# Community participation of citizen with mental/intellectual disabilities

A case study in the context of Tornhøjgård.

## Kabita Thapa Nordic Master of Social Work and Welfare

Supervisor: Pia Ringø | Ph.d. Assistant professor

Word Count: 18928

May 29, 2020 University of Aalborg Aalborg, Denmark ACKNOWLEDGEMENT

My deepest gratitude and appreciation towards the following people who guided and supported

me to complete this thesis project in a different way and without whom this research paper would

not have been what it is.

Pia Ringø, Associate Professor and my Supervisor, for her guidance, support, and considerable

time she has given to improve this study.

My Noswel Friends and Professors, for sharing their knowledge and motivating me to complete

this part of my education.

Sascha, for his continuous encouragement and assistance throughout this thesis period.

**Thomas Haugaard** (from the municipality of Aalborg) for helping me find the place of study and

to all the participants from Tornhøjgård who spent their time answering me and especially Dan

**Skov**, for facilitating the data collection process.

And To my Family. You all inspire me immensely.

Thank You!

1

### CONTENTS

ABSTRACT	4
CHAPTER 1: Introductions	5
1.1. Background to the research	5
1.2. The context of Botilbuddet Tornhøjgård	7
1.3. Statement of the problem	8
1.4. Significance of the study	8
1.4.1. Study aim and objectives	9
1.4.2. Research question	9
1.5. Definition of terms	10
CHAPTER 2: Literature Review	11
2.1. Development of the concept	11
2.2. Inclusion/ participation of mentally disabled citizens at various levels	12
Macro Level: World policies development and Research	12
Mezzo level: Nationwide development of Public system	13
Micro: local level institution within Municipal context	14
2.3. Social policies supporting community participation at the local level	15
2.4. Community participation	16
2.5. Deinstitutionalization	17
2.6. Role of the social worker in community participation	19
CHAPTER 3: Methodology	20
Overview of the chapter	20
3.1. Research Design	20
3.1.2. Orientation: Abductive Reasoning	22
3.1.3. Case Study Approach	22
3.2. Research Method and data collection.	24
3.2.1. Sampling and recruitment	24
3.2.2. Data Collection	25
3.2.3. Positioning	26
3.3. Data Analysis	27
3.3.1. Thematic Analysis	
3.4. Ethical consideration	28
CHAPTER 4: Analysis	30

4.1. The Living facility, its practice, and work approach:	30
4.1.1. The Living facility and practice	30
4.1.2. Work approach	32
4.2. Social worker's role and Challenges	33
4.3. The aspects of community participation	38
4.3.1. Labor market integration	39
4.3.2. Education	42
4.3.3. Social networking and relationship	43
4.3.4. Physical and leisure activity	45
4.4. The concept of community in Denmark	48
CHAPTER 5: Conclusion	50
5.1. Summary	50
5.2. Reflection on my experience	50
5.3. Strengths, limitations, and further recommendations	52
REFERENCES	54
ANNEX	60

#### **ABSTRACT**

The study was undertaken at Tornhøjgård, a local-level social facility working to meet the various needs of citizens with mental and intellectual disabilities. Some of these various needs that relate to the topic of study include support, accessibility, and availability of resources, social mobility, self-determination, development of skills to lead an independent life, etc. The study aimed at identifying the existing practice of community participation in the facility operating at a very local level; the understanding of which also came with a discussion on the meaning and importance this practice has given to the citizens and practitioners, as well as the role of the facility in achieving the broader objective of inclusion. The data were collected using the method of interview and observation from which the themes of 1. The living facility, its practice, and work approach 2. Social worker's role and challenges, 3. An aspect of community participation with the sub-theme of labor-market integration, education, social network and relation, and leisure and physical activities and 4. The concept of community in Denmark emerged. The findings within these themes are assessed alongside related policies and actions advanced by the Danish Government to facilitate the active inclusion of citizens in all social life. Then, previous research and literature under similar topics were examined to generate the discussion on the factor challenging and/or supporting the goal of participation.

**Keywords:** Community Participation, Inclusion, and Active inclusion Policies, Mental and intellectual disability, Roles, and challenges.

#### **CHAPTER 1: Introductions**

#### 1.1.Background to the research

Community participation is vital to one's well-being as it aids to foster a sense of belonging, enhance social networking, and support and create more opportunities for physical activity. Most of these are absent from the lives of people with mental and intellectual disabilities as they are less involved in community life, which further raises a concern regarding their physical and mental health (Carroll et al., 2018). But before this study further talks about the community participation of the people with mental and intellectual disabilities, it will define the two concepts within, i.e. 'Community' and 'participation.' To define it simply, the paper sees 'community' as a social, physical, and emotional connection of being together (Mannarini and Fedi, 2009) and the term 'participation' mean that citizens are involved in the decision-making process in factors that affect their lives, along with their ideas being valued and responsibilities shared. Collectively, they denote the process in which people involved in social, physical, and emotional relationships come together and actively engaged in decision-making on issues that affect their lives. (Heller et al. 1984, cited in Talò et al., 2014). In the specific field of mental health, it also includes the State's responsibility in providing citizens with an opportunity to engage in one's community life. Here, the term 'Community life' simply refers to the life and activities that take place within one's community.

Various national and international policies have been formulated and implemented to enhance citizens' personal, social, and physical environment and encourage their community participation. One of them is the convention on the Right of Person with Disability (CRPD) in 2006 by the United Nations (UN) which talks about the right of disabled people to effective and equal participation in society. Article 33 recommends the establishment of a framework by the government to promote relevant action at national to local levels (United Nations, 2006). The concept of active inclusion and community participation of people with intellectual disability has also been the key issue in the social policies among the OECD countries and was the part of European commission's 2008 recommendations (Eurofound, 2012; OECD, 2013).

Denmark has also recognized the major role of policy and recognizes the need for stronger action to prevent the exclusion of citizens with intellectual disabilities from social life. In line with the

above-mentioned international regulations and guidelines, the government has developed, revised, and implemented various national strategies under various ministries to ensure full community participation of people with disabilities (Eurofound, 2012). Since 1993, disability-related inclusion policies had been formulated, increasing access to education, social and physical infrastructure, and even opening up the job market. But the emphasis was largely on the form of physical disability and not on mental disability (McEvoy et al., 2019). Following the European Commission's 2008 recommendation, the sector on mental disability constituted in national policies has been gradually discussed in various national reports and the sensitization of the topic on this subject has been a priority ever since (McEvoy et al., 2019). Such sectors include education, including an explanation of the special education context; labor market inclusion, including the protected employment initiative; housing; e-inclusion; free choice, and a broader social context, including family life and relationships (The Ministry of Social Affairs and Integration, 2011). Such national policies have gained popularity at a local level and depending on the needs and resources available, the municipality has developed and implemented its regional strategy (OECD, 2013).

The World Health Organization's (WHO) definition of 'community Participation' (2001) also discusses the aforementioned domains and describes participation as an activity/involvement of people with others in the sphere in which they live (cited in Verdonschot et al., 2009). Enhancing participation in these spheres of social life is expected not only to improve the living situation of individual citizens but also contribute in creating an inclusive welfare system of equal and quality service for all (OECD, 2013). Social welfare institutions within municipalities are here the implementor of this concept of community participation and inclusion (Institut for Menneskerettigheder, n.d.).

Recognizing the role of policy and efforts made by the municipality in the creation of the supporting condition for the productive and fulfilling community participation of citizens with intellectual disability, this study simply aims at exploring how the process of community participation is taking place at a local level; taking Botilbuddet Tornhøjgård as a case study unit. This examination of the local context is used in understanding and analyzing what was generated at ground level as a result of formal policies and show how they make sense to those involved. During the study, particular attention has been paid to the ongoing practice and organizational rules and policies of citizen activation.

#### 1.2. The context of Botilbuddet Tornhøjgård

Tornhøjgård, a newly built welfare facility under Aalborg Municipality services is a living facility for people with various forms of mental and intellectual disabilities. The institution is the result of the Danish housing legislation i.e. §5 'secured housing institutions' in which it prioritizes the establishment of specially designed houses adapted to the needs of people with disabilities (Consolidation Act on Social Services, 2007; The Ministry of Social Affairs and Integration, 2011). The facility was established as an alternative to the traditional practice of institutional care which offers accommodation to the citizen with intellectual disability with other mental disabilities between the age of 18-85 and prepares them for independent living. The citizens are referred here upon meeting the Aalborg municipality's defined criteria that states 'those without total physical disability, who have no violence or anger related issues and who are not drug or alcohol addicts' (Handicapafdelingen, Aalborg Kommune, n.d.). It has been in operation since 2018, with 32 residents and 20 employees, including a social worker, therapist, healthcare worker, etc. With community-based living, the organization aims to provide more resources and the opportunity for citizens to experience role, relationship, and live an independent life based on their wishes and dreams (SOSU, 2019).

The building's physical infrastructure was designed to improve the accessibility of citizens and eliminates any physical barriers preventing one from participating. It provides the space for the personal and social needs of everyone whereas its location, i.e. In the middle of a residential area, prioritizes their right and the need to live and be part of the community. It contains several single rooms, small apartments, and common facilities. The service here is provided under *Botilbud til midlertidigt ophold - Serviceloven § 107 and Botilbud til længerevarende ophold- Serviceloven § 108* (Aalborg Kommune, 2016). The goal of short-term housing offering is to examine and improve the capacity of people to work that further clarifies potential housing and support measures. Whereas long-term housing focuses on addressing the citizens 'need for comprehensive support and care, as well as offering opportunities to develop and sustain social/life competences (Aalborg Kommune, 2016). Long-term accommodation is provided for those in need of extensive help with daily function, care, and treatment. Tornhøjgård, in collaboration with a similar institution, assists in the access to the labor market and also conducts various social-educational

activities and treatments intending to improve the individual's life skills (The Ministry of Social Affairs and Integration, 2011).

#### 1.3. Statement of the problem

In the past years, Denmark has developed and enforced an active inclusion policy in line with international legislation that aims to increase the community participation of citizens with mental disabilities (OECD, 2013). Given the policy emphasis, little is known about the experience, perception, and attitude of the citizen towards community participation in different social spheres (Verdonschot et al., 2009). Even within the four domains of social life stated above, it was seen that labor market integration was taken as a key element for the development of people with mental health problems and was also a major part of policies, national reports, and academia. But little focus has been placed on the other aspect such as participation in social roles and relationships and this prioritization of one domain over another has also been addressed by this research.

To gain a fuller understanding of the citizen perception of 'community participation' and how it gives meaning to their lives, much research is required in this area. Focusing on the citizens' experience can help develop a better perspective on what it means to be a citizen under such a program, as well as potentially inform and influence future policy objectives. Therefore, to explore the application of forms of community participation in the lives of citizens, the researcher used the participant observation and interview method in this study. The data collected through the method will also be analyzed concerning the various active inclusion policies implemented at a national, municipal, and organizational level.

#### 1.4. Significance of the study

The sphere of community participation is wide and how it is identified, addressed, and evaluated often varies (Akyurek and Bumin, 2017). With specific reference to community participation for mentally/intellectually disabled citizens, the issue has been prioritized in various international, national and regional policies and has been covered to some extent by academia (McEvoy et al., 2019). Most of the academic study discussed one or another aspect of community involvement, with most of them addressing labor market integration. Whereas, this study seeks to capture the insider's perspective of the established sense and significance of community participation,

illustrate how the citizens and social worker's approach it, and what supports and creates obstacles in doing so. Learning this will further support gaining an understanding of whether the policy and its implementation conform to what citizens are looking for and if they can recognize and accept it in their life. The result of the study will help the organization evaluate the impact of their practice in the life of citizens along with their position in the broader policy context. The result would also develop the organizational report, which further assists the impact of the policy on the ground level.

#### 1.4.1. Study aim and objectives

The overarching aim of this study is to explore the supporting and opposing components in national policies on mental/intellectual disabilities' inclusion that affects their understanding and needs of community participation. Such policies are seen as embodied in municipal and organizational policies which affect the daily lives of the citizen.

#### Specific objectives:

- To understand citizens mobility and experience in public spaces, services along with the opportunities and constraints they face while participating (via interview and observation)
- To investigate and understand the notion of inclusion/exclusion in the specific setting of Botilbuddet Tornhøjgård
- To identify factors within society and policy that increase/decrease the opportunity for community participation.

#### 1.4.2. Research question

The main purpose of this research is to gain an understanding of the forms and the process of community participation of people with mental with intellectual disabilities as they occur at the local level, articulated by municipal and national policies. This research, therefore, aims to gain understanding through the following research question:

"What does the notion of community participation include in the local level, and how has its meaning and practice been influenced by Denmark's adoption of policies regarding the active Inclusion of citizens with intellectual disabilities?- A case study in the context of Tornhøjgård."

Following the study, this research is also aimed at obtaining the answer to the following subquestion, which will help to address the broader question stated above.

- 1. How does the organization understand the concept of community participation and what role does it play in promoting the principle of inclusion?
- 2. What factors in policy and implementation support and prevent citizens from engaging in community life?

#### 1.5. Definition of terms

Citizens: The term citizen is used here to refer to an individual with an intellectual disability who is part of the Danish welfare system, and whose community participation, growth, and development have constantly sought by the policy, practitioners, and individuals themselves. The term has been chosen to address these people as it found to be a popular term used by social workers and other practitioners in Denmark and notably in Aalborg municipality.

