personal interests fall within the intellectual wellness dimension, and it is suggested that if one does not participate in personal interests, this wellness dimension may become unbalanced and lead to misalignment in other areas of life (SAMSHA, 2016). As noted earlier, people experiencing an SMI may not engage in personal interests to avoid stigma or to prevent becoming overwhelmed (Bromley, et al., 2013). Additionally, the use of developmental theories is essential when promoting engagement of personal interests to people in varying age cohorts (Thomas et al., 2017). For example, younger adults may be more interested in making intimate and personal connections with others than older adults. While older adults may be more interested in volunteering than younger or middle-aged adults (Thomas et al., 2017). Programming aimed to increase engagement in personal interests for those with an SMI that do not take a person's stage of life into consideration may not be effective for entire cohorts of a specific age group.

Supports

A psychosocial Clubhouse is a major support for those experiencing an SMI. The Clubhouse is a part of a larger network of Clubhouses, and they all have a mission to reduce the social and economic isolation for those experiencing SMI (Clubhouse International, 2021). Clubhouses offer a place for people to belong and connect with one another, reducing self-stigma and enhancing overall satisfaction and participation in life (Gallagher et al. 2015; Hammel, 2014; Treichler & Lucksted, 2018). There is ample evidence that Clubhouses provide supports for each area of community integration by providing a structured work-ordered day, multiple socialization opportunities, as well as resources to discover one's own personal interests (Carolan et al., 2011; Coniglio et al., 2012; Gumber & Stein, 2018; Kinn et al., 2018; McKay et al., 2018; Tanaka & Davidson, 2015).

Employment

Psychosocial Clubhouses that are accredited provide programming that supports those with an SMI to gain meaningful employment. One way that Clubhouses do this is by providing what they term a work-ordered day in which members develop healthy habits related to work. This is done as members work together with staff to keep the Clubhouse in running order. Members perform collaboratively in work units such as the kitchen unit, clerical unit, or cleaning unit and do so on a completely voluntary basis. In one study, members reported that having this structure gave them something to do which in turn helped to keep them out of trouble (Tanaka & Davidson, 2015).

Accredited Clubhouses also provide some form of formal employment program. This could be in the form of transitional employment, where the Clubhouse owns the job and provides off-site and on-site support to the Clubhouse member. Clubhouse staff are able to immediately step in when the member becomes overwhelmed. This form of employment provides the most

support. Clubhouses may also provide more common forms of employment support such as supported employment and independent employment programs. The idea is that Clubhouse members will move from a more supported form of employment, such as transitional employment, to employment programs with less support such as supported and independent employment programs (McCay et al., 2006). Through these programs and the work-ordered day, Clubhouses have been shown to help members with self-confidence, job skills, and learning more about themselves and what they value (Tanaka & Davidson, 2015).

Socialization

A study completed by Sanchez et al., (2019), suggests that educational pursuits, social interactions, and the acceptance of one's disability may positively influence perceived social effectiveness. Clubhouses have been shown to help people in each of these areas. A study by Jones and Selim (2013) describes a supported education program within a Clubhouse and how this helped its members pursue education through support and encouragement. Clubhouses have additionally been shown to positively impact one's social network and encourage recovery through peer support, acceptance, and belonging (Carolan et al., 2011; Coniglio et al., 2012).

Family social support, independent employment, and high self-efficacy may further support social integration into one's community (Gumber & Stein, 2018). Clubhouses have been highlighted as ideal places for those with an SMI to succeed in these areas (Carolan, et al., 2011; McKay et al., 2018). Being a member of a Clubhouse positively impacts social relationships as members are a part of a community of people in which they can build positive and nurturing relationships (Carolan et al., 2011). By having these opportunities for socialization within a Clubhouse, a person's sense of self is enhanced promoting self-efficacy and increasing chances to be successful in social situations (Carolan et al., 2011; Coniglio et al., 2012).

A sense of belonging has been shown to reduce self-stigma for those with an SMI (Treichler & Lucksted, 2018). This construct of "belonging" is important to community integration in the social arena: "Feeling valued, autonomous and appreciated in society and having access to social support are integral to relative social positions and these are all important factors in health and wellbeing outcomes" (Gallagher et al., p. 8, 2015). The Clubhouse environment has demonstrated the ability to promote this construct of "belonging" encouraging its members to be autonomous and empowered to engage in social relationships (Tanaka & Davidson, 2015). Additionally, Clubhouses may include social skills and interpersonal training to those members who are employed through the Clubhouse (Gumber & Stein, 2018). This training may positively influence how a person views themselves, increasing self-confidence in social situations.

Personal Interests

The opportunity to explore one's own personal interests is supported within the Clubhouse model by providing members with chances to make mistakes and learn from them in a safe environment (Carolan et al., 2017). Clubhouses are places that afford this population "real opportunities to develop social skills, interests, and recreational interests" and this directly relates to their "sense of self-worth" (Carolan, et al., 2011, p. 129). Additional support provided by a Clubhouse includes self-confidence, job skills, and learning more about themselves, what they value, and what they are interested in (Tanaka & Davidson, 2015).

While there is a great deal of research clearly demonstrating the benefits of Clubhouses, there is a need to understand what it is like for members to experience community integration within an unaccredited Clubhouse. Most studies are completed with Clubhouses that are accredited for obvious reasons: to demonstrate Clubhouses that are adhering to Clubhouse

standards as this represents the ideal. However, to move towards accreditation, it will be helpful to understand the lived experience of community integration for this local Clubhouse. With this rich understanding, Clubhouse programming can be better tailored to fit the needs of this specific population.

Relevant Theories

When considering the barriers faced by those living with an SMI and how Clubhouses can help, it is important to consider how this population engages in meaningful life activities that support overall health and well-being. The Model of Human Occupation (MOHO), the Clubhouse Model, and the Recovery Model all share the same goal of helping people to achieve balance in their lives through successfully engaging in everyday activities. While MOHO is broader in nature both the Clubhouse and Recovery models focus on the population that experience an SMI.

Model of Human Occupation (MOHO)

The Model of Human Occupation (MOHO) represents the person as an occupational being whose occupational performance is influenced by volition (motivational factors), habituation (roles and routines), performance capacity (the person's ability to do something), and the environment (O'Brien, 2017). MOHO uses systems theory which explains how these constructs are interconnected; a change in one construct can elicit a change in another. A person's ability to successfully engage in occupations over time depends on the interaction between a person's volition, habituation, performance capacity, and the environment. Successful interactions of these constructs result in a person receiving positive feedback and creating healthy changes over time. If the constructs change in a negative way, then the dynamic may

shift in an unhealthy direction resulting in diminished occupational competence and occupational identities (O'Brien, 2017).

Clubhouse Model

The Clubhouse Model is a community mental health model that supports people who experience an SMI by providing opportunities to integrate within the community. Clubhouses focus on providing employment, educational, and social support to their members. The model puts emphasis on using and building on members' strengths by working collaboratively with members to re-enter or maintain their space in the community (Clubhouse International, 2021). The Clubhouse model builds on MOHO as each is focused on enhancing a person's ability to successfully participate in occupations (i.e., employment, education, and personal pursuits). Clubhouses are places that provide a safe environment to be a part of something that is larger than oneself, positively influencing occupational identity and thus increasing one's performance capacity (Kinn et al., 2018).

Recovery Model

The Recovery Model overlaps with both MOHO and the Clubhouse Model. It is essential to believe that each person can live a life of recovery if any of these Models are to work. Recovery is when a person engages in changing behavior to positively impact their health and wellbeing while being self-motivated to maximize their potential in life (SAMHSA, 2012). The Recovery Model offers several important constructs that are essential to include while working with those who have an SMI. These constructs include health, home, purpose, and community (SAMHSA, 2012). The Clubhouse Model most closely aligns with the Recovery Model in the areas of purpose and community, as Clubhouses strive to engage members in living a life full of purpose and to be a part of their communities.

