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“Characteristics of social network relationships that improve social inclusion  
and wellbeing of women with intellectual disabilities  
in the Czech Republic”  
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This Dissertation is submitted in partial fulfilment of  
a M.A degree in Education – Erasmus Mundus

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Declaration

I, Merita Poni hereby declare that I developed this dissertation independently with the use of the resources listed in the bibliography. This work has never been presented before and can be used for reference by other researchers.

Signature

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## ABSTRACT

Women with intellectual disabilities need the support of social networks to be able to create relationships and to participate in community life. This qualitative research focused on analysing characteristics of the social networks that facilitate the social integration and community participation for women with intellectual disabilities in the Czech Republic. Through the use of semi-structured interviews, data was collected about fourteen women with intellectual disabilities in order to find out and understand how social networks hinder or facilitate the participation process and wellbeing, the aspects of social networks that enhance effective participation and boost wellbeing for them and why these aspects are important in increasing the quality of social relationships and the sense of belonging to community for these women.

Findings of the research revealed that social relationship difficulties and social network characteristics slow down the process of social inclusion and impact personal wellbeing in many ways. The research also found out that personal characteristics and environmental factors constitute the determinant factors for improvement of social relationships and increase of participation for women with intellectual disabilities. However, environmental elements are considered to be more influential than personal characteristics in supporting social integration of women with intellectual disabilities because they provide the basic structure for social relationships and as proven by research, environmental aspects address behavioural adjustment which compensates for the shortcomings of intellectual functioning, by affecting the ability of women with intellectual disabilities to better cooperate with environment. Although the environmental elements referring to community acceptance were known to have a role in facilitating relationships, women with intellectual disabilities social integration and meaningful relationships with community were minimal. Research participants considered family role, friendship quality and neighbourhood to be important aspects in supporting community inclusion and improved wellbeing of women with intellectual disabilities.

**KEY WORDS:** Women, intellectual disabilities, inclusion, wellbeing, social network.

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# CHAPTER ONE

## INTRODUCTION

*“A good life is lived with friends” Aristotle*

### **1.1 Introduction**

The first chapter is an introduction and discusses the following issues: the background and motivation of this study, followed by sections reporting what the study is about, the purpose of the study, followed by the context in which the study is carried out. Another section tells the significance of the study, while the final one provides the structure of this study report.

### **1.2 Background of Study**

#### *1.2.1 A long history of social exclusion for people with intellectual disabilities*

The issue of social participation has arisen as a consequence of inclusion policies implying that women with intellectual disabilities should be socially part of communities and should civically participate. However, whatever the good intentions of inclusion policies are, the social relationship and participation for women with intellectual disabilities remain a difficult task to be accomplished, due to the past legacy of exclusion and long-time institutionalisation of intellectual disability.

For a long time, people with intellectual disabilities have been concealed from society and congregated in segregate special provision to be cured, rehabilitated and trained to conduct a normal life and to be brought back in society. But in the following years, with the recognition that the intellectual disability cannot be cured, special provision program shifted from a training perspective to bring them near normality, to custodial care in institutions (Mandell & Fiscus, 1981; Kelly & Traustadottir, 2005).

Locating the problems arising from disability at the individual having an intellectual impairment, the society intervened to improve the person with intellectual disabilities

adaptive behaviour to meet the societal expectations. Instead of changing the perception on the worth of human being and valorising persons with intellectual disabilities for what they are, the society tried to make them comply to prescribed societal norms and values and to 'fit them into existing structures' (Amado, 1988, quoted in Chappell, 1992, p. 43).

By focusing on providing the pre-conditions for enabling an individual to cope with the demands of everyday living, the principle of normalisation overlooked the causes of devaluation making the notion of the 'normative' a desirable goal and a measure of achievement (Myers, Ager, Kerr & Myles, 1998). Thus, the normalization attempt produced adverse outcomes: persons with intellectual disabilities were devalued, as they could not fit into structured normative schemes. Subsequently, they were spaced-outside the mainstream (Armstrong, 2003). The segregation provision became the means of enacting societal policies of devaluation and oppression, though under the guise of care and benevolence (Wolfensberger, 1995). By giving them the status of otherness the society legitimized their alienation and social exclusion (Goffman, 1963). Persons with intellectual disabilities became completely dependent on social care, constituting the poorest group even among persons with disabilities (Inclusion Europe, 2005).

### *1.2.2 Double discrimination of women with intellectual disabilities*

As most persons with disabilities, women with intellectual disabilities do still live on the margins of society and are deprived from some basic human experiences, such as having their own home, creating a family and enjoying a social life (UN 2007, Disabilities). They lack necessary financial and social resources to fulfil their social needs. The extreme form of stigma and discrimination exerted by society on people experiencing intellectual disabilities has contributed to people with intellectual disabilities social isolation and exclusion from society (Mental Health Europe, 2007). The exclusion ranges from provision with limited social and occupational skills to denial of access in paid labour market, community access, social participation and citizenship (Barnes & Mercer, 2005).

The cause of severe disadvantages for women with intellectual disabilities is the double jeopardy of being both person with disabilities and female (Katovil, 1986). Almost all societies share a universal attitude toward women that positions them at an eternal childhood, de-legitimizes them from human rights and devalues their social status (De Beauvoir, 1949 [1972]). Gender beliefs and gendered practices are learned, enacted and reinforced by every social institution and imposed over women during the life course (Martin, 2003). Women are expected to have less to contribute to task performances than are men (Ridgeway & Corell, 2004). Setting higher standards for men than for women, society shapes lower expectations and social responsibilities for women. For women with intellectual disabilities the social expectations are even lower compared to other women and are the product of bias based on gender and disabling conditions, based on stereotyped traditional role of the female to be dependent (French & Swan, 2004). Furthermore, the stereotype of females as passive, dependent emotionally and needing protection has much in common with the stereotype of a person with intellectual disabilities.

Extensively, the society teaches women with intellectual disabilities the helplessness attitude by “shaping them into positions where they exercise little power, choice or control over their lives and or their aspirations” (Seligman 1975, mentioned by Anderson 1998, p. 39). Regrettably, the intellectual disability is often associated with stigma and social rejection. Subjected to a double discrimination and infantilisation, identified usually by their cognitive ability age rather than the natural one, women with intellectual disabilities live in a permanent childhood and have no adult roles (Black Well-Stratton, 1988). The social disabilism limits their access to qualitative life-long learning process and places barriers to their equitable social participation (Thomas, 2004). Consequently, “after twelve years of education, women with intellectual disabilities find themselves ill-equipped to do anything but remain in the family home or in institutions” (Katovil, 1986, p. 42). Not only are women with intellectual disabilities the most marginalized group within women and people with disabilities, but they are the most excluded among all women with disabilities as well.

### *1.2.3 Steps towards community inclusion*

The segregation policy has resulted in discriminatory practices of very poor quality institutional care, social deprivation, and inhumane methods of treatment (Mensell, 2006).

Today, the human rights violation of persons with intellectual disabilities is no longer tolerated. Therefore many countries are producing inclusion policies to keep them in community and support their participation in community life. Although actually practical implications of the inclusion policies are mainly resulting in physical integration, the aim in the long run is social inclusion.

Social relationships and networking are considered a prerequisite for meaningful inclusion, as they provide the sense of belonging. In addition, through socializing process social relationships provide the conditions for social participation and for lifelong education. Furthermore, contemporary social policies are targeting inclusion as an ultimate goal to rescue people with disabilities from long-term damage effects that social exclusion and alienation has caused them. Social inclusion of people with intellectual disabilities is a recent concept introduced by the social model of disability, which calls for removal of all societal barriers towards participation of persons with disabilities in order to allow them full enjoyment of human rights and citizenship status (Barton, 1993). The inclusion policies are based on the normalisation principle urging society to provide people with intellectual disabilities conditions of everyday life which are as close as possible to the patterns of mainstream society including interaction with others, such as family, peers, neighbours, and friends and guarantying both physical and social integration (Wolfensberger, 1972).

### *1.2.5 Is there any community inclusion for people with intellectual disabilities?*

Research has explored the degree of community integration of people with intellectual disabilities, measured in terms of the activities undertaken within the community, with less evidence on the character of personal and social relationships of women with intellectual disabilities. Studies investigating the impact of social relationship and community participation on personal life have reported an increase in satisfaction and wellbeing (Walsh, Emerson, Bradley, Schalock & Moseley, 2007). Although analyses of

life experiences have indicated that the gains are greatest with respect to the home environment, freedom and opportunities, women with intellectual disabilities have no significant relationship with community and their integration is restricted to social contacts with staff of social services within segregated settings (Ager, Myers, Kerr, Myles & Green, 2001). Despite being physically present in local communities, women with intellectual disabilities often remain, socially, outside looking in, while their participation in the social life of the community - through the development of a network of personal relationships - remains largely unrealized (Myers, 1998). Findings have evidenced more physical integration, which is the actual presence of the person in ordinary (community) settings, rather than social integration, which is about the formation of a range of relationships in these settings (Dagnan, Howard & Drewett, 1994). The evidence informs about the gap between being physically within and socially excluded in the community. Community presence may be a necessary, but not sufficient precondition for attaining choice in social participation (Myers, 1998).

Research literature has not found much on community acceptance and social networking, probably because the integration process is still going on, and there is no long history of community participation for persons with intellectual disabilities (Mansell, 2006). Studies on social networks and relationships report contradictory findings: some suggest that community integration is associated with increases in networks and relationships, while others report no change (Walsh et al., 2007). However, participants have reported to have more extensive social networks and more frequent contact with people in their social networks in community-based living rather than in large institution/campus (Emerson et al., 2000)

Furthermore, evidence has suggested that there exists a lack of awareness and preparedness to engage with persons with intellectual disabilities as consumers, neighbours, or as possible friends (Myers et al., 1998). Understandably, the long absence of people with intellectual disabilities in community has increased the wariness of neighbourhoods on the presence of them and sometime has nourished hostile behaviour towards them. In such conditions women with intellectual disabilities are at a relative

disadvantage in terms of opportunities for community participation or developing social networks.

#### *1.2.6 Recommendations for research*

General analyses of the determinants of social exclusion have drawn attention to the critical importance of neighbourhood and community characteristics (e.g., deprivation and withered social capital); however, the issue of social relations and networking as determinants of quality of life has received no attention (Walsh et al, 2007). Given the paucity of information in the existing literature, further research is recommended to measure indicators of organisational culture of community and aspects of neighbourhood and their impact on social capital and social participation (Walsh et al., 2007). Furthermore, the literature on gender and disability are in debt to women with intellectual disabilities situation analyses. This study is contributing to the existing literature on intellectual disability and gender studies in relation to social relationships and community participation as a means for social inclusion of women with intellectual disabilities.

### **1.3 Motivation to study**

The community living of people with intellectual disabilities is being forwarded by the social policies dealing with inclusion given the impact it has on the quality of life. However, the good intentions of inclusive policies are slowly being attained as the presence of women with intellectual disabilities in community life is merely a physical one and the cause is attributed to the personal characteristics for adaptation. Although the personal characteristics of women with intellectual disabilities are held responsible in creating and maintaining relationship with others, they should not be overemphasized. Personal communication skills and ability to perform in the areas of social responsibility and self-sufficiency are only to some extent prerequisites for social relationship and participation, for it is the combination with environmental factors that reduces the individual opportunities to perform well in daily self-responding tasks and interact with environment. Inside a person with intellectual disabilities limitations coexist with strengths and with appropriate environmental support functional capacity can improve over time so women with intellectual disabilities may be able to assume adult roles and

responsibilities in maintaining good relationship and contributing to community life. The role of social networks is crucial in assisting women with intellectual disabilities to overcome personal limitations and successfully function within community conducting quality lives among normal the population.

Working with people with disabilities, I have witnessed that women with intellectual disabilities are invisible in my society. By coming closer to their life experiences, I have realised that they live in precarious conditions highly marked by poverty. They are totally left aside by the community and except for social relationship with family no other people came nearby or across their lives. Their situation was overwhelming to me, whereby I got the impetus to challenge the social conventions and stereotyped beliefs working against women with intellectual disabilities by denying them the rights to live a life of dignity among us.

In Albania, the country I come from, many people consider women with intellectual disabilities less than children, reducing them to only one identity characteristic which is the cognitive age. By ignoring that women with intellectual disabilities have multiple-identities like everyone and considering that abilities and skills are foreign words to intellectual disability, the community has given them the 'door-in-the-face', effectively shutting them out. As a consequence they are locked behind doors fearing to get out in community because of rejection and abuse. In my neighbourhood it is a capital offence for a woman to be called by the name of a woman with intellectual disabilities. In such depriving conditions, opportunities for women with intellectual disabilities in my country to have relationship and meaningful life within community are just scarce.