Inclusion/Integration: When talking about citizen participation, we can see the use of both terms' integration', especially concerning the labor market and 'inclusion' in this study. Although these terms, do not have much difference in this paper, the difference between these two has been found to have a wider impact in the academic world of social science. Noting the difference, the researcher tried to give the meaning of those terms in this paper's context. Here, Inclusion is more related to placing citizens back into community life by removing barriers and encouraging everyone to participate as equal and valuable members of the community. Whereas integration would be the adjustment of the system for/by providing resources to meet the needs of the citizens with mental with intellectual disability, e.g. the provision of flex job in Danish social law (stated in the fourth chapter of this paper) (Eid, 2018).

#### **CHAPTER 2: Literature Review**

This chapter offers a description of the evolution of the idea of social inclusion and community participation and also describes the strategies implemented and Applied around the world and in Denmark to achieve it. All the information was based on previous research, books, and national and international document about the concept of community participation. The topic is divided into micro, mezzo, and macro levels to systematically address the concept of its international development to its local implementation phase. It further presents the discussion and conceptualization of the theories of community participation, deinstitutionalization, and the role of the social worker. The theories presented here have both been predetermined and have resulted from the data collected. Together, these two topics in this section provide the basis for the interpretation and critical review of the data in this study.

#### 2.1.Development of the concept

In the 1990s, the concept of social inclusion and exclusion emerged in line with the policy of eradicating poverty as a stated goal of the European Union (European Commission, cited in Larsen, 2003). Today, the term social inclusion is used as an umbrella term for vague concepts such as policies and measures to tackle unemployment, dependency and social isolation of various groups of people (Andersen, cited in Larsen, 2003). Here, the socially isolated groups listed by the European Commission include those with long-term unemployment, homelessness, physical and mental health issues, low qualifications, sexism, racism, drug abuse, old age, geographic area, or a combination thereof (European Commission, cited in Larsen, 2003). The policy measures for social inclusion of the EU Member State before the 2000s were relatively low, as there was no clear indicator until then (European Commission, cited in Gábos and Goedemé, 2016). In 2001, quantitative social measures were developed and used among the EU Member States to assess the social inclusion of these groups, thereby shifting the political focus on the 'wage labor inclusion' of those groups consisting primarily of people outside the labor market. (Veit-Wilson, cited in Larsen, 2003). Both the OECD and the European Commission have argued in favor of this form of participation, which was anticipated to be the most effective way of improving social inclusion (Larsen, 2003). Paradoxically, this focus of the inclusion policy labeled citizens who are not able to contribute to the labor market as less deserving and thus escalate their exclusion.

#### 2.2.Inclusion/ participation of mentally disabled citizens at various levels

#### Macro Level: World policies development and Research

The process of enabling disabled people have been centered around greater participation, inclusion, and equity in the social system (Priestley, 2001). The concept of equality might concern with the question of 'equality in what?' and 'to whom?'. Here, it simply means the equality in distribution and access to welfare and resources and opportunity among every citizen (disable or non-disable) (Gosepath, 2011). The first declaration on the right of persons with disabilities was adopted by the United Nations (UN) General Assembly in 1975 after which various long-term policies at the national, regional and global level were adopted, enabling their issue to raise from the margins to the mainstream of the international agenda (cited in Priestley, 2001). Progress continues during the 1980s, where different movements, strategies, and notions were adopted to assure, facilitate, and influence understanding of mental health issues from local to policy level (Ringø and Høgsbro, 2017). Some of the popular notions that emerged at the time include empowerment, user influence in the mental health system, and self-help; these notions still prevail in today's context of mental health (Ringø and Høgsbro, 2017). Further, to ensure rehabilitation, equal opportunity and social integration of individuals with (mental) disabilities in community life, the UN rule (1993) prioritized their accessibility and participation in areas as education, jobs, income maintenance, and social security, family life, and personal integrity, culture, religion, leisure, and sports (cited in Priestley, 2001). Subsequently, various countries around the world adopted the concept in their policy to implement the UN rules. At present, the inclusion and community participation of people with disabilities, mental health in specific, is an important goal that the policy, service provider and the individuals intend to achieve (Simplican et al., 2015).

As mentioned above, the concept of social inclusion has always been part of the mainstream policy since the 1990s and since the first wave of research involving people with intellectual disabilities, the subject has been in the academic world of social science. Around the 1970s and 80s, early researches were centered on physical inclusion into the community for those who left the institutions as part of the deinstitutionalization process (Amado et al., 2013). As the concept grew, the study started understanding the distance between disabled people and the community. Over time the academia shifted its focus and in present the notion of participation requires much more

than physical inclusion (Amado et al., 2013). It involves the active participation of the citizens in different domains of social life as domestic life, interpersonal relationships, social life activities such as education, jobs along with the community/civic engagement which includes leisure, religion, politics, etc. (WHO; Van der Meiet al., cited in Verdonschot et al., 2009).

#### Mezzo level: Nationwide development of Public system

In Denmark, the legal rights of people with disabilities have been strengthened under the social legislation act of 1998. However, However, the organization regulating this law and ensuring the right of people with disabilities has been here for a long time e.g. The Danish council of the organization of disabled people (DCODP), which created an index to monitor the implementation of UN Rules (Priestley, 2001). In the past, the country's policy was heavily focused on integrated, individualized and institutionalized care for mentally disabled citizens, but with the community acceptance and the policy shift towards the provision of multiple community-based services, it has helped to reintegrate and normalize the lives of citizens (Amado et al., 2013; Goodwin, 1997). Here, the concept of normalization refers to the idea formed to enhance social role which further leads to increased citizen's social capital and value in community life (Wolfensberger, 1972 cited in Amado et al., 2013). This normalization was facilitated by the process of de-institutionalization in Denmark's mental health sector. With its introduction in the US during the 1970s, the idea of de-institutionalization entered Denmark and gained popularity when the state shifted its responsibility for psychiatric hospitals to the counties in 1977 (Mossialos, 2007). The reform and development in Denmark were later more influenced by the UK, where its mental health sector, both institutional and community, experienced the most sustainable period of growth during the 1980s (The Mental Health Foundation, 2009). This was due to the increase in a greater awareness of the connection between physical and mental health, the impact of stigma, and many more. Although the budget was limited, reforms improved as the institution's number of patients decreased, a balanced number of patient-staff resulted in better nursing care, and multiprofessional collaboration and support from local authorities, third sectors, and private providers increased (Turner et al., 2015).

The adoption of legal rights and social needs of people with disabilities by the mainstream policy in Denmark during the 1990s along with its full and proper implementation resulted in the

establishment of a cross-sectoral partnership between the health and social sector (Mossialos, 2007). This partnership led to a practice of the concept of deinstitutionalization, under which the establishment of social psychiatry under the supervision of the municipality increased (Mossialos, 2007). When viewed from a mentally disabled citizen's viewpoint, de-institutionalization, and community participation is referred to as the opposite of living in an institution (Bray et al., 2003). Before the transfer of responsibility, the people with mental disability used to live in large segregated residential facilities that were initially designed to provide individualized service and the basic needs, i.e. food, shelter, and health care (European Commission, n.d.). As a pillar of the social inclusion program, de-institutionalization was used as the evidence begins to show that such large segregated institutions are unable to ensure a person-centered service and support for their community participation (European Commission, n.d.). The definition of de-institutionalized has also been used to illustrate the need for institutional and community-based service, as the prior physical separation has limited the citizen's ability and readiness to participate fully in community life. (European Commission, n.d.). This concept of de-institutionalization has been used as a major theory for analysis and has been further elaborated in the theory part of this chapter.

#### Micro: local level institution within Municipal context

Here, in the micro-level context of community participation, we take the case of *Botilbuddet Tornhøjgård*, a local-level organization operating as a living facility for people with mental/intellectual disabilities under Aalborg municipality. This organization can be seen as a prime example of de-institutionalization, where individuals with mental/intellectual disabilities are not in a segregated environment, but rather reside in a neighborhood setting with partial support from the organization and partial self-help (Aalborg Kommune, 2012). Following the prior mentioned policy-shift, Aalborg Municipality facilitated the implementation of nationwide social and labor market reform, introduced the flex jobs, assisted in the transition from education to employment, and established adequate resources for a common mental disorder (OECD, 2013). Whereas *Tornhøjgård* as its implementor introduced the policy in the lives of a citizen living there. Highlighting the theme of 'citizen at the center', Tornhøjgård, under the Danish disability policy implemented by the Aalborg municipality focuses on the holistic development of citizens with mental disabilities through the collaboration between citizen, staff, and community (Aalborg Kommune, 2012). With the core values of 'accountability', 'respect', and 'Presence' in its social

service acts, the organization/municipality aims to enable the participation of citizens with mental disabilities in different spheres of social life (Aalborg Kommune, 2012).

#### 2.3. Social policies supporting community participation at the local level.

The social policy mentioned here reflects the national system, but with its own regional and municipal characteristics. Although these policies are not exclusively oriented towards community participation, they act as a gateway to participation for people with mental health needs, especially for those who are part of local social facilities such as Tornhøjgård. In Danish policy documents, community participation/inclusion has become a central issue, and to achieve this, different measures such as the right of citizens to work, education, and housing has been taken in cooperation and collaboration with relevant providers (Hoof et al., 2011). The implementation responsibilities of these policies are decentralized to the municipal authorities that came with the structural reform in 2007. This has resulted in more public control and finance, social psychiatric services, day and night care facilities, housing facilities along with social contacts, and participation (including school, work, leisure) for people with mental disabilities (Hoof et al., 2011). In Danish policy, theses social psychiatric services are much more important in supporting their community life, whereas traditional mental health care plays a very small role.

The Danish government has published various national mental health care policy documents, including 'National strategy for psychiatry' ('National strategi for psykiatri'), 'the Action plan for psychiatry' ('Handlingsplan for psykiatri'), etc. (Sundhedsstyrelsen; Regeringen, cited and translated in Hoof et al., 2011, p. 28). These documents include the measures that are proposed and undertaken in achieving the goal of social inclusion and participation policy. These measures range from individual to group entitlement in the field of work (with shelter or flexible), education, (including special education program) housing, free choice, etc. (Hoof et al., 2011). Some of these provisions included under the national service act, facilitated by Aalborg municipality and implemented in a local organization, including Botilbuddet Tornhøjgård includes Social education Support (Socialpædagogisk støtte - Serviceloven § 85), protected employment (Beskyttet beskæftigelse - Serviceloven § 103), Activities and get-togethers (Aktivitets- og samværstilbud-Serviceloven § 104, visiterede tilbud), Housing offer for temporary and longer stays- (Botilbud til midlertidigt ophold- § 107, længerevarende ophold- § 108), etc. (Aalborg Kommune, 2016). The

other acts include (§ 81) the effort to improve individual social and personal functioning and(§ 104) offering activities and socializing service to the person to maintain or improve personal skills or living conditions (Consolidation Act on Social Services, 2007). Those who are unable to care for their own needs are provided 24-hours care within the housing facility under as stated under § 105 of Consolidation Act on Social Housing (2007) (cited in Engen et al., 2019). Further, the assistance in this accommodation is provided with a consultation with the citizen, based on one's specific needs and circumstances (Social Services Act § 1, cited and translated in Engen et al., 2019).

The key emphasis of these acts is to prevent the challenge of citizens through individually designed help along with the increment and appropriate of their resources, motivation, and networking (Aalborg Kommune, 2016). The social education act is focused on developing, maintaining, and limiting the loss of one's skills and the protected employment focuses on providing a citizen with the opportunity to contribute to society through the use of acquired skills (Aalborg Kommune, 2016). The next act of activities and get-together is focused on maintaining relationships and networking. This social activity was structured primarily based on citizens' dreams and needs and is centered on the self-help through arranging practical tasks, activities based on one's interests and hobbies, sensory stimulation teaching, and other social activities. These policies and their ideas also entail the objective of assisting citizens in everyday life together with providing them social support and explicit or implicit social skills training (Hoof et al., 2011). The policy goal as stated in these documents can be summarized as "improving accessibility, facilitating inclusion and participation and enhancing the quality of care and services" (Hoof et al., 2011, p. 28).

#### 2.4. Community participation

The study is guided by the concept of 'participation' which, in this research, has been explored with particular emphasis on the community life of people with intellectual disabilities. The notion of participation denotes a meaningful contribution regarding a decision that affects one's life. In practice, this involvement can take any form, including being well informed about the concern issues, giving/gaining feedbacks, taking responsibility, or even contributing ideas and alternatives through active collaboration with the community (WHO, 2005). Whereas the social definition of 'Community' is ambiguous and it appears difficult to define unless provided with some

specification (Mannarini and Fedi, 2009). Notwithstanding its ambiguity, the concept of community can be simply presented as a social, physical, and emotional tie formed by being together. Here, through community, an individual seeks some level of interaction, common interest, identity, and shared values (Mannarini and Fedi, 2009). In a general sense, the term 'community' and 'participation' (community participation) together denotes to the process in which people connected with social, physical and emotional ties, actively engaged in decision making in the issues affecting their lives (Heller et al., cited in Talò et al., 2014). Transferring this concept to the domain of mental disability, it may also refer to the availability of opportunity for them to engage in one's community. It also involves all sectors, i.e. civil society, community and practitioners, and citizens working together to become part of local communities with particular emphasis on developing citizens' life skills, opportunities and independence, rather than working with an institutional approach (Bray et al., 2003).

