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Education- the rainbow at the end of the tunnel.

- A study of a Supported Education Program in a consumer-operated organization, with a focus on experiences of stigma.

Acknowledgement

First of all we would like to thank Lotta at Sveriges Fontänhus for making this study possible through her encouragement and connections. We would also like to thank everyone at Genesis Club for the warm welcome and hospitality. An extra thank you to our informants for taking the time and answering our questions so genuinely. And a special thank you to Luke for being the best host ever and Mary for taking the time to show us Boston. And thank you Fountain House NYC for showing us your organization and activities.

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Abstract

Experiences of stigma, isolation and discrimination are major barriers to accomplish higher education for people with mental illness. It has been argued that students are not receiving sufficient support to overcome these barriers. This qualitative study explores perceptions and experiences of barriers to education with focus on stigma amongst participants in a Supported Education program. The Supported Education (SEd) program in this study is located in a consumer-operated organization, Genesis Club in Worcester, Massachusetts. The empirical material was collected through a two weeks participant observation in Genesis Club's Career Development Unit and through six interviews with members of the Clubhouse. The results show that the informants' experiences of stigmatization have acted as a barrier to education. The SEd program at Genesis Club assists the participants in overcoming barriers. Peer support, role models, empowerment, not using labels, focusing on what you can contribute are all examples of factors that are present in the informants' narratives about the SEd program at Genesis Club. Earlier research has shown that these all are factors that can counteract self-stigmatization. To problematize the results, the study has been inspired by theories on labeling and stigma.

Preface

We both took part in a course that was the result of collaboration between the Fountain House organizations in Sweden (Sveriges Fontänhus) and Ersta Sköndal University College in the fall of 2012. We got the opportunity to meet and study with members from four different Clubhouses in Sweden and among other things we then learned about the organization of Clubhouses and their way of functioning. We both appreciate the general approach of working side by side that exists at the Clubhouses. You contribute with what you can and practice what you want to improve with the help of others. The focus is not on your difficulties but on your capabilities, working and achieving goals together. We both wanted to learn more about this approach and thought that it could be of great help in our future vocation as social workers. Due to our interest in education and the lack of any comparable development of Supported Education (SEd) programs in Sweden we decided to contact the Fountain House in New York where they have a long history of running a SEd program. They in turn referred us to Worcester, Massachusetts where they had better opportunities to accommodate our study. We also got the opportunity to participate on a tour of activities in the different units at Fountain House New York.

In this thesis we have chosen to address and investigate people's perceptions and interpretations of reality and to discuss how these perceptions and experiences influence their everyday life. To put it in an ontological and epistemological context; we have used social-constructionism, a modern psychological variance of the idealistic perspective. According to social-constructionism an objective social reality does not exist. Instead, people's interpretations of reality create the construction of reality. And the people's definitions of their perceptions and interpretations of reality result in cognitive and behavioural consequences (Sohlberg, 2008:52-53, 248-249).

We also would like to take the opportunity to address the choice of using the term consumer in our thesis when talking about individuals who use mental health services. When we did our research in preparation to our field study we felt sceptical towards the term ”consumer” which we regularly came across in research articles about mental illness. During our time at the Genesis Clubhouse in Worcester we noticed that both members and staff at the Club used the term frequently. After learning some more about its origin and discussing it we decided to use it in our thesis. People who use mental health services coined the term “consumer” in an attempt of empowerment. Today the term has expanded to include anyone

who has received mental health services in the past, anyone who has a behavioural health diagnosis, or simply anyone who has experienced a mental or behavioural disorder.

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1. Introduction

Mental illness is on the increase in Sweden and above all among youth (Socialstyrelsen, 2012). Today the large majority recovers from severe mental illness and while not everyone makes a full recovery, it is possible to create optimal conditions to ease their way towards recovery (Topor, 2010:30).

Article 26, Habilitation and Rehabilitation, of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2013) calls on countries to strengthen, organize, and extend comprehensive rehabilitation services and programs. These programs should be based on multidisciplinary assessment of individual needs and strengths and start as early as possible (Officer & Posarac, 2011:95). Article 26 further calls on:

> *(...) appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. (UN, 2013)*

Society is becoming more and more knowledge-oriented. In Sweden the level of education is generally lower for people with disabilities than for the population at large (SCB, 2009). Schizophrenia and psychosis often begin in late teens and the onset of mental illness most commonly occurs between the ages of 15-21 (Newman et al, 1996:552). It is possible toconclude that the number of people in education when developing mental illness is high (Holmlid, 2002:28). A significant number of students who develop mental illness have difficulties in resuming their studies (SAMSA, 2011). A correlation between unemployment amongst youth and mental illness is not only a socioeconomic issue in Sweden but also in other parts of the world. Therefore it is of importance to consider how other countries address this issue and to find out what international research indicates (FOU Södertörn, 2013). Discussions in Sweden and the USA about their mental health systems share mutual topics such as social inclusion, community reintegration and recovery. These areas have been advocated as main principles of the mental health system in the new millennium in both countries (Corrigan et al, 2009:75)

A national survey of college students living with mental illness conducted by The National Alliance on Mental Illness, USA, showed that more than 62 per cent of the survey respondents no longer attended school due to mental health reasons and that stigma remains as the number one barrier for students seeking help (NAMI, 2012:4). Experiences of stigma, isolation and

discrimination are major barriers to accomplish higher education for people with mental illness. It has been argued that students are not receiving sufficient support to overcome these barriers (Mowbray et al, 2005:9). Education has been put forward as being a viable choice in rehabilitation plans. People with psychiatric disabilities report that their completion of educational goals has been interrupted by the onset of mental illness (SAMSA, 2011). The Supported Education (SEd) model emerged in USA during the 80s and is a program for individuals with mental illness who want to begin or resume their postsecondary education. SEd programs support consumers in making choices about the type of education and training they want to pursue and how they can acquire appropriate education and training opportunities. Importantly they also support them in completing their education until they have achieved their goals (SAMSA, 2011).

The frequency of different types of consumer-operated services in USA have greatly increased and one of the early established organizations is the Fountain House in New York and its associated Clubhouses throughout USA (Corrigan et al, 2009:78). Several Clubhouses in USA have SEd programs and according to Mowbray et al (2005:12) the majority of SEd programs take place in Clubhouses. There are international studies of SEd but we could only find one Swedish report on the subject published by FOU Södertörn (2013). In Sweden a study preceding a three-year project “En väg framåt” has been carried out at Lunds Fontänhus. The purpose of the pre-study was to contribute to the start of the Lund model of a SEd program (En väg framåt, 2012:1).

1.1 Problem statement

It has been reasoned that students with mental illness are not receiving sufficient support to overcome barriers to education. SEd is a program for individuals with mental illness who want to begin or resume their postsecondary education. The SEd program is still a new concept in Sweden. A study conducted in USA showed that stigma is the number one barrier for students with mental illness seeking help (NAMI, 2012:4). There is extensive international research about barriers to education for people with mental illness but not with a focus on stigma as a barrier or students’ in a SEd program perceptions and experiences of stigma.

1.2 Purpose

The purpose of the study is to investigate the perceptions and experiences of barriers to education, with a focus on stigma, amongst participants in a consumer operated SEd program. The aim is also to explore the participants' experiences of what type of support the SEd program provides.

1.3 Research questions

- Do the students in a SEd program experience stigma and view it as a barrier to education?
- If so, can the SEd program in a consumer-operated organization help the students in reducing experiences of stigma?

1.4 Relevance to social work

One of the professional groups assisting people with mental illness today, are social workers. Knowledge in psychosocial processes and of programs assisting consumers´ rehabilitation is therefore essential for social workers and according to Mowbray et al (2005:16) "Demands for social workers are likely to increase as more and more individuals with psychiatric disabilities are able to pursue "normalized" roles in the community …" Due to globalization we can today learn from other countries' experiences and social workers have a responsibility to acquire knowledge of rehabilitation programs relevant to consumers they as professionals meet with.

Education can help people who strive for satisfying living conditions, psychologically, socially as well as economically and social workers can assist consumers in achieving a post-secondary education. The SEd in Genesis Club is one example of how consumers and social workers collaborate in order to assist students in accomplishing post-secondary education. To make this collaboration successful social workers need to reach a deepened knowledge in existing barriers to education for people suffering from mental illness and methods helping to overcome these barriers.

1.5 The outline

In chapter one the introduction, followed by the problem statement, the purpose and the research questions is presented. Chapter two addresses the background of the study and

discusses recovery, stigmatization, the origin of SEd programs and Clubhouses. In chapter three the methods are presented. Chapter four presents the theoretical framework for this study, introducing labelling and modified labelling theory and chapter five presents earlier research. In chapter six and seven the results and the analysis are presented, followed by conclusions and discussion in chapter eight and nine. Quotations from an auto ethnographic story, that chronicles the author's struggle with mental illness within the context of the academy, are used to illuminate and exemplify the different research results in chapter five.

1.6 Distribution of work

Nelly: Acknowledgement, Foreword, Introduction, Background, Theoretical Framework, Earlier research, Results 6.2.2, Analysis 7.2.
Annika: Abstract, Genesis Club 2.3, Methods, Results 6.1, 6.1.1, 6.2.1, Analysis 7.1.
Annika and Nelly: Problem statement, Purpose, Research questions, Relevance to social work, Clubhouses 2.2, Conclusion, Discussion

2. Background

Mental illness is a multifaceted disorder and persons can experience the same disorder differently. Therefore services and treatments need to be individualized and the interactions between cultural, biological and psychosocial factors need to be considered (Unger, 2007:29,175, Perris, 1996:129). Categories of disorders are attempts to make sense of a collection of symptoms that may change over time, manifest themselves more at one time than another and are different for each individual. It is essential to emphasise that when you receive a diagnosis you do not "become" that diagnosis. Each person is more than his or her diagnosis (Unger, 2007:29). People with mental illness issues begin the recovery process for motives that are as diverse as the people themselves. Recovery is commonly described as a process (Unger 2007:176). Recovery puts the individual in focus and means that the consumer has begun a process to reinstate control over her/his life. This process is about: control in regard to symptoms, control in regard to treatment and other accommodations that are available and control of the consequences of stigmatization (Sundström & Topor, 2007:4). Consumers have been helped and taught by individuals with similar experiences – if they can so can I. People with mental illness, who discuss their experiences openly contradicts and questions the stigmatization that usually is connected with mental illness (Sundström & Topor, 2007:13).