On a more personal level, I am a gender studies teacher and over the years, I have been conveying to my students the ideals of a fair, just and caring society, for our lives can be better off. This has been an excellent opportunity for me to influence the young generation to upheaval the old stereotyped prejudices about women and to work towards changing the society and bringing it more to an egalitarian level.

My choice for studying the situations of women with intellectual disabilities is based on my job as an advocate for their human rights working with parents' organisations to bring them safely into society. I presumably believe that if we reverse our past heritage on gender and disability, we can provide chances to change the society, by changing ourselves first. Lastly, I believe that if changes can work for women with intellectual disabilities they can work for other marginalised women and for all people with intellectual disabilities as well.

#### **1.4 Quality of life approach**

This study investigates the quality of life for women with intellectual disabilities in the Czech Republic. In fact, the main reason for focusing on, and using, a quality of life approach is to encourage improvement in people's lives so that they become enriched and more meaningful (Brown & Brown, 2003). Recently, the quality of life for people with disabilities is being articulated as a foreword of inclusion policy agendas worldwide. The inclusion policies aim at enabling people with intellectual disabilities to live in community and target as an ultimate goal the improvement of quality of life for them.

The concept of quality of life stands upon two principles: (i) the normalization/ social role valorisation, which ascribes to people with disabilities valuable, acceptable and recognized roles within community, especially concerning social relationships and (ii) inclusion which encourages access of people with disabilities to all aspects of social life (Brown & Brown, 2003). Although there is an ongoing debate on what a life of quality should be, there is common agreement that the quality of life for people with intellectual disabilities should be as near as possible to the quality of life of the normal population

In order to measure it, the quality of life construct is simplified into concepts of life domains, each of which has a set of indicators that can be measured in objective and subjective ways. In this study, two domains of quality of life are searched, namely social integration and social wellbeing. The indicators related to these domains are social relationship and life satisfaction which are investigated by use of operational concepts



such as the presence of friends, the relationships with neighbours, and the range of activities that make life purposeful.

The information on the situation of social relationships of women with intellectual disabilities within community was gathered through interviews with mothers and sisters as research proxy participants, who rated the support from community and friends as preconditions for participation and wellbeing of women with intellectual disabilities. Obviously, the research would yield more interesting results if data on the lived situation of women with intellectual disabilities would come from them, but due to language barriers the research was limited to perceptions of familiars only. Mothers and sisters, in this study, are amongst the most active members of parents' organisations empowering women with intellectual disabilities to exercise choices and to improve their lives through relationship in community. Despite enormous efforts on the side of familiars, the access to a normal adult lifestyle for women with intellectual disabilities is still often restricted, partly because of the difficulties encountered in community in forming and maintaining social relationships (Brown& Brown, 2003).

### **1.5 Purpose of study**

The purpose of this research is to analyse the characteristics of social networks that enhance social relationship and wellbeing for women with intellectual disabilities. The ecological perspective on intellectual disability has established that the interaction of individuals with intellectual disabilities with environment and systematic application of individualised support can enhance human functioning (Schalock et al., 2007; WHO, 2007; AAIDD, 2008). Thus lack of support from social actors, as the most prominent environmental factors, can hinder the process of social integration of a woman with intellectual disabilities. Therefore, women with intellectual disabilities need family, friends and community support to be empowered to perform better in creating and maintaining a relationship and to be able to function effectively in their daily lives. By examining the characteristics of the social networks that boost social relationship and improve social performance, this study contains one central research question and two sub questions.

1. Central Question: How do social networks impact the community inclusion and social wellbeing of women with intellectual disabilities?

1.1 Sub-question: What characteristics of social network improve social relationship of women with intellectual disabilities?

1.2 Sub-question: How do social relationships affect the life satisfaction of women with intellectual disabilities?

### **1.6 Context and significance of study**

Having adopted a qualitative stance to the research, this study represents an attempt to report the situation of women with intellectual disabilities through mothers' and sisters' views obtained in fifteen interviews. The study was done in Prague, Czech Republic and participants were referred to the study by parents' organisations: Duha association and Parents and Friends of People with Down syndrome,

As mentioned above, in Albania, the idea of community participation and relationship for women with intellectual disabilities is not well-known or welcomed. Supporting women with intellectual disabilities to live and participate in community life is such a challenge not only to them, but to their parents and to the community based services as well. Therefore, one of the objectives of this research is to raise the community awareness regarding the social inclusion importance and ways for improvement of the quality of lives for women with intellectual disabilities through social relationship.

The investigation of environmental characteristics that facilitate social relationship and social performance of women with intellectual disabilities to live a life of quality among others is quite relevant to my civic engagement as an advocate of women with disabilities, because the findings will affect my professional performance in advocating better for their human rights. The information on the positive aspects of social networks improving relationship will be shared with parents and will be used to advocate for positive changes of both policy and practice. This research can be a step more for further research on disability and gender studies for me and for my faculty colleagues. I hope this

study can contribute to dismantle attitudinal barriers against women with intellectual disabilities in my community and influence people to think positively and support inclusion of women with intellectual disabilities as neighbours and friends.

The social policies promoting inclusion cannot be enacted by themselves, if people do not support the democratic principles they convey. In order for women with disabilities to conduct a life of dignity in community, social policies need to be translated into social services that expand beyond social institutions and day-cares. The policy should foresee effective ways for supporting the relationships women with intellectual disabilities inside community need to forecast the necessary resources to address the issue of social inclusion. Although it may look like an illusionary ideal to open the community towards meaningful relationships with women with intellectual disabilities, it is good to believe in it and work towards it in order to produce gradual changes.

### **1.7 Structure of study**

This Dissertation contains six chapters. Chapter one provides the rationale and the motivation for carrying out the research, the theoretical concept of quality of life that is investigated in the study; the purpose, context and significance of the study are explained as well, and the chapter ends with the study structure.

In chapter two the literature related to characteristics of social networks such as friendship, community acceptance and family support contributing to social integration and personal wellbeing is reviewed. By providing a logical flow in between themes, the literature material is organised in the following subheadings; intellectual disabilities, quality of life, social wellbeing, social relationship and social participation.

Chapter three provides the rationale for this research including paradigmatic issues, such as ontology and epistemology adopted by research. The data collection procedure and limitations related to it, data analysis and interpretation, issues regarding reliability and validity of research, methods used and ethical concerns are all discussed here.

Chapter four proceeds with data analysis organised around sub-questions to address the central research question.

Chapter five deals with the discussion and interpretation of the research results, providing a logical frame between the themes of research, by tightening up the sub-questions with the central research question. The discussion and interpretation is backed up by the literature reviewed in chapter two trying to address the main research question.

Chapter six relates to the conclusions of the research findings including possible areas of implications for professional development and recommendations for policy and practice. The dissertation process and research objectives are restated followed by a critical evaluation of this research including limitations of the methods and findings.

At the end of the study document is presented the bibliography section and includes a list of evidence documents referred to in the dissertation. The appendix section contains the interview protocol, one transcribed interview of a mother and one from a sister, labelled as Appendix A, B and C respectively

## **1.8 Summary**

In this chapter, the rationale and motivation for the research is discussed, including the explanation for the concept of quality of life and social inclusion, after which the context and the significance of the study are discussed. At the end is outlined the structure of the study containing an explanation for each section of the study, from chapter one to the appendix.

## CHAPTER TWO

### LITERATURE REVIEW

#### **2.1 Introduction**

The literature review comprises a set of theoretical concepts from sociology, social psychology and psychology to explain the characteristic of each component of the social networks and the impact it has on social relationship and wellbeing. Literature on intellectual disability has been reviewed extensively to give an insight into the contemporary developments in the field of community inclusion. The literature review has taken into account the key operational concepts for the study which are intellectual disability, quality of life, social network, social relationship and wellbeing. The review of literature begins with an explanation of intellectual disabilities that describes the limitations and strengths of the person with disabilities and the role of environmental aspects in improving adaptive functioning, where the intellectual functioning can be a stable attribute. The review of literature follows with the explanation of the concept of the quality of life and proceeds with clarification of the life domains investigated in the study, wellbeing and community inclusion. The literature continues with the explanation of the indicators of quality of life such as friendship/relationship and life satisfaction, and ends the section on quality of life by considering the operational concepts for quality of life indicators that are the social networks and their role in purposeful life activities. The recommendations on further research close the chapter, some of which are addressed by the study.

#### **2.2 Definitions of Intellectual Disabilities**

Intellectual disability (ID) is the currently preferred term for the disability historically referred to as mental retardation (AAIDD, 2008; Schalock, Luckasson & Shogren, 2007). Intellectual disability as referred in this study corresponds to the definitions provided by American Psychiatry Association in DSM-IV-TR on mental retardation, and by American Association of Intellectual and Developmental Disabilities on intellectual

disability and by World Health Organization (WHO) in ICF and ICD-10 classification of mental retardation, and corresponds to the term learning disabilities used in Great Britain.

I have preferred to use the term Intellectual Disability instead of Mental Retardation because naming communicates important social values and the term *mental retardation* does not communicate dignity or respect and, in fact, frequently results in the devaluation of people with intellectual disabilities (Schalock et al., 2007; Wolfensberger, 2000). The construct of intellectual disability belongs within the general construct of disability, which is a historically and culturally evolving concept (UNDP, 2006; Schalock et al., 2007). In sociological definition, intellectual disabilities represent the inability to meet societal expectations for role behaviours, while in educational terms it refers to below-average academic levels and behavioural problems (Mandell & Fiscus, 1981, p. 297).

The social approach has been followed by the clinical or medical approach that tried to identify the aetiology of intellectual disability with biological factors and intervened to compensate for the lack of normal abilities through rehabilitation, leading to segregation of persons with intellectual disabilities (Oliver, 1986; Finkelstein, 2002; Smart, 2001; Thomas, 2004; French & Swain, 2004).

A later perspective on intellectual disabilities developed in the dual-criterion approach, in 1959, by the American Association of Mental Retardation (AAMR), today American Association of Intellectual and Developmental Disabilities (AAIDD). Using both intellectual functioning and adaptive behaviour, the dual-criterion approach defines Intellectual Disability, interchangeably *mental retardation*, as referring to the sub-average general intellectual functioning that originates during the developmental period, before age 18 and is associated with significant limitations in adaptive functioning behaviour, as expressed in conceptual, social, and practical adaptive skills, in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety (AAIDD, 2008; DSM-IV-TR, 2002; ICD-10, 2007). Separate codes are provided for mild, moderate, severe and profound mental retardation and for

mental retardation severity unspecified (DSM-IV-TR, 2002). The dual-criterion approach has included age as an accompanying element (Schalock et al., 2007).

The IQ test is the usual instrument used to measure intellectual functioning, with a measurement error index of approximately 5 points, but it is not the best predictable intelligence score, as other factors, such as individual socio-cultural background, native language and associated communicative motor and sensory impairments may limit test performance. For instance, even if the IQ is lower than 70, the person would not be diagnosed with Mental Retardation if there are no significant impairments in adaptive functioning (DSM-IV-TR, 2002). Impairments of adapting functioning, rather than a low IQ, are usually the presenting symptoms in individuals with intellectual disabilities.

Adaptive functioning and behaviour represent the conceptual, social, and practical skills that people have learned to be able to function in their everyday lives and refer to how effectively they meet the standards of personal independence expected of someone in their particular age group, socio-cultural background, and community setting (AAIDD, 2008; DSM-IV-TR, 2002; ICD-10, 2007). Adaptive behaviour refers to a person's ability to perform in the areas of social responsibility and self sufficiency relative to what is expected by his or her social and cultural age group. Since these expectations vary for differing age groups, the adaptive behaviour will vary at different ages. For example, during early adolescence the variations would be seen in application of appropriate reasoning and judgment in mastery of the environment and in social skills, i.e. interpersonal relationships and participation in group activities; while in late adolescence and adult life the variation can be seen in vocational and social responsibilities and performances (Mandell & Fiscus, 1981).

Significant limitations in adaptive behaviour impact a person's daily life and affect the ability to respond to a particular situation or to the environment (Schalock et al, 2007). Adaptive functioning may be influenced by various factors, including education, motivation, personality characteristics, social and vocational opportunities, and the mental disorders and general medical conditions (DSM-IV, 2002). Problems in

adaptation are more likely to improve with remedial efforts than is the cognitive IQ, which tends to remain a more stable attribute.

Intellectual disability may be associated with a general medical condition, e.g., Down syndrome, and with mental disorders, e.g., Autistic Disorder and Pervasive Development Disorders, with a prevalence that is estimated three to four times greater than in the general population (DSM-IV-TR, 2002).

A new ecological perspective on intellectual disability has evolved that focuses on the person–environment interaction and recognizes that the systematic application of individualized supports can enhance human functioning (Schalock et al., 2007). A similar socio-ecological conception of disability is reflected in current publications of WHO, ICD-10(2007) & ICF (2006), that consider intellectual disability as an impairment, which, combined with environmental factors, causes problems in individual functionalities in performing daily self-responding tasks. The organic and social factors give rise to functional limitations that reflect an inability or constraint in both personal functioning and performing roles and tasks expected of an individual within a social environment (Schalock et al., 2007).