Gaps in Literature

Social integration outside of the clubhouse may be a crucial factor in overall community integration for its members. It is unclear at this time whether social integration outside of the clubhouse is valued by the members or if this idea is a construct that is expected to be valued. Recovery-oriented community integration processes are often tied to integration into the "mainstream" and Bromley et al., (2013) discuss how some of the literature contradicts these findings as some people often avoid mainstream interaction to avoid stigma and protect their sense of self. Thus, it is apparent that additional research is needed into the lived experience of community integration for those living with an SMI. Particularly for those attending a Clubhouse that is currently unaccredited. All studies reviewed included Clubhouses, who are currently accredited. Thus, additional research done with populations who are a part of an unaccredited Clubhouse is warranted as these Clubhouses may not offer formal employment and education programs.

Conclusion

Community integration for people who experience SMI is seen as vital to living a healthy and productive life. Community integration connects to the Clubhouse model because it focuses on helping people engage in their community within the areas of employment, socialization, and personal interests. All these areas are important within the Clubhouse model. The ability for a person to engage in occupations related to community integration can be realized using MOHO. Understanding that humans are a part of a dynamic system and that changes to any parts of that system could increase or decrease occupational performance will undoubtedly contribute to sustainable programming being developed by the Clubhouse as they move towards accreditation.

The literature provides information about several barriers to community integration including but not limited to, low levels of perceived social effectiveness resulting in negative role identification (Sanchez et al., 2019), an overall loss of performance capacity resulting in a diminished occupational identity (Kinn et al., 2018), and lower levels of paid work compared to the rest of the population (SAMHSA, 2017). The literature also provides a multitude of supports regarding successful community integration that Clubhouses provide for its members with SMI. These include a sense of belonging and connectedness (Gallagher et al., 2015; Hammel, 2014; Tanaka & Davidson, 2015; Treichler & Lucksted, 2018), autonomy (Tanaka & Davidson, 2015), connecting with others, and being a part of the work-ordered day (Carolan, et al., 2011; Coniglio et al., 2012).

These supports and barriers relayed within the literature are essential to understanding the lived experience of community integration for those with an SMI. However, there is a gap in the literature when it comes to the lived experience of community integration for those with an SMI who are members of a Clubhouse that is still in the process of becoming accredited. It is essential to understand the firsthand experiences of community integration for those with an SMI in this environment to create programming that targets community integration in an authentic manner.

CHAPTER III

METHODOLOGY

Chapter III Methodology provides an overview of the literary and theoretical supports for the study in addition to the study design and sample, instrumentation, and ethical considerations. A more detailed account of the theoretical and literary support can be found in Ch. II Literature Review. The purpose of this research is to further understand the lived experience of community integration for those living with an SMI who are members of an unaccredited Clubhouse. The goals of this research are to contribute to scholarly understanding of an under-investigated topic and to support the development of future Clubhouse programming.

A review of the literature was completed to achieve a more complete view of the supports and barriers of community integration for those living with a SMI. Both supports and barriers of community integration are categorized into 3 primary areas: employment, socialization, and personal interests. This categorization supports the definition of community integration given by CARF (CARF International, 2022).

To understand the supports and barriers to community integration for this population, it is necessary to gain a direct understanding of their own lived experience of it. After a thorough understanding of the lived experience of community integration for this population at a local Clubhouse, it is anticipated that programming developed towards this end will be more effective and personalized thus creating better outcomes for the Clubhouse members.

Literary & Theoretical Support

Too often programs are developed for populations without the direct input from the population itself. To create programs that are truly effective and sustainable, one must first deeply understand the experience from that person’s point of view. The importance of this view

is what influenced the creation of this study. The Clubhouse that was chosen for this study is not currently accredited and is working towards meeting the standards set forth by Clubhouse International. This means that it is currently developing programs aimed towards aspects of community integration such as employment, opportunities for socialization, and the pursuance of personal interests. If the local Clubhouse within this study is to create programming for those experiencing an SMI that is sustainable, there needs to be an understanding of how people are currently experiencing various aspects of community integration in their current environment.

The literature reviewed for this study heavily focused on the supports that Clubhouses offer as well as the barriers that those with an SMI experience in their day to day lives. This review was used to develop and design this study and add to the rich understanding of community integration for those with an SMI, particularly those who attend an unaccredited Clubhouse. The databases that were searched for this literature included CINAHL Complete, PubMed, APA Psych Info, APA Psych Articles, Consumer Health Complete -EBSCOhost, Health Source – Consumer Edition, Health Source – Nursing/Academic Edition, MEDLINE Complete, and Soc INDEX with full text. The Boolean search terms used were as follows: "Community Integration" AND "Serious Mental Illness," "Employment" AND "Serious Mental Illness," "Employment" AND "Community Integration" AND "Serious Mental Illness," "Clubhouse" AND "Community Integration, and "Clubhouse" AND "Employment." In addition to this, the following governmental and professional organizations were included in the search for literature: National Institute of Mental Health (NIMH), National Institute of Health (NIH), Commission on Accreditation of Rehabilitation Facilities (CARF International), Substance Abuse and Mental Health Services Administration (SAMHSA), Clubhouse International, and the National Alliance on Mental Illness (NAMI).

The literature reviewed determined that the most efficient way to gather this information was through spending time with those who are experiencing an SMI at the local Clubhouse. The use of a qualitative approach was deemed appropriate to guide further analysis of the lived experience surrounding employment, socialization, and personal interests for those with an SMI. This type of approach would allow for a rich and in-depth account of the experience of community integration by members of an unaccredited Clubhouse.

The developed semi-structured interviews and questions were guided by The Model of Human Occupation (MOHO). This model provides a way to understand how a person maintains occupations overtime by looking at three things: a person's source of motivation to participate in occupations, how a person organizes their occupations, and a person's physical and mental abilities to participate in occupation. This understanding contributed to the development of specific questions that were used to delve into the lived experience of the Clubhouse members. Questions were asked surrounding five themes: person factors, habituation, mental health context, community integration, and employment.

Each theme and question were ordered in a specific way to ensure flow of the interview. Personal factors were used to start the interview and included questions about the members' interests, values, and goals. Not only did these questions set the stage for gaining rapport, but it also gave the interviewer more information about their motivations to do the things they do. The theme of habituation came next in the interview and questions revolved around the person's habits, roles, and routines both within and outside of the Clubhouse. This gave the interviewer information on how that person organizes and structures their daily occupations. Questions about the person's mental health followed and provided important contextualizing information about their life and how mental illness has affected it. The themes of socialization and employment

were discussed towards the end of the interview to provide an in-depth understanding of these aspects of community integration. The nature of the semi-structured interview allowed for a natural eb and flow of conversation weaving in and out of these themes, often out of order.

The Clubhouse model and the Recovery model both contributed to a more nuanced understanding of those experiencing SMI and the supports that can be offered through a Clubhouse. These models with the addition of MOHO served as a guide to determine two broad research questions:

- What is the lived experience of community integration for members of a local Clubhouse?
- How is the lived experience of community integration for those living with an SMI impacted by the Clubhouse?

Design & Sample

The research design consisted of a semi-structured interview using a phenomenological method with the use of the Hermeneutic approach throughout the study. Prior to beginning the study, a protocol was submitted to the University of North Dakota's Internal Review Board (IRB) and approval was gained. Appendix A contains the IRB approval letter.

Phenomenology was appropriate to understand the lived experience of the participants being interviewed. The Hermeneutic approach is based on the philosophy of Martin Heidegger and asserts that the phenomenon being studied and the researcher studying it are inseparable (Heidegger, 1962). This is because the context that people are a part of influences how they view the world. Thus, working with a Hermeneutic framework, the researcher can come to conclusions that are fused with both the researcher and the participants' views on the phenomenon (Dibley et al., 2020).