The tendency to categorize people and group individuals into types and classes have been dominating amongst humans from ancient time (Rotter, 1954:25). When growing up you

incorporate the stereotypes of your culture (Major & O'Brien, 2005:395-396). Stereotypes often associated with mental illness include social incompetence and dangerousness. In short, prejudice is agreeing with the stereotype and emotional reactions, discrimination is the behavioural response to prejudice. Negative stereotypes such as the ones mentioned above; notions of dangerousness or incompetence can be harmful to people living with mental illness (Corrigan, 2012:464). Social psychological models describe stigma as comprising stereotypes, prejudice and discrimination (Major & O'Brien, 2005:394-396). In research literature public stigma has been distinguished from self-stigma. Public stigma is the discrimination directed against people with mental illness by individuals from the general population. Self-stigma is harm to self-esteem as a result from internalizing stereotypes (Corrigan, 2012:464). Stigma has been shown to harm people with serious mental illness in different ways (Corrigan, 2012:465).

2:1 The Supported Education program and its origin

In the 80s a number of programs that met the definition of SEd began to emerge (Unger, 2007:14). They were based on the need to provide relevant services for an expanding group of people. Services that should be offered in settings viewed as non-stigmatizing, based on the assumption that this would be the best setting in order for vocational and social skills training to be successful. Young adults perceived day treatment settings within the mental health system as being too stigmatizing (Unger, 2007:7). It was a radical departure, from the medical model of curing an illness and/or providing psychotherapy, to instead assisting consumers in returning to education (Unger, 2007:12). This new approach reflected other transformations within the mental health field. Psychosocial centres such as the Fountain House in New York had begun this work. Rather than trying to "cure" a person, enhanced functioning was the aim. Psychosocial rehabilitation (PSR) is a program for consumers to develop social, occupational and living skills that can support them in living as self-reliantly as possible in the society (Unger, 2007:9). PSR programs are designed as a partnership between the consumer and the professional caretaker (Mowbray et al, 2005:7). Consumers and family members request for PSR services that could help people with mental illness to restart or begin higher education was a contributing factor to the launch of SEd. A request that reflects the statement that all should have access to education in accordance with article 26, in the Universal Declaration of Human Rights and the belief that people with mental illness can learn, attend classes, and improve their vocational options.

SEd is primary founded on PSR. But SEd also incorporates client-centred therapy and social learning theory (Unger, 2007:15). So although SEd practitioners do not aim to develop therapeutic relationships their aim is to encourage and support in accordance with client-centred therapy (Rogers, 1951:19-30). Social learning theory states that learned behaviour is modifiable, it changes with experience. According to social learning theory behaviour is also influenced by social context and not only by psychological factors (Rotter, 1954:85-86). Important components to the theoretical perspective is thereby; the belief that a person can change through learning by experience and with emphasis on the meaningfulness of the environment (Unger, 2007:16). The definition of SEd is:

> *Education in integrated settings for individuals with severe psychiatric disabilities for whom postsecondary education has been interrupted or intermittent as a result of severe psychiatric disability and who, because of their disability need on-going support services to be successful in the environment. (Unger et al, 1990:10).*

The core principles of SEd are:

1. Access to and participation in an education program is the goal.
2. Eligibility is based on consumer choice.
3. SEd services begin soon after the consumer expresses interest.
4. SEd is integrated with treatment.
5. Follow-along supports are continuous.
6. Consumer preferences guide services.
7. SEd is strength based and promotes growth and hope.
8. Recovery is an on-going process facilitated by meaningful roles.

(Unger.K, 2013)

Principle 8 stresses that we are all defined by the roles we play, and consumers are no exception. Being a worker, student, family member or friend are all meaningful roles that give context to living a meaningful life. Being a student provides consumers the opportunity to take a valuable role in society. Instead of being measured as “patient” consumers can be viewed as a student and an active member in the community. SEd stresses that rehabilitation work should begin on day one, as soon as the consumer has expressed interest, as stated in principle 3. The consumer’s interests and plans should be in focus. Another central element in SEd is a trusting relationship between the individual and the rehabilitation counsellor and/or the peer participants in the SEd program (Unger, 2007:13, 14). SEd may advocate for students, the

long-term goal however is to develop students capability and skills in advocating for themselves which is consistent with PSR (Mowbray et al, 2005:12).

Three SEd Prototypes are the self-contained classroom, the on-site support model and mobile support. These were the types that were considered as being most common in the beginning and were offered in mental health centres and educational institutions (Mowbray et al., 2005). While these were originally considered separate implementation models, recent literature suggests that the majority of programs offer flexible and individualized services in different locations (SAMSHA, 2011).

2.2 Clubhouses

In New York the first successful working community emerged in 1948 to ease the devastating social impact of mental illness. Fountain House, New York became the first Clubhouse and was founded by consumers on the premise that members are active partners in their recovery. General aims are that members should experience a reduced sense of isolation and increase their fulfilment, purpose and stability. In their Mission statement The Fountain House describes their goal as follows: “Our goal is a high quality of life for all members, ongoing improvement and the ultimate elimination of stigma against those with mental illness.” (Fountain House, 2013)

Activities and programs, according to the Clubhouse model, are designed to provide opportunities and produce the desire and confidence to pursue them. In the Clubhouse model members and staff are co-workers. The work is organized in units and it is exclusively work in the operation and enhancement of the Clubhouse community. The work-ordered day is described in the International Standards for Clubhouse Programs (with 36 standards) as follows:

> *15. The work-ordered day engages members and staff together, side-by-side, in the running of the Clubhouse. The Clubhouse focuses on strengths, talents and abilities…*
>
> *19. All work in the Clubhouse is designed to help members regain self worth, purpose and confidence…*
>
> *(ICCD, 2013)*

The 36 International Standards for Clubhouse Programs were developed in 1989 and the International Center for Clubhouse Development (ICCD) was founded in 1994.

In 2012 there were more than 340 Member Clubhouses all over the world. (2012 Annual report, ICCD)

2.3 Genesis Club in Worcester, Massachusetts

> *The Genesis Club was established in 1988 to assist individuals with a mental illness to obtain employment, education, housing, wellness, and friendships. Genesis Club membership is open to anyone who has a diagnosis of a mental illness. The Clubhouse provides a place of hope, dignity, friendship and recovery.*
>
> *Genesis Club is a member of the International Center for Clubhouse Development (ICCD). ICCD Clubhouses are founded on the realization that recovery from serious mental illness must involve the whole person in a vital and culturally sensitive community.*
>
> *(Genesis Club, 2013)*

The activities at Genesis Club are based on member/staff partnership. Members and staff are working together, side-by-side in all aspects of the Club. The work at the Clubhouse is organized into seven different units. The members are free to chose which unit they prefer to volunteer in. The units are: membership services, business and research, food services, career development, café and maintenance, training and development and housing.

3. Methods

In this section the methodological process is described, including ethical and methodological considerations.

3.1 A qualitative approach

We have used a qualitative approach based on participant observation and semi-structured interviews “Qualitative studies are idiographic- that is, they seek to study in depth the unique characteristics of individual experience.” (Coolican, 2009:562). Our intentions with this study have not been to generalize our results, but to explore a group of Clubhouse members’ perceptions and experiences of barriers to education, with a focus on stigma. We also wanted to seek knowledge of a SEd program in a consumer-operated organization and if it support students in overcoming barriers.

3.1.1 Participant observation

The participant observation is a method that can give the researcher the possibility to be involved in peoples “day-to-day interactions within their normal network of human group relationships”. (Coolican, 2009:137). We have used the participant observation in order to get an insight in the SEd program at Genesis Club; to get an understanding of how the different supports work and to get the opportunity to interact with people involved with the program. “The observer can experience life from the perspective of the individual, group or organization of interest.” (ibid.). The intention was not to do interpretations of people’s behaviour.

The participant observation also enabled us to come in contact with informants. The sources for the results presented about the SEd program derives from publications, printed information from the Clubhouse, Internet publications and notes from our observations. The results obtained from the participant observation during the two weeks in the Career Development unit are presented in the result section 6.1.

3.1.2 Interviews

The choice of using semi-structured interviews gave us the possibility to focus on themes consequential to the purpose of the study and the opportunity to have a flexible process (Bryman, 2002:301). An interview guide (see appendix 2) was used. The interview guide was organised in four sections. Open-ended questions were posed in order to allow the informants to speak as freely as possible about their own experiences, from their own perspective. The choice of using semi-structured interviews also gave us the possibility to pose follow-up questions to let the informants develop their reasoning further (ibid: 305). The interview guide starts with information about the informants’ academic status and present contact with the SEd program. Following themes are about barriers to education, stigmatization related to education, about what the SEd program at Genesis Club contributes and the meaning of education for the informants’ well being. The interviews were conducted the second week of our stay, at the Clubhouse in a private space, with one exception where the interview took place at the college campus of one of our informants. We were doing the interviews together, alternating who was posing the questions. The interview with the informant at campus was conducted in a cafeteria and with a member of staff present. How this affected the interview will be discussed further under ethical considerations. This interview was completed in less than 20 minutes. All the other interviews were completed in one sitting during 30-75 minutes.

All the interviews were recorded. The results from the interviews are presented in the result section 6.2.

3.2 Selection of literature

It is essential to review accumulated knowledge related to ones research questions (Neuman, 2011:124). We wanted to place our study in a context and make it relevant related to earlier research (ibid.). To find relevant literature we started with searching in Internet databases. We searched in Academic Search Premiere, DiVA, ERIC, PsykINFO, SOCINDEX among others. Search words leading us to the research we have used in this study were: supported education, mental health AND education, mental illness AND education, barriers AND education, stigma, stigmatization, labelling theory, peer support, education programs, psychiatric disabilities among others. Research that we found in the databases led us further to other literature. Karen Unger´s *Handbook on Supported Education Providing Services for Students with Psychiatric Disabilities* (Unger, 2007) has been our primary source of information concerning the method of SEd. The theories on labelling and modified labelling derives from publications from Bruce G. Link's and Jo C Phelan's *"Labeling and Stigma"* (2010*)* and "*Conceptualizing Stigma"* (2001), Peggy A. Thoits's "Sociological Approaches to Mental Illnes" (2010) and Thomas J. Scheff 's *"Being mentally ill- A sociological theory"* (1999).

3.3 Procedures

The point of departure for this study was that we wanted to study the SEd program in a Clubhouse. With the help from a Swedish contact in Sveriges Fontänhus (Fountain House Sweden) we found the location for our field studies at Genesis Club in Worcester, Massachusetts, USA. We were participating in the daily work at the Career Development unit (CDU) during two weeks in April 2013. The agreement with the Clubhouse was to spend two weeks of internship there in order to do our field studies for our bachelor thesis.

We started with searching for literature about SEd, which led us to literature about education and mental health and barriers to education. In doing so we discovered that stigma and stigmatization was frequently highlighted as an important aspect in the SEd. Next we formulated our purpose.