The course of Intellectual Disability is influenced both by general medical conditions and by environmental factors such as education, environmental stimulation and appropriateness of management. If an underlying general medical condition is static, the course is more likely to be variable and to depend on environmental factors. The importance of this evolutionary change in the construct of disability is that intellectual disability is no longer considered entirely an absolute, invariable trait of the person (Schalock et al., 2007).

Intellectual Disability is not necessarily a lifelong disorder. Individuals who had it in their early years, manifested by failure in academic learning tasks may, with appropriate training and opportunities, develop good adaptive skills in other domains (DSM-IV-TR, 2002). Within an individual, limitations often coexist with strengths and with appropriate



personalized support the life functioning of the person with intellectual disability generally improves (AAIDD, 2008). Intellectual abilities and social adaptation may change over time, and may improve as a result of training and rehabilitation, so, many adults will be able to work and maintain good social relationships and contribute to society (ICF & ICD-10, WHO, 2007).

Clearly, people with intellectual disabilities can benefit from education and training programs like any other individual. Since mid-twentieth century society recognizes that many people with intellectual disabilities can learn to live independent and semi-dependent lives; therefore services now emphasize an educational perspective to prepare these individuals for a greater level of self-sufficiency in adulthood (AAIDD, 2008). The majority of people with intellectual disabilities are only mildly delayed, and most of the causes are attributed to environmental factors related to socio-economic status (Mandell and Fiscus, 1981). With appropriate support they can live successfully in the community, either independently or in supervised settings. In addition, both abilities on which intellectual disability is measured, intellectual functioning and adaptive behaviour to interact appropriately within social environment, can be enhanced by education, training and communication, and with proper special education, vocational and social training most people with intellectual disabilities can be educated to successfully function within the community and blend into the normal population (Mandell & Fiscus, 1981).

### 2.3 Barriers to social relationships of with women with intellectual disabilities

Like many people with disability, women with intellectual disabilities have been suffering social rejection and stigma. The ‘unquestionable’ lack of friendship and relationships of women with intellectual disabilities with other people looks pretty ‘normal’ and unproblematic to society. The justification for such attitude is rooted in the stereotyped belief that those who are intellectually disabled do not understand the importance of relationships. Because the cognitive functioning of persons with intellectual disabilities corresponds to that of children, people tend to equalize women with intellectual disabilities with eternal children. This status has denied women access to adult roles and social status and causes them social disability.

By identifying these women with intellectual impairment only, people reduce the integral personality of women with intellectual disabilities, ignoring that they have multiple-identities like all women, as daughters, sisters, wives, mothers, friends, workers and citizens (Feuser, 1996; Deal, 2007). After all, society has failed to notice the capacity of women with intellectual disabilities to adjust their behaviour to the social context. More regrettably, society disregards the fact that development of human beings as individuals and community members depends on relationship with society, for this constitutes the main source of social existence. Consequently, society has blocked the agency of human relationships which accounts most in determining personal development and social enablement as community actors. As a result cultural barriers replicate themselves and result in social rejection and alienation, which throws away women with intellectual disabilities, into a world of loneliness and isolation. For a long time, the effects of social exclusion have negatively impacted the quality of life for women with disabilities by deteriorating it in every aspect. Like all persons with intellectual disabilities, women with intellectual disabilities have had diminished opportunities for social relations, and have suffered ‘social exclusion, alienation and marginalization’ in society for a long time (Parsons, 1999).

## **2.4 Theoretical frame of quality of life**

### *2.4.1 Quality of life for people with disabilities: an emerging concept*

A contemporary, human rights-based approach promoted in the social model of disability, has put a strong emphasis on social inclusion and wellbeing as indicators for the quality of life. Conceived in terms of human rights, social inclusion policies try to provide women with intellectual disabilities opportunities for social participation ‘as an affirmation of the value of personal choice, independent living and self-control’ (Barton, 1993, pp.253). The shift of paradigm on disability from medical to social model reflects a transformed vision of what constitutes the life quality for people with intellectual disabilities. As a quality indicator, social relationships and participation are used to monitor social exclusion and to contribute to reduction of inequalities and injustice

(Felce, 2000; Slee, 2001; Walsh et al., 2007). By thinking in inclusive terms, people may see women with intellectual values differently and be able to engage in relationships with them.

#### *2.4.2 The definition of quality of life*

The definition of quality of life in this research is borrowed from Brown & Brown's (2003) book "*Quality of Life and Disability*", in which quality of life is described by attributes called social indicators such as social equity, employment, education, etc.

A life of quality is a life that is very meaningful to individuals and that provides them with resources, such as having an interesting and enjoyable job to go to, feeling safe, confident and happy, feeling close to those people with whom life is shared, having fun, and having freedom of choice and a richness of opportunities to choose from. The guiding principle of effective quality of life is that all humans are entitled to enjoy quality lives. When applying a quality of life approach, this principle ensures a focus on ways to help people enjoy their lives to the fullest possible extent.

Five essential ideas in a quality of life approach imply that: it addresses things that are important to all human beings, it is personal, individuals can judge specific aspects of their own lives, all parts of life are interconnected and quality of life is ever-changing (Brown Brown, 2003).

When we use a quality of life approach, we focus specifically on five key application principles which focus attention on the processes that are most important to the person at the present time, including things that the person shares with other humans; (i) it works to ensure that the person is satisfied with those aspects of life that are important; (ii) it stresses that opportunities to improve must be within the person's grasp; (iii) it insists that personal choice should be exercised wherever possible in selecting opportunities; (iv) it improves self-image; (v) it increases levels of personal empowerment (Brown & Brown, 2003). Quality of life integrates these by maintaining that all people with disabilities are entitled to lives of quality, and that it is the responsibility of society as a whole, and of individual members of society, to try to ensure that satisfactory quality of life is attained.

The concept of quality of life stands upon two principles: (i) the normalization / social role valorisation, which introduced the concept of normal and valued lifestyles for people with intellectual disabilities; and (ii) inclusion, which refers to access to all aspects of society by people with disabilities. Normalisation encourages ascribing to people with disabilities valuable, acceptable and recognized roles within community settings, especially concerning social relationships. Access of individuals with intellectual disability to a normal adult lifestyle is still often restricted, partly because of the difficulties encountered in forming and maintaining social relationships.

#### *2.4.3 Measurement of quality of life*

Quality of life is measured by longitudinal and cross-sectional measurement tools applied to three main domains: being – who the person is, belonging – people and places in person's life, and becoming – activities of life. These are further sub-divided into sub-domains: physical, psychological and spiritual being; physical, social and community belonging; practical, leisure and growth becoming. The key questions are: how important is it to the person, how satisfied is the person with it, what are the opportunities for the person in this life aspect, and does the person make decisions for the life aspect. There are two types of measurements for the quality of life indicators: objective and subjective measurement. Objective measurement describes measurement that has a 'truth' or external validity to it because it can be done the same way by different people at different times, while subjective measurement is a term used to describe ways of recording people's perceptions of things, their thoughts, feelings, attitudes and values. Subjective measurement records information that is centred in the expressed thoughts and feelings of the person, but can be reliably collected using standardized methods by different people and often on different occasions. Many attributes of humans and human life change can be measured subjectively, and these are attributes we need to measure. The 'truth' lies in how authentic the expression of thoughts and feelings is.

For measuring quality of life proxy participants' views may be used as an alternative way of collecting information. They are called proxies because they speak, to the best of their

ability, for individuals who cannot speak clearly for themselves. The information from proxy measures may well be very useful, but it is not the same thing as information from subject individuals themselves. Both involve perceptual information, but proxy information is different because it is perception from a person other than the subject. For this reason, proxy measures are identified as such, and not assumed to be the perceptions of the subject.

#### 2.4.4 Quality of life (QoL) model

Walsh et al. (2007) present a recapitulated version of the quality of life model which includes core domains and indicators developed by Schalock et al., 2006 (Walsh et al., 2007). Current quality of life models are based on two essential components: three domains of quality of life and respective indicators pertaining to them. Quality of life domains are operationalised through *quality indicators* that are defined as: “QoL-related perceptions, behaviours and conditions that give an indication of a person’s well-being (Walsh et al., 2007, p.4).” The dimension of social exclusion is a key *determinant factor* that has drawn attention to the critical importance of neighbourhood and community characteristics (e.g. deprivation from social capital) (p.5). Table 1 shows the domains and indicators of quality of life.

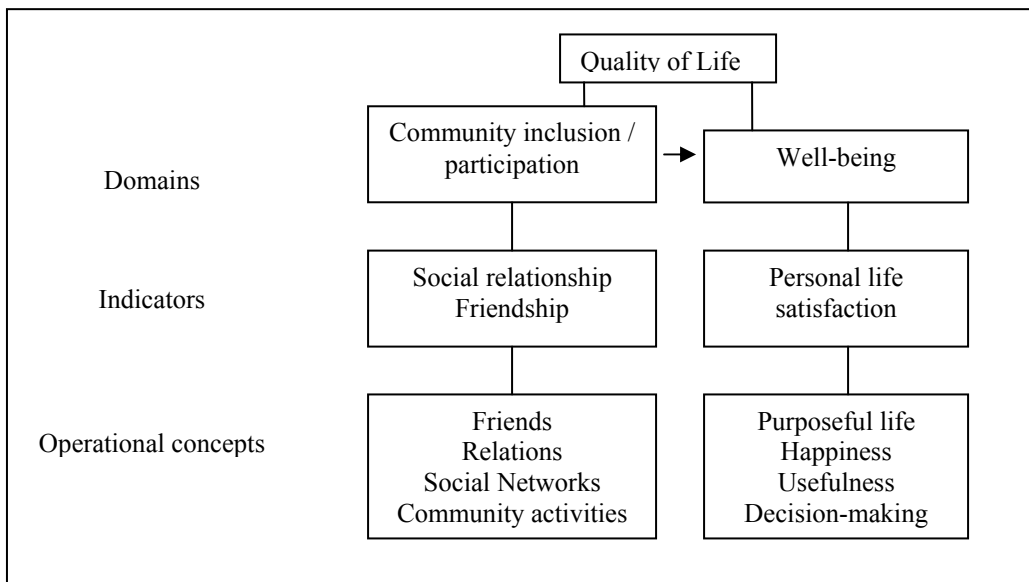
Table 1: Quality of Life Core Domains and Indicators

Independence	Civic Engagement & Social Inclusion	Well-being
Personal skills	Social networks and friendship	Mental health
Material wellbeing	Community activities	Physical health
Self-determination	Education/Employment	Personal life satisfaction
Other	Other	Other

*Source (adapted version):* Supported Accommodation Services for People with Intellectual Disabilities: A Review of Models and Instruments used to measure the Quality of Life in different various settings, by Walsh et al., 2007

The domain of Social Inclusion is comprised of three indicators: social relationships / friendship, community-based activities, and education / employment. The indicator of social relationships and friendship is assessed through three operational concepts, including friends, relations with others, participation in leisure activities. Box 1 below shows how two domains of life indicators are simplified for measurement into operational concepts. Not all quality of life indicators can be examined in this study. Only two indicators, social relationships/friendship and personal life satisfaction are specifically examined in this study. This choice is justified by the central research question about the role of social relationships on participation and wellbeing.

**Box 1 QoL Model**



*Source (adapted version):* Supported Accommodation Services for People with Intellectual Disabilities: A Review of Models and Instruments used to measure the Quality of Life in different various settings, by Walsh et al., 2007

**2.5 Social Networks**

Social network refers to individuals who are linked together by social relationships (Marshall, 1998). The social network is defined primarily in terms of resource dependencies, with network interactions chiefly oriented towards resource maximization and people who make up the network share a common consideration of world-views,

social values and normative assumptions (Baldock et al., 2007). Social relationships developed within social networks are the human social bonds that build social capital. Social capital refers to reciprocity and trust-based relationships derived from membership in social networks and collective action (Karp et al., 2004). Depending on the quality of social relationships, social capital can be both a source of personal social wellbeing and the glue of social cohesion, and given the two-dimensional construction - *bonding* the close relationship and *bridging* to other neighbourhoods - the social network has the power to connect and integrate people in participative relations and collective solidarity (Halpern, 2004, cited in Baldock et al, 2007, p.36). Human social behaviour is shaped by the social relations in which it occurs and social relationships are conditioned by the structures within which they are embedded (Willer, 1999).

Naturally, the social networks of women with intellectual disabilities are composed of people who live around them, such as: parents, siblings, friends, teachers, neighbours, work-colleagues, school-mates, peers, support care assistants and any appropriate person or agency, which would help them without regard to reciprocity of help exchange (Myers, 1993: AAIDD, 2008). The social network serves as the main source of support for women with intellectual disabilities to live and participate in community life. Social networks generate synergy in promoting and supporting initiatives that encourage inclusion within communities and provide the necessary resources to promote the development, education, interests, and personal wellbeing of a woman with intellectual disability.