Participants of the study were found using a convenience sampling method which included past and present members of a local Clubhouse. Due to the nature of the Clubhouse, all past and present members have been diagnosed with an SMI and are 18 years and older and thus were eligible to participate. Members who lived out of town or had a guardian were excluded from the sample. 50 Clubhouse members were contacted, seventeen people agreed to be a part of the study, one person declined, and the rest either moved or were unreachable. Two people did not end up completing interviews due to scheduling conflicts.

The Executive Director of the Clubhouse was given the inclusion and exclusion criteria and made the initial contact via telephone to 50 members who met the inclusion criteria for this study. The co-investigator was present for each phone call and assisted with the scheduling of interviews as people were contacted. If people did not answer, a voicemail was left. The script used for the initial contact can be found in Appendix B. Over the next two weeks, follow-up phone calls were made for those that received voicemails during the initial round of contact.

Interviews were scheduled to occur at the Clubhouse in a private room between the hours of 9am and 4pm. When a participant arrived for an interview the informed consent paperwork was introduced. Members were given plenty of time to read the informed consent document and ask any questions. If the member chose to participate in the study, they signed the documents with the co-investigator signing subsequently. The informed consent document contained the purpose of the study, how long the study was to continue, including the time commitment for the interviews, how the interviews were to be carried out, the benefits and risks of taking part in the study, a description of what is to happen with the data collected, a statement of confidentiality, as well as contact information for the IRB board and project advisor. The informed consent document is in Appendix C.

To keep with ethical standards of the study, no part of the study was initiated until after approval was given by UND's Internal Review Board. All interviews were recorded using a recording device. Interviews were then transcribed manually into an electronic document and were stored in an encrypted folder on a personal laptop which was locked with a password. The recording device was stored in a locked cabinet at the Clubhouse throughout the data transcription process. Only the co-investigator had access to the recorded interviews. Once all audio recordings were transcribed, they were destroyed. This occurred approximately two weeks after data collection. Once transcribed, each participant was assigned a unique study ID that was posted on their interview transcript. All identifying information including names and locations were removed from the interview transcript. Records of the transcribed interviews, consent forms, and all other pertinent research data will be kept in a locked location with the primary investigator for three years after the study has ended and all data has been analyzed per institution guidelines.

Instrumentation

A semi-structured interview format was used to collect data about the Clubhouse members' lived experience of their mental illness and community integration. The interview began with general demographic information. The interview was divided into five sections which were outlined using MOHO as a guide. To begin the co-investigator-built rapport and laid a foundation by asking questions about personal interests and motivations. Questions then led into the theme of habituation followed by questions that contextualized the participants experiences with mental illness. Questions on socialization and employment were then discussed. Following the nature of the semi-structured interview, questions were varied between participants allowing

for rich information to surface. The semi-structured interview can be reviewed under Appendix D.

Data was analyzed and interpreted using a Hermeneutic stance by both the primary and co-investigator. This was done by first analyzing preconceived understandings of the phenomenon by reflecting on prior experiences and biases experienced by the primary and co-investigator as stated in the hermeneutic approach. After this reflection, the primary and co-investigator then analyzed and interpreted the interviews by being completely open to questioning their own ways of thinking and inviting new ways to emerge. The process is ongoing and cyclical, pausing to think about that which requires deeper reflection (Dibley et al., 2020). Heidegger's philosophy suggests that humans understand meaning through the context in which they come from and often the true meanings of things are hidden by different social, historical, or cultural perspectives (Dibley et al., 2020). The hermeneutic circle was used throughout this study. The researcher discovered pre-understandings of the phenomenon through the literature review, developed a semi-structured interview based on the findings and guidance of an occupation-based model and then completed the interviews. The co-investigator then read and re-read the interviews, began to understand the common themes of the interviews while coming back to the philosophical underpinnings of the approach to guide interpretation. Common themes were compared against the other primary investigators' perception to triangulate the data. At the same time the co-investigator engaged in pausing to reflect on personal, social, and historical contexts affecting the interpretation to come to final conclusions represented as personal and intimate crafted stories. These crafted stories were smaller summarized versions of the transcribed interviews. 13 out of the 15 personal stories were checked by the interviewee for accuracy.

Ethical Considerations

The inclusion of a vulnerable population in this study is justified as full integration into one's community and thus having the benefits of employment, social connections, and overall increased quality of life are known to be limited within this population (Bromley et al., 2013; CARF International, 2022; Carolan et al., 2011; Gumber & Stein, 2018; Hanisch et al., 2015; Sanchez et al. 2019). It is necessary to include this vulnerable population in this study to better understand their own lived experience of community integration to provide more effective social programming. The specific population being studied includes those with a serious mental illness who are members of a local clubhouse. The members who attend the clubhouse do so of their own free will and choice. Thus, it is expected that they will also be able to choose on their own whether to participate in the study via the informed consent process. Those who cannot give their own consent, have difficulty understanding the consent process, or who may rely on a legally authorized representative will not meet the inclusion criteria for this study.

The executive director of the clubhouse assisted with the initial contact of the participants. To avoid undue influence on the participants the co-investigator led the formal recruiting and interviewing process. While the executive director made initial contact this is not considered to be undue influence because the clubhouse model puts him in a collaborative relationship versus an authoritative position with the members.

Ch. III Methodology discussed the literary and theoretical supports for the study in addition to the design and sample, instrumentation, and ethical considerations. Ch. IV will discuss the results of the study.

CHAPTER IV

Results

The results consist of eight main themes captured through the 15 semi-structured interviews. These themes were deduced from an initial coding system containing 1,531 codes. After the initial coding process each interview was summarized into smaller documents. Another round of coding was completed with these smaller documents. Once this round of coding was completed seven general themes surfaced describing the overall experience of community integration for the members of a local Clubhouse. Coding and theming analysis was supported through use of the hermeneutic circle to create the "fusion of horizons" between researcher and research participant (Dibley et al., 2020).

Traumatic Life Events Influence Function

Many Clubhouse members at one point in their lives experienced a traumatic event that caused mental and/or physical pain. These events relate to the daily difficulties one experiences because of one's mental health. For example, one participant shared that he was adopted at an early age and discusses traumatic experiences he has had with his adoptive parents. Due to this he never really felt like he belonged and turned to drugs and alcohol at an early age (Interview 500030). Additionally, traumatic loss was shared by a participant who lost his wife to an aneurysm while finishing college. Shortly after he then lost his mother. The grief coupled with major depression overcame him and he became homeless for four years (Interview 50036). There were many other instances of members sharing traumatic experiences that affected their ability to function.

Living with an SMI but not receiving a diagnosis until later in life comes with trauma as well. One participant discusses her experiences with her children before she received the correct

mental health diagnosis and got on the proper medications. She states, “they went through a lot when they were younger with me, because I was undiagnosed. So, you can imagine, I mean I’d end up for a month in depression where I couldn’t even get out of bed. And then when I was manic sometimes, I was just crazy” (Interview 50029, pos. 151). This experience of a late diagnosis impacted both her and her family and contributed to traumatic experiences for all involved. Many other people experienced traumatic life events and they impacted each person’s mental health and in turn affected their ability to function.

Community Integration is Desired by Majority Despite Barriers

Members report utilization of multiple supports outside of the Clubhouse. One participant describes how Al-Anon and Over-Eaters Anonymous (OA) had a huge influence in his life and states, “that’s given me probably the most strength that I have” (Interview 500038, pos. 112). One member discusses how the NAMI support group gave him a space to “air out how you’re handling or mishandling your meds and your reactions with the therapist” (Interview 500028, pos. 105). This utilization of supports outside of the Clubhouse demonstrates community integration in relation to support services.