The first week we were participating in the work-ordered day, side-by-side with members and staff. After three days we started to ask for permission to carry out interviews with

members. During the first week we had the opportunity to make contact with a number of members, of whom we wanted to interview. During our second week we conducted the interviews and continued collecting information through participation in the activities at the Clubhouse.

3.4 Sampling

We have used a convenience sample for our interviews. This strategy is not ideal, but as Bryman (2002:313) explains, this approach is usually due to the access to people and used when the intention not is to create a representative sample. The informants were consumers we met during our internship at CDU. We decided to try to find as many female as male informants, younger as well as older (middle aged). They were either students or had prior experiences of being a student in higher education at colleges or universities. They were all members of Genesis Club and somehow connected with the CDU (they either worked there or were students in the SEd program). All the members we asked said yes to being interviewed. The interviews were carried out with six members. Four of the informants were current college students and were receiving support from the SEd program when the interviews were carried out. They were all studying part time when the interviews were conducted, but were all aiming to study full time the next semester. Three of those were in their early twenties and one was in the late forties. The other two informants had prior experiences of higher education; one of them had been in the SEd program last semester, but had interrupted the studies, the other informant was taking a foreign language course as an evening class. They were both about fifty years of age. Two of the informants were female and four were male. Our intention was to interview as many women as men, but the sixth informant cancelled the interview in the last minute and we found a new sixth informant through suggestions from staff and carried out this interview in the last hours of our stay. This affected our sample and also the circumstances for the interview. This will be problematized further in the ethical considerations section.

3.5 Method of analysis

We transcribed all the interviews; three interviews each and the transcriptions were made verbatim and in full. Coding data in qualitative research is as Neuman (2011:510) describes it "to organize the raw data into conceptual categories and create themes and concepts". The interview guide was created in order to structure our analysis. It was structured according to

themes. The themes derived from the understanding of our theoretical framework and earlier research. Findings during the preceding participant observation and conversations with our informants and other members at the Club had also supported the theoretical framework. Both of us processed all of the interviews according to the questions in the interview guide by extracting what we saw as relevant information to answer our two research questions. After doing so we discussed the material and decided to continue the categorisation, dividing the results between us according to the different themes in the interview guide. In doing so we discovered common themes in the informants narratives that facilitated the analysis of the results. As all our questions, with the exception of the first introductory questions, aimed at answering our two research questions we then decided to present the results according to them. The results were later on analysed by using theories on labelling, modified labelling and stigma and relevant earlier research. *A theoretical reading of interviews*, according to Kvale & Brinkmann (2009: 236) doesn't necessary demand a systematic method for analysis as long as the researcher reflects theoretically on specific themes.

3.6 Validity and reliability

"Validity means truthfulness. In qualitative studies, we are more interested in achieving authenticy than realizing a single version of "Truth"." (Neuman 2011:214). This means trying to offer a fair and honest narration, true to the experiences of the people we study (ibid.). We have tried to reach authenticity by creating an interview guide with as straightforward and open-ended questions as possible, by recording the interviews and transcribing them verbatim and in full. We posed follow-up questions when necessary and reformulated the questions if necessary for the understanding. We also guaranteed anonymity to all our informants, conditions hopefully helping the informants to feel safe giving as truthful answers as possible. There is one exception to this; one of the interviews was conducted under different circumstances, which affected the interview and therefore might have affected the validity to some extent. This will be problematized under ethical considerations.

"Reliability means dependability or consistency. It suggests that the same thing is repeated or recurs under identical or very similar conditions" (Neuman, 2011:208). In qualitative studies this is difficult to achieve due to that we often study unstable processes and that the interaction between the researcher and the people we study affects the result (ibid: 214).
We conducted our interviews at a certain time and place with a group of six individuals with different experiences. The relations between us and the informants varied due to how much

time we had spent together during our stay and to how our relations developed. This, of course, might have influenced the results. Our intention is not to claim consistency or to generalize our results. What we can say about the reliability of this study is that we found common themes in the informants' narrations and support for our results in earlier research. Neuman expresses that "diverse measures and interactions with different researchers are beneficial because they can illuminate different facets or dimensions of a subject matter." (Neuman 2011:214)

3.7 Ethical considerations

Ethical considerations has for us been an ongoing process during the preparation, the collecting of empirical data as well as considering how to analyse and present our material. We have considered the principles of *Privacy, Anonymity and Confidentiality* that are essential to academic research (Neuman 2011:152). Neuman talks about how "Survey researchers invade a person's privacy when they probe into beliefs, backgrounds, and behaviours in a way that reveals intimate private details" (ibid.). He states that even if people know that they are observed they are not aware of what the outcome of this observation will be. An ethical researcher has to violate privacy to a minimum and only for legitimate reasons. He or she also has to protect the obtained information about the participants from public disclosure. Not disclosing takes two forms: anonymity and confidentiality were anonymity means that participants' identity is protected by not disclosing their names (ibid.). Confidentiality means that research data is hold in confidence, secret from the public by not releasing information that may link the individuals to specific responses (ibid: 153). Neuman (ibid: 149) also describes that people need to know exactly what they are going to participate in and he states that this information should be a written agreement, with information about their rights and what they are being involved with: an informed consent.

The first day of our internship we informed all members and staff in the CDU the reason for our internship in their unit. We gave a brief presentation of ourselves, why we were going to participate in the activities at the unit; that we were going to write a bachelors thesis about the SEd program at Genesis Club. We also declared that all participants in our study was guaranteed anonymity, no names were to be disclosed. This information was repeated during our stay as new members (that we had not met before) arrived to the unit as well as when we met students at campus visits. We also gave this information several times at meetings with all the units. After three days and after having asked staff and management for their consent we

then started to ask members if they wanted to participate in an interview. We informed about that the interview would be about the SEd program, with focus on barriers to education.
We created a consent form (see appendix 1), that was distributed at the time for the interviews and the informants were asked to sign it. We informed about the aim of the study, the methods, about anonymity and the right to withdraw at any time. We also informed about how the study was supposed to be used and published. We did not want to influence the informants with our aimed focus on stigma and stigmatization and therefore we did not mention this theme.

To protect anonymity we had decided to leave out all the participants' names. As the Genesis Club is a rather small and intimate place and on account of that the study was going to be distributed to anyone interested of reading it at the Club we realized that the informants could risk being disclosed by their fellow members or staff. People at the Clubhouse were also well aware of who our six informants were. By way of precaution we therefore decided not to give the informants fictitious names, but instead to mix all the informants in the results, not revealing who was saying what; the informants' answers were presented as anyone in the group and the age and gender of each person was never linked to a certain quotation. Of course there is still a possibility that members or staff knowing the informant could identify the individual out of the information this person revealed. We considered this to be a minor problem as the informants were well aware of this fact and as the questions were formulated to be of a character that we did not consider being too intimate, provided that the informant did not choose to disclose more intimate details.

3.8 Methodological considerations

Although we have considered the ethical principles above to protect our informants there was one noteworthy mistake made. Our sixth informant was found in the last minute, with help from a staff member. With limited time the interview was conducted under different circumstances than the others. Under those circumstances we did not act as ethical and methodological as in the other interviews. With this informant we had not met before the interview and we only had a verbal agreement to meet for an interview through a staff member. We were conducting this interview at campus in the outdoor space of a cafeteria and with the staff member present. There were also other students sitting close to us during the interview. The informant read and signed the informed consent form, but when we already had started the interview we realized that this situation was not really protecting our informant

according to the ethical principles. We then decided to leave out some of the more delicate questions. This affected the outcome of the interview and we first considered not using this information. Some of the information was nevertheless of a character that we found to be of interest and we later on decided to include this information in our results.

The fact that we were doing our research, including the interviews, in another language than our native has most probably affected our results to some extent. We consider this to have certain advantages as well as disadvantages. The balance of power that might arise in an interview situation is something that is important to be aware of. We believe that this balance might have been affected in a positive way due to the fact that we were our informants' inferiors as regards language. Sometimes the informants had to be patient with our not always perfect English and we sometimes had to rephrase our questions or to ask the informants to repeat or explain words or expressions. The disadvantage of doing research and interviewing in another language is supposedly more obvious. There is always a higher risk for misunderstandings or misinterpretations.

3.9 Limitations

Sweden and USA have two different welfare systems. Our study is undertaken in a social and cultural context, which is different from Swedish conditions. Our ambition was not to generalize our results from this study, but after realizing that we do not have SEd programs as developed in Sweden, we think that Genesis Clubs' SEd program might be something we could learn from.

In this study we focus on mental illness in the social context. We have not considered the medical conditions of our population or focused on differences regarding diagnoses or medical treatments.

The SEd program at Genesis Club also addresses prospect GED (General Equivalency Diploma) students or students in vocational programs, but we decided to limit our study to students in higher education.

4. Theoretical framework

Labelling theory is a modern sociological theory in psychology used to understand mental disorder and the social context of its treatment. The theory played an important part in the movement to deinstitutionalise the mentally ill (Thoits, 2010:120). Modified labelling theory is developed from the labelling theory and is less radical and does not dismiss medical or

therapeutic treatment but also focus on the social context and coping strategies of stigmatization. The labelling theory and the modified labelling theory are applicable to this study when they discuss consequences of stigmatization and labelling.

4.1 Labelling theory

Labelling theory is founded on the assumption that most of the reality, which is experienced by humans is socially constructed (Scheff, 1999:46). The idea that people who are labelled as deviant and treated as deviant becomes deviant is another basic assumption (Scheff, 1999:86). Scheff defines deviance as a normative violation that may obtain three responses: stigma, segregation and labelling (Scheff, 1999:45). Most normative violations are not seen as deviance, what decides this is how the social group reacts to an individual's deviance.

> *In a crisis, when the deviance of an individual becomes a public issue, the traditional stereotype of insanity becomes the guiding imagery for action, both for those reacting to the deviant and, at times, for the deviant himself. When societal agents and persons around the deviant react to him uniformly in terms of the stereotypes of insanity, his amorphous and unstructured rule-breaking tends to crystallize in conformity to these expectations, thus becoming similar to behavior of other deviants classified as mentally ill and stable over time. The process of becoming uniform and stable is completed when the traditional imagery becomes a part of the deviant's orientation for guiding his own behavior. (Scheff, 1999:85).*

According to labelling theory the unfortunate outcome of stigmatization can be an identification with the mental patient role. Patients come to expect psychiatric symptoms from themselves and therefore also display the symptoms: a "self-fulfilling prophecy". Thereby most mental disorders can be considered to be a social role according to labelling theory (Scheff, 1999:86-87). Labelling theory is of importance when it reminds us that mental illness is, to some extent, socially created and sustained and that we therefore should use diagnosis and labels with care. Wrongful diagnosis can occur and societal reactions based on stereotypes can make the recovery process more difficult and possibly longer (Thoits, 2010:123). The earlier forms of labelling theory have been criticized for overestimating the importance of labelling as a cause of sustaining mental illness (Thoits, 2010:122).