AAIDD (2008) has identified nine categories of social activities realised with support of social networks. These social activities contribute to meeting the 'needs for love and belonging' as illustrated by Maslow (1954) in the five basic needs hierarchy: survival, safety, love, self-esteem and self-actualisation:

Social Activities ensured by social networks include (AAIDD, 2008):

- Socializing within the family
- Participating in recreation and leisure activities

- Making appropriate decisions
- Socializing outside the family
- Making and keeping friends
- Communicating with others about personal needs
- Engaging in loving and intimate relationships
- Offering assistance and assisting others

These activities emphasize the sense of community connectedness, of personal interdependency and belonging. It is closely aligned with the sociological concept of 'social capital' and is inversely related to loneliness (Cummins & Lau, 2003). Like other people, women with intellectual disabilities may belong to multiple communities such as clients group or same age group of women, but the primary community is the one that exerts the dominant influence over socialization and psychological development, and it is composed of family, friends and neighbours (Cummins & Lau, 2003).

Social networks, through social bonding, provide the conditions for women with intellectual disabilities to live in community. As least restrictive environments, social networks do not label women with intellectual disabilities by medical diagnosis, but call them by their name. In these networks, women with intellectual disabilities are people first. Valuing women with intellectual disabilities for who they are, social networks enable social acceptance and avoid institutionalisation. Knowing the specific needs of the women with intellectual disabilities, social networks can provide strategies that optimize individual functioning and improve social and personal living circumstances over time (AAIDD, 2008). The process of normalization of relationships within community, worked out in social networks, involves both physical integration and active participation (Cummins & Lau, 2003). Subsequently, any discussion of community life participation needs to address both the individual's 'adaptation' to the community, and the responsiveness of the community to the individual (Myers et al., 1998).

In conclusion, social networks provide a wealth of social links to women with intellectual disabilities and inter-connect them to the community. The individualized network can



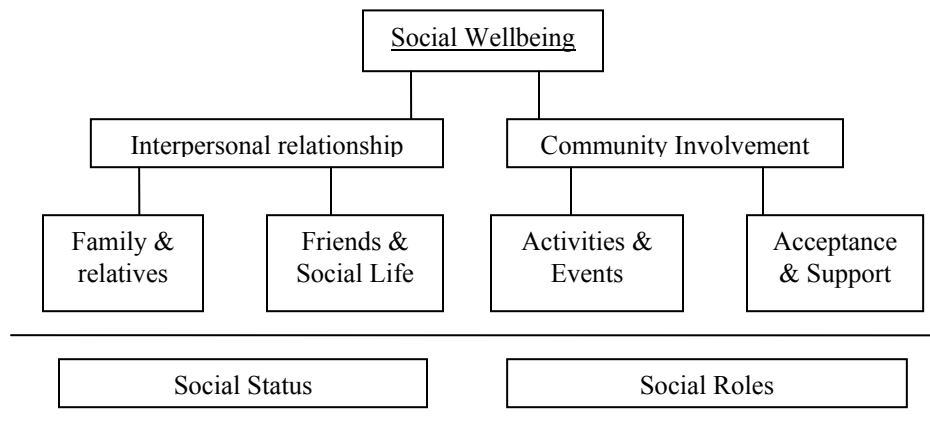
improve personal functioning, promote self-determination, and enhance the well-being of a person with intellectual disability. Support provided by social networks also leads to community inclusion of persons with intellectual disabilities. Lately, social networks have become an important part of a person-centred approach to providing care to women with intellectual disabilities by improving living environments (AAIDD, 2008).

## **2.6 Social networks' impact on wellbeing**

Wellbeing of persons with disabilities is the ultimate goal of inclusion policies. The practice related to the implementation of inclusion policies informs that the process of social integration for persons with intellectual disabilities is going slowly. The majority of studies have reported an increase in personal life satisfaction of persons with intellectual disabilities living in community, while only few report no change (Walsh et al, 2007). It seems to be generally assumed that the more frequently people experience community living and integration the better their lives will be (Cummins & Lau, 2003). The friendship provided through social networks appears to be central to health and emotional and social wellbeing of persons with disabilities living in community (Emerson & Mc Villy, 2004).

Felce (2000) has identified social wellbeing as an indicator of quality of life, providing the explanation: *Social wellbeing* includes two dimensions: (i) the quality and breadth of interpersonal relationships - intimacy and reciprocal affection within household life, with family and relatives, and with friends and acquaintances, and (ii) community involvement or social inclusion - community activities undertaken and the level of acceptance or support given by the community. Both may be summed up as a social status and set of social roles.

Figure 2 Social wellbeing



*Source: Felce, 2000 Quality of Life for People with Learning Disabilities in Supported Housing in the Community: A Review of Research, Centre for Evidence-based Social Services*

In Felce’s explanation social wellbeing is a central property of social relationships. As humans, it is in our nature to be sociable and live with others. Usually, the most significant others to us are our family members, friends and neighbours who constitute the closest social network which help us build social capital (Baldock et al, 2007). However, the norm of social responsibility would oblige us to be altruistic and to help not only those who depend on us, but other needy persons outside our family circle as well (Myers, 1993). After all, social responsibility is not a matter of good will but of justice (Reinders, 2002).

The social bonds we create in social networks provide a sense of belonging and impact both mental and physical health (Papalia & Olds, 1992). Without empathy and care for one another the concept of social networks would not even exist (Myers, 1993). We need these others, to whom we are attached, to survive mentally and to develop as people and as communities. It is a natural inclination for human beings to long to be welcomed and accepted by others (Reinders, 2002). Society grants us social status which is the essence of our social value. Women with intellectual disabilities, generally devalued by society, need to have social value in order to be rescued from the effects of devaluation, and to be able to manage their lives by occupying Social Valued Roles (Wolfensberger, 1995).

Like other people, women with intellectual disabilities have unique differences and characteristics, but similarly to all, they share a common need - to have a good life. A good life includes other goods as well such as love and friendship (Reinders, 2002). Similar to other women, women with intellectual disabilities have aspirations and expectations for their life. Tamara's story, narrated in Traustadottir's (2000) book, "Women with intellectual disabilities finding a place in the world," is the story of a woman everlastingly dreaming to be loved:

Next to the road, in the field, on a little hill, there is a nice flower. It stands there in the rain, the sweltering heat and in the hot sun, all night and all day. It's got nice light-blue flowers. It looks like a blue-eyed woman, holding a toddler in her arms and waiting for her husband. They call this flower 'chicory'. I'm chicory too. I've been waiting all my life for a miracle: like a fairytale prince...I'm chicory forever ('What is life like,' Chapter One, Tamara Kainova with Maria Černa, the Czech Republic, p.30).

More importantly, intimate relationships act as a buffer against the effects of adversity and are associated with higher subjective well-being (Cummins & Lau, 2003). Creation of meaningful relationships and support within social networks result above all in personal social wellbeing. Social relationships nurture the values of kindness, sociability and solidarity. Additionally, they develop major personality dimension (extroversion) which is known to underpin the characteristics of social affiliation (Cummins & Lau, 2003).

We all depend on each other even if ironically we seem to be independent and less engaged in social ties (Papalia & Olds, 1992). No matter the frenetic individualistic lifestyle, our independence is just a temporary stage and we will eventually be dependent on the support of others. We crave social interaction when it is absent, and rate relationships with family and friends as the most important life domain; the one that provides us with the greatest sense of satisfaction (Cummins & Lau, 2003).

From an ontological viewpoint, individuals would not survive outside community, nor would community exist without individuals composing it; the former would lead to moral death, while the latter would just present a state of social anomie in which the existence of humanity would be questioned and social organization would collapse (Durkheim, 1897 [1951]).

Clearly, the benefits of social network relationships reach far beyond personal wellbeing; they are the means towards social participation which is definitely an important aspect of citizenship. However, looking at the process of change that has been enacted over the past decades, we are discovering that, in the long run, the success of inclusion for women with intellectual disabilities may depend on the strength of their social networks much more than on their individual rights for formal civic participation as, ‘ultimately, it is not citizenship, but friendship that matters’ (Reinders, 2002, p.5).

### **2.7 Social networks as a means for community inclusion**

Social networking has constituted the central theoretical work in the discipline of sociology, in an attempt to understand the nature of social bonds between individuals and society. The social bonds we create through supportive networking connect and unite us to life and society (Durkheim, 1897 [1951]). Life would not be social if we had to question the interaction with others. We need to socialize in order to meet our personal needs and interests and fulfil societal expectations. Our interaction and participation in social activities are guided by cultural conventions of shared values and social norms. The society in which we live is the source of mutual moral support. Although we take the normative conventions of society for granted, they cannot be enacted without our actions enabling them, for we are the society. As human beings, we have the potential to constantly recreate our cultures and to change the social world, including the possibility of creating a more humane society (Karp et al., 2004).

The community living process originally was intended to allow persons with intellectual disabilities to live in the natural micro-environment of family and neighbourhood, thus avoiding institutionalisation. In 1972 Wolfensberger published *The Principle of*

*Normalisation in Human Services*, a core theme being that people with learning disabilities need to live in local communities with appropriate support if they are to be valued as equal citizens and ‘people first’ (Whitehouse et al, 2001). The philosophy underpinning community living outlines as an ultimate goal social inclusion. To this end, the social integration of people with intellectual disabilities in community is both the aim and a process by which inclusion is achieved (Emerson, 1985).

Obviously, community living has resulted in a higher presence of women with intellectual disabilities in community settings, which is an important achievement for further integration, but community presence does not guarantee social participation (Myers et al., 1998; Emerson et al., 2000; Ager et al., 2001; Cummins & Lau, 2003). Briefly, the main challenge for women with intellectual disabilities is their social participation on equal basis with other citizens. Regrettably, the policies developed for the goal of inclusion thus far have aimed at contractual formal citizenship much more than the informal dimension of civic relationships (Reinders, 2002). What is expected to be achieved with community living is not yet visible, for women with intellectual disabilities need social network support to be socially included.

Converse to expected positive changes reported on community living, recent studies report a low level of social participation (Dangan et al., 1998; Young et al., 1998; Emerson et al., 2000; Kim et al., 2001). The subsequent decline may be caused by inconsistent efforts to provide and maintain conditions that ensure actualisation of opportunities for social relationships and participation (Whitehouse et al., 2001; Arvidsson et al., 2008). While suggesting gains in formal rights such as self-determination and personal choice, the analyses of life experiences of people with intellectual disabilities living in community have not indicated increases in relationships and participation (Myers et al., 1998; Ager et al., 2001).

Nonetheless, persons with intellectual disabilities have reported that friendship and social activities with community, both mediated by social networks, are very important to them (Emerson & McVilly, 2004). Basically, what women with intellectual disabilities are

asking for is to participate in other people's lives, which requires these others to accept and appreciate them. This is what Reinders (2002) calls the moral essence of community living. Further, in respect to the public morality of including women with intellectual disabilities as equal citizens, Reinders (2002) raises the following question: 'We create space to include persons with intellectual disabilities as citizens in our institutions, but do we also include them in our lives as human beings?'(p.3).

Given the sociable nature of social network relationships, people's differences in image and abilities are tolerated and sometimes even welcomed (Myers, 1993). As noted above, environmental factors can influence the capacity for social adaptation. By developing the social ability of adaptation, women with intellectual disabilities can live well in society, and even lose the diagnostic qualification of intellectual disability (Mansell & Fiscus, 1981). After all, what can better qualify for an environmental facilitator than a collective social force, such as a social network? As the means for lifelong education, social networks can perhaps be the most powerful environmental actor that can increasingly improve adaptive functioning and social participation. Furthermore, besides lifelong educational support, social networks provide the source of life opportunities such as personal choice, civic engagement, friendship and intimate relationships. In general, studies on friendship report that without social network agency support all efforts for social inclusion would be limited only to carers and professionals, resulting in poor social relations of people with intellectual disabilities (Ager et al., 2001; Emerson & McVilly, 2004; Dudley, 2008).

By according respect and participating opportunities in social life through development of personal relationships, social networks can contribute to the achievement of one of the core outcomes of quality of life: social inclusion (Ager et al., 2001). Obviously, this ambitious project requires development of a politics of culture that seeks inclusion of women with intellectual disabilities in their capacity as fellow citizens by urging us to include them first as our friends (Reinders, 2002).

## 2.8 The socialising agency of social networks

### *2.8.1 Social networks' socialising role*

Socialisation is an endless educational process exceeding beyond school age and institution. Social networks are a very important socialization agent and play a crucial role in the lifelong learning process of women with intellectual disabilities.