#### 2.5. Deinstitutionalization

Deinstitutionalization has existed in the western world since the 1950s, a concept adopted by many states in an attempt to shift the responsibility of people with mental disability from institutions to community care using a series of legislative, legal, and financial measures (Piat, 1992). It can also be seen as a process of humanizing patient service in an institution related to mental health. Bachrach (1978) provides a popular three-tier definition of deinstitutionalization where he claims it to be a 'process', 'fact', and 'philosophy' (cited in Piat, 1992, p. 201). As a *process*, it involves developing the community resources and shifting the care of citizens from institution to community, *facts* are related to statistics of citizens admitted to and discharged from institutions and *philosophy* is more concerned with individual right to live in the least restrictive environment. The philosophical definition assumes that "the community can and is willing to provide the required care" for the betterment of the citizens (Bachrach, cited in Piat, 1992, p. 201). It also assumes the shifting of responsibility, not only from institution to community but also from practitioners to citizens. Looking at all three definitions, we can say that the concept of deinstitutionalization in this study is more closely tied as a process than to facts. Whereas some of its philosophical elements were also reviewed during this study.

Deinstitutionalization as a process also relates to what Goffman (1968) states as being away from the total institution. He describes the 'total institution' as a notion where numbers of people with similar life issue or character who have been cut off from wider society work, reside, and live together in an enclosed space for a considerable period under formal administration (Goffman, cited in Davies, 1989). The opposite concept of this total institution would be a basic social arrangement in which people reside, work, and take part in various activities under multiple authorities in different places without a single general plan (Goffman, cited in Davies, 1989). This decentralization of authority and separation between various life sectors such as jobs, health, education, etc. and the absence of one absolute power holder is what we can find in the definition of deinstitutionalization as a process.

Although the concept of deinstitutionalization emerged from around the world in the same period, it advanced with different goals. For North America, it was aimed at promoting the citizens' rights alongside the economic incentives and saving costs; although later economic study demonstrated it to be wrong (Piat, 1992). Whereas in Europe, including Scandinavia, it was stimulated by the demand for labor in the post-war period, leading to the employment and economic relief of deinstitutionalized (Warner, 1989). In Denmark, deinstitutionalization and community care have been the explicit goal of the policy (Hoof et al., 2011). With the transition from large residential service to a small one, priority was given to reforming the public service and enabling citizens to live in the community. One of the major reforms came with the Social Services Act of 1998, in which citizens were entitled to live in their own homes irrespective of the type of housing, supporting their dignity, right to privacy, and self-determination (Ministry of Social Affairs, cited in Engen et al., 2019). The evaluation of the 1998 act has shown some positive life changes for people with a mental disability, but the problem in the practice of ideals of self-determination, inclusion, and active citizenship continue to exist (Høgsbro et al.; Langager et al., cited in Engen et al., 2019). Until now, the country has been able to lower psychiatric beds and provide residential care and supportive housing to a relatively large number of citizens (Hoof et al., 2011). However, criticism persists regarding the implementation of the concept of deinstitutionalization. One of the constant criticisms pointed out by social science research states that despite the fact that priority has been given to participation and self-determination, power has not been transferred completely from authority to citizens nor citizens can freely decide how to live (Altermark, 2017).

As the main interest of this research is the idea of inclusion/participation, the use of the concept of deinstitutionalization further helped in understanding and analyzing the findings of the study. Furthermore, the professionals providing services to the citizens in the community or small social facility start developing new and innovative approaches to working to reach the goal of successful integration back to the community life (Piat, 1992). This new approach adopted for the citizens' inclusion has been a major part of this research. Nonetheless, the negative consequences of deinstitutionalization, a dominating theme in academia have not been ignored (Piat, 1992).

#### 2.6. Role of the social worker in community participation

A variety of literature expresses the different roles of a social worker and there is no single universal knowledge or set of skills/expertise specified for this profession (Asquith et al., 2005). However, it is agreed that social work is committed to supporting and enabling those whose lives, for various reasons are negatively affected by social elements. Social work has many functions of dealing with various failures in social areas and connecting this with the mental health setting, has the function of integrating the isolated citizens back to community life and work to assist them in their overall development (Asquith et al., 2005).

From the beginning, the social worker has always played some role in the issue of mental health. They were, however, unable to contribute fully to this field and were always taken to be a secondary profession (Aviram, 2002). With deinstitutionalization, the role of a social worker in the mental health sector gained popularity as there was an increased need to assist the shift of citizens from institutions to community care (Aviram, 2002). As part of this community care, social workers embraced their traditional knowledge and interests of understanding and responding to the need not only of an individual but of their environment, i.e. Family, social relationships, and even the physical structure (Aviram, 2002). Putting it in the context of this research, the paper is interested in looking at the current role of a social worker in a social facility in enabling citizen participation. However, this aforementioned role of a social worker that came with the change in social policy, i.e. Decentralization, which is used when analyzing the findings regarding the practitioners' perspective on their roles and practices.

#### CHAPTER 3: Methodology

#### Overview of the chapter

This research aimed at exploring and understanding the perspective of citizens' participation in the community lives within the context of a social-welfare organization. This section presents the details of the methodological approach that has been used as a guiding framework in an attempt to develop the study and address the research question. The study uses the qualitative research method alongside the exploratory and does not intend to test any set of hypotheses, nor was the theory entirely specified beforehand. The research was, however, committed towards the methodological framework set out below, through which the paper addressed the stated problem. The methodological framework includes ontological and epistemological background, methodological approach, research design, data source, and analysis strategy. The coherence among these sub-topics has been given importance in this chapter. The chapter concludes with the ethical consideration of the study.

#### 3.1. Research Design

#### 3.1.1 Constructivism: Ontology, epistemology, and Axiology

The methodology of the underlying study adopts a philosophical view of constructivism. The notion of constructivism or social construction includes the creation of reality/knowledge through social interaction, respectful negotiation, and relationship (Guba and Lincoln, 1986). Looking at an ontological stance, this study focuses on the multiple and subjective nature of reality. (Berger and Luckmann, cited in Leavy, 2014). Whereas the epistemological stance is more concerned about the knowledge process and answers to the question "How we know what we know" (Guba & Lincoln; Ponterotto, cited in Leavy, 2014, p. 82). Here, Stake (2006) argues that to understand this 'how', one requires to gain the experience of the activities as it occurs in the context (cited in Harrison et al., 2017). Considering the social reality being multiple and contextually created through continuous interaction and interpretation, the research seeks to capture reality through the participants' interpretation and view of the situation being studied (Guba and Lincoln, 1986). This captured interpretation is further used as an instrument in providing insight on a broader issue.

This orientation is closely aligned with the case study approach adopted by the study, which is motivated in discovering meaning and understanding of the experience in context and use it to further understand the issue (Harrison et al., 2017). This constructivist idea further adds up to the study by helping it to seek and understand the meaning of socially constructed/ interpreted reality and how it manages to take hold of policy-making and bring about a change in the institution. Moreover, the concept of community participation is also a constructed knowledge that has been incorporated into the social and institutional structure and enforced in the policy, the implementation of the constructionist world view is presumed to be the best fit to develop this study. Altermark, (2017) follows this idea of socially constructed knowledge from the standpoint of being 'included' and 'excluded' and in the same paper, Morton (2003) emphasized the existence of the societal and the political notion of defining certain people, and ideology as 'other' and their downgrading in relation to the 'normal' civilized world. The presence of these ideas has been constructing the way we shape our identity as well as that of others and given the role that these 'constructed ideas' play in policymaking and institutional change, the study sought to explore what concepts were involved in the institution's adoption of the model of community participation. The idea addressed here will also be analyzed and interpreted by exploring and understanding how the concern stakeholders find value and meaning in community participation of people with disabilities.

Talking about the axiology, it is concerned with the role of the researcher and his/her values in the process of knowledge generation (Lincoln et. al, cited in Leavy, 2014). The dependent nature of the relationship between the researcher and research is said to generate bias when producing and analyzing the results. Meanwhile, this relation is also believed to enhance the trustworthiness of the result, since it incorporates multiple perspectives on the subject (Leavy, 2014). Therefore, during the process of knowledge generation, the researcher has attempted to use a systematic approach, such as identifying, describing, and 'bracketing' to eliminate my values that might create bias and subjectivity. The research also attempted to gain the perspective of multiple actors to highlight the diverse knowledge and to fairly represent their views. The goal behind this was also to justify and validate the knowledge acquired in the situation where it was not always possible to eliminate the researcher's subjectivity.

#### 3.1.2. Orientation: Abductive Reasoning

The study dominantly embraces abductive reasoning in its orientation, where it allows one to move back and forth between induction and deduction (Morgan, 2007). Here, in this research, the abduction reasoning includes using data to generate theory, an aspect of inductive and then again used those theories to narrow down the themes to conclude, thus the element of deductive reasoning (Bryman, 2016). In other words, the inductive results here served as a guide to the aim of deductive reasoning and vice versa (Morgan, 2007). The data analysis decision was not completely pre-built into the research design, but the values and prior knowledge researcher in the subject matter have certainly influenced the selection of final theory and the prioritization of themes generated from data. Moreover, it needs to be noted that in this particular research, the logical connection between theory and data was made by reflecting and using multiple connections and approaches (Morgan, 2007). Simply, some theories have been taken into consideration when evaluating the data, while others emerged from the data itself, thereby making the design more interactive within.

#### 3.1.3. Case Study Approach

As defined by Yin (1989) Case study is simply an intensive study of a single unit that describes and explores the event as it occurs in the everyday context (cited in Crowe et al., 2011; Gilgun, 1994). This research follows this very definition and takes Tornhøjgård, a residential facility for mentally disabled people, as a unit of interest for an in-depth investigation of the questions as 'how and why the approach community participation is incorporated by the organization' and 'how does it contribute to the growth and development of its citizens?' In exploring this how, the paper will be looking at the role of the organization in mediating the policy ideas of community participation to the practice, including its contribution to citizens' everyday lives and experience. This approach of the case study was particularly adopted because of its ability to capture detailed and multiple perspectives on a particular aspect of the case. This further helped in identifying the influence of a social system and understand the situation in context (Crowe et al., 2011; Gilgun, 1994). Therefore, it is important to state that the case study is not applied here as a research method but simply a choice of obtaining information in the context. If wanted, it can also be used to determine the pathway for future comprehensive research.

Stake (1995) characterizes the case study into 3 major types: intrinsic, instrumental, and collective case study (cited in Crowe et al., 2011). These types are separated based on their nature of being explorative/guided by interest, the aim of understanding particular phenomena, and involvement of multiple case studies respectively (Crowe et al., 2011; Grandy, 2010). This research possesses the character of both the intrinsic and instrumental case studies in the process. i.e. the research is guided by the researcher's interest in exploring the subject matter which then is used in understanding and describing the particular ongoing phenomena (Grandy, 2010). Due to its multiple research interests, it is difficult to position this case study in one or another type. This choice also coordinates with the abductive reasoning selected for the study. For example, the instrumental part focuses more on established theory, i.e. the theory of community participation in this study, while the intrinsic part of the case study is more exploratory and has contributed to the emergence of a theoretical framework. Therefore, the choice of both the case study and reasoning supported the research in moving back and forth between data and the theory.

Next, this study tends to reflect the broader phenomena of community participation by looking at a single institution. Thus, any generalization of the result will be a basic working hypothesis and merely an applicable conclusion (Croobach, cited in Gilgun, 1994). Rather than aiming to reach any kind of conclusion, this study is more focused on investigating the embraced idea and interpretation of community participation, its processes and barriers, and understanding the current situation in which the implementer and the citizens operate (Gilgun, 1994). This investigation of ideas and perception is also in line with the constructionist approach which guides the study's analysis. As stated in various sections of this chapter, this (case) study is heterogeneous and constructivist in its philosophical underpinning, has an abductive approach to theory and includes multiple data collecting methods such as participant observation, interviews (both semi-structured to unstructured) and secondary data source i.e. organization's reports and documents (Gilgun, 1994). The study took place in multiple settings within 2.5 weeks.

This concept of the case study has been used while planning and undertaking different stages of research starting with the selection of the case i.e. Tornhøjgård and then gaining access to it. The process of selecting and gaining access has been defined in the section 'sampling and recruitment'. Certain criteria had to be met by the participants/participant organization to be included in the

research, as the aim was to get a diverse point of view under the same theme of community involvement. The criteria in the selection involved:

- An organization working for people with forms of mental disability
- Which aims/works on assisting citizen towards any sorts of involvement in the life of the community
- A part of the Danish welfare institution and address the topic of active community participation

Upon meeting these criteria, the researcher worked on the next stage of clarification on the data collection and analysis method which is described later in this chapter.

#### 3.2. Research Method and data collection.

The study uses the qualitative research method alongside the exploratory approach in its design supporting the case study approach. By choosing the 'qualitative research' method, this paper followed a design that is flexible and adaptative to the changes (Marshall & Rossman, Cited in Taylor et al., 2015). The exploratory nature is adopted here to gain insight on the issue addressed in the research question and the descriptive is more inclined towards describing what research finds from the case (McNabb, 2004). This nature corresponds to my study as it sought to understand the participants' knowledge of community participation, its application in welfare service, and its significance in the lives of service users. However, it is important to state that the addressed knowledge here is not a representation of the word rather very contextual and does not necessarily lean towards providing the definitive solution problem (Stake, cited in McNabb, 2004).

#### 3.2.1. Sampling and recruitment

During the fieldwork period in October of 2019 in Aalborg municipality, where the researcher got a chance to visit social facilities for the citizens with a disability and elderly. Most of those facilities as the municipality has stated, are residential homes that are provided for life force. One of them was Tornhøjgård, a residential facility for people with various mental disabilities and intellectual disabilities where the citizens live their life with some support from practitioners and partly self-help (Handicapafdelingen, Aalborg Kommune, n.d.). As found in the facility's website it states that the citizens living here are expected to participate in day employment. As the social facility

had been found to meet all the criteria set out in the case study section of this study, the researcher came into contact with the leader of Tornhøjgård with the help of the initial contact established during the fieldwork in the Aalborg municipality. The contact was further established through emails and visits, from where the researcher was able to explore the organization's work structure and services and built a relationship with its members. The process of data collection had begun with the willingness of the members of the organization to participate.