4.2 Modified labelling theory

In modified labelling theory it is argued that rejection and discrimination by other people are not necessary for a self-fulfilling prophecy to occur. But it states that persons who have been diagnosed and hospitalized are well aware that negative stereotypes of mental patients in general are hold by the public (Thoits, 2010:122). When the consumer then gets back to their

every day life these stereotypes takes on personal significance. Because the awareness of the stereotypes the consumer expects rejection and discrimination from other people and engages in different coping strategies:

1: avoiding contact with other people
2: concealing information about his or her psychiatric past
3: attempting to educate others about mental illness to combat stereotypes.
(Thoits, 2010:122).

Link and Phelan described their conceptualization of stigma as follows:

> *In our conceptualization, stigma exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labelled persons to undesirable characteristics – to negative stereotypes. In the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of "us" from "them." In the fourth, labelled persons experience status loss and discrimination that lead to unequal outcomes. Stigmatization is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination. Thus we apply the term stigma when elements of labelling, stereotyping, separation, status loss and discrimination co-occur in a power situation that allows them to unfold. (Link & Phelan, 2001: 367).*

5. Earlier research

In this chapter we will present research concerning stigma, the so called "why-try effect" and barriers to education.

5.1 Stigma

Stigma is a social construction and exists in its social context (Corrigan, 2012:468, Major and O'Brien, 2005:395). When helping people in overcoming self-stigma it is essential not to imply that stigmatization is the fault of the individual and therefore not only the responsibility of the individual (Corrigan, 2012:466). "Stigma is a social injustice and an error of society. Hence irradiating it is the responsibility, and should be a priority, of that society." (Corrigan, 2012:466).

PSR practice recognize that successful rehabilitation outcome require changes at the macro level as well as at the micro level. Macro level changes include addressing the stigma that prevents consumers from fully taking part in their communities (Mowbray et al, 2005:17). The awareness of stereotypes, conscious or subconscious, is more or less inescapable. Agreeing with them and as a result believing that they are truthful in describing

one's self and others with mental illness is certainly open to challenge. Consumers are often subjects of stigma and identified consequences of stigma can be; diminished self-esteem and self-value, social rejection or isolation and lowered expectations. Which in turn undermines hope and faith in being able to achieve goals (Unger, 2007:40, Corrigan et al, 2011:2). Individuals in a study made in Massachusetts identified self-stigma as the most damaging effect of stigma (Unger, 2007:41). Consumers often self-stigmatize but there are others who seem ignorant to its effects. There is also another group that report anger at the injustice of stigma and who takes it on as a personal goal to make a change (Corrigan, 2012:468).

> *If I am writing for any reason, it is to demystify and demythologize depression; the best way to promote understanding and fight ignorance is to speak out, to make my version of the story part of the permanent record. (Jargo, 2002:746).*

Speaking out against stigma and discrimination can help individuals to cope with stigma (Wahl, 1999: 467-478). One of the elements to reduce stigma concerns direct social contact with consumers. This has been shown to be effective for example in relation to police officers and school students (Pinfold, 2005:129, Pinfold et al, 2003:343). Empowering people appear, when consulting research, to be another way of reducing self-stigmatization. Empowerment has been argued to be the antidote to stigma, the opposite of self-stigmatization (Corrigan, 2012:466). Empowerment defined here as comprising power, activism, righteous indignation and optimism. Examples of ways in which consumers can empower themselves or be empowered are; promoting participation in formulating care plans and crisis plans and taking part in treatment and service evaluation (Corrigan, 2012:466, Thornicroft et al, 2008:2). Empowerment is an appropriate tool for change. It prescribes what "might be done" to influence goals instead of "what should not be done" to achieve these goals (Corrigan et al, 2009:78). Consumers involved in peer support programs report less self-stigma, higher feelings of hope and better quality of life (Corrigan et al, 2011:7).

A common way of dealing with self-stigma is by not telling other people about your mental illness and trying to conceal it, coping strategy number two in the modified labelling theory. A lot of consumers worry that others will find out about their psychiatric status and treat them differently (Wahl, 1999:471). Though research has shown that disclosure is associated with reduced negative effects of self-stigmatization on the quality of life (Corrigan, 2012:465). Some uses selective disclosure by differentiating people with whom private information is disclosed versus people from whom this information is kept secret. Selective disclosure may have some positive results such as an increase in supportive peers but might still as a secret

represent a source of shame (Corrigan et al, 2009:79). A theory of stigma reduction that motivates anti stigma interventions is that changes in attitudes about mental illness increase help-seeking behaviour and in turn increased help-seeking behaviour will lead to treatment. This will promote recovery and secondarily reduce social stigmatization (Goldman, 2010:1289-1290). In one study it was reported that according to tutors the most frequent difficulty was the unwillingness of students to receive help (Mowbray et al, 2005:9). Another study identified stigma as the number one barrier for students to seek help (NAMI, 2012:4).

> *I worry about the capacity of the canonical story of depression to define me, the responses of those around me who don't understand and see me as "crazy," the power of my brain chemistry to bring me down again, my inability to sustain a story of health, all of which conspire to keep me stuck in this darkness. When I left school last fall, the dean and I decided to be forthright about the reasons, a strategy to quell potential rumours, but more important, a way to bring the unspoken illness of depression out into the open. For Erin, my revelation offered comfort. She too struggles with depression, though in her case depression is coupled with periods of mania. I feel unsure about how to progress, how much of my personal life to share with this student. Again, I find myself negotiating that fine line between respected professor and vulnerable human being. Does her knowing the gory details about my struggle with depression enhance or hinder our relationship as student and teacher? "I wish antidepressants worked for me," I say, and then I hear myself narrating my experiences of the past year, the guilt over abandoning my students, my months on the couch, the alcohol, an anxiety laden return to school. The words gush out of me. "I am so happy to be back. But at the same time, I worry people don't see me the same way. I am not the same person." "For a year I have lived as "Depression Barbara" and now I am fighting my way back to "Professor Barbara," unsure as to how the two might coexist. But perhaps there is no way back, the Professor Barbara I once knew gone forever. I don't know who will take her place, and where depression will fit in. "I know, "Erin jumps in. "When I first heard my diagnosis—manic- depression—I freaked! It sounded so big, so scary. To take on that label . . ." her words drift off. (Jargo, 2002:746).*

A related consequence of self-stigmatization is what has been called the why try effect, in which self-stigmatization interferes with life goal achievements (Corrigan, 2012:465). Why try is a variant of modified labelling theory in which the social rejection linked to stigmatization contributes to low self-esteem. As stated before modified labelling theory outlines the behavioural consequence of self-stigma. The why try effect addresses the lack of confidence that may follow self-stigmatization and reflects doubts that may arise. Doubts such as; "-Why should I even try to get a job?" (Corrigan et al, 2009:76).

5.2 Barriers to education and human capital theory

A study by Megivern, Pellerito & Mowbray (Megivern et al, 2003:217-231) identifies barriers to higher education for consumers. The participants had prior experience of difficulties related to mental illness during college education. The majority of the participants, more than fifty per cent had experienced "decreased emotional and behavioural skills", a little less than twenty

per cent had experienced "declining academic performance" and about ten per cent were showing experiences of "decreased self-efficacy" (believe in ones own ability). The participants social life was reported being affected during college enrolments and this included experiences of stigma and discrimination. Generally the participants were reluctant to inform at the faculties about their mental illness and the vast majority had not been utilizing campus-based counselling or disability services.

Another study used the Human Capital Theory to predict wages and to explain employment outcomes among individuals living with psychiatric illnesses. The study showed that educational level and work history were positive predictors of wages for people with mental illness. Supporting the statement that investment in building the human capital of people living with mental illness can come to improve their employment success (Gao et al, 2011:117-124). SEd for persons living with psychiatric illness should also be introduced during the early stage of the illness to be most effective in reducing the length of disruptions in the continuation of education and employment (ibid, 2011:123)

6. Results

First the procedure of the participant observation in the Career Development Unit at Genesis Club is described. Next the results depicting the SEd program at Genesis Club and the results from our interviews are presented.

6.1 Participant observation

During our two weeks at Genesis Club we participated in the work ordered day in the Career Development Unit (CDU). A work ordered day at a Clubhouse means that members and staff are working side-by-side in order to execute the tasks of the day. All units start the day with a planning meeting were all assignments for the day are written on the white board and all present, members and staff members choose what work tasks they want to carry out. The work force may differ from day to day, members chose how much and when they come to the Club, some are there everyday, some not as often. During our two weeks we participated as two fellow workers, part of the work force. As days passed by we became more and more focused on details about the SEd program and on our planning of the interviews and for that reason we did not participate to the same extent in the daily work at the unit. During the second week we gave priority to main assignments in the SEd program such as campus visits and other supportive tasks and to conduct our interviews.

Through participating in the different activities, talking to members and staff we had a chance to get an insight into what possible barriers to education and needs of the students that the SEd program could help the students to deal with. The following section describes how we apprehend how the SEd program functions as a support to students in the program.

6.1.1 Supported Education at Genesis Club

The Clubhouse assists members to reach their vocational and educational goals by helping them take advantage of adult education opportunities in the community. When the Clubhouse also provides an in-house educational program, it significantly utilizes the teaching and tutoring skills of members.

(Standard 25, International standards for Clubhouse quality, ICCD)

The SEd program at Genesis Club is a part of the Career Development unit that also includes *Transitional, Supported* and *Independent Employment*. The program addresses members who are students or who want to study. The aim of the program is to help people achieve their educational and vocational goals. As mentioned above the three prototypes in SEd are the self-contained classroom, the on-site support model and mobile support. Genesis Club provides mobile support, at the Clubhouse, at campus and in the community. The support includes:

Guidance in determining educational goals and school/training selection
-Literacy
-ESL (English as Second Language)
-GED (General Equivalency Diploma)
-Certificate and vocational programs
-Degree Program
-Assistance with school application process
-Assistance with financial aid, grant and scholarship application process
-On-going support on-campus and in the community while enrolled

(Genesis Club, 2013)

Members who are students or considering studying have the possibility to enter the SEd Program. It is open to all members of the Club and there is also a possibility to become a member to get support from the program. Staff working with SEd are all working in the

Career Development unit (CDU). Out of three employees, one person works mainly with SEd, one person works with SEd and employment and the third person works mainly with employment. All staff members are nevertheless available to students in the program if needed. Members who are engaged in the SEd program (those receiving as well as those giving support are in the CDU as well as in other units in the Club. For instance a SEd student as well as a peer partner can work in one of the other units at the Club.