In spite of this, social networks have a social-facilitation effect for women with intellectual disabilities, since the presence of others boosts performance on easy tasks of everyday (Myers, 1993). It is known that the main challenge to persons with intellectual disabilities is the complex process of academic education mainly concerned with numeracy and literacy. In practice, women with intellectual disabilities may fail in academic learning, but they may excel in non-academic school activities (Mandell & Fiscus, 1981). Free from heavy academic programs and full of non-competitive activities, social networks teach women with intellectual disabilities not only to perform simple tasks, but with more time they can teach them how to react to more complex life situations. Therefore the lifelong-learning process is not only as relevant to women with intellectual disabilities as to all people, but it is especially beneficial to the education of women with intellectual disabilities as it enhances their social skills to cope with societal demands during their adult years.

Social agency encompasses a much larger range of socializing actors than social networks. For the purpose of this research, this study concentrates on the very close socialising agents that compose the primary circle of women with intellectual disabilities. They are the parents, siblings, friends and neighbours, who constitute the bonding dimension of social capital and bridge connectedness to larger social communities.

### *2.8.2 Parents' agency*

The family and children influence each other in many important ways (Papalia and Olds, 1992). Family includes the primary caregiver to whom the individual is mostly attached. Naturally children get closely bonded to mother and father in their early stages. Attachment is an affectionate reciprocal relationship between people. Interestingly, girls

report close relationships with mothers that help them develop trust and autonomy to be ready for friendship with other people (Papalia & Olds, 1992).

As the first socialisation agency, parents play an important role in developing social skills that serve children with intellectual disabilities to enter the world beyond home. Early socialization is an important step toward complex relationships in school-age and adolescence. The family environment is the first setting where social roles and norms are taught. More importantly, family is likely to be a non-coercive environment where the wishes of a woman with intellectual disabilities are respected and where her best interests are kept in mind free of ideological dogma (Cummins & Lau, 2003). Not only are the social components of family linkages important to life quality, but the fact is that the greatest advocates and protectors of women with intellectual disabilities are most often their families (Spreat & Conroy, 2002).

Typically, parents of children with intellectual disabilities are concerned that their children will not be able to function normally in society and will fail to meet societal expectations as they grow older. For example, they fear for the child's education, professional career, and heredity of the disability in grandchildren (Strnadova, 2006). Parents worry much about their children's welfare after they die. They hope their other children will not have to bear the burden of the constant care for the person with intellectual disabilities in the future and that their children with intellectual disabilities are able to get a job and take care of themselves. To this end they are helping to promote the establishment of group homes for persons with intellectual disabilities in community and their fears would be alleviated if their children learn to care for themselves and lead a somewhat independent existence aside from family (Mandell & Fiscus, 1981). Obviously, most of all, they want their children to be happy.

### *2.8.3 Siblings' agency*

Beside parental relations, another important relationship for women with intellectual disabilities is the one with brothers and sisters. Relationships among siblings are likely to be the longest-lasting. Siblings influence each other in both positive and negative ways.



Siblings may have fought continuously as children, but they may have been the best friends to each other as well. Siblings share the same roots and parental values, and probably deal more candidly than anyone else with their sibling with intellectual disabilities.

But, siblings' feelings are negatively affected by the disinterest that parents show towards them, when caring more for the child with intellectual disabilities. They feel parents are less sensitive to their needs and interests compared to the child with intellectual disabilities who gets all attention. Moreover, they feel they receive more orders and criticism, and less time for conversation, with parents. The perceived parental neglect enhances rivalry for love and attention and may incite negative behaviour towards the child with intellectual disabilities. Older siblings may adjust better to such a situation if fathers give them extra time and attention to make up for mothers' involvement with the child with intellectual disabilities (Papalia & Olds, 1992).

While some rivalry exists, so do affection, interest and companionship. Older siblings carry some responsibility for caring for the younger child. Same sex siblings tend to be a bit closer and play together more. Especially, older sisters are more likely to share, cooperate and hug. Children with intellectual disabilities usually become attached to their siblings for a longer time than other children do, in constant need for love, attention, approval and acceptance. The environments siblings create affect not only future relationship of women with intellectual disabilities but personality development as well. In middle-life, siblings tend to stay more in touch and are ready to help. Usually as siblings grow older, especially sisters, relationships become closer (Papalia & Olds, 1992).

#### *2.8.4 Friends' agency*

Friendships and social networks are extremely important to all of us and there is no reason to believe that women with intellectual disabilities are any different (Whitehouse et al., 2001). Friends are the source of emotional support and wellbeing and close ties with them help foster both mental and physical health (Emerson & McVilly, 2004).

Friendship starts in childhood, but in adolescence it reaches the greatest intensity of all the lifespan. All age groups seek in friendship mutual help, interaction and liking, and usually friendships continue from mid-childhood to adolescence and sometimes to adulthood.

In adolescence friends are more intimate, cooperative and compete less. Loyalty is a critical feature of friendship in adolescence and continues to adulthood as well (Papalia & Olds, 1992). Adolescents who have close friends are high in self-esteem and consider themselves competent. Good friends are the long-standing interconnections to a wider world for women with intellectual disabilities. Youngsters having friends with intellectual disabilities report that this friendship has impacted their lives in a positive way; by making women with intellectual disabilities happy they are rewarded with happiness feelings (Felce, 2000; Traustadottir, 2000). Sadly this is not the general picture as only few persons with intellectual disabilities report having friends without disabilities. In their research, Emerson et al. (2005) found that only one-third of persons with intellectual disabilities reported seeing friends without intellectual disabilities at least once a year, whilst the rest saw friends who also had intellectual disabilities.

Research is not suggesting that friendship among women with intellectual disabilities has no value, but by emphasising the general absence of other age-peer friendships, research has largely ignored friendships between people with intellectual disabilities (Myers et al., 1998; Felce, 2000). Similar to others, women with intellectual disabilities tend to choose friends who are like them (Dangan et al., 1998; Cummins & Lau, 2003). Studies suggest that personal characteristics of persons with intellectual disabilities such as age and social skills are very important in relationships. However, the environment in which a person lives is a more significant factor than the individual characteristics regarding form and content of activities with friends (Dangan et al., 1998; Ager et al., 2001; Whitehouse et al., 2001; Emerson & McVilly, 2004; Arvidsson et al., 2008).

Women with intellectual disabilities in adult life are in need of women friends of their age, but women of their age devote more time and energy to family and work. An

individualistic lifestyle of socially integrated activities would leave no time for other aspects of life (Cummins & Lau, 2003). Furthermore, adults search for few supportive and qualitative friends (Papalia & Olds, 1993). Because of infantilisation and de-genderisation of intellectual disabilities, women with intellectual disabilities are not qualified for friendship by other women (Clements et al., 1995; Traustadottir, 2000). Deprived of both the real opportunities to meet people and the support required to take advantage of the opportunities, women with intellectual disabilities face difficulties in developing meaningful relationships (Whitehouse et al., 2001). Therefore, studies have found only modest increase in friendship, which mostly relies on staff and other service users like themselves during daily activities in segregated settings (Dangan et al., 1998; Felce, 2000; Ager et al., 2001; Hundert et al., 2002; Emerson & McVilly, 2004).

#### *2.8.5 Neighbourhood*

Our sense of community is enhanced by active association with selected members of our own families and non-family friends in our neighbourhood with whom we share a common interest of some kind and who have a similar life profile to ourselves (Cummins & Lau, 2003). As mentioned above, social relationships with other people seem to enhance mental and physical health, while emotional support from people in neighbourhood helps minimize the effect of stress and loneliness. At the same time, social ties may foster a sense of meaning and coherence in life (Papalia & Olds, 1992; Felce, 2000).

Highlighting the environmental impact on persons with intellectual disabilities, Emerson (1985) argued that the success of inclusion into community settings is determined much more by the characteristics of environments that teach and support positive behaviour adjustment than personal characteristics only. Few studies on community integration convey an optimistic picture, suggesting an increase in the use of community leisure activities and contacts with people without intellectual disabilities during these activities (Dangan et al, 1998). Most recent studies, suggest that unfortunately, persons with intellectual disabilities exposed to community have found effective social integration

extremely difficult to achieve (Whitehouse et al., 2001; Hundert et al., 2002; Cummins & Lau, 2003).

It has been argued that physical exposure is a necessary but not sufficient condition to create a sense of community and may instead create a sense of alienation, for it is social, not physical integration that has a reliable positive influence on well-being and participation (Young et al., 1998; Hundert et al., 2002; Spreat & Conroy, 2002; Cummins & Lau, 2003; Emerson & McVilly, 2004). A fuller understanding of the impact of neighbouring community settings on social participation would depend upon identifying factors that are associated with gains in social adjustment in community environments (Dangan et al., 1998; Felce, 2000; Whitehouse et al., 2001; Hundert et al., 2002; Baker, 2007).

Anyway, women with intellectual disabilities who are placed in neighbourhood do not automatically develop new interpersonal skills and the wider community does not always readily accept previously marginalized people. In order to be part of a community, people need to develop relationship networks (Whitehouse et al., 2001). Finally, to include women with intellectual disabilities in equal capacity, people should include them in their informal community relationships as well. As Reinders (2002) put it: If community living is a human experience, we should expect that persons with intellectual disabilities *want* to be included in the lives of others and we should expect them to *want us* as friends and companions (p.3).

## **2.9 Recommendations of previous research**

The literature has recommended further research in three areas of social networks impacting the lives of women with intellectual disabilities: the socialization process, social wellbeing, and social participation.

In relation to friendship, further attention needs to be given to research and practice initiatives aimed at increasing levels of friendship activities (Emerson & Villy, 2004). Personal skills have been identified as influential in the realm of friendship creation and

maintenance so far, therefore research is recommended on the influence of environment on adaptive behaviour (Myers et al., 1998).

To the aim of inclusion, follow-up research might consider what factors best predict the formation and stability of outside friendships and how they influence social participation (Dudley, 2008). However, drawing attention to the apparent failure of people with intellectual disabilities to develop relationships with non-disabled people, research has placed a greater value on these relationships than naturally occurring relationships between people with disabilities (Myers et al., 1998). It is evident that if we are to promote an inclusive society and enhance the quality of life for people with intellectual disabilities, further research is needed to better understand and more effectively support people's aspirations for, and experiences of friendship (Emerson & McVilly, 2004). Research must place a greater emphasis on the relationship between age and community involvement and subjective expectations in a lifespan perspective (Ager et al., 2001).

In terms of neighbourhood impact, given the paucity of information in the existing literature, particular attention should be paid to measuring indicators of neighbourhood deprivation and impact on social capital (Walsh et al., 2007). For community integration to be beneficial for the persons being integrated, it must involve a 'sense of community' such that they feel part of a readily available, supportive and dependable social structure. To this end, a new literature is required to redefine community integration and engender a sense of community (Cummins & Lau, 2003).

Research on intellectual disabilities has been 'gender-blind,' ignoring the fact that the views, experiences, and needs of men and women differ from each other, impact people with disabilities lives differently, and are by no means always compatible. These differences must be addressed, rather than ignored (Clements et al., 1995).

On the quality of life, research should contrast the typical situation for people with intellectual disabilities to that of society as a whole, in order to explore whether

environmental conditions support a lifestyle for women with intellectual disabilities typical of the wider population (Felce, 2000).

In conclusion, citizenship goes beyond formal rights; it is about social inclusion by gaining membership in community (Baldock et al, 2007). For that reason, the goal of inclusion ultimately raises a philosophical question - what a good life is and whether there is a place for people with intellectual disabilities in it – that research should address by exploring more the cultural aspects that influence society's morals with the aim of creating an inclusive society (Reinders, 2002).

## **2.10 Summary**

Living in community can positively impact the lives of women with intellectual disabilities because it fosters social ties and social capital. The interconnection of women with intellectual disabilities with the community is realised through social networks composed of family, friends and neighbours. The relationship with community can impact both social belonging and social participation and can affect personal wellbeing. Community inclusion and wellbeing are both core domains of quality of life.

Personal characteristics are considered to be important in creation and maintenance of social relationship. The literature suggests that improved personal abilities are not the only variables that can guarantee automatic acceptance and inclusion of women with intellectual disabilities. The success of community inclusion depends on the combination of both personal and environmental aspects. But, the latter is more influential in inclusion, because it teaches people with intellectual disabilities positive behavioural adjustment (Emerson, 1995). The interventions to improve relationships of women with disabilities with community should work both ways simultaneously, from individual to environmental aspects.

Findings on friendship do not discriminate on gender aggregates, so we have to consider the findings as relevant to women as well as to men. Women with intellectual disabilities have friends like them amongst people with disabilities in social services offered in

segregated settlements. Friendship among them is the main source of socialisation and communication for women with intellectual disabilities outside family.