While having a multitude of options for support regarding their mental illness members had a challenging time integrating in their communities outside of these support systems. Mental health symptoms were mentioned as barriers for community integration. One participant discusses that she enjoys participating in Special Olympics, but lately she has not been able to participate due to a bout of depression (500041). Another participant describes how she is a little apprehensive to venture out into the community because of her dyskinesia and worries about people judging her.

Anxiety and social isolation were additional aspects that made social situations difficult for participants. When first becoming diagnosed with an SMI one participant shares "Well, I just isolated, I didn't want to talk about what was wrong with me. I didn't want to tell anybody anything about me. So, I pretty much isolated for a period of time" (Interview 500029, pos. 310). Having anxiety in social situations were common experiences as another person shares that she gets extremely nervous and anxious when she goes out in public, sometimes hearing things that are not there (Interview 500031).

It can also be hard to fit in socially after being diagnosed with an SMI as one participant shares that most of her friends did not have mental health issues. She says, "I'm afraid to make conversation, I'm afraid I'll say the wrong thing" (Interview 500031, pos. 98). Another member shares his difficulties with fitting in, "It's a little hard, because I was there all alone. If there is a group, I'd be there all by myself" (Interview 500030 pos. 325). Many other members report living by themselves and not having others to join them in community outings.

Despite these barriers that people experienced in social settings, people were still interested in becoming more involved in the community. One participant shared that he needs to get out more and be around people (Interview 500040). Another member shares that outside of volunteering and fundraising events organized by the Clubhouse she is not involved within the community, "I'm just involved here… not very community involved and stuff so" (Interview 500041, pos. 231). She was interested in becoming more involved in the community but expresses that it's hard to be involved in things because she never knows when her symptoms are going to act up (Interview 500041).

Employment is Desired by Majority Despite Barriers

When discussing experiences surrounding employment, many echoed the need for the employer/job to be flexible and understanding. One member shares that he would be interested in a part-time job if they were able to be flexible with his church as well as NA/AA obligations as he puts extremely high value on these supports (Interview 500026). When discussing things that make it hard to find and keep a job, one member explains "it seems to just be… people don't take me seriously or think that I can't do it… because sometimes it takes me a little longer to catch on to stuff" (Interview 500034, pos. 180). This person tells of a time that she had a boss that was patient and kind and gave her small tasks to do at first and eventually, she was able to handle the job without any extra assistance. She simply needs a little extra help in the beginning to learn things and then she is good. She states, "I have to have an understanding boss to know my situation so he can give me tasks that I can perform correctly" (Interview 500034, pos. 183). Furthermore, many jobs do not allow for members to leave if they need to due to mental illness, as one member shares, "a lot of time you are working by yourself, you can't leave the store, something happens, an emergency happens, you can't just leave, you get mentally over stimulated you can't just leave" (Interview 500033, pos. 120). Not being able to take a mental time-out while working is difficult for many living with an SMI.

Being too slow at a job is something that was shared by people and echoes the lack of flexibility/understanding experienced by the members from employers. One member has attempted working at gas stations and fast-food restaurants, but she was not quick enough for what the job demanded when the lines at the register got long. It was too stressful, and she would get too much anxiety to handle it. She recounts one time that her manger got upset with her, "And that manager, I was just not fast enough, and he got mad at me, he was young, he was like… I just didn't do good on the cash register. I don't know, I'm not good at that but I'm good

at other stuff" (Interview 500037, pos. 233). This experience of being too slow on the job was experienced by other members as well.

Other barriers to employment described by members included impaired cognitive function. One member talks about how frustrating it is to have a brain injury, only being able to work part-time, and having to deal with memory issues, "and then I got a brain injury and my memory sucks, my short-term memory" (Interview 500030, pos. 151). He goes on to describe a situation at work where his boss wanted him to remember multiple things and got frustrated with him when he could not. He said he tried his best and even had a job coach through the Brain Injury Alliance, but he still struggled to keep a job. He says, "I'm brain damaged, not brain dead" (Interview 500030, pos. 162).

Another member who experiences a learning disability paired with partial deafness explains, "and I don't know anybody that would hire a person who can't hear, when you got to understand everything, and I don't really understand everything everybody says. I got to… not only, not only do I have to translate what they said… I got to figure out what they are meaning" (Interview 500035, pos. 129). He goes on to say that he is not interested in pursuing employment at this time because he feels he has too many barriers to overcome. He says, "Idk, until I get hearing aids and they cure my back… no. I think I have too much disability to… for a real workplace to look at… that I could even help them" (Interview 500035, pos. 167-173).

Many other barriers were experienced by members throughout the interviews. These included substance use, sleep apnea, hospitalizations, and traumatic life experiences. Despite the barriers that the members experience, one member points out the importance of self-advocacy and a strong understanding of one's own limitations:

> I want to encourage people to go ahead and apply for work. They just need to know their limitations so that they aren't over-worked or taken advantage of. And that they don't have to expose their mental illness, give it a label. You can just say, I have issues, and this is how I cope with it. This is why I can do this job and not that job, without using it as an excuse but it's actually a reality, I can't work 40 hours. Or, I can't lift heavy loads, it's the same thing, I can't do cashier because I'd have to stand there and meet with so many people but I can do displays, I can put things on the shelves, you know… different… just to know their own personal limitations going into work. (Interview 500039, pos. 310)

While most of the members wanted to work, some people do not have an interest in working because they are either retired or simply content with their situation. One member states that she is content with not being employed. She doesn't feel that she is able to work because of how overwhelmed she gets in public (Interview 500031). Four people interviewed were retired and thus not currently in the job force.

Education is Valued but is Currently Unachievable for Most

Education was seen as a valued endeavor for many of the participants. 13 out of 15 participants mention some form of education. Three people graduated with a degree but many struggled or were not able to finish the degree. Many people were passionate about the area they were studying and were frustrated that they could not finish. One member shares how she loves to learn and values her education. Out of high school this member got a full ride scholarship to Creighton University. She describes how her first semester of college went great and it was not until her second semester that her mental illness hit hard. She was not able to finish at Creighton and ended up withdrawing from her classes. Her dad and her sisters both have degrees, and she is

very frustrated and bummed that she was not able to receive hers. She explains, “mine was taken away from me because of this stupid brain I have and the disabilities I have and uh, the flood with the mental illness… I can’t control my psychosis except through medication and even medicated I still have breaks, breakthroughs, and that’s very frustrating” (Interview - 500041 (1), Pos. 201). This person wants to eventually go back to school (Interview 500041).

Participants experienced multiple other barriers when it came to completing their education. Some members discussed how they had difficulty getting certified in trade schools. Others talk about how they were unable to pursue their chosen careers because they couldn’t finish school due to the onset of a mental illness. Traumatic events, such as a significant other passing away or a parent passing away also affected the ability to finish the academic endeavors they were pursuing.

Disability Benefits and Housing Experiences

Many Clubhouse members have some form of disability benefits. Others additionally struggled with housing. This may be because they were not able to take care of their home, they owned a home and had to sell because they couldn’t own a home and receive disability, or they experienced homelessness. Five out of the 15 people interviewed mention having been homeless at some point in their lives.

One member used to own their home but had to sign over the house to his parents because he could not get disability benefits if he owned property (500026). Another member lived in a group home when he was living in Colorado and then his parents died and left him a house in Wyoming. Thus, he is not eligible for social security disability benefits. This person shares that he can barely take care of his own place and has had difficulty with people taking advantage of him by staying in his home and not paying rent (Interview 500035). Another

member shares that she used to own her own home but ended up selling it due to the upkeep being too much for one person after her husband died (Interview 500029). Others discuss spending some time at the homeless shelter and share that the homeless shelter only allows people to sleep there, so during the day, they had to find something else to do (500032).