SEd at Genesis Club is today a well-developed program, which has arisen from the need from members, according to staff and members. Influences from the Supported Employment (SE) program, which is of older date, have helped in the development of the program:

> *We have learned not only to help people to get enrolled; we have to continue after that with the support. We didn't know that from the beginning, we learned from Supported Employment. (staff member).*

From the participant observation at Genesis Club we got an insight in the activities included in the SEd program, such as:

-applying/ enrolment
-financial aid- signing up
-help with Baer scholarship as well as applying for other scholarships
-help with disabilities in universities and colleges
-campus visits, peer partner support, tour in group
-outreaches

To make a decision to begin an education can be a big step for young people. To begin with there is the procedure of applying and getting enrolled. In the SEd program at Genesis Club members can be assisted in the process with all the major steps to get enrolled in the education program they have chosen. Already in deciding what university or college to apply to there might be barriers to overcome. Staff and members offer assistance in finding and visiting different schools as help in making these decisions. They also assist in contacting the Disability Services at a college or university of interest. The Disability Services offers accommodations to students, such as tutoring, longer testing times et cetera. According to members and staff some universities and colleges had well developed Disability Services others were less satisfactory.

To get the possibility to study, in USA, the financing might be of importance. Through SEd at Genesis Club prospect students have the possibility of applying for the Baer scholarship of

up to 1.500 US dollars. Prospect students get assistance in applying for this, as well as other grants and scholarships. From talking to staff and members we were informed that there are a variety of scholarships for higher education in USA, but they might be hard to find, so SEd can assist in finding them.

Throughout the whole process from application to the actual period of study an important thing in SEd is the campus visits. These are conducted for several different reasons. Staff and members do tours to give members of the Club inspiration or to give prospect students the possibility to have an apprehension of a certain university or college. On these tours they can make requests about application, enrolment, financing, Disability Services at school et cetera.. Another type of campus visit is the student support visit, one of the major supports during the student's entire education. A member of the staff and a member, a so called *peer partner* meet with the student at campus in, for instance, the cafeteria to check out how everything is going at the moment for the student. The peer partner can be anyone from the Clubhouse with relevant experience to the student's situation. For these visits, there is a specific sheet with questions to ask which are related to important needs for the student, such as tutoring at the school, upcoming tests and projects, but also questions about how things are going or if the student has any concerns et cetera. There are also questions about how and when the student wants to have the next contact with the unit. Being a peer partner first time, there is also another sheet with information about what the peer partner support is meant to offer. The students decide themselves whether they want to have campus visits or not, some students prefer to meet with staff and peer partners at the Clubhouse or somewhere else outside campus. During our time at Genesis Club we accompanied staff and peer partners to several campus visits. We had the opportunity to experience how reciprocal a campus visit could be between a peer partner and the student. Experiences were exchanged, as well as advices:

> *S (staff), M (member) and I drive to a campus visit at QCC (Quinsigamond Community College). It is M's first campus visit. He tells that he wants to start studying again. He is a new member and he says that he feels like he finally is "on track", for the first time of his life. This thanks to Genesis Club. He has tried several times to complete his studies, but never managed. We meet with C (college student) in the cafeteria. He takes three classes, two of which he has no worries and one, English language, were he has a professor who doesn't seem so fair, S knows about this professor. C has a lot left to do, he has a little less then two weeks before exams and he is pressed for time. S listens and encourages. One of the assignments is to purchase five "heavy" newspapers, find articles in all of them and write some kind of résumés. Just to get the papers is both expensive and difficult, you can understand. M engages in the conversation, he criticises the professor for not having been explicit about how to accomplish the assignment in the written instructions and he suggests that C can look in litterbins on the way to and from college, people use to throw their papers away. S asks if C has a plan and what kind of support he needs. He says that he gets some help from his brother and that he wants outreach and another campus visit next week. M tells C that he wants to start studying again; he has some problems because he*

interrupted his studies earlier. C gives him some practical advice and encourages him. The two guys who have never met before, both with different difficulties, instantly engages in each other's problems. M leaves to check some things up about enrolment. C tells me that he failed in his studies and dropped out last year. He got in contact with Genesis and with their support he has managed his studies since last fall. S then tells C about her "tough" study experiences. Meantime M has checked some things up, concerning enrolment, he wants to check something up with financing, but there is a long line, so S gives him the advice to call and book a time instead. M says that he has to solve the financial issues to be able to study." *(Campus visit, from author's notes)*

Outreach is one of the well-established activities at a Clubhouse. CDU contacts students as well as other members regularly, sometimes for particular reasons, but also just to check how things are going. The outreach can be a telephone call, a postcard or an email. Facebook is checked every day to see if there are any messages from members as well as to outreach people. Facebook also update staff and members of what is going on in people's everyday life and it can give a hint that somebody maybe needs support.

After the planning meeting M (member) and me sit by the computer to check Facebook (It is M's first time checking Facebook at the unit. I have heard M several times say that she wants to learn how to do everything in the unit). Facebook is checked every day to see how members (students) are doing. A few members have written short messages about how things are going and there are some friend requests. S (staff) comes to assist us and gives us instructions how to do. We answer the messages, check who is on the chat, exchange a few sentences with one or two of them and write messages to a few others after having checked their log. S seems to keep a check on most of them, he instructs us what to ask and answer. M does the writing. (Outreach, from authors notes)

About once a year all members do a *goal plan* and an *action plan*. The goal plan deals with what the member wants to accomplish and it has a target completion date. The action plan describes the member's current situation, future plans and challenges. It is made to identify specific steps, which will lead to the achievement of the member's goals. With the holistic perspective that the Clubhouse hold, the action plan deals with the member's whole situation: health, housing, vocational training and social, educational and financial circumstances. The goal plan and the action plan are up-dated regularly, at least once a year.

As soon as a member express a need for support considering education of any kind she or he can have this support from the Career Development unit. One of the daily working tasks at the unit is to take a round in the Clubhouse to talk to young members and to try to engage them considering educational possibilities as well as employment issues. This task is called Engage Young Adults (E.Y.A) on the whiteboard of daily tasks. There is also a weekly meeting involving people from all the units at Genesis, T.A.P.S: Transitional Age Peer Support, where issues considering young members' over all support is dealt with. These meetings also focus on young members circumstances considering education and need of support regarding this matter.

6.2 Interviews

The result of the interviews is grouped under themes that became visible during processing the result. The result is presented in accordance with the research questions.

6.2.1 Do the students experience stigma and view it as a barrier to education?

All the informants had experiences of barriers to education; some of them were talking about reading and learning disabilities. One of the older informants had a reading disability that was discovered quite late in life, this despite thirty-five years of attempting to study.

> *I found out actually about five years ago that I actually do have a reading disability, there is a diagnose number two but there is no nice name as dyslexia, it is a reading disability, it is comprehension and concentration and then when that's get compromised then I just get more and more upset and can't get any reading done (...)*

This disability still affected the informant to the extent that feelings of lost self-confidence were expressed.

> *I feel like I am never going to pass English, I feel like, I kept thinking in my mind that if I could be anywhere successful now I have to not be working, going to my English class have to be the only responsibility that I have… And when they come up with this failure in English, it devastates me you know, it doesn't makes me feel like going on…*

One of the younger informants had a learning disability that was discovered in early age, nevertheless this did not imply that there was an understanding of this fact throughout the entire education. In college the informant had to self-advocate to receive help.

> *I've definitely experienced barriers to education, in first grade I, like when I first started going to school I was like age 6 and I was told that I had a language based learning disability which basically makes everything in school, especially mathematics and English difficult for me, that I have trouble writing and spelling things and… it just, I had to be in special ed. classes since first grade and then I go after college and suddenly colleges don't necessarily have to honour that, that you're special little ILP (Individual Learning Plan, authors comment.(...) You don't get to have that (...) you have to self-advocate. And I did all right with that but the college that I picked did not understand mental illness.*

Symptoms of mental illness was something all informants had experienced as barriers to education, the symptoms could be physical and they could often affect the informants to that extent that they had to interrupt their studies.

> *When I was going to Quinsigamond my agoraphobia, my anxiety, when I first went there I had to sit near the door, I was not comfortable, it's not like that now, but one of the teachers, you go there the first day and you get a feeling how the teacher is, the professor. And he wanted to seat us*

alphabetically, so, that gave me a big clue, some of the people said that he is really peaky and I said OK I'm dropping this class, so…

Oh yes oh yes. The barriers to my education are very intrinsically connected with my mental illness (…) in the past I had taken other courses that I never finished, it was basically… one of the biggest barriers was simply losing interest, I actually had four attempts before this class, four attempts at a college credit…

There were also experiences of difficulties in understanding mental illness in schools and sufficient support was not available.

Unfortunately many colleges and universities around here don't seem to understand mental illness. I was shipped back and forth between school, the hospital didn't want to take me so they dumped me back at school, the school didn't want me so they sent me back to the hospital. And I bounced back and forth, pretty much failed on my classes, only made it through a year and then a few months of college before I seriously attempted suicide and I told the school counsellor before I did it, that I need help, I have a plan to kill myself. He turned me away and said- oh just call your therapist and I did and thank god my therapist picked up the phone… So college had, was a nightmare for me, that even now going to Quinsigamond is a challenge, because I was greatly traumatized by that.

Sometimes help had been available at Disability Services at school.

(…) in my earlier attempts I actually had an agreement with Disabilities Services that my accommodation would include the ability to stand up and walk around in the back of the class if needed because it helped to keep me awake. (…) And I knew it wasn't because I wasn't interested because they were saying interesting things and I wanted to learn but it was something meditational related or illness related I don't know which. Luckily I have changed the medication and I don't have that problem any more.

We asked the informants if they had experiences of being stigmatized or whether anticipated stigmatization had affected their educational circumstances. They were also asked what the concept of stigma meant to them. One of the informants defined stigma as follows.

The concept of stigma means to me people making generalizations and discriminations against people who have mental illnesses. I feel that such stigma is inappropriate and people should be treated on an individual basis according to their personal needs.

Stigma and stigmatization are not unfamiliar concepts for the informants. To reduce stigmatization is a major aim in a Clubhouse. When it comes to perceiving and experiencing stigma we found different results. Some of our informants had experienced being stigmatized during their education.