The contact women with intellectual disabilities have with environment consists of physical exposure, which may be a necessary but not sufficient condition for social integration. Disclosure to community can even produce counterproductive effects for it may create a sense of alienation. The community is not yet open to fully accept and welcome women with intellectual disabilities as friends and neighbours. The fact that women are not included in society is attributed to the minimal attempts of community to accept and cooperate with them.

Family support is considered to rate higher than friendship and community acceptance. Families are interested in providing their members with intellectual disabilities social ties in community in order to enable them to conduct a semi-independent life. But families are facing community resistance in accepting and supporting persons with intellectual disabilities. Family members are the best advocates for the rights of women with intellectual disabilities. But, the future implications for social relationships of women with intellectual disabilities will depend much on community willingness to accept them and to understand both their limitations and strengths.

## CHAPTER 3

### METHODOLOGY

#### **3.1 Introduction**

This chapter is about the methodology of research. The chapter begins with an introductory section, in which are detailed the sections composing this chapter. It continues with the section on the rationale for choosing qualitative research as the main strategy for research, comprising an explanation of the ontological and epistemological approach for the study, including the theoretical perspectives adopted in this research. The following section proceeds with methodological components: the instrument for collecting data, methods for collecting data, data collection, approach to data analysis, validation and reliability, and ethical concerns for the research. The last section is a summary of the methodology.

#### **3.2 The role of research for inclusion**

Current inclusion policies represent a major challenge for the entire society, imposing first of all changes to existing mentality and requiring open-mindedness to embrace the democratic principles contained in it. One of the foremost missions of inclusion research is to study the conditions for realizing inclusive communities. By examining social problems in the light of culturally determined needs and objectives, research identifies conditions for adapting society to the huge challenges of a rapidly changing world (Raivola, 1986). While informing both policy-making and practice, research advocates for societal change that addresses paradigmatic issues concerning what kinds of societies for what kinds of people are most appropriate?



Concerned with solutions of modern problems, research aims to understand them and to contribute to the construction of meaning and knowledge (Cohen & Manion & Morrison, 2007; Robson, 2002).

### **3.3 Research paradigms**

The research paradigm represents the viewpoint on the world and conditions the way to go about investigating it. Some major typologies of research paradigms are defined as positivism, realism and constructivism and are composed of three components; ontology, epistemology and methodology (Gray, 2004; Bryman, 2004). As expressed in the etymology of the term ‘onto’-being and ‘logos’-science, ontology is concerned with the nature of being, asking about the nature of reality, while epistemology is concerned with knowledge, methods, validity and issues related to it, by asking how do we know the reality. Methodology deals with how do we attempt to know the world and what methods to use.

In the positivist paradigm the reality is a given one, having a reality of its own, unconditioned by human action, while in the constructivist paradigm the reality is socially constructed by social actors’ interaction and meaning. Considering that reality is socially constructed and not predefined and unchangeable, I decided to use the interpretive-constructivist research paradigm as most appropriate in answering my research questions. As Bryman (2004) states, the interpretive-constructivist researcher interprets the interpretations of research participants (p.444). By investigating the experiences of women with intellectual disabilities through mothers’ and sisters’ words, I have interpreted the interpretations represented in their thoughts, views and feelings.

### **3.4 Ontological stance**

The research is based on the Parmenidean ontology of *being* that considers reality as objective and composed of clearly formed entities with identifiable properties, which can be represented in words, concepts and symbols (Walliman, 2001; Crotty 2003; Gray, 2004). The present qualitative research has involved an interpretive, naturalistic approach to the world, by researching things in their natural environment and attempting to make

sense of phenomena in terms of meanings people bring to them (Denzin & Lincoln, 2005). To this end, the study has extensively interpreted the social relationships of women with intellectual disabilities seen through the eyes of their mothers and sisters with the aim to render their lived experiences visible. As a social researcher, I am concerned with the individuals (*idios*) and their human affairs which makes the research idiographic (Crotty, 2003).

The reality of life for women with intellectual disabilities is not conditioned only by themselves, as environment plays a major role as well. These two variables do not operate disconnected from each other. Inclusion and wellbeing of women with intellectual disabilities depend on readiness of community to cooperate with them as neighbours and friends. This entails that the community have the resources for relationships and can use them in favour of inclusion and wellbeing. By considering women with intellectual disabilities as valuable persons, the community actors can construct a better reality for women and for themselves.

### **3.5 Epistemological stance**

#### *3.5.1 Constructivism*

Based on a constructivist epistemological stance that considers meaningful reality as socially constructed by the subject's interaction with the world (Robson, 2002; Crotty, 2003; Gray, 2004; Bryman, 2004; Cohen et al, 2007), I have explored the meaning of relationships, friendship, love and social networks as constructed in participants' words and not outside them. In practice, researching the reality of social life is like solving a puzzle (Bryman, 2004; Bell, 2006). Evolving over time, social events and individuals' behaviour are unique and largely non-generalizable, while social situations are constantly fluid and context-affected (Cohen et al., 2007). To solve the puzzle, I had to become interpretive *bricoleur*, to be able to approach the object of study with a radical open-mindedness and to interpret people's behaviour in terms of their norms, values and culture (Crotty, 2003; Bryman 2004; Denzin & Lincoln, 2005). Furthermore, by adopting a constructivist stance, and making use of and being sympathetic with gender theory and disability studies, I do consider that concepts of gender and disability are socially

constructed, and therefore can be dismantled (Rapley, 2004; Ridgway & Correll, 2004; Risman, 2004; Thomas, 2004; McClimens, 2007).

The reality of women with disabilities in this research is known through the intentional relationship between the knower and the known interacting to collect data for answering the questions on:

- How social networks impact community inclusion and wellbeing of women with intellectual disabilities
- What characteristics of social networks contribute to the social relationship
- How social relationships contribute to life satisfaction

By investigating these questions, I could comprehend the complexity of social reality for women with intellectual disabilities, the doors of which were opened to me by their mothers and sisters.

I have used interpretivism, as a theoretical perspective linked to constructivism, to explain how the meaning of social relationship in form of networks is played out in the interaction between the subjects and the outside world. The *verstehen* (interpretation) of mothers' and sisters' perception reflects the social reality of women with intellectual disabilities.

### *3.5.2 Social interactionism*

Aiming at analysing the social interaction of women with intellectual disabilities from the sociological perspective, this research is oriented by the model of symbolic interactionism. The study has employed the theoretical concept of social relationship as used in theory of social psychology and makes use of qualitative methodology because this approach is extensively used in studying social interaction (Silverman, 2000). By using the interactionist model of relationship construction, the study tries to explain how the social capacity of women with intellectual disabilities to socialize with others develops through interaction. As theory confirms, social transactions are constructed in daily interaction with others (Karp et al., 2004).

### *3.5.3 Feminism*

Furthermore, I have adopted a feminist epistemological stance that encourages the unpacking of taken-for-granted ideas about women with disabilities that place them in eternal infantile and degendered position (Fine & Asch, 1998; Blackwell-Stratton et al., 1998; Martin, 2003). Aiming at social justice for women, the research has problematised the adverse situation of women with intellectual disabilities by making their alienation visible and naming the social institutions that frames it (Olesen, 2005).

### *3.5.4 Empirical Nature of Research*

This research is concerned with social policy and especially with anticipated outcomes with regard to inclusion of women with intellectual disabilities. The predictive purpose of this study is to address the (research) question of: what is likely to occur in the future for the social inclusion of women with intellectual disabilities as the result of the inclusive policies and how will they be included? Having an exploratory nature, the study has employed the use of interview as the main research strategy to find out what is the situation of women with intellectual disabilities with regard to social inclusion. The content analysis of literature is used as an additional technique to confirm the research question derived by the theory of social-psychology and to corroborate research findings (Bryman, 2004; Fraenkel & Wallen, 2008). Qualitative study allows better understanding of another culture (Silverman, 2000), this is a further reason I have chosen it while conducting the research in a country different than my own.

## **3.6 Research Methodology**

### *3.6.1 Qualitative methodology*

To approach real world social problems, researchers make use of strategic methodologies, broadly defined as quantitative or qualitative, which define the way of studying a phenomenon and condition the choice of methods (Silverman, 2000; Bryman, 2004). Dependant on the research purposes and questions, the choice of methodology represents the researcher's view of the world and directs the research design into fixed-quantitative or flexible-qualitative models (Robson, 2002). I have chosen qualitative research methodology for this study rather than quantitative, because the research is

concerned with the understanding of subjects' 'inner experiences' and the 'forms of social interactions' between them and society, viewed through the eyes of proxy participants and based on the 'cultural meaning' they attach to those experiences (Silverman, 2000, p. 89).

In qualitative research the meaning-making is conceived through the interaction between a researcher and participants, as the meaning of social phenomena is constructed by social actors and is not predetermined (Bryman, 2004). The interaction between the knower and the known is intentional and 'intentionality' presents an innate agency of the knower to construct the social reality (Crotty, 2003). Converse to quantitative methodology, in qualitative research the meaning is *constructed* not discovered (Gray, 2004). The subjects construct their own meaning of reality (Robson 2002; Gray 2004). It is difficult to capture the meaning people attach to reality in quantifying categories.

By using a qualitative approach I intend to not only comprehend the reality in which women with intellectual disabilities live, but to contribute to the construction of a better one in partnership with their families participating in this research. My viewpoint is that since social properties are defined by interactions of the social actors and meanings they attach to them, and then we can engage in the enterprise of defining better terms for better living conditions of women with intellectual disabilities.

### *3.6.2 Research design*

Research methods represent the instruments and ways of collecting data and usually follow the earlier decision on the chosen methodology (Cohen et al. 2007). The major concern of interpretive epistemology is the interactive link between researcher and participants as through this channel the researcher can gain access to people's common-sense thinking and research participants can help construct the reality with the researchers (Bryman, 2004; Robson, 2004; Mertens, 2005). Qualitative methods allow the immersion of the researcher in the social settings, and facilitate inter-subjective understanding between the researcher and the participants (Mertens, 2005). Collected data are analysed

and interpreted in order to suggest relationships between patterns or variables and to infer generalisation and theory (Gray, 2004).

This research is a naturalistic empirical study corresponding to the symbolic interactionism theoretical perspective and to ethnographic style. Data in this research are collected through the method of interview and the choice is influenced by interpretative-constructivist stance adopted in research methodology. Literally the term inter-view is a view between people, shared and negotiated in a dynamic social moment (Cohen, et al., 2007). Interviews are flexible tools for data collection used to portray events in subject's terms in a specific context by capturing the reality in perceptions and views of participants (Cohen et al., 2007). The semi-structured interview is used as a research tool for the data collection in this study. The content and procedure of interview have been organised in advance prior to data collection and have been informed by the approach of quality of life, used in previous research on intellectual disabilities.

### **3.7 Data collection**

#### *3.7.1 Data obtained*

This study aimed at examining the quality of life for women with intellectual disabilities. To this end, the data collected provide information on two life domains: social inclusion in community and personal wellbeing of women with intellectual disabilities. The social relationship is an indicator for community inclusion while life satisfaction is an indicator for wellbeing. Environmental factors and social actors contribute to the fulfilment of quality of life. The social network, socializing agencies and the community atmosphere influence the opportunities for inclusion and wellbeing of women with disabilities. The information yielded in the data is used to address the relationship between social properties of social relationship and quality of life. The data collected provide information in four areas:

- friendship and relationship (activities undertaken with friends, frequency of contacts);
- community support (contact with neighbours and use of community resources);
- family support (the nature and amount of support);

- life satisfaction (purposeful activities, feelings and wishes and decision-making).

### *3.7.2 Site of research*

Data were obtained from active members of parents organisations. Three parents' organisations were directly involved in this study, Duha, Club of Friends of People with Down syndrome and Czech Inclusion (Association for Support to People with Mental retardation in the Czech Republic). I visited Duha day-care centre during a community open day where all neighbouring people were invited to participate including the elected officials, municipal administration and social service. I went there with my mentor, Prof. Maria Černa, who introduced me to the clients of the day-care centre and to the management staff with whom the sample and the protocol of interview were discussed. I visited all the workshops in which women with intellectual disability were working to produce handcrafts and services such as ceramics, woodwork, paper-packing, textile, art studio, gardening and the bar-café. The sheltered workshops were helping women with intellectual disabilities to develop their occupational skills in order to be employable and to access the open labour market. The visit at the day centre did not last more than half a day, but I could grasp some fragments of how women with intellectual disabilities were involved with job tasks and how they were interacting with their workshop colleagues. The visit at Club Down was arranged by Prof. Černa in cooperation with parents and professionals working in the centre. The centre provided the premises to conduct the interviews as well. Through a discussion with a senior specialist of the centre, I was informed about different support activities for children with Down syndrome, targeting both rehabilitation and socialisation aspects. The remaining part of research participants were members of the Czech Inclusion.