One member shares that he would like to move to Cheyenne because there is more to do there, but he has section 8 housing so that becomes difficult to move without losing that benefit (Interview 500036). This same person was homeless for four years. He ended up applying for section 8 in every state and decided that whoever called first, that's where he was going. Wyoming called first. When he arrived in Casper he stayed at the homeless shelter until his apartment became available. He got an excellent job at the Burlington railroad. He then had to make a choice, keep the job, and not keep the housing or take the housing and find a different job. If he kept the job, he would be making too much money to qualify for section 8 housing so then he would have to find housing. If you have a job the homeless shelter only lets you stay for 2 months and then you must leave. So, he figured that his chances of getting his needs met would be better if he took the housing and left the job. He talked about how it was difficult to find employment being homeless because you did not have a physical address

Due to being on disability benefits participants share that they are only able to work part-time and have a worry of losing benefits if they work more than they are supposed to. Others discuss structural barriers that they face such as not having access to transportation due to being on a limited income. When they do have access to transportation, such as public transportation, they often must spend hours of their day for a single planned trip. Others who do have a car often worry about what they will do when/if it breaks down due to being on such a limited income.

Many members discussed how living on disability benefits gives them barely enough resources to get by.

Experiences with Mental Illness

Multiple people received their diagnosis later in life. This limits the possibility of recovery in later years in their lives when school and employment are less attainable. One member who is 48 years old just recently received a schizophrenia diagnosis. He also has a reading disability and has a lot of trouble comprehending things. He explains that he used to have a lot of ambition to overcome these obstacles but that now he has lost a lot of that passion. Another member was not diagnosed with her schizophrenia until she was 44. She believed that she suffered from schizophrenia long before she was diagnosed, but she kept it a secret:

> I didn't even want to let anybody know I was hearing voices or… I'd like to try and take cues from other people, what was going on around me and just try to follow suite, keep the schizophrenia under wraps and not let anybody know about it because there's so much stigma. (Interview 500039, Pos 247-249)

Not only was she keeping her diagnosis a secret to shelter herself from the stigma but also her young children, "I didn't want them to live with stigma, having a mother whose mentally ill" (Interview 500039, pos. 276). She wants other people to know that "you can have schizophrenia and be a mommy or daddy" (Interview 500039 pos. 280).

In addition to receiving a late diagnosis, people discussed a variety of other mental health and physical barriers that make it difficult to participate in everyday life. These included the experience of a traumatic brain injury with a co-occurring depressive disorder, difficulties with comprehension, inability to sleep, lack of motivation, and negative symptoms experienced with schizophrenic disorders. These negative symptoms ranged from keeping one's living spaces

clean to having trouble sequencing and completing general tasks. Furthermore, those members who are retired experience unique barriers to occupational participation. One member who is retired talks about the difficulty of the physical symptoms that come with ageing while also having schizophrenia, “being older, it’s an adjustment to keep track of different things I need to do” (Interview 500039, pos. 27).

Moreover, hospitalizations were discussed by 53% of those interviewed. One member shares that she has been hospitalized 33 times but has not been to the hospital since 2007. She describes what changed for her was that the last time she left the hospital she left with a treatment plan and stuck with it. She has accepted the fact that to live a life of recovery she will be in outpatient treatment for the rest of her life (Interview 500039). This same sentiment was echoed by other members who were also on a path of recovery. Four out of the 12 members interview discussed currently being in recovery.

Clubhouse Benefits Reduce Barriers to Participation

The members interviewed mentioned several benefits that they experienced from being a part of the Clubhouse. The top three benefits described by the participants include structure and stability, giving people something productive to do, and providing social interaction.

Having somewhere to go that provides structure and stability for those with an SMI has been deemed an invaluable support by many of the members interviewed. Routines have changed for one participant since becoming a member of the Clubhouse as she now comes 3 times a week and this motivates her to get up early and get dressed. She says, “And that’s good for me because sometimes I’ll stay in my pajamas for three days, you know the same clothes for three days or whatever. So, it’s good for me to get out and do things” (Interview 500031, pos. 76). Another member also talks about his routine changing once becoming a member of the

Clubhouse because he focused more on his hygiene and household chores. He states, “yeah, because it got me to shower more and uhm… do the laundry and yeah, I’m just doing better being here” (Interview 500035, pos. 106). Another member explains that she has been able to transfer her skills learned at the Clubhouse to her home environment and participates “in the activities like fixing lunch or cleaning up after. You know, it kind of helps with daily routines at home. It carries over” (Interview 500039, pos. 36).

The structure and stability that the Clubhouse provides has also helped members with their mental health symptoms. A member explains that the Clubhouse has really helped him manage his negative symptoms that he experiences:

> The Clubhouse helps me get to work and get that mindset of cleaning and staying hygienic and staying on top of food, just the adult things you know, having to clean your house, having to buy groceries, just that struggle I think that when I come here and I cook and I prepare food with people and talk with people and then that’s another thing, that sense of community obviously but I think it also just helps me to stay more organized in my own life. (Interview - 500038, Pos. 39)

Additionally, giving the members something productive to do has influenced their lives. One member says that she enjoys coming to the Clubhouse because it gives her something to do and be a part of, “I like to come here, especially when I’m down and out and depressed and I feel like I need to start over. I always come back here and like it always helps me get grounded as far as you know, feeling like I’m a part of something, and uhm, I mean just not sitting at home by yourself and doing nothing” (Interview 50034, pos. 18). One member says that it was nice for her to be able to go somewhere for a few hours a day instead of sitting out in the cold when she was homeless “When I first started, it was kind of nice because when they were at the house on

David, it did give me something to do other than walking around the street with my things" (Interview 500032, pos. 131). Another member shares that she enjoys coming to the Clubhouse, "It was nice, I always enjoy it. I like to get out of the house to do stuff, it's nice to have a place that has things going on" (Interview 500034, pos. 50). She explains that "having a place like the Clubhouse to come to, I'm not in the hospital as much. It makes a big difference, keeping me out of the hospital is like a main goal" (Interview 500039, pos. 68).

Another meaningful benefit of being a part of the Clubhouse is to have somewhere to go during the holidays, as one member says "Well, the first thing I didn't want to be alone on the holidays this year. And it was good because I didn't have to be alone on those holidays (Interview 500029, pos. 54). Socialization is yet another benefit that the Clubhouse provides. Being a part of the Clubhouse has helped people feel like they belong as one member shares, "once I got into the Clubhouse it was nice to get to know people and stuff like that. So, I was a part of the community" (Interview 500034, pos. 52).

Other benefits include the feeling of having purpose in one's life as one member describes, "I'm happy being back here. That helps me mentally, mentally that helps me a lot. Gives me purpose" (Interview 500029, pos. 368). Another member loved everything that the Clubhouse stood for and was excited to get involved. "I just really fell in love with what it could do for somebody with a mental illness who didn't have support in the community. And the ideas of the Clubhouse were also very appealing to me, some place to go during the day that wasn't like a day hab, and you didn't have to pay to be there, and you also were involved in doing things and learning stuff. There was always a meal that was cooked, and people would help out with that, and we learned a lot" (Interview - 500041 (1), Pos. 13). Yet another member shares that, "Yeah when I was coming to the Clubhouse, I had more purpose in my life because I'd get up

and I'd come here and I'd do things and I felt more a part of it and I felt like I mattered and that my presence here mattered" (Interview - 500041 (1), Pos. 152).

The ability of the Clubhouse to adapt to one's disability is also of great importance. One member talks about all the things he does at the Clubhouse such as washing the dishes, taking out the trash, serving the food, and making the coffee. He shares this in a frustrating tone saying that this is all he can do. He says, "this isn't a… I mean this is kind of work but… it's not like work… it's not like the work force or the workplace… this place adapts to my disability" (Interview 500035, pos. 185).