Definitely when I was going to the four year university and living there, at the college were I was being harmed at, there was definitely a huge stigma that I walked around with, a huge label that I was the crazy person, I was the campus freak to the point that people started finding out about it and some of my peers decided to take pictures of me being taken out by ambulance and posed – haha look at the freak all over Facebook. So yeah I've been stigmatized but I've found now that

I'm getting better that I'm able to not wear that label cause to me the stigma is to wearing a label on your forehead that you're defined by your illness. And also a lot of it was me learning not to define myself as my illness. That I'm an individual who has this. Not, anxiety and depression is me, that I am anxiety and depression, no I'm not.

In relation to who the informants had felt stigmatized by varied, sometimes they had perceived stigmatization in contact with professors having attitudes because they had to do more and showing no empathy. Sometimes the informants had perceived being stigmatized by peers; they had felt being seen as different and looked down upon and sometimes they had been harassed.

What I went through in school, in elementary school, I well, we called it being made fun of then, but it was bullied, I was kept back in classes and kids can be really cruel… so I held that in for so many years, not to show them that they're affecting you and it still affects me to this day were I feel left out of something, that I'm being rejected… It's a tender spot with me.

And the look I got from that student- like how in the world could you go to College and you can't read. It's not that I can't read; it's that I can't read well enough.

Three of the informants talked about self-imposed stigma and not having felt comfortable disclosing their mental health problems.

So, myself then I did not feel comfortable in the school scene, I wouldn't even say mental illness back then. I kind of stigmatized myself.

I was not comfortable telling any of the teachers what was going on with me…

I wouldn't really blame it on the stigma unless it is self-imposed and I that I would because I am giving myself the bad message - you are stupid, you can't do this dadada, so its my own you know, my own self generated stigma…

Three of the informants did not have experiences of being stigmatized; two of them were explaining this due to not having used accommodations at school, instead having had support from the Clubhouse, where "there is no stigma".

(...) the singular place where I get help from really for the most part like I said I don't go to the disability office much and I don't have any accommodations, the singular place where I get help if it ever were possible for me to feel stigmatization is a place where there is no stigma in that senses. It is a place where I can go in and say that really, potentially say that I am very frustrated at my work now and I am falling behind and that there are a lot of stuff going on right now and they would be able to work it out with me having full knowledge that I have mental illness but using no stigma so Genesis really cut that whole out you know it really wipes that out. The place where I get the most support is also the place where there is no stigma. And I think that is a major goal of the Supported Education at Genesis to be that place that where people can come in and get help and any kind of fear retribution or looking down upon.

6.2.2 Can the SEd program in a consumer-operated organization help students in reducing experiences of stigma and other barriers to education?

The informants brought up different types of support that the Genesis Club supplies to participants in the SEd program. Support like reaching out to the participants, checking that they do not fall behind, reminding them of important dates, funding issues, applying for scholarships, helping with connections and making sure they get the resources they need at campus. The two different supports that all informants mentioned in one way or another was encouragement and the knowledge of that they always are there when they need them. That if the informants have a question they have someone to ask that they trust. One informant stated that the SEd program at Genesis Club is what really makes the difference when it comes to personal support and opportunities to discuss problems that can occur in school. That you do not go to school and bring difficulties up, so having an outside support is really helpful.

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> *(...) I think of my level of use it is just knowing that there is somebody I could talk to even if I actually never really called them, just knowing that they are here that at least is getting me to the door of the school and trying again(...)*

One informant talked about how getting *Transitional Employment* through Genesis Club helped the informant to prepare for picking up education again.

> *(...) since that Transitional Employment which has connected to my education very actively I learned what it was like to just get up in the morning and you know get cleaned up, get ready to go and get on that bus and just do it. It was one of those moments of just do it.*

One informant also talked about how going to the Clubhouse before class was being a help in preparing for a day in school.

> *I like to spend some time in the Club just grounding myself every day and being with people that I know are supporting and then I go to class.*

One informant differed from the other informants due to that the support the informant had received at Genesis Club had not been sufficient.

> *Supported Education didn't work for me and it is not any bad comment to the Clubhouse or to the unit or Mass Rehab, it is just a lot of the things just didn't fly out right.*

One informant talked about the Genesis Club in comparison with other types of mental health rehabilitation counselling that exists in Massachusetts and stated the way of work at Genesis as being non-stigmatizing and a “unique thing”. They do not view you as you are “lacking in something” instead they focus on what you have to offer, what you can do and what opportunities there are, they support in a positive way. Another informant elaborated with the fact that diagnoses are not discussed at the Clubhouse, if not the members bring it up.

> *(...) one other thing is that staff, they don’t know peoples’ diagnoses unless they want to share that with them, so they work with them as people, not as somebody with diagnosis... And that is just all of them, and people have more dimensions to themselves than just what that label is.*

All informants brought up the importance of the social interaction at Genesis Club and the importance of having people that recognizes, understands and supports you and whom you in turn can recognize, understand and support. One of the informants brought up that having other Clubhouse members acting as role models is important.

> *X was actually in school before I started going back and she struggled a lot and she had a lot of accommodations but she was kind of an inspiration for me, she still is because we... Because she was going to school so I thought if X can do it I can do it, you know, so X was a big inspiration and she really made it…*

One informant mentioned that the Genesis Club makes presentations where they tell other people their stories in a way of giving support and information to the community. The fact that the informants often had a history at the Clubhouse and already had relations with the members and staff there facilitates the support.

> *(…) the part that I do like is that coming here and talking to people here, they already understand me, they already understand the nature of my mental illness, that they know how to work with me better than…where a, like the school, they know how to work with my learning disability and my difficulties in math and English and help me with some stress and stuff. But actual like, any sort of ideation or serious mental illness stuff that’s coming up Genesis can deal with that better than, they kind of know where my breaking point is, I definitely know that if I came to them and they didn’t feel I was safe, they would know where, that’s something I’ve run into with school and just in general life a lot of times people get a bit worried because they don’t understand and they think and if they’re some sort of professional, a nurse or something, as soon as I say -I have thoughts of harming myself, they are obligated and feel that they are obligated to send me straight to the hospital.*

All the informants talked about how they received different types of support from different individuals. That it exists a difference between receiving support from a staff and a member but not that one being more valuable than the other. For the informants studies meant all from

being something that could lead to a vocation, helping to build confidence and added self value, a hobby, a place in society and an interest. Two informants stated that SEd is one of the most important programs the Clubhouse has to offer. That if you actually can have an education you can get a better type of employment and not feel like you are grovelling and staying in poverty, "education is always the rainbow at the end of the tunnel".

> *The employment was the key factor in "Career and Development" and in the Clubhouse and of course it was kind of a no brainer when people realized that we had to, that we have to integrate education here because people want to get better careers, not TEs (Transitional Employment, authors comment) forever. They want to get better careers and the best way to do that is to get education as well. So Supported Education is very important for the Clubhouse community and it raises people up and beyond that level of just doing what needs to get done and it helps people to achieve their dreams more than if it wasn't there.*
>
> *I think that every Clubhouse member should really use it. I think it is the best advantage we really have, a Clubhouse can get you a job, a really good job, but you know if you actually can have the education you can further on. Hopefully the type of stress the type of lifestyle that you have will thrive with the better type of jobs and not have to, you know, feel like you are grovelling and staying in poverty and continue with that downwards spiral, education is always the rainbow at the end of the tunnel.*

7. Analysis

The analysis is presented under the same headlines as the result.

7.1 Do the students experience stigma and view it as a barrier to education?

Earlier research has defined mental health problems' interfering with studies in categories such as "decreased emotional and behavioural skills", "declining academic performance" and "decreased self-efficacy" (Megivern et al, 2003:221-222). Experiences of stigma and discrimination were also discovered (ibid: 222). All the informants had experienced barriers to education. Some of them talked about how their mental health symptoms had affected their behaviours; they described how they had struggled with anxiety and agoraphobia and therefore had needed to sit by the door. Another informant had needed to walk back and forth at the back of the classroom. All but one of the informants had previously interrupted their education or changed classes for reasons connected with mental illness. One of the informants expressed having lost confidence in being able to succeed in English language studies, indicating low self-efficacy.

In universities and colleges in USA students with disabilities have a right to receive support from the Disability Services at campus, extra tutoring as well as other accommodations. Previous research has shown that students are reluctant to inform about their struggle with their psychiatric symptoms and unwilling to receive help at campus (Mowbray et al, 2005:9) (Megivern et al, 2003:223). One of the three coping strategies in modified labelling theory is

concealing information about ones psychiatric past. According to the informants some of them had not wanted to expose their difficulties and therefore had not received any help from the Disability Services at campus. There are themes in their narratives of not having been comfortable disclosing information about their mental illness in fear of being seen as different. Earlier research has showed that disclosure reduce negative effects of self-stigmatization (Corrigan, 2012:465). As mentioned above, a survey has shown that stigma was the number one barrier for students seeking help (Nami 2012:4). According to labelling theory people who are treated as deviant become deviant (Scheff, 1999:86). Deviance is a normative violation and might lead to stigma, segregation and labelling (ibid.,1999:45). Self-imposed stigma is mentioned in the informants' narratives. Three of the informants described how they had felt stigmatized from being treated as deviant in school, by professors as well as by peers. One of the informants talked about having had the feeling of wearing a label saying "the crazy person". The informant had internalized the stereotype of the diagnosis, but later on learned how to get rid of that stereotype:

> *(...) I've been stigmatized but I've found now that I'm getting better that I'm able to not wear that label cause to me the stigma is to wearing a label on your forehead that you're defined by your illness. And also a lot of it was me learning not to define myself as my illness. That I'm an individual who has this. Not, anxiety and depression is me, that I am anxiety and depression, no I'm not.*

In modified labelling theory it is described that experiences of rejection and discrimination are not necessary for a self-fulfilling prophecy to occur, being diagnosed with mental illness is enough to be aware of negative stereotypes of people with mental illness (Thoits 2010:122). Unger argues that it is essential that a person with a diagnosis of mental illness does not "become" that diagnosis. "Each person is more than his or her diagnosis" (Unger, 2007:29). Self-stigma consists of awareness of, agreement and applying the stereotype to oneself (Corrigan et al 2009:75). The effect of this process leads to diminished self-esteem and self-efficacy. This might lead to difficulties for people in achieving life goals (ibid.) (Corrigan et al 2011:2) (Unger (2007:41). The why-try effect is a consequence of self-stigmatization (Corrigan 2012:465). The why-try effect might explain the resignation described by the informant who talked about struggling with English language studies, having the apprehension that it was impossible to succeed.