### *3.7.3 Sample*

The sample is a subset group of population that is investigated to provide answers to the research questions. Usually the sample used in qualitative research is smaller than in quantitative research (Cohen et al., 2007). The sample used in this study is a non-probability type of sample and as such targets a particular group, in the full knowledge that it does not represent the wider population; it simply represents itself (Cohen et al.,

2007). The sample of this research represents the characteristics being sought; therefore it is a purposeful one. The sample is composed of fourteen women with intellectual disabilities, of age 15-40 years old, living in the city of Prague. The research investigates the social relationships among adolescent, young and adult women with disabilities. The sample is named research subjects to differentiate it from research participants, who are the mothers and sisters interviewed instead of women with intellectual disabilities. It was not possible for me to interview women with intellectual disabilities in a direct way, due to language barriers.

This research is a cross-sectional study, comparing three age cohort groups' differences and similarities. The division of the group into three sub-groups takes into account the essential age differences regarding social roles and life expectations. I am providing below a short explanation on the age definition of the research subjects.

#### *3.7.4 Age group definition*

The person's age status in society is determined by social, cultural and biological factors and the meaning attached to the age categories is defined by the age structure of society (Karp et al., 2004). A person's life span is chronologically divided into childhood (0-12 years), adolescence (13-20) and adulthood (20-60), with the latter being divided into young adulthood, middle age, and late age (Papalia & Olds, 1992). In this study young adulthood will be divided into early adulthood (20-30) and young adulthood (20-40). For use facility early adulthood is called young age and young adulthood is named adult. So the subject sample is composed by three age cohorts: adolescents, young and adults.

The age group lifestyles are different given the social roles ascribed to age. For example the adolescents go to school, while some young people go to school and some go to work. Usually, adult people have a job. Youngsters are in search of life possibilities, job, and residential shift from home and have a distinct lifestyle from both adolescence and adulthood. Adolescence is marked by substantial physical and cognitive changes and is a time of being in search of the self, while adult age people have an established identity and seek to fulfil the adult roles of worker, spouse and parent (Papalia and Olds, 1992).



### *3.7.5 The level of intellectual disabilities and other characteristics*

Another characteristic for designing the sample was the level of intellectual disabilities, which corresponds to three code definitions for Mental Retardation at DSM-IV-TR (2002) mild, moderate and severe. The profound level and unspecified group was not included in the research. The majority of subjects, eleven (68%), fell into the category of moderate to severe intellectual disabilities, while two fell into the severe category and only one had a mild level of intellectual disability. The intellectual disability was associated with Down syndrome in five subjects and with Autism Spectrum Disorder in one. All except three subjects have siblings. Adolescents and young people were living with families while three adults were living in group homes, run by parents' organisations.

### *3.7.6 Rationale for choosing the sample*

Social relationships are important for everyone, whatever the age or life stage. But the nature and quality of relationships are different for different age cohorts. Meaningful relationships and purposeful life activities are carried out in different ways by different age cohorts. Life satisfaction has different sources and reasons for adolescents, the young age and for the adult, as their activities are different and the lifestyle depends on personal and group characteristics, in which age counts a lot. For example, a girl of eighteen years old may find satisfaction in life with classroom peers and engage more in sport during leisure time, while the reason for a woman of thirty five to be happy with life may be the job relation and organised lifestyle.

The age differences between adolescents, young and adult women in this study mainly consist of lifestyle, nature of relationships, kind of friendship, and type of activities, interests and aspirations. These differences impact their qualities of life and their relationships. Aspects of lifespan stages are addressed through the comparison between groups.

### *3.7.7 Research Participants*

Due to language difficulties for me, in consultation with the parents' organization, it was decided to conduct the interviews with mothers and sisters as the closest carers and best informed about the situation of women with disabilities on whom this research is based. The participants group was composed of active members of parents' organizations. The participants were fourteen; eleven mothers and three sisters. The choice of a mixed participants group was made to increase validity of the research by comparing two proxy participants' views on the same social phenomenon and same subject group.

### *3.7.8 Access and permission*

The parents' organisations provided access to the sample of mothers and sisters. The organisations provided a list of names of their members to be contacted. Due to the language barrier I could not carry this task myself, but a native researcher, Prof. Maria Černa who has served as my mentor, contacted and arranged all meetings and interviews with mothers and sisters. She translated both written and oral interviews. I addressed to all participants a courtesy letter of intention explaining the scope of interview and asking for their cooperation. All contacted mothers agreed to cooperate for the interview and allowed tape-recording the interview.

## **3.8 Method for data collection: interview**

### *3.8.1 Interview as data collection method*

Data were collected through the use of semi-structured interviews. The interview procedure in data collection was similar for each participant. Before collecting data, the organizations were contacted to be informed of the scope of the research and were consulted on the sample selection and interview protocol. With the help of management staff it was fixed the time schedule for interviewing and place where interviews would take place. Following consultation with parent's organizations, I completed fourteen semi-structured interviews with mothers and sisters.

### *3.8.2 Interview sections content*

The interview had six sections: demographic, relationships in schools, in work place, in community, in family and wellbeing (please refer to appendix A). The second, third,

fourth and fifth sections addressed questions related to the operational concepts of social networking such as friends, family and neighbours, while the sixth section contained questions on the operational concept of purposeful activities of women with intellectual disabilities. The information on the operational concepts would provide answers to both research sub-questions: (i) on the contribution of social networks to the establishment of social relationships and to life satisfaction, and (ii) on contribution of purposeful activities to the satisfaction with life. The operational concept of social network was used to examine the impact it has on both indicators of quality of life: social relationships and satisfaction from life. Besides social relationships, life satisfaction is influenced by activities of everyday life as well, whether they are purposeful or not, whether they provide positive or negative feelings of being useful, happy, lonely, anxious or rejected, and whether the activities are decided by women themselves or not, and what women would wish for having in life. The indicator levels of social relationship and life satisfaction would report the situation of community inclusion and social wellbeing of women with intellectual disabilities. By addressing the questions related to two indicators of quality of life, the main research question on the contribution of social networks to community inclusion and social wellbeing would be answered as well. The last section on wellbeing closed the loop of investigation.

### *3.8.3 Instrument for data collection*

The data are collected by semi- structured interviews. The interview model was adapted by the interview protocol, based on the model of quality of life (QOL), developed by Walsh (Walsh & LeRoy, 2004; Walsh et al., 2007). Quality of life is a concept described by attributes called social indicators such as social equity, social relationship, friendship, employment, education, and so on (Brown & Brown, 2003), and can be measured in two ways: objective and subjective. For examining the quality of life for women with intellectual disabilities, mothers and sisters were asked instead of women themselves, due to the language barrier. The information from proxy participants is very useful, but it is not the same thing as information from subjects. Both are perceptual information, but it is different information because it is from a different person's perception. For this reason, proxy perceptions are not assumed to be the perceptions of the subject.

### *3.8.4 The quality of life model*

As mentioned in Chapter 2, the quality of life for people with intellectual disabilities is estimated in three life domains: independent living, social inclusion and wellbeing. In this study two of the life domains are explored, social (community) inclusion and social wellbeing. The indicator for social inclusion is social relationships and for social wellbeing it is life satisfaction. Each indicator is reduced into operational concepts. The operational concepts related to social relationships are family, friends, and neighbours that constitute the social network. The operational concepts for the domain of social wellbeing are the activities that make life purposeful and stimulate positive feelings such as happiness and usefulness and boost capacity for decision making. It is worthy to note, that social relationships have a direct impact on social well-being.

Based on the model of quality of life, the research examines how the operational concepts contribute to the life quality indicators. Specifically, the research examines social relationships in terms of whether the relationships work well (and serve as sources of quality) or not (thus constituting needs), and considers the factors that help improve well-being or that hinder its development (Brown & Brown, 2003)

## **3.9 Approach taken for data analysis**

### *3.9.1 Constant comparison*

Qualitative data analysis involves organising, accounting for and explaining the data; in short, making sense of data in terms of the participants' definitions of the situation, noting patterns, themes, categories and regularities (Cohen et al., 2007).

The approach used for data analysis was comparison at two levels: subjects' age groups and proxy participants. Assessment based on qualitative data tried to get at the true nature of relationships and situations of women with intellectual disabilities by describing the characteristics of social interaction and aspects of the micro-social environment in which they live.

Based on the research questions and following the interview sessions sections, the data were examined in terms of four themes: family support, friendship, community inclusion and wellbeing.

The data collected in the first section of the interview includes demographic information including age, living place, marital status and sibling order. The data collected in sections two and three of the interview, which corresponds to relationships in school and work place, are coded under the theme of friendship. Besides friendship, these two sections contain data on the context of education and employment which are analysed under the theme of wellbeing, clustered at the category of purposeful life activities. The data from section four of the interview on social relationships with community are organised under the theme community inclusion. Questions were also asked about recommendations for changes in personal and environmental level for improvement of social relationship, inclusion and wellbeing. The data of fourth session of interview on relationships within family are organised within the theme of family support. The data of last section of interview on wellbeing are organised under the theme of social wellbeing. This theme collated data from other interview sections in order to analyse the life satisfaction with activities done happiness, likings and disliking usefulness , wishes and decision making .

Each theme disaggregated the grouped data into the corresponding age groups. This division reflects better the personal development, social roles, society expectations, individual interests and aspirations between adolescents, young and adult women.

### *3.9.2 Data codification and analysis*

The data analysis proceeded through a systematic series of content analysis of interviews (Cohen et al, 2007). The strategy for data analysis was based on the editing approach which is flexible and uses no *apriori* pre-definite codes. The initial set of materials obtained from interviews was codified based on the researcher's interpretation of the meaning of the patterns in the text (Robson, 2002).

Codification is based on the variables representing people's characteristics linked to the research questions (Robson 2002; Auerbach & Silverstein, 2003). The variables used for codification were the subject's age and proxy participant's relation to the subject. According to age the subjects are grouped into three age cohorts: adolescents (15-19), youngsters (20-29) and adults (30-40). Codes for age of subjects are as follows: adolescence is AD, young age is Y and adult age is A. The code AD (1-5) applies to five adolescents; Y (1-4) applies to four young women; A (1-5) applies to five adult women. According to proximity to the subject, the proxy participants are divided into two categories and codified: mothers (M) and sisters (S). Codes are combined to track the data source for each proxy participant informing on a respective subject. So the final set of codes is: MAD (1-5) for mothers of five adolescents, MY (1-4) for mothers of four young women, MA (1-5) for mothers of five adult women, SAD (1-5) for sisters of five adolescents, SY (1-4) for sisters of five youngsters and SA (1-5) for sisters of five adult women.

In order to keep the flavour of the original data derived from semi-structured interviews, I have deliberately focused on individual responses of each proxy participant, quoting verbatim accounts. Through a progressive focusing and reflection, the data have been transcribed and tabulated in order to select the most significant features to be focused on. A summary of interview data reflects the salient features of emerging issues such as the role of friends, neighbours and family support for social relationships of women with intellectual disabilities. Following the main outlines of the phenomena of study as defined in the research question, the data have been grouped under each block per thematic, and put together to make a coherent story (Vengraf, 2001; Cohen et al, 2007).

### **3.10 Research validity**

#### *3.10.1 Validity*

Validity and reliability are very important in qualitative research. Validity refers to the appropriateness of the inferences, while reliability refers to the consistency of the inferences over time, location and circumstances (Silverman, 2000; Bryman, 2004; Fraenkel & Wallen, 2008). Concerning the validity of qualitative research, Bryman

(2004) proposes at least two criteria: trustworthiness and authenticity; whereas Crotty (2003) says that there is no true or valid interpretation in constructionism, but the useful interpretation. Furthermore, Robson (2002) states that reliability in qualitative research involves honesty. After all, because 'it is very difficult to prove anything in social research' *reliability* is preferred instead of generalisability (Opie, 2004, p. 10). In qualitative research *internal validity* is required, which means that findings must describe accurately the phenomena being researched (Cohen et al., 2007).

In this research *internal validity* is ensured by using mechanical means to record the data, in order to retrieve data at any time to check for accuracy, and peer's examination of data. To foster internal validity, I have reported the situation through the eyes of participants, thus ensuring authenticity of data.

Another means for increasing validity of research was the validation of interview measures, known as *convergent validity*, by which I compared the interview measures with other research measures already shown to be valid (Cohen et al, 2007). In this study interview measures are borrowed from previous research on quality of life for people with intellectual disability (Walsh et al., 2007; Brown and Brown, 2003) therefore the validity of interview is comparable with the proven validity of previous research (Cohen et al., 2007). This consistency has provided *construct validity* of instrument, meaning that the construction of instrument is largely agreed in literature, and *content validity*, meaning that the instrument used in this study comprehensively covers the researched items.

Being a foreigner to the culture of the researched, I have strived for *cultural validity* to ensure that the study is accurate to the culture where research is done. With the appreciated contribution of Prof. Černa, both interview protocol and participants information, are translated in a culturally appropriate way. The triangulation of sources of information, of peer debriefing and theories have ensured the credibility of this inquiry.