One member talks about people with a mental illness having more support especially with the option of being able to go to a Clubhouse:

> Yeah, and they think that people with mental illness feel more confident they have advocates and job coaches and just… social club and that you learn to get comfortable with yourself and so it makes jobs and even just simple part time jobs it just makes it easier to work and to go out to community functions because you are more comfortable with yourself, and you are who you are, and people have to accept it for that. And I think also, here, at the Clubhouse, even when you act out or somebody is acting out, they get understanding where… it's like wow your having a really bad day, instead of people freaking out and being all upset and scared. You know, call the police and here come the white coats and things. It's more like oh you're having a really bad day is there anything I can do to help? Or it just makes it that much easier to be out in public and at least want to, even want to go out and do different things that's available in the community. (Interview - 500039, Pos. 264)

This excerpt exemplifies how the Clubhouse helps people to be a part of their communities.

The Clubhouse is not the right fit for some people because it is too slow paced, they are busy with life outside of the Clubhouse, or they are receiving other community support that is more of a fit for them. For example, one member shares that he did not come to the Clubhouse often, just during big holidays. When asked why he did not come more often he explains that his brother and him are caretakers to three older ladies and that keeps them remarkably busy (Interview 500028). One inactive member shares that she was referred to the Clubhouse a few years ago but only came twice. She said that there were other things in her life that were taking priority at the time, and she felt that she was just looking for something different. When she came the couple of times that she did, she said it was just too slow paced for her (Interview 500033).

She goes on to describe herself as being highly functioning and this is the reason the Clubhouse did not seem like the right fit. However, she goes on to say that "I'm too high functioning to be here is pride. That's a thought of pride… like I'm better than… and that's a dangerous place for me" (Interview 500033, pos. 40). She mentions that if she did start coming to the Clubhouse, then it could help her to have some accountability (Interview 500033). She expresses that she is open to becoming more involved at the Clubhouse in the future, "If I can be a help to [the] Clubhouse I would want to be open minded to it and then also realizing that [the] Clubhouse has something to offer me. And not be so prideful like" (Interview 500033, pos. 147). Other members had experiences within the Clubhouse that were not conducive to their recovery. This ranged from conflicts with staff to not enjoying being around others who are mentally ill.

CHAPTER V

Conclusion

Summary of Analysis

The experiences of community integration for Clubhouse members are multifaceted and can be summarized within seven themes: (1) Traumatic life events influence function; (2) community integration is desired by the majority despite social barriers; (3) employment is desired by majority despite barriers; (4) education is valued but is currently unachievable by most (5) disability benefits and housing experiences; (6) experiences of mental illness and substance use; and (7) clubhouse benefits reduce barriers to participation. These themes can be conceptualized through MOHO's four main constructs: Habituation, volition, performance capacity, and the environment.

Habituation can be understood as how people choose to organize their occupations (Kielhofner & Brooke, 1980). Traumatic life events, social barriers, lack of employment, the inability to be successful with education pursuits, being on disability benefits, and the overall experience of mental illness influences the organization of occupations. Many members' routines lack meaningful opportunities to engage in occupations because of the barriers that they experience. For example, when members discussed their routines they consisted of ADL's, home-management, and leisurely activities. Valued occupations such as employment, education, and socialization were absent. This then impacts valued roles such as student, employee, and friend as many people are conflicted with the roles they value and the roles that they are currently active in. Volition, or why people choose the occupations that they do are also impacted by the themes found within this study (Kielhofner & Brooke, 1980). Traumatic life events, being on disability, experiencing homelessness, lack of socialization, and the inability to finish college

degrees all result in a lack of control over one's life. Many have been unable to achieve what is expected of them by society such as maintaining employment, getting an education, and having positive social relationships. They struggle to fulfil their ambitions to lead a healthy and successful life.

Performance capacity, or the skills and abilities that enable people to perform their occupations is also impacted (Kielhofner & Brooke, 1980). Mental illness may result in slow processing and comprehension and is experienced by many members. This affects their ability to integrate within their communities as it affects their performance in many occupations.

The skills a person has, the way the skills are used to organize their occupations, and the reasons behind why they choose the occupations they do informs how a person performs in a particular occupation, and this performance will determine the level of participation (Kielhofner & Brooke, 1980). Thus, if a person lacks the skills needed to successfully participate in an occupation this will then affect their performance of said occupation and limit their participation. When participation of occupations is limited over time, like it is with those who experience an SMI, a person's occupational identity is negatively impacted (Kielhofner & Brooke, 1980). A person's occupational identity is based on occupations they engage in (or do not engage in), individual experiences (traumatic life events, stigma, lack of social experiences), and who they want to become (they want to be employed, be a good friend/family member, finish school and accomplish goals). A person's occupational identity is negatively impacted by SMI and thus impacts their engagement in occupations overtime (occupational competence). This then impacts a person's overall occupational adaptation, or a person's desired way of living (Kielhofner & Brooke, 1980). Due to the multiple barriers that members experience when participating in

occupations that lead to community integration the dynamic of occupational adaptation is challenged.

Furthermore, occupations exist within an environmental context that influences all aspects of occupation (Kielhofner & Brooke, 1980). There is both a physical and a social context. Homelessness and difficulties with housing are a part of the physical environment and impact how a person interacts with their environment. The social environment impacts occupations as well and is a major part of people's lives. Many members desire social contact and to be around others and be a part of their communities. However, the social environment often provokes anxiety and exacerbates mental health symptoms due to societal expectations.

The local Clubhouse within this study has been cited by each member to positively influence one's occupational identity and competence as the Clubhouse provides structure, stability, a place to socialize, and overall widespread support.

Discussion

The first research question that this study aimed to answer was: what is the lived experience of community integration for members of a local Clubhouse? The lived experience of community integration is separated into barriers and supports in the areas of employment, socialization, and personal interests.

Barriers

Regarding barriers of employment, the study results shared many things in common with the literature reviewed. Barriers relating to cognitive abilities and difficulties within the workplace were found to be a common experience among members. Barriers related to a person's mental illness as well as social and structural disadvantages were also common both within the literature and as reported by members within this study. Results from the study that were unique included

not having an understanding boss or employment environment that considered their individual needs. Many people reported being too slow with their jobs and that their job did not last long due to this. This may suggest that there is a need for employers to have a better understanding of task analysis and the grading of tasks. Additionally, one member shares the importance of the person with the disability understanding their limitations and advocating for themselves within the workplace.

The barriers to socialization within this study sample were comparable to those found within the literature. Members report overall difficulty integrating into their communities and socially with others due to physical and mental health symptoms. The literature suggests that the psychiatric symptoms experienced may impact a person's perceived social effectiveness (Sanchez et al., 2019). While this study did not look at this outcome in particular, members discussed how they experienced anxiety in social situations paired with a tendency to socially isolate. This may have contributed to their view that it was hard to fit in socially. Not having access to transportation also impacts a person's ability to engage in meaningful occupations, whether that be for employment, socialization purposes, or personal interests. It is also interesting to note that having a late diagnosis correlates with negative relationships and overall well-being. Though this does not imply causation, it was of special note that many people were diagnosed in the later years of their life. Addiction/substance use was not particularly researched within the literature review, but this is a relevant aspect of many members lives and impacts their participation in meaningful occupations.

Other barriers impacting one's ability to successfully engage in personal interests include the experience of a traumatic life event. These events cause imbalance in one's life and influence how one performs in everyday activities. Additionally, a lack of motivation, negative symptoms,

sleep apnea, and symptoms of ageing all contribute to a disruption in occupational participation. Not being able to finish one's education due to mental illness is also a barrier not only for one's personal interests, but also for employment and socialization as well. Other members discuss that having a lack of education and a lack of overall skills impacts their ability to be successful within the realm of community integration.

Supports

The second question that this study aimed to answer was, how is the lived experience of community integration for those living with an SMI impacted by the Clubhouse? The Clubhouse is supportive of community integration throughout the literature review, and this was echoed by many members interviewed.