Some of the informants spoke about not having received support until having failed in completing their studies several times. Even when mental illness was disclosed adequate help was not always available. One of the informants talked about how colleges and universities do

not seem to understand mental illness. The informant had been sent back and forth between hospital and campus and had not received support from a school counsellor. This informant also talked about having had to self-advocate to receive adequate accommodations when entering college, this despite the fact of having had support in earlier education. Another informant had not been diagnosed having a reading disability until very late in higher education despite having failed and interrupted the studies several times before.

The awareness of other people's stereotypes is present in all the informants' narratives. How they have experienced and dealt with this varies. Three of the informants had been affected negatively from experiences of stigmatization with consequences for their education situation. Three informants had not experienced being stigmatized, two of them referred to not having been seen as different in the school scene. One reason for this was explained with the fact that they had used no or few accommodations. These informants had also suffered from disabilities due to mental illness and they were in the SEd program at Genesis Club. This might be an indication that there are student needs that cannot wholly be met at campus and that the input from other organisations serves an important additional function.

7.2 Can the SEd program in a consumer-operated organization help students in reducing experiences of stigma and other barriers to education?

Stigmatization exists on several levels and has direct consequences for individuals in their life experience. Stigma is a social construction and thereby the responsibility of the society (Corrigan, 2012:466). It is society's responsibility to develop and implement strategies to reduce consequences of stigmatization. Changes in society's attitudes to mental illness can make it easier for consumers in seeking support. Which in turn can come to promote recovery and secondarily also reduce social stigmatization (Goldman, 2010:1289-1290*)*. Research has shown that one of the elements to reduce stigma concerns direct social contact with people with mental illness (Thornicroft et al, 2008:2). One way to do this would be to support consumers in their pursuit for education and at the same time enable their integration into society.

Assisting consumers to reach their life goals and putting them in charge of their support and treatment is essential for the recovery process (Sundström & Topor, 2008). The results show that the career development unit gives each consumer individualized support. Consumers taking part in the SEd program at Genesis Club write an action plan and a goal plan approximately each year where they state what they want to accomplish and describes their

current situation, future plans and challenges. In their plans they articulate what kind of support and accommodations they need to fulfil their academic goals. Research has proved individualized support to be of importance in the recovery process (Unger, 2007:29, Perris, 1996:129). The type of support emphasized by all the informants was encouragement and the knowledge that they had somewhere/someone to turn to in case of need. Both in recovery, PSR and SEd literature the relationship between the consumer and the rehabilitation counsellor and peers are central elements (Unger, 2007:13):

> *(...) but the part that I do like is that coming here and talking to people here, they already understand me, they already understand the nature of my mental illness, that they know how to work with me better than…where a, like the school, they know how to work with my learning disability and my difficulties in Math and English and help me with some stress and stuff. But actually like, any sort of ideation or serious mental illness stuff that's coming up Genesis can deal with that better than, they kind of know where my breaking point is…*

If empowerment is the opposite of self-stigmatization the work they do in the SEd program at Genesis Club should be a way to reduce consumers' experiences of self-stigma (Corrigan 2012:468). Their ambition is to encourage, enable consumers to develop self-advocacy skills, show consumers how they can find information at the campus and what kind of accommodations that are available. And it is the consumer's responsibility to take the initiatives and to accomplish their academic goals. As one informant put it Genesis Club "have a big door in but an even bigger door out". The members are members for life and are always welcome, but the ambition is that the members will be active citizens in the community where they live. Several informants stated that they do not experience any stigmatization at Genesis Club or in the way they work at the Genesis Club. As mentioned above empowerment is an appropriate tool for change, when it focuses on "what might be done", instead of "what should not be done" or maybe "what cannot be done" (Corrigan et al, 2009:78). At the Genesis Club they work with individuals and not diagnoses and everyone is expected to contribute according to their own capacity. Individuals represents more than their label (Unger, 2007:29, Perris, 1996:129). According to labelling theory diagnoses and labels are socially created and can have negative consequences for individuals (Scheff, 1999:86-87). Both earlier studies and the result from this study show that consumers are concerned about being defined as their mental illness, defined as "crazy" and that people's behaviour around them will change (Jargo, 2002:746). This gets completely "cut out" at Genesis Club through the way they work, as one informant expressed it.

Genesis Club is a place where a lot of social interaction takes place. Several informants brought this up as being positive. One of the three coping strategies for self-stigmatization mentioned above is isolation i.e. avoiding contact with other people. Genesis Club can be a first step in integrating with the community, a place to be recognized and appreciated, a place where stigma does not exist. One informant also explained how another participant in the SEd program at Genesis Club had been a role model and an inspiration for the informant to take the first step in returning to higher studies. The participant's accomplishments brought hope; if the participant could so could the informant. This is something Sundström and Topor (2008) describe as being an important part in many consumers recovery process.

Attempting to inform others about mental illness to combat stereotypes is one of the three coping strategy in modified labelling theory. One of the informants is doing presentations about Genesis Club and is telling people his story. Disclosure has been shown to decrease the effects of self-stigmatization (Corrigan 2012: 465).

The result shows that being a student implies several different things for the informants, for example it means; added self-value, practical achievement towards a future vocation, interests and taking an active part in society. As mentioned above the SEd programs eighth principle states that the recovery process is facilitated by meaningful roles. A role of a student is a meaningful role in the society. Another interpretation of the effect the SEd program give the consumer was raised by two informants. They both argued that education can lead to better jobs and that better jobs in their turn can lead to better lifestyles and end the experience of being economically marginalized.

> *I think that every Clubhouse member should really use it. I think it is the best advantage we really have, a Clubhouse can get you a job, a really good job, but you know if you actually can have the education you can further on. Hopefully the type of stress the type of lifestyle that you have will thrive with the better type of jobs and not have to, you know, feel like you are grovelling and staying in poverty and continue with that downwards spiral, education is always the rainbow at the end of the tunnel.*

As mentioned above research regarding human capital and mental illness have showed that both educational level and work history are positive predictors of wages for individuals living with mental illness (Gao et al, 2011:123).

The majority of the informants had received information about the existence of Genesis Club through a counsellor or through a hospital contact. Which shows the importance that the professional groups serving people with mental illness have knowledge about what services the mental health system has to offer. As stated before one of the professional groups serving

people with mental illness are social workers. The demands for social workers knowledge's in this field are likely to increase (Mowbray et al, 2005:16).

8. Conclusions

The results show that the informants have experiences of stigmatization as a barrier to education. The SEd program at Genesis Club assists the participants in overcoming barriers. Peer support, role models, empowerment, not using labels, focusing on what you can contribute are all examples of factors that are present in the informants' narratives about the SEd program at Genesis Club. Earlier research has shown that these are factors that can counteract self-stigmatization.

9. Discussion

Article 26, CRPD, clearly states that all the member countries of the United Nation should strive to strengthen, organize, and extend comprehensive rehabilitation services and programs with the goal to enable persons with disabilities to attain social and vocational ability and full social inclusion and participation in all aspects of life. Education should be equally accessible to all and to achieve this, stigmatization in connection with mental illness needs to be addressed. Experiences of stigma cause, as we have learned from the results; hurt, anger, discouragement and damage to self-esteem. These experiences have led consumers to conceal their psychiatric histories from others. Stigma experiences produce conditions adverse to the goals of recovery. Social work in rehabilitation contexts can reduce discriminatory stereotypes, by establishing that consumers with support can attain recovery goals and become active citizens (Mowbray et al 2005:16).

Topor discusses in his book "Vad hjälper?" (2008:31) a substantial study made by WHO that showed that severe mental illness occur in all cultures and that the probability to recover when you had received a schizophrenic diagnosis was higher in developing countries (59%) than in industrialized countries (39%). Topor explores four possible reasons from which two were that the market for employment functions differently. Assuming that it is still easier to find chores for an individual, who cannot participate fully in working life, in developing countries than it is in the industrialized world; in the developing countries you can for example find chores in the agricultural sector. Individuals with mental illness in developing countries do not end up being marginalized from both the social and the working community to the same extent as in the industrialized world. Cultural conceptions about the origins of mental

illness and the way to recovery also differ; where in the industrialized countries the focus lies on the individual and confusion exists about how the society is supposed to "fix" the illness; in developing countries a more spiritualized model of explanation of illness is common and the situation is generally experienced as being more hopeful. Both these models of explanation point to the important role of society in these matters. Stigmatization is caused by the society and therefore it should be the societies' responsibility to eliminate the harmful stereotypes, which exist about people with mental illness. The society should confront stigma and self-stigmatization.

Policy makers need to offer financial funding for rehabilitation programs that addresses stigma. We noticed that to be able to run a SEd program successively the collaboration between college and universities, policy makers and social workers are of significance. They need to be capable of complementing each other and of having good communication. Social workers can cooperate with consumer groups and introduce SEd services. Educational achievements are often the goal for numerous consumers today (Mowbray et al, 2005:9). Education, as we have learned, can hold great significance to consumers for example: as a part in the recovery process, offering a meaningful role in the society and as a steppingstone to a better lifestyle. It is, as one of the informants put it, a "no brainer" to understand that education needs to be integrated in rehabilitation programs because consumers want to get better careers, and to get better careers the best way is to get education.

As mentioned earlier (SCB, 2009) the level of education is generally lower for people with disabilities than for the population at large in Sweden and mental illness is on the increase, above all among youth. This knowledge should be enough to stress the importance of developed educational programs for people with disabilities. Supported education is today in its initial stage in Sweden and learning from the experiences of developed methods such as the Clubhouse model of the SEd program is supposedly a way of addressing this increasing problem in Sweden today.

From our results we found that although universities and colleges in USA today are obliged to offer accommodations to students with disabilities and the fact that all our informants were or had been in need of support, all of them did not choose to use the accommodations at campus. As we speculate, the explanation for this possibly is linked to the knowledge of public stereotypes in the society. Earlier research (Megivern et al, 2003:220-223) (NAMI, 2012:4) also showed that students avoid seeking help at campus. Our study took place in a peer partnership organization. Is civil society the answer for the need of support

for the students or will fighting the stereotypes in society eventually make stereotypes and stigma disappear and with that facilitate help seeking at campus and in the community? The answer is naturally not simply formulated as either or and the question is obviously a lot more complicated.

We agree with the report (FOU Södertörn, 2013) that stated that we could gain from an increased knowledge of mental disorders in educational environments. One possible solution is to expand the usage of SEd and expand the cooperation between the mental health service, social service and public school service. We also believe that civil society will remain an important complement to these services. To explore these cooperative possibilities is something we hope to be able to see in future research.