#### 3.2.2. Data Collection

The paper is structured around the main question of "How does the community participation of citizens take place in the residential facility of Tornhøjgård"? Consistent with this qualitative design, an in-depth semi-structured interview was used to generate the employed data. The choice of the in-depth and semi-structured interview has also been influenced by its ability to unfold a conversation in a way that provides participants with an opportunity to pursue the issue they feel is important (Longhurst, 2009). During the interview, broad and general questions were asked allowing participants to create the meaning of the situation. Whereas the question for the interview with the citizens was predominantly based on the observation and was intended to lead to a discussion with other participants present there. This insight into what people think and find meaningful is further interpreted and analyzed to answer the research question. This method also aligns with the constructivist approach as it entails the diverse experiences of stakeholders' knowledge, meaning, and identity attached to the concept of community participation (Leavy, 2014). Further, the use of multiple data sources under the case study method enhances the internal validity of the study (Crowe et al., 2011).

Hence, to explore the adoption of the community participation framework, participant observation method, and semi-structured, in-depth interviews for the primary data collection on various occasions were used. While the secondary data source for the theoretical framework was derived from various sources, such as scholarly literature and organizational publication. A total of 7 service users were observed during 3 days period and among them, 3 were the part of a group interview. Due to the language barriers between citizen and researcher, social worker assistance was taken for translation. Whereas 2 social workers, including the organization's leader and a social worker whose main task is to facilitate citizens in carrying out the skill development and community-related activities, were interviewed on 2 different occasions. Field notes were also

taken during the observation period which was used when preparing a questionnaire. These data were collected between 19<sup>th</sup> February to 9<sup>th</sup> March 2020.

#### 3.2.3. Positioning

The research design section of this study indicated that I would use a systematic approach to recognizing subjectivity, reflect my values, and when possible eliminate biases in the process of knowledge generation. While this recognition and reflection was part of every section of the research, I chose to use 'positioning' as an approach to discuss my 'social-cultural position/status, previous knowledge and assumption of the studied topic along with the personal experience, belief, biases and linguistic tradition' (Berger, 2013, p. 220). I am an international social work student from Nepal, in Denmark. When pursuing my degree here and writing about community participation in the Danish context, I found the difference in the very definition and perception of the community among many differences between these two states. Although the community is a unified body of individuals linked to a common interest for both countries, there has been the strong presence of characters as a kinship relationship, the permanence of neighborhood (Merriam-Webster, n.d.; Masolo, 2002), along with invisible placement and guided practice and restriction (social/moral) on one's role and function in the definition of community where I come from. Furthermore, the term community participation has always been a strategy of development, here community members work together with the outsiders (people involved in the project) meet the needs of poor communities along with the targeted goal of the project. Whereas, here in Denmark, the notion of self-determination, equity, and individualism was seen to be present in the concept of community and community participation. I recognized the inevitable influence of this view on the way I would question and communicate with participants, and to eliminate any possible negative influence, I first decided to observe, to learn more about the situation and then I asked the questions based on both what I saw and what I wanted to know more. Furthermore, I acknowledge that my various positions, as a student, researcher along with my background has affected the process of filtering, coding, meaning-making, and presenting the information gathered during the study. This reflection also leads to the decision of collecting the information about the participants' concept of community and although this information does not directly contribute to answering and posed research questions and objectives, it increases the researcher's understanding of the notion of community and participation. Although I have tried to compare and contrast the

notion of community and participation, it is important to note that the field of mental health, institutional concept, and social facilities, together with the development of Western mental health, was very different and often incomparable from what I was previously exposed to. This new perspective has also helped me to understand self-interference, helped to report the findings with minimum interpretation possible, and analyze them based on the research aim, policy, and literature.

Besides, my status as a social work student also greatly facilitated in creating a network with Tornhøjgård and gaining the participants. Social worker participants express their confidence in me that I understand the role and challenges of a social worker as I am trained to be them. Whereas my position of being international was a great barrier to the creation of a direct connection with the citizens, mostly because of the language barrier where I always had to take the support of social worker's translation to understand them. Overall, this process of positioning helped me to maintain awareness of myself as distinct to and sometimes as a part of the world of study (Mason; Porter, cited in Berger, 2013) and critically look at the generated knowledge.

#### 3.3. Data Analysis

#### 3.3.1. Thematic Analysis

The data collected for this study were examined using 'thematic analysis', for which Braun and Clarke, (2006) paper on the subject was used as guidance. This method of analysis was adopted because of its theoretical freedom, flexibility, and accessible approach to qualitative data analysis (Braun and Clarke, 2006). As stated in the very definition of thematic analysis, this paper follows the process of "identifying, analyzing, and then reporting the pattern (theme) that emerged from observation and interview" (Braun and Clarke, 2006, p. 26). The detailed description of this reported data is covered in the discussion section accompanied by the information provided in various chapters of the paper.

This study focused on acquiring knowledge about the practice of community participation in Tornhøjgård and what meaning the participants attached to this practice. A range of themes linked with multiple domains of community participation has appeared within which the one capturing the essence of research questions and objectives were further presented and analyzed.

A six-phase analysis outlined by Braun and Clarke, (2006) has been used which includes:

- 1. Familiarization with the data (including transcribing verbal data)
- 2. Generation of initial codes
- 3. Searching for themes
- 4. Reviewing themes
- 5. Defining and naming themes
- 6. Producing the report

The verbal data were manually transcribed in Microsoft Word, from which the initial codes were highlighted in different colors. These codes were then grouped under various initial headings (themes). Some repetitive patterns were noticed during this grouping process which was further labeled under different themes. The fourth step of 'reviewing' helped in finding the non-repetitive, but key statements that were extracted from the document and labeled under the updated theme. All these defined themes were reported under the finding sections and were further used in the discussion section to make an argument to answer the research questions.

#### 3.4. Ethical consideration

It was important to consider the ethical issues associated with the research and the research participants. Ethics simply means moral behavior. Transferring it in the sense of research, it is concerned with misconduct such as misrepresentation or alteration of data, authorship, and knowledge ownership and originality (Fox and Braxton, cited in McNabb, 2004). For this study, sufficient information was provided for potential participants through an interview guide and verbal communication. Their choice of joining the study was highly prioritized, as an outcome of which the researcher was able to gather valuable information while at the same time losing some potential participants.

With ethical consideration comes the concept of ethical dilemmas and uncertainties where the researcher has a direct/indirect negative impact on the lives of the participants (McNabb, 2004). At any point in the research, the dilemma could come from anywhere and it cannot be fully planned. Nevertheless, considering the participants' stated position, this study addressed the moral

and professional standards along with the ethical codes before creating any contact with the citizens.

For this study, the ethical principle was obtained from the theoretical foundation by Jerry Mitchell (1998) which includes 'truthfulness, thoroughness, objectivity, and relevance' (cited in McNabb, 2004, pp. 69-70). The principle of *truthfulness* speaks of research being unethical if one deliberately misrepresents the purpose of the study, the data, and even do not fully inform the participants about the study or the dangers that may arise as a result of sharing information. The *thoroughness* is to be methodologically concerned through and following all the steps in the study and not cutting edge in their design (Mitchell, 1998). *Objectivity* refers to the researcher remaining unbiased throughout the study and not infusing personal feelings in the collected data. And the final *relevance*, which is simply defined by Mitchell (1998) as the responsibility of the researcher to make the research understandable and useful to every participant, if possible.

These foundations by Mitchell (1998) helped in guiding this research ethically when preparing, conducting, and reporting the study. Nevertheless, it is important to understand that even though the guiding principle states what you can and cannot do in research, the moral principle goes beyond the stated rules. There is no comprehensive theory capable of stating when to do what and one always needs to follow his/her moral conscience in the face of dilemma or uncertainty (McNabb, 2004).

#### **CHAPTER 4: Analysis**

This section puts the findings of the study and the discussion of those findings together and explores the topic of what the organizational structure looks like, how it understands the concept and puts it into practice, what roles do practitioners play, along with their expectations, attainments, and barriers to practice. The themes emerged from the data include 1. The living facility, its practice, and work approach 2. Social worker's role and challenges, 3. An aspect of community participation with the sub-theme of labor-market integration, education, social network and relation, and leisure and physical activities and 4. Concept of community in Denmark. The title suggested for the themes was derived from the objectives of the study, and also appeared repeatedly during data collection. Under the themes, it tries to answer different objectives and subquestions stated in the very first chapter of the study. Together, with the help of related theories and policies, they aim to answer the broader question of 'What does the notion of community participation and how the policies related to the active inclusion policies of citizens with mental/intellectual disability have been influencing this notion at Tornhøjgård.'

#### 4.1. The Living facility, its practice, and work approach:

The theme 'living facility, its practice, and approach to work' presents the findings of the organization's social and physical structure that allows us to gain an understanding of the concept of community participation and the role it plays in promoting the principle of inclusion. The finding then uses the related policy and literature to answer the first sub-research question mentioned in chapter 1. Whereas the second sub-question has been used in every section within this chapter in an attempt to answer the major research question. It is further divided into two sections, the living facility and practice, and the work approach of the social workers.

#### 4.1.1. The Living facility and practice

At first, the researcher was introduced to the physical structure and location of the facility which is in the middle of the community that is built with private apartments and common spaces for 32 citizens who were referred here upon meeting the municipality's defined criteria. The community around includes private housing, and other public buildings such as schools, grocery stores, stores center, etc. This introduction to the organization was followed by the question of the importance

of its location and what role it has in citizen's community participation, which, according to the social worker was is to minimize the physical distance and enable their physical presence in the society. It was also added that the single apartment was there as it prioritizes citizens' privacy, personal life, and something of their own, despite being in a residential home. Looking at this theme in-depth, it reveals that this integrated living arrangement is the result of the continued progress of the concept of deinstitutionalization, simply defined as a shift from institutions to community care of people with mental disability (Piat, 1992). When explaining the physical structure and its relation to social participation, the social worker 2 stated, 'it is a resident's home (...) not an institution with a closed door and windows.' Despite this, the presence of citizens with a similar form of mental disability under one roof with 24-hours available professional care clearly shows that it is 'reproducing some of the features of the institution' that the deinstitutionalization process tried eliminating (Piat, 1992, p. 205). This feature is also similar to what Chow and Priebe, (2013) mentioned as a form of re-institutionalization, where the citizens end up in places as supported housing, residential home, or any other facility. Moreover, as aforementioned, the citizens living in the Tornhøjgård came there based on a reference by the municipality and codecision of the professional at Tornhøjgård and this shows that the 'free choice' of a citizen in choosing a residential place or type of assistance stated in a national report (Bengtsson, 2009) does not exist in this scenario. Altermark, (2017) characterizes this as the 'post-institutionalization era' where the citizens have gained more liberation and freedom from institutional life, but the practitioner/state still has total power over them.

One of the interesting findings of the study was to learn that the views and dreams of the citizens regarding their residence during the construction of the building were taken into consideration. When asked about their understanding of community participation, the social worker replied that giving voice in decision-making is what they consider important and gave the very example of making them a partner in the decision concerning the construction of the facility. To this, the social worker stated:

"They (citizens) said what they dream and hope for... Researchers showed them many pictures and then they were given a canvas to make their dream of where they want to live and what they want to have there. Then they (researcher) made a report and we look at the reference

from different places and gave a report to the company who were going to build this house. (Social worker 2)

The same social worker further emphasized on the facility's constant attempt in seeking new and creative ways of giving shape to the citizens' dreams and wishes. Regarding this, citizens were asked about their opinion on the public and private accommodation of the facility where they said that they are already happy with their apartment and that they want it to be more equipped if any. Moreover, it was noteworthy that social workers ensure that the voice of the citizens is heard, and they do so by making their dream come true in practice. This process of actively incorporating citizens in the planning phase, respectful listening, taking their view of what they consider meaningful, and transforming it into practice in line with the concept of participation employed by the study.

#### 4.1.2. Work approach

The work approach of social workers at Tornhøjgård showcases very interesting pathways and obstacles towards the community participation of citizens. The theory and policy of inclusion/participation demand for increasing one's life skills, opportunity, and independence to achieve the goal of community participation (Bray et al., 2003; Aalborg Kommune, 2016). Whereas, in practice, working to bring citizens closer to the community is rather complex and as dynamic as the concept of community itself (Bray et al., 2003). Although the main organizational approach to work is participatory, the perspective, interpretation, and priorities of the individual social worker differ and were found to have both positive and negative effects, and sometimes even challenged when working towards the goal of participation (Karibeeran and Kuruvilla, 2015).

One of the main comments made by social workers during interviews and informal conversations was about their approach to work, where they tended to be more careful, more protective, and progressed slowly by taking one step at a time while working with citizens. Some social workers perceive this approach of being careful and protective attitude as what citizens need and can manage. One social worker also added that this has more to do with avoiding unnecessary negative experiences that can immediately diminish the confidence of the citizens and this effect on the development of their social skills and even the progress they have made so far. This statement can be critically argued that there is an attachment to the concept of vulnerability underlying in this

basic description of the group by the social worker 1. Moreover, this acknowledgment of citizens' vulnerability compared to others, on the one hand, creates the division between 'them' and 'outside world', while, on the other hand, this acceptance encourages us to understand them concerning the underlying biological, psychological and sociological cause (Ringø and Høgsbro, 2017; Altermark, 2017). After gaining insight into their vulnerability and causes, it is easy to recognize the policy crack and work towards the design and implementation of appropriate policies (Chan, 2009).