The Clubhouse is cited to be supportive in employment as they have programs to gain meaningful employment such as the implementation of the work-ordered day (Tanaka & Davidson, 2015) as well as formal supported or transitional employment programs (McKay et al., 2006). Clubhouses have been shown to help members with self-confidence, job skills, and learning more about themselves and what they value (Tanaka & Davidson, 2015). While this Clubhouse does not yet have formal supportive or transitional employment programs, they do offer other supports. Additional supports found within this study includes the Clubhouses ability to adapt to the disability of their members, provision of a relaxed setting with minimal pressure, along with overall structure and stability.

Within the literature, Clubhouses have positively impacted social networks of their members and encourage recovery through peer support, acceptance, and belonging (Carolan et al., 2011; Coniglio et al., 2012). Clubhouses provide a setting where one can be a part of a community where positive and nurturing relationships are built (Carolan et al., 2011). The

Clubhouse environment enhances one's sense of self by having opportunities for socialization which then influences self-efficacy and increases chances to be successful in social situations (Carolan et al., 2011; Coniglio et al., 2012). Clubhouses also provide a sense of belonging (Tanaka & Davidson, 2015), as well as opportunities for social skills and interpersonal training (Gumber & Stein, 2018). The study showed comparable results for the area of socialization as members described the Clubhouse as a place that provides them with purpose and inspires hope. Several members also discuss how the Clubhouse has provided a space in which they feel they belong to, giving them a place to go instead of isolating at home.

Clubhouses can also help people with supported education (Jones & Selim, 2013). They have been shown to provide members with chances to make mistakes and learn from them in a safe environment (Carolan et al., 2017) and offers them opportunities to build self-confidence, job skills, and to learn more about themselves (Tanaka & Davidson, 2015). While this Clubhouse doesn't have a formal education program, the nature of the work-ordered day provides many benefits. This study showed that members appreciated the Clubhouse because it helped them to stay productive within the Clubhouse as well as outside of the Clubhouse. Many people do not own vehicles and the Clubhouse provides transportation when other transportation options are not available. Additionally, members also cite the Clubhouse as a support system that helps them stay out of the hospital.

Implication for the practice of OT

According to the Association of Occupational Therapy (AOTA), occupational therapy has the distinct value "to improve health and quality of life through facilitating participation and engagement in occupations, the meaningful, necessary, and familiar activities of everyday life" (AOTA, 2016, pg. 1). Occupational therapists practice within a variety of settings including

community based mental health settings. Psychosocial Clubhouses are environments that provide mental health services in a community setting and are a perfect fit for occupational therapy. Clubhouses provide a space for those who experience an SMI to be a part of meaningful occupations and integrate within their communities. They do this by creating a structured work-ordered day that offers opportunities to gain employment, pursue education, or participate in other occupations that hold value (Mahaffey et al., 2019).

The Clubhouse Model and the foundations of occupational therapy share some of the same principles. While occupational therapy encourages engagement in meaningful activity and believes this contributes to health and well-being, Clubhouses encourage participation in the work ordered day and views this as contributing to mental health recovery and a sense of community. The goals of the Clubhouse match the goals of occupational therapy as programs offered within the Clubhouse promote employment, education, and socialization, and these match the domain of occupation within the occupational therapy framework (AOTA, 2020).

Furthermore, those living with an SMI experience many barriers within several of the areas of the determinants of health. These include barriers to social interaction and support, transportation, access to health services due to low cognitive abilities, substance use, and many others referenced within this study. Occupational therapists have a critical role to play in addressing these barriers through population-based interventions to promote occupational participation and thus enhance the lives of those living with an SMI (Braveman, 2016). The Clubhouse environment is a suitable place for occupational therapists to provide population health services to those in need.

Future recommendations

Understanding this lived experience may help society outside of the Clubhouse to develop more efficient and meaningful community integration programming and policies for those with an SMI. It is hoped that the information gathered from this study will contribute to de-stigmatization efforts regarding mental illness in general and provide more open dialogue about how to better serve this population throughout our community. It is recommended that occupational therapists continue their efforts in population-based therapy to support the advocacy efforts for this population.

Within this study it was found that many people experienced co-occurring disorders among their experience of SMI. These included physical dysfunctions, learning disabilities, and developmental disorders. Future research is needed to understand the implications on occupational participation when people experience multiple disabilities. It may also be relevant to understand the differences in community integration outcomes between active and inactive members.

Strengths & Limitations

The rigor of this study was enhanced through the reflexivity practiced by both the principal and co-investigators throughout the research process. Reflexivity was used as both researchers reflected on aspects of their personal selves and what they brought to the study, and how this may help or hinder the research. After this reflection action was taken through meditative thinking or journaling to work through the prejudice or bias. For example, the co-investigator kept a reflexive journal and one of the entries read:

> I am constantly working through my own pre-conceptions in my head. The main one that comes about is that those with an SMI are often dishonest. This thought may be colored by the fact that I grew up with a sister who has an SMI. Though, it is not my job to discern whether the people I am interviewing are telling the truth or not. To be authentically true

> to the interviews then I must believe that what they are saying is true and I must also be conscious in how my past experiences affect my thinking. Even if something isn't true, there's a reason one may embellish or tell a lie, and the reason is a part of them and who they are.

This is an example of how the bias of the researcher was taken into account and was consciously worked through in order to remain authentic to the study.

Furthermore, meditative thinking was used throughout the data collection process as the co-investigator took care not to lead participants into answering a question based on the co-investigators pre-conceived ideas of what the answer should be. This looked like phrasing questions with a "can you explain that further" instead of "is that because " Lastly, meditative thinking was used during the analysis of the data by the co-investigator asking themselves if they are seeing what they want or expect to see or are they being open to new explanations and meanings.

In addition to being reflexive throughout the study through a reflexive journal and meditative thinking, rigor was further enhanced through member checking of the interpretative summaries collated by the co-investigator post interview. This gave the members a chance to check the accuracy of the summarized interview transcripts. The primary investigator also completed coding and thematic analysis and compared this to that of the co-investigator. This provided additional sources of triangulation, further enhancing the rigor of the study. The study is valid and reliable as it answered the research questions presented and a thorough explanation of how the study was provided. and the demographics of the population represented is comparable to the general population.

Limitations of this study include a small sample size which may influence the generalization of the results. The demographics within this sample were of an older age group. The youngest person interviewed was 40 years old. Not having any one under the age of 40 leaves out a younger generation and may also affect the generalizability of the study. While many methods were used to control bias, it is inherent within a qualitative study that bias was present. The quality of the interview questions and lack of experience from the co-investigator leading the interviews is another limitation of this study. Lastly, time constraints common for that of a doctoral capstone project may have impacted the quality of the analysis.

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APPENDICES

APPENDIX A

IRB APPROVAL

Division of Research & Economic Development

Office of Research Compliance & Ethics

Principal Investigator: Nicole Catheryn Harris
Project Title: Iris Clubhouse: Experiences of Community Integration
IRB Project Number: IRB0003897
Project Review Level: Expedited 6, 7
Approval Date: 12/13/2021
Expiration Date: 12/12/2022
Consent Form Approval Date: 12/13/2021

The application form and all included documentation for the above-referenced project have been reviewed and approved via the procedures of the University of North Dakota Institutional Review Board. Attached is your original consent form that has been stamped with the UND IRB approval and expiration dates. Please maintain this original on file. ***You must use this original, stamped consent form to make copies for participant enrollment. No other consent form should be used.*** The consent form must be signed by each participant prior to initiation of any research procedures. In addition, each participant must be given a copy of the consent form.

Prior to implementation, submit any changes to or departures from the protocol or consent form to the IRB for approval. No changes to approved research may take place without prior IRB approval.