One thing worth mentioning is also a reflection that we have been discussing during our research. Could the fact that you are in need of support from an organization that assists people with a diagnosis of mental illness itself be stigmatizing to some people? The fact that you have to find people with similar experiences to receive an understanding for the difficulties you might have as somebody with a mental health problem? To be “one of us”, can it also be a fact confirming that you as a citizen are “one of them”? We did not find anything indicating this during our time at Genesis Club, but this possible dilemma is something we think could be of interest for future research.

10. References

Bryman, Alan (2002). *Samhällsvetenskapliga metoder* (1 uppl.) Malmö: Liber ekonomi

Coolican, Hugh (2009). *Research methods and statistics in psychology* (5th ed.) London: Hodder Education

Corrigan, Patrick W., Deepa Rao. (2012). On the Self-Stigma of Mental Illness: Stages, Disclosure, and Strategies for Change. *Canadian Journal of Psychiatry*, 57, (8), 464-469.

Corrigan, Patrick.W, Rafacz, Jennifer & Rüsch, Nicolas. (2011). Examining a Progressive Model of Self-Stigma and its Impact on People with Serious Mental Illness*. Psychiatry Research.* 189(3), 339–343.

Corrigan, Patrick.W., Larsson, Jonathon E., Rush, Nicolas. (2009) Self-stigma and the "why try" effect: impact on life goals and evidence-based practices. *World Psychiatry.* 8, 75-81.

Building human capital to increase earning power among people living with mental illnesses.

Holmlid, Ann (2002). *För en öppen högskola: om förutsättningar för studenter med psykiska och neoropsykiatriska funktionsnedsättningar*. Stockholm: Studentbyrån, Univ.

Kvale, Steinar & Brinkmann, Svend (2009). *InterViews: learning the craft of qualitative research interviewing.* (2. ed.) Los Angeles: Sage Publications

Gao, N.,Smith, L., Gill, K. & Pratt, C. (2011). Building Human Capital to Increase Earning Power among people Living with Mental Illness. Psychiatric Rahabilitation Journal, 35, (2), 117-124.

Goldman, Howard H. (2010) Progress in the Elimination of the Stigma of Mental Illness, *American Journal of Psychiatry.* 167, (11), 1289-1290.

Jago, Barbara J. (2002). Chronicling An Academic Depression*. Journal of Contemporary Ethnography*, 31, 729-757.

Link, Bruce G., Phelan, Jo C. (2001) Conceptualizing Stigma. *Annual Review of Sociology,* 27, (1), 363-385.

Link, Bruce G., Phelan. Jo C. (1999). Labeling and Stigma. Horwitz, Allan V. & Scheid, Teresa L. (Ed.). *A handbook for the study of mental health: social contexts, theories, and systems* (pp. 571-587). New York: Cambridge University Press

Major, Brenda; O'Brien, Laurie T. The Social Psychology Of Stigma (2005) *Annual Review of Psychology.* 56, (1), 393-421.

Megivern, Deborah., Pellerito, Sue., Mowbray, Carol. (2003). Barriers to higher education for individuals with psychiatric disabbilities. Psychiatric Rehabilitation Journal, 26, (3), 217-231.

Mowbray, Carol T., Collins, Mary E., Bellamy, Chyrell D., Megivern, Deborah A., Bybee, Debora, & Szilvagyi, Steve. (2005) Supported Education for Adults with Psychiatric Disabilities: An Innovation for Social Work and Psychosocial Rehabilitation Practise. *Social Work*, 50, (1), 7-20.

Neuman, William Lawrence (2011). *Social research methods: qualitative and quantitative approaches* (7. ed.) Boston, Massachusetts: Allyn and Bacon

Newman, Denise L., Moffitt, Terrie E., Caspi, Avshalom, Magdol, Lynn, Silva, Phil A., Stanton, Warren R. Psychiatric disorder in a birth cohort of young adults: Prevalence, comorbidity, clinical significance, and new case incidence from ages 11–21. (1996) *Journal of Consulting and Clinical Psychology,* 64, (3), 552-562.

Perris, Carlos (1996). *Ett band för livet: Bowlbys anknytningsteori och psykoterapi.* Falköping: Natur & Kultur

Pinfold, Vanessa, Thornicroft, Graham, Huxley, Peter & Farmer, Paul. (2005). Active ingredients in anti-stigma programmes in mental health. *International Review of Psychiatry*, 17, (2), 123-131.
Pinfold, V., Huxley, P., Thornicroft, G., Farmer, P., Toulmin, H., & Graham, T. (2003). Reducing psychiatric stigma and discrimination: Evaluating an educational intervention with the police force in England. *Social Psychiatry And Psychiatric Epidemiology*, *38*(6), 337-344.
Rogers, Carl R. (1951). *Client-centered therapy: its current practice, implications, and theory.* Boston: Houghton Mifflin.
Rotter, Julian B. (1954). *Social Learning and Clinical Psychology*. New York: Prentice-Hall
Substance Abuse and Mental Health Services Administration (SAMSA). (2011). *Supported Education: The Evidence.* Rockville: Department of Health and Human Services.
Scheff, Thomas J. (1999). *Being mentally ill: a sociological theory.* (3. ed.). New York: Aldine de Gruyter
Sohlberg, Peter & Sohlberg, Britt-Marie (2009). *Kunskapens former: vetenskapsteori och forskningsmetod.* (2.uppl.). Malmö: Liber.
Thoits, Peggy A. (2010). Sociological Approaches to Mental Illness. Horwitz, Allan V. & Scheid, Teresa L. (Ed.). *A handbook for the study of mental health: social contexts, theories, and systems. (electronic resource).* (pp. 106-124). New York: Cambridge University Press.
Thornicroft, Graham., Brohan, Elaine., Kassam, Aliya. & Lewis-Holmes, Elanor. (2008). Reducing stigma and discrimination: Candidate interventions Published *International Journal of Mental Health Systems* 2, (3).
Topor, Alain. 2010. Vad hjälper? Vägar till återhämtning från svåra psykiska problem. (e-book). Stockholm: Natur & Kultur
Topor, Alain & Sundström, Klas. (2007). *Återhämtning - en introduktion. Återhämtning. Vad är det? Hur är den möjlig?* Stockholm: Psykiatri Södra Stockholm, SLSO, FoU-enheten
Unger, Karen (2007), *Handbook on Supported Education Providing services for Students with Psychiatric Disabilities.* Baltimore: Paul H. Brooks Publishing Co.
Wahl, Otto K. (1999). Mental Health Consumers' Experience of Stigma. *Schizophrenia Bulletin,* 25(3):467-478

Internet resources:

Fountain House. (2013). *Mission Statement.* Retreived May 26, 2013 from: http://www.fountainhouse.org/content/mission
Genesis Club. (2013). *Our Mission.* Available at: http://www.genesisclub.org/GENESIS_TRI_FOLD_BROCHURE_HANDBOOK_2012.2.pdf
Genesis Club. (2013). *Career Development*. Retrieved May 12, 2013 from: http://www.genesisclub.org/career_development.html
Gruttadaro, Darcy & Crudo, Dana. (2012). *College students speak: A survey Report on Mental Health*. Arlington: NAMI, the National Alliance on Mental Illness. Retrieved April20, 2013 from: http://www.nami.org/Content/NavigationMenu/Find_Support/NAMI_on_Campus1/collegereport.pdf
International Center for Clubhouse Development (ICCD), (2012). *International Standards for Clubhouse Programs.* Retrieved May 12, 2013 from: http://www.iccd.org/quality.html

International Center for Clubhouse Development (ICCD), (2012). *2012 Annual report.* Available at: http://www.iccd.org/annual-report.html

Officer, Alana, Posarac, Aleksandra (2011). *World report on disability 2011*. World Health Organization. Available at: http://whqlibdoc.who.int/hq/2011/WHO_NMH_VIP_11.01_eng.pdf

SAMSA. (2013). *SAMHSA's Working Definition of Recovery from Mental Disorders and/or Substance Use Disorders.* Retrieved May 10, 2013 from: http://blog.samhsa.gov/2012/03/23/defintion-of-recovery-updated/

SCB (2009). *Funktionsnedsattas situation på arbetsmarknaden: 4:e kvartalet 2008.* (2009). Stockholm: Statistiska centralbyrån. Available at: http://www.scb.se/statistik/_publikationer/AM0503_2008K04_BR_AM78BR0903.pdf

Socialstyrelsen. (2001). *Gränsöverskridande rehabilitering - Hur gick det sedan?- En uppföljning av 111 verksamheter för personer med psykiska funktionshinder.* Available at: http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/11303/2001-103-6_20011037.pdf

Socialstyrelsen. (2012). Folkhälsan i Sverige. Årsrapport 2012. Stockholm: Socialstyrelsen. Available at: http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/18623/2012-3-6.pdf

United Nations (2013). *Article 26 - Habilitation and rehabilitation.* Retrieved May 5, 2013 from: *http://www.un.org/disabilities/default.asp?id=286*

Unger, Karen. (2013). *Supported Education with Dr Karen Unger.* Retrieved May 5, 2013 from: http://www.supportededucation.com/elements.html

11. Appendix

11.1 Appendix 1: Consent form

Informed Consent

We are students in Social work at Ersta Sköndal University College in Stockholm, Sweden. We are studying The Supported Education Program at Genesis Club in order to write our bachelor thesis.

Our aim with the study is to discuss possible barriers for education related to mental illness and different ways to overcome them in a peer-partnership organization. The method is participant observation and interviews with members of the Clubhouse.

Participation is voluntary and it is free to withdraw at any time. Participants are anonymous which means that actual names will not be revealed. The thesis will be shared with students and teachers at the University and published on the web site of the University and is therefore open for the public.

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11.2 Appendix 2: Interview guide

1.

- How and when did you first come in contact with Genesis Club?
- How did you first come in contact with the Supported Education Program at Genesis Club?
- How often are you in contact with the Career and Development Unit?
- Are you studying right now? *What are you studying?*

2.

- Have you experienced barriers to education? *–If yes, what kind of barriers?*
- *Does the Supported Education Program help you to overcome barriers?*
- Have you due to mental illness felt stigmatized during your studies? *What does the concept of "stigma" mean to you?*
- Have you abstained from enrolling or interrupted your studies because of anticipated stigmatization?
- *Have stigmatization affected your educational circumstances in any other way?*
- Have you avoided seeking help due to anticipated stigmatization?

3.

- How do you experience receiving support from other members?
- How do you experience giving support?
- How do you experience receiving support from staff?
- Do you think that members and staff have equal influence in the planning and implementation of work at the Clubhouse?

4.

- Have you received support from Genesis Club's Supported Education Program that you don't think you could receive elsewhere? *If yes what kind of support?*
- What do studies contribute to your welleing?
- Do you have any other comments about Supported Education?