Next, it was stated by the organization's leader that sometimes social workers are easily unaware of how their perceived support makes citizens more dependent on them. The social worker opened up about the existence of attitude in social workers where they put their judgment on citizens as being unable to carry out some tasks and tend to make the easiest possible choices. This creates barriers to the potential development of life skills on the one hand and challenges the political objective of independence and the right to self-determination on the other (Bray et al., 2003; The Ministry of Social Affairs and Integration, 2011). This fact has been classified as taking away the voice of the citizen by the leader of the organization which contradicts the organizational goal of supporting citizens in taking more responsibility and independent choices (SOSU, 2019). It aligns with what Engen et al. (2019) mentioned in their paper as 'making citizens dependent on interaction with the professional to receive care, guidance and support, irrespective of their ability to decide for themselves' (p. 234).

#### 4.2. Social worker's role and Challenges

The next important topic that emerged from the practitioners' working approach is their role which has created an impact on the lives of the citizens. As the title suggests, it aims to understand the role of the social workers at Tornhøjgård in promoting the principle of inclusion. Moreover, the challenge section presented here consisting of both the social worker's challenge in their work as well as the challenge of the difference between policy goal and practice.

Most of the time, it is found that the social worker's contribution or role has had a positive influence on the meaning and practice of citizen's community participation, whereas some other times it contained unintended negative attributes as well. The changing role of the social worker since the process of deinstitutionalization to community care was evident in the organization

(Aviram, 2002). After the process of deinstitutionalization, the importance of the social worker in the mental health profession and their involvement in citizens' lives increased (Aviram, 2002). The result of this increased involvement can be seen in the context of Tornhøjgård, where the practitioners are regularly making efforts to create a sustainable link between citizens, their families, communities, and even the social organization set up under national/municipal policies.

The role of a social worker as a 'networker' was the very first to identify the role in this study. Grob (1983) talks about social workers being hired in the mental health sector during the 1920s to create a functioning network between citizens and the community which unfortunately did not extend beyond the narrow realm of mental health institutions (cited in Aviram, 2002). With the various national mental health care policies, this role as a networker has surfaced again and its practice can be seen in the living facility of Tornhøjgård where they attempt to connect citizens with the social networks around. These social networks are used to tackle their problem effectively and to ease community participation (Karibeeran and Kuruvilla, 2015). This attempt to increase the network to solve the problem of the citizen is further discussed in the area of social relationships and networking and is repeated in the section on leisure and physical activities.

Social worker's role as 'social supporter' has also been highly prioritized in the organization which, in return, is said to have highly motivated citizens to participate in activities, including work and education. In response to the question posed regarding the role that the social worker should play in facilitating the inclusion, both the interviewed social workers emphasized the importance of letting the citizen know that their voices matter and that they are important and interesting in their lives as well as in others. Cobb (1979) supports this role of a social worker and defines social support as providing information to the citizen to believe that they are loved, cared for, valued, and belong to the network of communication where they have mutual responsibilities (cited in Sarason, 2013). Adding to this is the statement by House (1981, p.39) where he provides the details on the role as a social supporter; this includes 'emotional concern, instrumental aid (goods and services), information (about themselves and the environment, advice) and appraisal (cited in Sarason, 2013).

This is consistent with the statement made by the social worker regarding their role in providing adequate answers to their queries and showing them what else exists out there. To this, he stated:

"... because if you do not want to talk and do not provide an answer to their small queries then they just close the topic and adapt to what people give to them. But if you give them opportunities to be interesting (..) then they contribute in their way." (Social worker 2)

This role of social support is presumed to positively affect citizens' health and well-being. Following this is the role of a 'facilitator,' where, as mentioned earlier, the social worker not only facilitated the shift from institution to community care during the deinstitutionalization process (Piat, 1992), but they are still facilitating to ease their living in the community. The purpose behind this facilitation/assistance is to promote the individual's ability to adapt to the new situation and enable them to take care of themselves, facilitate their daily lives and eventually improve the quality of life (§ 1 of Consolidation Act on Social Services, 2007). This role has been confirmed by the citizens, where they naturally describe Tornhøjgård as a better living facility with a lot of choice and help than the one they had previously experienced. Moreover, this organization, its policy, and work/role of the social worker, all are said to be directed toward enabling community participation and improving citizens quality of life.

O'Reilly, Lancioni, and Kierans (cited in Bray et al., 2003) mention the popular notion that citizens need a very structured day in their lives but the analysis of this data revealed the contrary. Having more spontaneous activity than a fully structured day was what the citizens explained to prefer, and the social worker 1 also explained that with this they were getting away from the old idea of these citizens needing very same and structured day in a protected environment. The need for a spontaneous and daily change of activity was also used in emphasizing the importance of social workers taking on different roles to meet citizens' needs and greater policy demands of inclusion. Furthermore, the social worker 1 often speaks about the demanding nature of society along with citizens being stigmatized, which includes not being seen, heard, or understood. When asked, the citizens stated: "Our doctors are not nice". Agreeing with this, the social worker addresses the significant impact of the negative experience on the life of a person with a mental disability. She further described citizens at Tornhøjgård as a person with an intense need for social and moral support, but on the contrary, this is not what the citizens face when they try to interact with society.

"... the people are accepting more and more these days, but negative things happen also in Denmark and not every people have the patience to deal with them and especially when they sometimes do things that are not in the social rules.' (Social worker 1)

For the inclusion of the citizen in the community, there needs to have a feeling of belonging, which Biklen (1983), explains as gaining support as well as having control over one's life (cited in Bray et al., 2003). However, the aforementioned situation of being stigmatized by the community members including professionals in social settings and during activities shows that citizens are far from receiving full community support. Although, public and the private organization has launched a national-to-local level anti-stigma campaign aimed at changing people's attitude towards mental health, the need for the role of the social worker as an 'advocator' to end discrimination against citizens has been identified. As mentioned in theme 1, the social workers mentioned having worked to normalize the presence and involvement of citizens in the community and its activities hoping that this would have some kind of impact on stigma and discrimination. Here the role of a social worker as a social mobilizer can also be seen as they bring citizen's and community members together intending to raise awareness on the one hand and assist the development of citizens' skills through the use of community resources on the other ("WHO | Social Mobilization," n.d.). While this idea of mobilizing and normalizing the life of citizens in the community brings them closer to being the part of the community, it also contains the discussion of what 'normalization' of citizens is? Is it making the everyday life and behavior of the citizen closer to the norms and patterns set by the mainstream society (Nirje, cited in Flynn and Lemay, 1999), Or is it more about accepting them as they are, and supporting potential skills development? As reflected in Eurofound's active inclusion policy review (2012), the Danish government's inclusion and participation policies appear to be inclined towards the latter and mention about making possible for citizens to participate fully in societal activities irrespective of their ability and further strengthening their focus in citizen's competency Whereas the social worker stated that with increased physical appearance in society, the citizens get better in a social situation as they will be mirroring the social skills from 'normal' people. This statement by the social worker shows the incline towards citizens learning and adjusting their lives according to the ideals of mainstream society(Altermark, 2017). Although both of the norms about normalization is about taking part in community lives on the same basis as everyone else (Flynn and Lemay, 1999), the focus of the policy 'prioritizing the autonomy and self-determination of citizens' as a leading principle in community participation (Hoof et al., 2011, p.28) seems to be lacking when community participation is prioritized and practiced by the social worker. This also supports the notion of power that lies still in the hands of the public (citizens and officials) and restricts the citizen's decision about how to live (Altermark, 2017).

Despite this contradictory view of social worker/practice to literature and policy statement, it was also evident that the social worker working at the Tornhøjgård was regularly made aware of the efforts needed to bring the citizen closer to being a part of the community. This recognition of the lacking and strength of their working approach was the result of using the method called 'Marte Meo' for the appraisal, stated the social worker. With this method, the educational/informative sessions and activities are recorded and later used to enable discussion between and among social workers, stakeholders, parents, and citizens themselves, which is useful in enhancing social worker's self-learning and citizen's skill development (SOSU, 2019). Further, the organizational policy demands developing competent social workers through training, supervision, and assistance, to meet the citizens, need for support. By using different methods and with the practice of different roles, social workers at Tornhøjgård are trying to enhance the participation of the citizen at the various levels of the community. Similarly, for those citizens who were not able to communicate their thoughts properly, the social workers are seeking and providing alternative ways to express their needs, interest, and even the preferred way of participating in community life.

'We are providing them with cameras or magazine to find out if they will find something that interests them or something important for them and maybe they can cut it, clip it'(Social worker 2)

This example reflects the distinctive capacity of a social worker to adopt and provide a person-centered approach (Murphy et al., 2012) to enhance their communication skills and identify their needs and wants. Using such an approach corresponds to the challenges the citizens in daily lives. Additionally, the social worker stressed three components that one needs to have before playing any role in increasing citizen's social participation, i.e. Social mindset, social work values, and professionalism. The 'social mindset' includes the focus of skill development of a person (practitioners and citizens) than focusing on the process, 'social work value' includes the code of

ethics by NASW, (1996) which promotes the principle of justice, dignity and worth of the person, human relationship and developing competence. These stated components were the main values of the organization that the social worker pointed out and translated from the organization's web page.

With the aforementioned role of networker, social supporter, advocate, mobilizer, and other various roles based on the needs and demands of citizens and even members of society, social workers are working to enhance community participation of the resident at Tornhøjgård. Supporting this role and practice of community participation in the political reform of deinstitutionalization and various policy formulated to actively integrate citizens back into the social-labor market.

## 4.3. The aspects of community participation

The participation of citizens in different domains of social life was analyzed through observation, interviews, and documents provided by the organization. Along with this, the organization's awareness, planning, and initiatives to develop a presence in areas where community participation is lacking were observed. This subject of participation and non-participation will be the content of the sub-themes presented below. These sub-themes include the area as *Labor-market integration*, *Education, social relation*, and *physical activity and leisure*. As regards daily participatory activity in the community, there was no particular set of information at an individual level, which shows that there is not any list of a structured approach for citizens' community participation but rather adopts a flexible approach following the citizen's needs. This, according to the social worker, is the way to distance them from the past where they used to treat citizens differently and structure their day to meet the institutional goal.

The terminology of participation and self-determination has been repeatedly prioritized and stated under various social policies, acts, and literature related to mental health care since the last decades of the 20<sup>th</sup> century (Altermark, 2017). Thus, the findings from Tornhøjgård will be further discussed and analyzed with the help of these policies and published literature. Besides, the influence of these policies on increasing/decreasing the opportunity for community participation will also be part of the discussion. Examining the findings further, it was found that the feeling of belonging plays a very important role for citizens to participate in any of the below-mentioned

domains. Here, the sense of belonging is connected to getting control over one's life issue, free choice, support, and a feeling of contribution and importance in other lives (Biklen, 1983 cited in Bray et al., 2003). This component of a feeling of belonging has arisen repeatedly emerged under the theme 'aspect of community participation' and will be discussed in more detail below. As mentioned in the earlier part of the discussion that, in the organizational structure, the relationship to past mental health practices is still somewhat evident, it was discovered that the social worker was equally trying to distance themselves, their activities, and citizens from it. As an example of this, it was found that prioritizing citizen need, and their feeling of belonging is now more important than meeting the institutional goal. Furthermore, the concept of inclusion and participation is adopted and understood as a break with the past (Altermark, 2017).

## 4.3.1. Labor market integration

In multiple literatures and national and international policy papers cited in different sections of this study, the integration and participation of people with mental health problems in the wage labor market was a predominant topic. This prioritization in the labor market was also evident in every interview and discussion related to community participation and was even given priority on the organization's website. Supporting policy initiatives such as § 1 of the Social Pension Act, which states about the provision of protected employment for the citizens with reduced physical or mental disability or a provision of flex job in the case where citizens cannot obtain or maintain employment under normal conditions in the labor market (Consolidation Act on Social Services, 2007). Further, the municipal responsibility and offer of employment programs for persons with special social problems are highly prioritized and marketed. Looking at the practice, it was found that citizens were supported to be part of the paid/voluntary labor market based on their interests and abilities, including the provision of training to improve their skills. This was done through the partnership of the municipal level organization named 'Aalborg Aktiv". While this integration helps citizens to improve their social and specific work skills, motivation and personality, it still holds the concept that being part of the community means that one has to be considered worthy of it, and for this citizens need to make a productive contribution to the sector is of importance to others in the society (Altermark, 2017; Chatterji et al., 2011). This was evident with Citizen 1 who said it was uninteresting and not important for her to be part of her previous work but still ending up doing it for a long time. Further, as stated by the social worker 1, the policy regarding the

downsize the government pension for the citizens has been formulated in Denmark. To this, he stated, *Yeah, money is the problem because they do not have high pensions as they used to get*" (Social worker 2). OECD, (2013) report explains this situation by stating that the large and growing number of citizens under the age of 25 are moving into various forms of disability benefits with little or no job experience. This, on the one hand, forced citizens to adjust their living conditions, limit their social movement, and cost-effective choice of participation in activities, while, on the other, it was used to present the economic importance of labor market inclusion (Hoof et al., 2011).