You have approval for this project through the above-listed expiration date. When this research is completed, please submit a termination form to the IRB. If the research will last longer than one year, an annual review and progress report must be submitted to the IRB prior to the submission deadline to ensure adequate time for IRB review.
Sincerely,

Michelle L. Bowles, M.P.A., CIP
Director of Research Assurance & Ethics

APPENDIX B

PHONE SCRIPT FOR PARTICIPATION IN STUDY

I am calling today to see if you would like to participate in a research study that the Clubhouse is participating in. Participation in the study would include being interviewed about your mental illness and your lived experience of employment and community involvement. Your participation is completely voluntary. The interview will take place at the clubhouse and transportation can be arranged. Thank you for your consideration.

APPENDIX C

STATEMENT OF INFORMED CONSENT

THE UNIVERSITY OF NORTH DAKOTA

CONSENT TO PARTICIPATE IN RESEARCH

Project Title:	Iris Clubhouse: Experiences of Community Integration
Principal Investigator:	Rebecca Reeves rebecca.rimel@ndus.edu
Phone/Email Address:	**Occupational Therapy**
Department:	*Nicole Harris*
Research Advisor:	
Research Advisor Phone/Email Address:	Nicole.harris@und.edu **307-268-3126**

What should I know about this research?

- Someone will explain this research to you.
- Taking part in this research is voluntary. Whether you take part is up to you.
- If you don't take part, it won't be held against you.
- You can take part now and later drop out, and it won't be held against you • If you don't understand, ask questions.
- Ask all the questions you want before you decide.

How long will I be in this research?

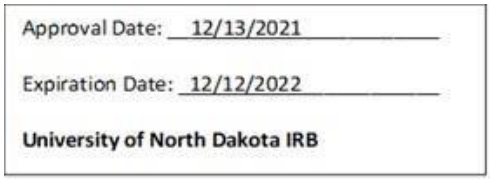
You will be interviewed in a semi-structured format for approximately 30-90 minutes. You will also be asked to check the information that was gathered from you to make sure that it is accurate. This will be done approximately 1-2 weeks after the interview and will take approximately 30-60 minutes.

Why is this research being done?

The purpose of this research is to look at what it is like for somebody with a serious mental illness to fully participate in the community. Community participation can include social activities or employment. We hope that the results of this research will help to improve the social and employment programs that are provided to you within the clubhouse and within the community.

What happens to me if I agree to take part in this research?

If you decide to take part in this research study, you will take part in an interview, which will take anywhere from 30 to 90 minutes, and can be scheduled at your convenience to occur at Iris Clubhouse. In this interview, I will ask you questions about your general background, i.e., age, employment, education, etc., what motivates and interests you, your daily routines, habits, and roles, your mental health diagnosis, different things you do in the community, and what kind of



employment you may have had. You are free to skip any questions that you prefer not to answer. Your responses will be recorded using an electronic recording device with your permission.

Could being in this research hurt me?

The most important risks or discomforts that you may expect from taking part in this research include the possibility of feeling uncomfortable or embarrassed when answering questions during the interview. Mental fatigue may also occur. Whenever someone uses a device to record information, there is also a risk that your identity may become known to others.

Will being in this research benefit me?

The most important benefits that you may expect from taking part in this research include increased knowledge of your self-identity. In addition, the future knowledge gained from this research may help to inform programming offered by the clubhouse that will in turn benefit you.

How many people will participate in this research?

Approximately 25 people will participate in this research. This includes current clubhouse members and past clubhouse members.

Will it cost me money to take part in this research?

You will not have any costs for being in this research study.

Will I be paid for taking part in this research?
You will not be paid for being in this research study.

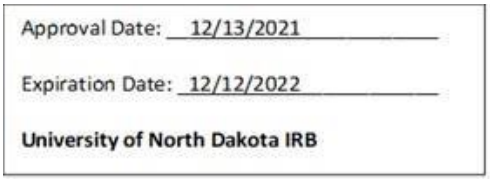
Who is funding this research?
The University of North Dakota and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.

What happens to information collected for this research?
Your private information may be shared with individuals and organizations that conduct or watch over this research, including:

- Iris Clubhouse
- The Institutional Review Board (IRB) reviewed this research
- The research advisor

All audio recordings will be listened to and then typed into a computer. The audio recordings will be kept in a locked and secure location at the clubhouse for approximately 2 weeks. Once typed into the computer, the audio recordings will be destroyed, ensuring your privacy.

We may publish the results of this research. However, we will keep your name and other identifying information confidential. We protect your information from disclosure to others to the extent required by law. We cannot promise complete secrecy.



Data collected in this research might be de-identified and used for future research or distributed to another investigator for future research without your consent.

You should know, however, that there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your

information to a court or to tell authorities if we believe you have abused a child, or you pose a danger to yourself or someone else.

What if I agree to be in the research and then change my mind?

If you change your mind about being in this study, contact the researchers to let them know.

Who can answer my questions about this research?

If you have questions, concerns, or complaints, or think this research has hurt you or made you sick, talk to the research team at the phone number listed above on the first page.

This research is being overseen by an Institutional Review Board ("IRB"). An IRB is a group of people who perform independent review of research studies. You may talk to them at 701.777.4279 or UND.irb@UND.edu if:

- You have questions, concerns, or complaints that are not being answered by the research team.
- You are not getting answers from the research team.
- You cannot reach the research team.
- You want to talk to someone else about the research.
- You have questions about your rights as a research subject.
- You may also visit the UND IRB website for more information about being a research subject: http://und.edu/research/resources/human-subjects/research-participants.html

Your signature documents your consent to take part in this study. You will receive a copy of this form.

Subject's Name: _____

_____ _____

Signature of Subject Date

Approval Date: 12/13/2021

Expiration Date: 12/12/2022

University of North Dakota IRB

I have discussed the above points with the subject or, where appropriate, with the subject's legally authorized representative.

_____ _____

Signature of Person Who Obtained Consent Date

APPENDIX D

SEMI-STRUCTURED INTERVIEW

Demographics

- How old are you?
- What is your highest level of education?
- What is your employment status?

Person Concepts

- What motivated you to become a member of the Clubhouse? What motivates you to continue to be a member of the Clubhouse?
- Tell me 3 things that you are interested in that bring you joy.
- Tell me 2-3 things that are important to you.
- Are you currently working towards any goals?

Habituation

- How does/has the clubhouse help(ed) you to develop healthy habits?
- Tell me about the different roles you had before becoming a member of the clubhouse.
    - How have your roles changed since becoming a member of the clubhouse? Since you've no longer been active in the clubhouse?
- Tell me about your daily routine?
    - Has your routine changed since becoming a member of the clubhouse?
    - Since you stopped coming regularly to the clubhouse?

Contextualizing Questions

- What is your mental health diagnosis?
- When were you first diagnosed?
- Can you describe to me what it was like trying to fit in with your peers after being diagnosed with this?
    - Move to community integration questions

Community Integration

- What social activities do you enjoy doing?
- What community events have you attended?
    - Church, volunteer events, fundraising events
- What is it like for you to be in a social setting?
- Describe other things that you would be interested in doing within the community.
- Do you feel that you are able to work well with others? Why or why not?
- What is it like for you to participate in group activities?

Employment

- Were you working prior to your mental health diagnosis?
- Can you describe to me what it was like to try and find work in the community after your mental health diagnosis?
    - Ask if diagnosed after working age (16+)
- Tell me about your work experiences. What places have you worked and what positions have you held?
- Did you enjoy the work you did?
- Share with me your social experiences that you had while working. What were your co-workers like? Did you enjoy working with other people?
- Tell me about any volunteer experiences you may have had.
- If you haven't had a job, is paid employment something that you want to pursue? If not, is non-paid employment of interest to you? Why or why not?
    - Do you feel that you are able to work?
- What are some things that make it hard to find a job?
    - Keep a job?
    - Social aspects
    - Physical environmental aspects.