Furthermore, the political focus of 'wage labor integration' has resulted in the stigmatization of those citizens who were unable to enter the labor market for some reasons as unworthy of being part of the community, and this has paradoxically contributed to their exclusion (Altermark, 2017; Larsen, 2003). It was also disclosed that the labor market involvement and earnings of citizens do not compare to others as most of them are part of voluntary work or earns a really low wage. To illustrate this, the social worker spoke about the citizen's current situation on the labor market where only one citizen has been able to obtain a job that pays him a regular wage and that most citizens contribute to the labor market but are either paid less or not paid at all, and that does not benefit them financially. Therefore, a combination of low finance, the political focus on labor market integration, and relatively high costs for participating in community-based activities have limited social movement and participation; further contributing to limiting the skills needed to be a part of community life.

Looking at the work-life domain of community participation in Tornhøjgård, it appears that two major challenges have prevailed. First, the failure to incorporate everyone on the labor market despite the inter-organizational partnership and, second, the failure to improve/increase working citizen's participation in other areas of community life. Concerning the first challenge, the labor market policy has included some financial incentives as a strategy to encourage private employers to employ citizens with disabilities (Eurofound, 2012). The challenge persists, however, as it has been found that the intensive does not compensate for the employer's financial investment in citizen training and employment, and that appears to discourage the employer. This was evident in the statement of social worker 2 where he gave the recent example of a citizen whose work was terminated since one of the citizens was also unable to contribute as efficiently as others and the co-workers lacked an understanding of the situation.

"She works in (name) social organization and one worker there had an issue with her and said that she could not fit in there. (...) She was going there and was happy (....) now the citizen's work suddenly stops and has been hurt, and this is a social organization and them if anyone should understand the citizens (...) now it is our work to make him/her understand what happened, talk about the experience there and learn from this incident and tell that it was not his/her mistake". (Social worker 2)

We can see the connection between mental health and the ability of individuals to obtain and maintain jobs, as well as the willingness of employers to provide the necessary adaptation for citizens. This problem with integration citizens in employment is also mentioned by Chatterji et al., (2011), in which they talk about how it is common for citizens to face direct or indirect discrimination concerning employment and how this affects their financial situation and ultimately affects participation. Following the negative experience, the social workers of the organization said that they tend to reach such a situation by acknowledging the citizens' emotions and by attempting to prevent emotions of guilt and anxiety through dialogue. This in line with the role of a 'supporter' mentioned under the theme of 'Social worker's role' of this chapter. Additionally, studies have found that such negative labor marker results could lead to low self-esteem for individuals and increase the risk of other psychiatric disorders which is opposite to the goal of inclusion. (Chatterji et al., 2011).

The second challenge can be related to the prioritization of the labor market integration by the policy than any other domain of community participation. Contrary to the prioritization, the social worker pointed out the existing situation in the labor market where not everyone involved has been able to be part of the community and improve their social skills. Here, one social worker added:

"I have seen some of the citizens who for many years working in the same place all their life in Vodskov and of course they find difficult to get out in the society because they are with people with the same disability and they go to work and come back home (...) they do not learn social skills because they only mirror themselves." (Social worker 1)

With this, the social worker pointed out that, intending to involve a greater number of citizens on the labor market, the municipality is creating possibilities for citizens to engage in both the public and private employment. But as mentioned, integrating citizens in the private sector has a different challenge of its own and this results in a majority of the citizens working with other citizens in the Vodskov area (municipal department of the elderly and disabled), and that sometimes leads them not to develop any Social skills.

Nonetheless, the organization aims to provide them with some sort of job that will serve the goal of both the policy and provide meaning and happiness in the life of citizens. And along with the challenges there has been evidence of equally positive results. For the individual working citizen, their integration in the labor market gave them skills and self-confidence to be in the community, and above all, they found something they could contribute to, which increased the sense of importance in their own lives and others. Whereas for the organization, the financial boundaries provided them space and potential for innovation where they could start working towards the establishment of new partnerships and cooperation with neighborhood activity centers and organizations within and beyond municipality. This approach to work has made it easy for citizens to access services at low rates while being able to connect directly with members of the community.

#### 4.3.2. Education

Community participation means inclusion in everything that is part of the community itself and education is one of the main parts of how we live within the community (Bray et al., 2003). This sub-theme of education is connected to the method of enabling community participation of citizens by developing their potential, personalities, and other social skills and abilities. One of the ways that the living facility has prioritized the education domain is by developing a small year-long project named 'a meaningful-day activity' (*translated*) where citizens take part in classroom education; including reading and writing, and in practical education; including broader social, environmental, and economic aspects five days a week. Stating the project's goal of teaching citizens how to read and write along with various social issues and competences, the social worker highlighted their enhanced skills in getting out in the community and dealing with everyday life activities. While this particular project said to have arisen out of the need to involve active yet unemployed citizens in meaningful activity, the underlying factor of most citizens not having education beyond compulsory schooling plays a huge role in underlining the importance of this educational project in the lives of the citizens involved. As a result of the project, the involved

social worker stated to have seen enormous growth in citizen's self-esteem and social skills and assume that this development will further open up the pathways for citizens to participate in other spheres of community life. The fact that the importance of education and entitlement of citizens to a classroom or other form of vocational education set out in national and organizational policy documents has also played a huge role in the creation of this project.

Despite the national and municipal effort for compulsory education (primary and secondary), the high early termination of schooling among the citizens was discovered. This was confirmed by social worker stating:

'the education for them stopped after primary level and they do not learn more, then they get out for a place where they can be for the next 20-30 years doing nothing interesting and that is a problem, I think education is important, and they need to evolve too." (Social worker 1)

The fact was not only evident in Tornhøjgård but was also part of policy reviews and much social science literature (Bray et al., 2003; OECD, 2013). Also, as stated under the theme of the *living facility and its practice*, we can see the features of re-institutionalization as mentioned by Chow and Priebe (2013) and Piat, (1992). Moreover, not only does this situation affect citizens' personal development, but it has also made access to other domains of the community as a labor market or community institution, ultimately creating an obstacle to achieving the policy objective of inclusion. This situation along with the existence of the assumption and stigmatization of citizens being unable to take part in educational activities, as stated by the social worker, shows the challenge in full integration and shows that people with mental/intellectual disabilities are still not equal (Altermark, 2017). To this, Hoof et al., (2011) suggest the creation of public anti-stigma campaigns along with the education of professionals who are directly or indirectly involved in the lives of people with mental disabilities including mental health professionals.

#### 4.3.3. Social networking and relationship

The researcher's first observation was related to this sub-theme, where most of the citizens were in small groups. The social worker said most citizens have a group they identify as members of and that group is formed with each other based on their commonality. Whereas others are formed as they commute to the same workplace or on the same route. This domain of social networking

and relations were found to have a significant level of influence in determining and enhancing the community participation of the citizens. This influence was evident in the participant's statement explaining how important it is for them to have a friend with whom they can talk to and can together take part in educational, physical, and recreational activities. It was found that every member of these groups has his or her role and responsibility. E.g.: To support the group's least capable member. It was also important for citizens to have a good relationship and to be liked and appreciated by the people at work. In this context, Newton et al. (1994) stated two major aspects of a social network: 'people described as important to an individual' and 'people with whom activities are undertaken' (cited in Bray et al., 2003, p. 11). This aspect was evident in the citizen's group, in which they identify themselves as a member and where they explain to "practice qualitative relationship, feeling of belonging and also have a mutual responsibility" (Newton et al., cited in Bray et al., 2003, p. 11). This group relationship also acts as a support system and tends to drive the participation of citizens in other domains of community life.

While this aspect of the citizen-to-citizen social relationship was not the goal of inclusion policy, its role in achieving any other policy goal is undeniable, and realizing this, the relationship among the facility has been given enormous priority. The mutual responsibility undertaken by the citizen within a group can also be classified as a form of participation as WHO (2005) describes participation as any decision that affects their lives, including being informed, taking responsibility, and collaboration with community members. Although this relation within the facility is playing positive in the citizen's lives, it was found that the social network beyond the facility and family (in the case of some citizens) seems to be lacking. One observation made by the research led to the understanding of this aspect of a social relation which was later posed as a question in a semi-structured informal interview with the citizens. Though present in the same space, the citizens have had no sort of dialog with any people. When asked whether or not they interact or want to interact with people in the community, one citizen stated.

(...) no, we do talk to many people outside, I want to talk with many people, so I have a friend inside Tornhøjgård, and I visit my family. (Citizen 2)

As an answer to the same question, another citizen stated: "I like to go out and buy stuff and talk with people, but I don't know if they want that. The only people from outside I talk to is my friend who sometimes comes to visit me" (Citizen 1)

Further, the emphasis of the Social Services Act is on enhancing networking (Aalborg Kommune, 2016) seems to have been on paper and claimed to be challenged when attempting to implement it. The challenge for this was stated to be coming from both the citizen and community members. Citizens found it difficult to communicate their thoughts and both parties found it difficult to understand and converse along. This further proves the previously stated need and importance of making citizen's physical presence common and normal in the society along with the public antistigma campaigns and education as suggested by Hoof et al., (2011). A critical look at citizens confined relationships and support within the facility, i.e. between fellow citizens and practitioners, further demonstrates their reliability for carrying out activities, care, and support. The citizen's reliability in daily interaction with professionals as stated by Engen et al., (2019) is linked to the fact that a citizen's autonomy and self-determination has not been achieved and further restricts the possibility of community participation and the development of other sources of social support (Newton et al., cited in Bray et al., 2003).

# 4.3.4. Physical and leisure activity

The theme of leisure and physical activity arose in an attempt to understand what citizens do in their free time, and how or whether the organization uses their free time as an opportunity to engage citizens in public or social activities. Leisure and physical activity, just as it is an individual and private pursuit, is also an important area of community involvement. For citizens with intellectual/mental disabilities, this involvement, on the one hand, helps to express their choice, develop independence, self-esteem, and confidence, and, on the other, strengthen community connections. (Bray et al., 2003). The finding presents this sub-theme as a domain within community participation which has been able to include every citizen regardless of their degree of mental disability, previous experience, or particular sets of skills. Citizens are more likely to take part in organized physical and leisure time activities depending on their interests and experiences. The usefulness of this domain for social workers in understanding citizens' choice and ensuring the meaningfulness of the activities carried out along with teaching citizens how to express their

choice has been mentioned in multiple types of research. (Jahoda A, Cattermole M.; Browder, Cooper, and Lim, cited in Bray et al., 2003). According to Browder et al. (1998), this can be done by offering different options, seeing which activities they are more involved in, performing better, exhibiting fewer problems, and having more cooperation (cited in Bray et al., 2003). This method providing choice and facilitating the expression of their thoughts and choices is assumed to enhance their participation not only in the physical/leisure activities but also in other domains of community participation. The social worker validates this analysis by commenting on the extra time and effort that the citizens have put into the activities of their interest, and further acknowledges the improvement of their performance if done in a group. Moreover, the leisure activity and the vacation trip that this social facility organizes is something that the participant's citizens stated to have been looking forward to. When asked more about their physical and leisure activity two citizens said:

"I like this place better than where I come from and because from here, we go for a vacation and I keep my money for that". (Citizen 1)

Moreover, this prioritization of activities is supported by the policy where § 81 of the Consolidation Act on Social Services (2007) talks about putting special efforts to improve opportunities for the citizens through contact, access, and activities.

The study further tried looking at citizen's and practitioners' experience of accessing public spaces, along with the opportunities and constraints they face while taking part in the activities. This citizen's statement above reveals that leisure activity is important for them and when further asked about the activities they are interested in doing, they said that they would like to go to a club and go to the fitness center with a partner, but they are expensive. Their statement about this includes, "So, at the weekend I stay inside and watch tv-program a lot", and "I listen to a lot of music and visit my family", and "..sometimes my friend visit me" (citizen 1 and 2). This statement shows the direct relation between finance and social participation, especially in terms of the choice they made for social participation/non-participation. As these passive activities were found to predominate in the facility, it was also evident that the organization is constantly striving to find an alternative and feasible way to connect citizens with the neighborhood's physical activity center to improve their social and physical mobility and ultimately improve their life quality.

As mentioned earlier in the theme labor market, the received disability benefit from the state, as mentioned by a social worker, is less than what the citizen use to get before and it is merely adequate to have access to socio-physical activities in established sports and activities center. Hence it is even more important to establish a good network with the neighborhood center to increase citizens' access to social and physical activities. This could also mitigate the challenges of community participation that has resulted from public transport costs and a lack of private transport for citizens. While the cost of accessing the activity remains a challenge, it has been found that the clubs and bars in the city center are creating a welcoming environment for citizens which is promoting their participation in social spaces in a positive way.

Further emphasizing the organization's efforts and face barriers in creating active and informative leisure / physical activity, the social worker stated:

"I am trying to find someone who could teach them some creative stuff but it has been difficult to find a teacher and when we are in a bigger group I take them to the Gigantium once a week and it is obviously for their fitness but these activities we are doing, I think, I want it to affect the choice they make when we are off from the setup day activity." (Social worker I)

First, in this statement, the social worker refers to the challenges of finding external support for skills development through recreational activities for citizens, and the challenge of finance surfaced here again. Next, attention has been given to physical activity because of its contribution to health and compliance with this is the statement by Bray et al., (2003), which talks about the situation where citizens with mental/intellectual disabilities are at increased risk for health-related problems due to their rare involvement in physical activity. Finally, there has been mention of the role of social workers in influencing the choice they make during their free time. Here, the statements of the social worker clarify how the social facility uses this domain as a means to influence and enhance participation and, in doing so, faces challenges.

Focusing on challenges and barriers, it was found that because of the presence of uneven numbers of citizens to practitioners, the issue of spending free time is seen less as a way of providing individual choice and preference, and more as a group activity and time filler. Felce et al., (2000) also point out in their study this need for staff resources in social facilities to increase the opportunity for citizens to go out and participate in community activities. Moreover, participation

in leisure/physical activity varies between working and non-working citizens. Despite this, most of the citizens were reported to have been able to participate in at least one activity at any public place which suggests the degree of presence and participation within the community.

## 4.4. The concept of community in Denmark

For the social-living facility, acquiring full community participation of its citizens is naturally a major goal towards reaching the aim of policy. But before learning what is qualified as participation, it is important to know what consists of the understanding of the term community. The dynamic nature of the concept has been acknowledged before by the researcher and in the interview, this query was covered by the question regarding the places/activities that the organization wants its citizens to take part in along with the place where citizens think they belong to. This was also followed by what kind of places have they tried involving the citizens. It was interesting to see that the word community is connected more with the community organization and activity centers than the collection of individual citizens, families, or neighborhoods.

"We talk to different kinds of a sports organization and ask them do you have any social responsibility for people with handicap and lot of organization wants to be part of that and if we have enough citizen who wants to participate then they create something for us," (Social worker 2)

In the paper by Walker (cited in Bray et al., 2003), the description of community participation is given to the concept of 'sense of place' which talks about involving positive attachment or identification with a place. Connecting the finding with this concept of 'sense of place', Sport and physical activity centers were seen as a greater enabler of community participation. Citizens also talked about these activities center when asked about the aforementioned question of where they want to be. This led to a previously mentioned understanding of the influence of social workers in the lives of citizens and citizen's reliability on social workers in determining their choice of activities, which can be both positive and negative as explained in the sub-theme of social networking and relationships.

Next, away from the past idea of community, based on monocultural and traditional values (a character of community which still exist on the part where the researcher is from), the Danish

concept of community was found to have incorporated a variety of concepts, including the geographical distance and one's sense of place and belonging (Bray et al., 2003). But with this varied description of the community, it was notable that none of the interview participants mentioned talking to neighbors, individuals, or families living/working around unless explicitly asked.

"We would like to see them talking to people around, but that does not happen here, but if you go to the sports club you will find socially-minded people. (...) You find these organizations everywhere in Denmark and that is the place where you can trust people and there, we connect people, we network, we socialize." (Social worker 2)

Here, one can find that this contact with these sports-based community organizations is taken as a crucial aspect of community participation even though these organizations are not particularly for people with mental disabilities. From the social worker's point of view, this is the situation because the Danish society is more individualized and these sports-based community organizations play a major role in the development of community attitudes within a society where one's life and services are growing more individually. Connecting it to the philosophical point of constructivism, we know that the conceived knowledge of community participation differs from context to context. In the Danish social context, it means involvement in neighborhood activity centers which are further assumed to be best fitted by the political institution and adopted to bring about the desired change in the policymaking process.

## **CHAPTER 5: Conclusion**

This final chapter starts with a summary of the major findings regarding the citizens' participation in the community and the policies that supported or opposed it. After that, the chapter includes the researcher's reflection on the experience of the thesis period followed by the study's strengths and limitation and the chapter ends with an attempt to identify areas for future research.

## **5.1. Summary**

The main aim of this research was to explore the practice of community participation at the local level and understand how Denmark's adoption of policies on the active inclusion of people with intellectual disabilities has been influencing this explored meaning and practice of community participation? Looking at the forms of community participation, it was found that the entire process of an engaging citizen in community life, focused by policy and implemented at the local living facility, was driven by the process of deinstitutionalization that emerged in the Western world. This was evident through the organizational focus on i.e. free choice and self-determination, an objective highlighted during the deinstitutionalization process. During the study, different roles of social workers and organizations were found including the role of Networker, social supporter, sharing responsibility, facilitator in social-physical activities, advocate; all of this indicated the changing role and importance of social work in the lives of citizens and the mental health sector. Besides, the various policies relating to the active inclusion of the citizen ranging from citizens entitled to work, education, housing, free choice, skill development were found to support the organization's community participation initiative. Further, inadequate finance, the perception of community and practitioners, dependability on social workers, and the policy focus on qualifying the citizens on the socially described definition of 'capable citizen' rather than embracing person as they were found to be challenging factors (Altermark, 2017).

## 5.2. Reflection on my experience

This reflection on my experience is presented to highlight the dilemmas and insights gained during this thesis period. Initially, I chose the topic to conduct a comparative study and understand the difference and possible similarities between the practice of community participation in Denmark and Nepal. Whereas the mental health sector was chosen as it was my topic of interest and also because it helped narrowing down the topic. As mentioned in this study's positioning section and

as anticipated, the concept of community participation was not similar, but it was also realized that the difference was too vague and self-evident for the comparative study to be carried out. It was found during the interview that the concept of community (participation) for the Danish includes the place where they gather for formal/informal organizational activity such as a sports center and end when they return home, whereas the concept of community (participation) in Nepal begins and ends within your neighborhood, and does not include any formal/informal organization. It is important to note that this statement has been my personal experience and is generalized and that there is always an exception. Because of this very reason, the study was made more exploratory in which I could increase my understanding of the topic and, if possible, generate new knowledge for the readers. But, once I get into the subject in-depth, the dilemma arises. For me, the subject under study was newer than for anyone at Aalborg University to whom I would submit this thesis. Even the concept of deinstitutionalization was something that I never came across until I joined my master's degree. Therefore, I could not say if my thesis which is based on the limited knowledge that I gained during this five-month study would generate any valuable/new knowledge. The next dilemma that I am going to present here arose because of my social, cultural, and economic background. It was repeatedly pointed out during the study that the financial challenge constituted the major barrier to citizen participation in the community. The further discussion on this revealed the actual amount that the citizens get for physical/social activities per month. Knowing the amount made it difficult for me to see how finance is still a challenge, as the participant has stated, and also led me to reflect the concept of absolute and relative poverty. I, therefore, decided to use the concept of 'bracketing' and present the challenge as stated by the participant, although it was personally challenging for me to comply with this. The final reflection was noticed during the observation period of 3 days. The interaction with the social worker gave an impression of a situation where it would be difficult to connect with the citizen because I am an outsider who could not speak Danish. Instead, I found out a completely different situation. The first meeting was uncomfortable, and the citizens were indifferent to me for unknown reasons which made it even more difficult for me to approach them. But as soon as I seek help from the citizen to figure out the transport to the destination, the attitude of the citizen changed, and they began to help me with their hand gesture. Afterward, it was easier and comfortable for us to approach each other for the rest of the observation days. This made me realize that my request for help could have made it easier for them to relate with me and see me as someone who needs help just as much as they do.

All of these experiences have contributed to improving my learning while making the thesis period challenging and interesting at the same time.

## 5.3. Strengths, limitations, and further recommendations

The research's very first strength and limitation came with the case study approach employed in this research. This strength and limitation were based on the researcher's understanding of the subject matter and is derived from the case study method's description as presented in McNabb's, (2004) book. Following the case study approach guidelines, the researcher tried to discuss each topic in-depth, understand why the things are the way they are, and then try to make sense of the situation rather than just describe it (McNabb, 2004). Furthermore, since the topic of the study is also about connecting the policy that influenced the findings, the researcher acknowledged and tried to recognize and understand the complexity of political process. While the political process such as deinstitutionalization has been linearly presented using multiple resources, the research understands that the process is not as single-faced as show and only provides a snapshot of the phenomenon (McNabb, 2004). For example, this study simplifies the definition of deinstitutionalization as just a shift from institutional to community care of people; a process that has done the ultimate good for citizens like connecting them back to the community, prioritizing their right and position among the general public and even helping to underline the importance of the social work profession in the mental health sector. But its other side, i.e. other ideological, philosophical and economic factors that lead to the process of deinstitutionalization, its rise as an unclear and ambiguous policy and its failure to incorporate the ideas and voices of the community, were not part of this study's analysis (Piat, 1992). Besides, the study has very fewer participants than anticipated and because of the language barrier, the researcher had to rely on a social worker's translation to obtain the opinion of the citizen. It is also important to recognize that the conditional nature of social science research, i.e. finding's dependability on the place, time, researcher, and participation, influences its validity as its total replication is not possible. However, the research attempted to gather a thick description of the studied topic through the use of multiple sources and participants in the data collection process.

The present study was limited to finding and understanding the process of community participation and did not examine broader topics that are attached to the study such as the concept of empowerment, notions of normalization, citizenship, discrimination, the abovementioned aspect

of deinstitutionalization (i.e. its negative and positive impact) and even the knowledge and competence of social workers. Although some of these topics did not arise directly during the findings, it could have been the part of the discussion, but the researcher chose to limit oneself within the boundaries of the research question due to time limitation, the vagueness of these concepts, chosen methodology and interest. Therefore, any future research undertaken on a similar topic could be carried out from the point of the above notion.

## REFERENCES

- Aalborg Kommune, 2016. Serviceniveau Voksen-Handicap [WWW Document]. Ældre- og Handicapforvaltningen. URL http://www.e-pages.dk/aalborgkommune/1528/html5/ (accessed 3.16.20).
- Aalborg Kommune, 2012. Serviceniveau for Voksen Handicap [WWW Document]. Ældre- og Handicapforvaltningen.

  URL https://www.aalborg.dk/om-kommunen/organisation/%C3%A6ldre-og-handicapforvaltningen (accessed 3.16.20).
- Akyurek, G., Bumin, G., 2017. Community Participation in People with Disabilities. Occupational Therapy Occupation Focused Holistic Practice in Rehabilitation. https://doi.org/10.5772/intechopen.68470
- Altermark, N., 2017. Citizenship Inclusion and Intellectual Disability: Biopolitics Post-Institutionalisation. Routledge. https://doi.org/10.4324/9781315109947
- Amado, A.N., Stancliffe, R.J., McCarron, M., McCallion, P., 2013. Social Inclusion and Community Participation of Individuals with Intellectual/Developmental Disabilities. Intellectual and Developmental Disabilities; Washington 51, 360–75.
- Asquith, S., Clark, C.L., Waterhouse, L., Scotland, Education Department, Information and Analytical Services Division, Scotland, Social Research, 2005. The role of the social worker in the 21st century: a literature review. Information and Analytical Services Division, Scottish Executive Education Department, Edinburgh.
- Aviram, U., 2002. The Changing Role of the Social Worker in the Mental Health System. Social Work in Health Care 35, 617–634. https://doi.org/10.1300/J010v35n01\_15
- Bengtsson, S., 2009. Report on the social inclusion and social protection of disabled people in European countries Focus on Denmark [WWW Document]. EPALE European Commission. URL https://epale.ec.europa.eu/is/node/3277 (accessed 4.15.20).
- Berger, R., 2013. Now I see it, now I don't: researcher's position and reflexivity in qualitative Research. Qualitative Research 15, 219–234. https://doi.org/10.1177/1468794112468475
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. Qualitative Research in Psychology, 3 (2). pp. 77-101. ISSN 1478-0887. https://doi.org/10.1191/1478088706qp063oa

- Bray, A., Gates, S., Ed, M., 2003. Community participation for adults with an intellectual disability. National Advisory Committee on Health and Disability 50.
- Bryman, A., 2016. Social Research Methods. Oxford University Press.
- Carroll, P., Witten, K., Calder-Dawe, O., Smith, M., Kearns, R., Asiasiga, L., Lin, J., Kayes, N., Mavoa, S., 2018. Enabling participation for disabled young people: study protocol. BMC Public Health 18, 712. https://doi.org/10.1186/s12889-018-5652-x
- Chan, D.M., 2009. Mental health: Central to Human Development 6.
- Chatterji, P., Alegria, M., Takeuchi, D., 2011. Psychiatric disorders and labor market outcomes: Evidence from the National Comorbidity Survey-Replication. J Health Econ 30, 858–868. https://doi.org/10.1016/j.jhealeco.2011.06.006
- Chow, W.S., Priebe, S., 2013. Understanding psychiatric institutionalization: a conceptual review. BMC Psychiatry 13, 169. https://doi.org/10.1186/1471-244X-13-169
- Consolidation Act on Social Services [WWW Document], 2007. Retsinformation. URL https://www.retsinformation.dk/forms/r0710.aspx?id=175036. (accessed 4.27.20).
- Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A., Sheikh, A., 2011. The case study approach. BMC Med Res Methodol 11, 1–9. https://doi.org/10.1186/1471-2288-11-100
- Davies, C., 1989. Goffman's Concept of the Total Institution: Criticisms and Revisions. Human Studies 12, 77–95.
- Eid, N., 2018. Integration vs Inclusion in Education System.
- Engen, M., Rømer, M., Jørgensen, A., 2019. Public Care for People with Intellectual Disability in Denmark Ideals, Policy and Practice. Scandinavian Journal of Disability Research 21, 228–237. https://doi.org/10.16993/sjdr.582
- Eurofound (2012), Active inclusion of young people with disabilities or health problems, Publications Office of the European Union, Luxembourg.
- European Commission, n.d. Transition from institutional to community-based services (Deinstitutionalisation) [WWW Document]. URL https://ec.europa.eu/regional\_policy/en/policy/themes/social-inclusion/desinstit/ (accessed 1.18.20).
- Felce, D., Bowley, C., Baxter, H., Jones, E., Lowe, K., Emerson, E., 2000. The effectiveness of staff support: evaluating Active Support training using a conditional probability approach.

- Research in Developmental Disabilities 21, 243–255. https://doi.org/10.1016/S0891-4222(00)00040-8
- Flynn, R.J., Lemay, R.A., 1999. A Quarter-century of Normalization and Social Role Valorization: Evolution and Impact. University of Ottawa Press.
- Gábos, A., Goedemé, T., 2016. The Europe 2020 social inclusion indicators., in: P o v e r t y R e d u c t i o n i n E u r o p E : S o c i a l P o l i c y a n d I n n o v a t i o n. Presented at the 7th Framework Program of the European Union.
- Gilgun, J.F., 1994. A Case for Case Studies in Social Work Research. Social Work 39, 371–380.
- Goodwin, D.S., 1997. Comparative Mental Health Policy: From Institutional to Community Care. SAGE.
- Gosepath, S., 2011. Equality, in: Zalta, E.N. (Ed.), The Stanford Encyclopedia of Philosophy. Metaphysics Research Lab, Stanford University.
- Grandy, G., 2010. Instrumental Case Study, in: Encyclopedia of Case Study Research. SAGE Publications, Inc., Thousand Oaks, pp. 474–475. https://doi.org/10.4135/9781412957397
- Guba, E.G., Lincoln, Y.S., 1994. Competing paradigms in qualitative research, in: Handbook of Qualitative Research. Sage Publications, Inc, Thousand Oaks, CA, US, pp. 105–117.
- Handicapafdelingen, Aalborg Kommune, n.d. Handicaptilbuddene, Botilbud i Fagcenter for Livskraft [WWW Document]. URL https://handicaptilbuddene.aalborg.dk/fagcentre/fagcenter-for-livskraft/botilbud/institution?InstId=256 (accessed 2.17.20).
- Harrison, H., Birks, M., Franklin, R., Mills, J., 2017. Case Study Research: Foundations and Methodological Orientations. Forum Qualitative Sozialforschung / Forum: Qualitative Sozial Research 18. https://doi.org/10.17169/fqs-18.1.2655
- Hoof, F.V., Knispel, A., Schneider, J., Beeley, C., Aagaard, J., Putten, M. van, Keet, R., Snuverink, S., 2011. Outpatient care and community support for persons with severe mental health problems: A comparison of national policies and systems in Denmark, England and the Netherlands. Netherlands Institute of Mental Health and Addiction, Ladenius Communicatie BV, Houten.
- Institut for MenneskerettighederHuman Rights, n.d. Disability [WWW Document]. INSTITUT FOR MENNESKERETTIGHEDER. URL https://www.humanrights.dk/our-work/our-work-denmark/disability (accessed 2.26.20).

- Karibeeran, S., Kuruvilla, C., 2015. Community Participation Towards Effective Social Work Practice. Indian Journal of Applied Research 5, 16–18.
- Larsen, J.E., 2003. Social Inclusion and Exclusion in Denmark 1976 to 2000, in: Social Policy Research Centre (UNSW). Presented at the Australian Social Policy Conference, p. 51.
- Leavy, P., 2014. Oxford Handbook of Qualitative Research: Oxford Handbook of Qualitative Research. Oxford University Press, Incorporated, Cary, UNITED STATES.
- Longhurst, R., 2009. Interviews: In-Depth, Semi-Structured, in: International Encyclopedia of Human Geography.
- Mannarini, T., Fedi, A., 2009. Multiple senses of community: the experience and meaning of community. Journal of Community Psychology 37, 211–227. https://doi.org/10.1002/jcop.20289
- Masolo, D.A., 2002. Community, identity and the cultural space. Rue Descartes n° 36, 19–51.
- McEvoy, R., Tierney, E., MacFarlane, A., 2019. 'Participation is integral': understanding the levers and barriers to the implementation of community participation in primary healthcare: a qualitative study using normalization process theory. BMC Health Serv Res 19, 1–14. https://doi.org/10.1186/s12913-019-4331-7
- McNabb, D.E., 2004. Research methods for political science: quantitative and qualitative approaches. Routledge Publication, London and New York.
- Merriam-Webster, n.d. Definition of COMMUNITY [WWW Document]. URL https://www.merriam-webster.com/dictionary/community (accessed 5.6.20).
- Morgan, D.L., 2007. Paradigms Lost and Pragmatism Regained: Methodological Implications of Combining Qualitative and Quantitative Methods. Journal of Mixed Methods Research 1, 48–76. https://doi.org/10.1177/2345678906292462
- Mossialos, E. (Ed.), 2007. Health system in transition, Denmark-Health System Review. European Observatory on Health System and Policy 9, 187.
- Murphy, D., Duggan, M., Joseph, S., 2012. Relationship-Based Social Work and Its Compatibility with the Person-Centred Approach: Principled versus Instrumental Perspectives. British Journal of Social Work 43, 703–719. https://doi.org/10.1093/bjsw/bcs003
- NASW, 1996. National Associacion of Social Workers (NASW) [WWW Document]. NASW National Associacion of Social Workers. URL https://www.socialworkers.org (accessed 5.1.20).

- OECD (Ed.), 2013. Mental health and work: Denmark, Mental health and work. OECD, Paris.
- Piat, M., 1992. DEINSTITUTIONALIZATION OF THE MENTALLY ILL: Theory, Policy, and Practice. Canadian Social Work Review / Revue canadienne de service social 9, 201–213.
- Priestley, M., 2001. Disability and the Life Course: Global Perspectives. Cambridge University Press.
- Ringø, P., Høgsbro, K., 2017. The conception of disability and mental illness in advance welfare states a review and a proposal, in: Social Work and Research in Advances Welfare States. Routledge, pp. 185–196.
- Sarason, I.G., 2013. Social Support: Theory, Research and Applications. Springer Science & Business Media.
- Simplican, S.C., Leader, G., Kosciulek, J., Leahy, M., 2015. Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. Research in Developmental Disabilities 38, 18–29. https://doi.org/10.1016/j.ridd.2014.10.008
- Social supervision Nord (SOSU), 2019. Seneste tilsyn- Tornhøjgaard (Supervision Report No. 3), Tilbudsportalen. Botilbuddet Tornhøjgaard.
- Talò, C., Mannarini, T., Rochira, A., 2014. Sense of Community and Community Participation: A Meta-Analytic Review. Soc Indic Res 117, 1–28. https://doi.org/10.1007/s11205-013-0347-2
- Taylor, S.J., Bogdan, R., DeVault, M., 2015. Introduction to Qualitative Research Methods: A Guidebook and Resource. John Wiley & Sons, Incorporated, Hoboken, UNITED STATES.
- The Mental Health Foundation (Annual report), 2009. United Kingdom.
- The Ministry of Social Affairs and Integration, 2011a. SOCIAL POLICY IN DENMARK.
- The Ministry of Social Affairs and Integration, 2011b. Social Policy in Denmark [WWW Document]. URL http://www.oim.dk/media/14947/social-policy-in-denmark.pdf
- Turner, J., Hayward, R., Angel, K., Fulford, B., Hall, J., Millard, C., Thomson, M., 2015. The History of Mental Health Services in Modern England: Practitioner Memories and the Direction of Future Research. Med Hist 59, 599–624. https://doi.org/10.1017/mdh.2015.48
- United Nations, 2006. Convention on the Rights of Persons with Disabilities (CRPD) [WWW Document]. URL https://www.un.org/development/desa/disabilities/convention-on-the-

- rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html (accessed 2.26.20).
- Verdonschot, M., Witte, L., Reichrath, E., Buntinx, W., Curfs, L., 2009. Community participation of people with an intellectual disability: A review of empirical findings. Journal of intellectual disability research: JIDR 53, 303–18. https://doi.org/10.1111/j.1365-2788.2008.01144.x
- Warner, R., 1989. Deinstitutionalization: How Did We Get Where We Are? Journal of Social Issues 45, 17–30. https://doi.org/10.1111/j.1540-4560.1989.tb01552.x
- WHO, 2005. Participation. World Health Organization. URL https://www.who.int/gender-equity-rights/understanding/participation-definition/en/ (accessed 3.18.20).
- WHO| Social Mobilization n.d. WHO. URL http://www.who.int/healthpromotion/social-mobilization/en/ (accessed 4.30.20).

## **ANNEX**

# Master's thesis on Community participation of people with intellectual disability - a case study of Tornhøjgård

Please note that this Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate)

## **Section 1: Information Sheet**

#### Introduction

First of all, thank you for your time. I am a student conducting research on the topic of community participation of people with intellectual disability which is partly the field of your work and I would like to invite you to be the part of this research. I am studying a Nordic master's in social work and Welfare at Aalborg University. Below, I will be explaining what the research is about and the issue I am focusing on. You are highly welcome to ask me any questions in case you have any queries regarding the research. Also, you are allowed to talk about this to anyone that you feel comfortable talking to. I would like you to reflect on whether to participate and whether to answer questions asked during the interview. If you are confused with words or concepts, I will take time to explain as we go along. If you have any more questions or confusion, you can ask me anytime.

#### Purpose of the research/interview

This research is for the partial fulfillment of the requirement of the master's degree. The major research question I am studying is "How has Denmark's adoption of policies on "Active Inclusion" of people with intellectual disabilities have been influencing the meaning and practice of grass-root community participation? a case study of Tornhøjgård." The concept of inclusion is very vague and open. In this research, I am interested in getting the viewpoint of the stakeholder that are directly and indirectly the part of the "active inclusion' policy adopted by the country. The research will be focusing on exploring the perception of the member as this research is based on learning about the situation and experience. I am really interested in your experiences and opinions regarding the subject matter, so there is no right or wrong.

**Type of Research Intervention** 

This research will involve your participation in an interview which will be about one hour.

The interview follows the format of a semi-structured interview where the interview will be guided

by me. The interview will be recorded and will be used for the purpose of this research only. Every

information you share will be confidential, and no one except the researcher you met will access

the information documented during the interview. Your identity will not be mentioned in any

document (written or recorded).

The research takes place over a period of 4 months (February 2020-May 2020). During this time,

I will be visiting you only once for interviewing you and multiple times for observation (if you

work directly with Tornhøjgård). The interview/observation will take place from mid-February to

mid-March.

**Information sharing** 

All the information provided will be treated confidentially and the knowledge gained during the

research period will be shared anonymously among the social work academics at Aalborg

University. Disguised extracts from the interview may be quoted in the research paper. After the

completion of the result, you will be getting a summary of the result.

If you have any questions, you can contact me at:

Kabita Thapa: kavitathapa1995@gmail.com

Nordic master's in social work and Welfare (NOSWEL)

**Aalborg University** 

**Section 2: Consent to take part in research** 

\_\_\_\_\_, have been invited to participate in research about

Community participation of people with intellectual disability - a case study of Tornhøjgård

and I voluntarily agree to participate in this research. I have read the information about the research

in section 1: Information sheet, provided to me with this informed consent. I understand that even

if I agree to participate now, I can withdraw anytime or refuse to answer any of the questions. I

61

have had an opportunity to ask a question about the study. I agree with my interview being audio-

recorded and I am entitled to access the information I have provided at any time while it is in

storage. I understand that I am free to contact any of the people involved in the research to seek

further clarification and information.

Name of Participant:

Signature of Participant:

Date(d/m/y):

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my

ability made sure that the participant understands that information stated above.

I confirm that the participant was given an opportunity to ask questions about the study, and all

the questions asked by the participant have been answered correctly and to the best of my ability.

I confirm that the individual has not been coerced into giving consent, and the consent has been

given freely and voluntarily.

A copy of this informed consent has been provided to the participant.

Name of Researcher:

Signature of Researcher:

Date(d/m/y):

62

## **QUESTIONNAIRE**

- 1. Can you give me a brief description of this place (Tornhøjgård) and what it does?
- 2. With which group of citizens do they mainly work?
- 3. How long have they been worked with the group?
- 4. How many citizens are you directly in contact with?

## Main questions

- 1. Can you briefly tell me what is your role (in Tornhøjgård)? What kind of tasks do you and your colleague undertake?
- 2. What kind of activities do you conduct among the citizens?
- 3. What was the main idea behind it?
- 4. How do you think citizens like/dislike the idea of going to new places and learning new things?
- 5. What do you understand by the term "social inclusion" or community participation?

Among literature, there are four major aspects of community participation, mainly

- Socio-personal Relationship
- Productive inclusion: job and education
- Leisure and physical activity
- Any other aspect you think is important?
- 6. What is your view behind the inclusion of people with intellectual disabilities in these spheres of social life?
- 7. What other intervention approaches (besides these you are involved in) will help for the effective community participation of citizens.
- 8. Based on your experience with the citizen what do you think is the most valuable for them?
- 9. What are the benefits to the social inclusion of people with disabilities to the community members?
- 10. What are the challenges for their inclusion in society? How Can We Support Increased Role on the Part of the Larger Community?

- 11. Do you think, in Denmark, the people with intellectual disability has been taken as equal to the citizen without a disability? (outside social work community)
  - Have you seen/face any sorts of discrimination against them?
  - If yes, what needs to be changed so that they are seen as equal by everyone?
- 12. What local or national level policies do you know about (intellectual) disability?
  - Do you have any suggestions that needed to be included in the policy?
  - What about the active policy's focus on labor market inclusion- a transition from education to employment (Is it too demanding)
- 13. Do the participants you are working with have a social media presence? Do you think it has helped them to include them with the other aspect of social life?

## To citizens (About...)

- Tornhøjgard physical structure, (their private rooms and public spaces within)
- Their everyday life
- Social relation, friends, and family
- Job/education
- Things they want to do/change
- Opinion about other people
- Things they are learning at the classroom
- Leisure and physical activities
- Relationship with social workers at Tornhøjgård
- Their interaction with new people