Framed under the feminist epistemology, this study has a *catalytic validity*, as it exposes the adverse situation of women with disabilities to community and suggests a political agenda for change.

### *3.10.2 Reliability*

In qualitative methodologies reliability includes fidelity to real life, context and situation specificity, authenticity, comprehensiveness, detail, honesty, depth of response and meaningfulness to the respondents (Cohen et al., 2007).

In order to control for reliability, I have made use of semi-structured interviews using the same format of questions for each participant. Another way of ensuring reliability in this research was by certifying that each interviewee understood the same question in the same way and was enabled to demonstrate the own way of looking at the situation (Silverman, 2000). In order to increase reliability, I have followed the steps suggested by Kvale (1996, pp.148-9, cited in Cohen et al., 2007) on interviewing that I am briefly listing here: I have extensively consulted the theories to know the subject matter in advance in order to conduct informed research; I have constructed the interview in a way that each stage was clear to the participant; I have used a clear and understandable terminology ensuring both comprehension of questions by participants and the coverage of material; and during the interview, I allowed sufficient time for each participant to answer in their own way; in interviewing process, I was not only interested in gathering data for the research, but I have been equally interested, sensitive and empathic to participants' feelings, using active listening; I have checked the reliability and consistency of responses by well-placed questioning and by recalling earlier statements made by participants.

Reliability assumes replication of the same research in other situations over time, but the situations in naturalistic studies include uniqueness and idiosyncrasy of situations, such that the study cannot be replicated (Cohen et al., 2007). Since in qualitative research, a double hermeneutic takes place, meaning that the interviewer interprets the interpretations of interviewees of given situations, then reliability becomes dependent on



subjectivity of interpretations. To avoid the level of bias and subjectivity of interpretations in this research and to ensure internal validity, I have made use of peer debriefing by Prof. Černa who conducted an independent audit of the process of inquiry to evaluate whether results are consistent with data.

### *3.10.3 Triangulation*

To add validity to the research I have used triangulation, by contrasting the subjects groups and participants groups. The use of triangulation reflects an attempt to secure an in-depth understanding of the phenomenon in question, adding rigor, breadth, complexity, richness and depth to inquiry (Flip, 2002, cited in Denzin & Lincoln, 2005, p.4). Triangulation is the use of two or more methods, set of data, group or researchers, just to name a few that are employed to avoid bias and to empower research validity.

This study has employed *time-triangulation* by utilising cross-sectional design that collects data at one point in time to ensure synchronic reliability (find similarities) of data (Cohen et al., 2007). In data triangulation the information is gathered from two kinds of participants, mothers and sisters, to increase objectivity. Another type of triangulation is use of *group analysis*, focused on the interaction patterns of women with intellectual disabilities, according to age, with the groups in community.

## **3.11 Limitations of research methodology**

### *3.11.1 Researcher values*

I have tried to be unbiased in the research, though I cannot prove warranty, since being intrinsic to my identity, societal values might have affected the research process and findings. It is a known fact that interviewers and interviewees alike bring their own experiential and biographical baggage with them into the interview situation (Cohen et al., 2007). After all, it is not possible to take a value-free stance in qualitative research. The axiology of interpretive episteme asks for the researcher to stay close to the object and convey personal values through research.

### *3.11.2 Language difficulties*

Knowing that the roles of communication, symbols and language are fundamental to interpretive researchers (Birbili, 2000; Burges et al., 2006), this study would yield more interesting results if I knew the language of the participants. Therefore, I consider the language barrier as a major limitation for the study. Because of language, the research could not be conducted with women with intellectual disabilities themselves. However, the rhetoric of qualitative research celebrated the expression of opinions of mothers and sisters who wanted their daughters' and sisters' stories to be heard.

### *3.11.3 De-contextualisation of data*

The issue of reliability does not reside only with the preparation and conduct of interview or data collection only, but extends to data analysis as well (Cohen et al., 2007). In transcription of interviews, the selection process is inevitable. However detailed it might be the transcription process involves interpretation of social situations. The level of abstraction evolved in the interpretation process de-contextualises the data and loses the integrity of individual responses. To avoid the dispersion of individual input, I have tried to keep fidelity to participants' meanings in transcribing, analysing and interpreting each single participant perception.

### **3.12 Ethical issues**

Research has always an underlying moral agenda (Fraser et al, 2004; Denzin & Lincoln, 2005). The constructivist ontology drained in me the spirit of criticism against the culture of social rejection that has led to segregation of women with intellectual disabilities. By use of interpretative practice I could make the world of women with intellectual disabilities visible with the aim of transforming it in a more humane way (Denzin & Lincoln, 2005).

A major concern for me has been the interactive link with participants in a foreign culture to gain access to their common-sense-thinking (Bryman 2004). Wishing to avoid the difficulties of becoming a community insider, I tried to collaborate effectively with research participants and share the decision-making with them (Mertens, 2005; Fraenkel & Wallen, 2008). Following the axiology of interpretive episteme that advises the

researcher to stay close to the subjects, I constructed a good relationship with mothers and sisters trying to show them my solidarity for their efforts to improve their family members' lives. Their values, self-interpretation and representation of their experiences were of great importance to the research (Opie, 2004).

The use of qualitative methods allowed immersion in the subjects' social settings and facilitated inter-subjective understanding between me and participants, helping us to construct the 'reality', by merging our viewpoints on the social world (Robson, 2004; Bryman, 2004; Mertens, 2005). As a researcher, I maintain an equal status with participants in research, striving to strengthen my own and their self-reflection on societal values impacting social relationships and networking of women with intellectual disabilities. Furthermore, the constructivist paradigm granted me the freedom to express my own values to participants (Mertens, 2005) during the interview introduction phase, by explaining to them the scope of the research and my interest in doing it. After interviewing, I could confirm that I had shared values with them (Bryman, 2004) on what is a good life for women with intellectual disabilities by agreeing with Aristotle's saying "The good life is lived with friends". As feminist research, the study aims at challenging the long-held stereotyped prejudices on gender and disability in order to bring an end to the perpetuated social exclusion. Secondly, it shows solidarity with the subjects and participants by embracing and promoting their cause for inclusion, equalisation of opportunities, emancipation and democratisation of society. The study aims at empowering the subjects to engage in self-advocacy for their human right to live a life of dignity in community. Lastly, one of the objectives of this study is to provide parents some evidence they can use in lobbying for policy to remove exclusionary practices. This transformative intentionality is fundamental to my research ethics.

### **3.13 Summary**

This chapter was about the methodology used in this research. It started by stating the role of researcher in promoting human rights and informing policy. Concerning the research paradigm, the ontological stance is realism and the epistemological approach is interpretive-constructivism. The chosen methodology is qualitative as it permits the

interpretation of people's perceptions of the situations, their thought and feelings. Symbolical interactionism is the theoretical perspective adopted to construct the meaning of reality as described by interviewees. Data collection informs about the data obtained on fourteen subjects, women with intellectual disabilities, after the information provided for them by proxy participants, their mothers and sister as the best informed on the situation. The site of research is Prague. Three parents' organisations participated in research by providing the sample and consulting about the interview protocol. The sample of fourteen subjects was divided into two age cohort groups to reflect better the differences among young and adult women regarding social relationships and life satisfaction. The participants were active members of parents associations. The method of data collection is the semi-structured interview, which was adapted from the previous literature on measurement of quality of life. The data were analysed under the comparison approach between subjects and participants. Validity, reliability and triangulation are extensively explained. The limitations at the methodological level relate to language barriers, values axiology and de-contextualisation of data. The ethical concern highlights the political aim of research having an emancipation purpose.

## CHAPTER 4

### ANALYSIS

#### **4.1 Introduction**

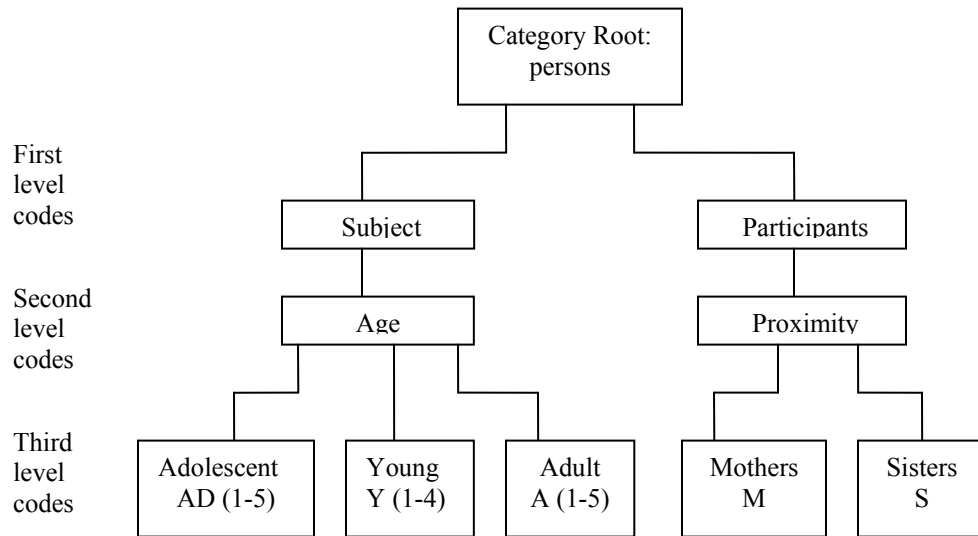
In this chapter, the collected data for this research is analysed. In analysing the content of data, the focus is placed on addressing the research questions. The analysis is done by subheading the research questions and categorising the answers evidenced from data. The resulting themes are the outcome of the patterns analysed in data collected from the interviews. Information relevant to the context of research with regards to relationships is discussed separately. Categories used in the data analysis are theory-driven and presented in form of pre-ordinate categorisation: family support, friendship, relationship with community and wellbeing. Content analysis is used to make references from data text worked out during interview transcription. Meaning created through inferences is drawn from the context of research.

#### **4.2 Data analysis process**

##### *Codification*

The data analysis started with the analysis of the sample of text and continued with the definition of units of analysis and the categories to be used for analysis. The text of data was reviewed in order to code the data and to place them in categories. Categories were compared to draw similarities and to make links between them. The last stage of data analysis was the concluding phase in which theoretical conclusions are drawn from the data text. The research questions have been informed by theory. The information contained in data is gathered from proxy participants who informed about the situation of research subjects. The units codified are both subjects and participants. The codification helped to structure the data content and to identify to which subject did the information given by proxy participants corresponded. Figure 2 shows the codification based on units.

**Figure 2 Tree index codifications**



*Source: Adopted by Robson (2002) Real World Research*

The data text is put into categories which then are grouped into themes. Data analysis has noted the inconsistencies and similarities of information yielded by interviews. The construction of categories contributed to the creation of domain analysis, meaning that units of analysis are grouped into themes to form a coherent set of domains. During the process of categorisation, unitised data have been separated and referred to different categories to provide inferential and descriptive information. At the end of analysis, data content is summarised to present the material in a manageable form. The conclusions are drawn by clustering the issues into the themes and relating findings to theoretical framework.

Data content analysis is divided into two parts, respectively corresponding to the first research sub-question and to the second sub-question, trying to address the central research question. In order to address the main research question, evidence was sought from the interviews to find out how social network impact the social relationship process and personal social wellbeing of women with intellectual disabilities. Data was collected

from mothers and sisters who reported on the social relationship support coming from three social actors, family, peers and neighbours, and informed on the role of social networks on life satisfaction. The data analysis has tried to make a logical link among the actors of social networks and their role upon social relationships and wellbeing. Satisfactory relationships are an indicator for both inclusion and wellbeing.

### *Analysis of the Sample and Participants*

The subjects of this research are women with intellectual disabilities who due to language barriers did not participate as direct informants; therefore their situation is informed by proxy participants, mothers and sisters who, being the closest persons to them, are considered as most reliable informants. The subjects are fourteen women with intellectual disabilities, whose age varied between 15-40 years old. Based on age differences with regard to social roles and societal expectations the subjects sample was divided into three age cohorts: adolescents age 15-19, young women age 20-29 and adult women age 30-40 years old. There is almost an equal proportion between age groups: five subjects are adolescents, four subjects are young women and five subjects are adult women.

The majority of subjects fall into the category of moderate to severe intellectual disability, and in five cases the intellectual disability is associated with Down syndrome and one with Autism. Young subjects live with their family while half of adult women are living in supported living arrangements. The subjects of this study have not experienced residential institutional care, except for one young woman who has been institutionalised for 20 years. All girls and women have siblings, except for three. None of the women is in a love relationship, except for one who has a boyfriend, but the majority reported to like to be married and having children.

Study participants are mothers (eleven) and sisters (three) of women with intellectual disabilities who are clients of social services provided by parents' organisations. Participants involved in this study were very active members of parents' organisations advocating for the rights of their proxy familiars. As proxy participants, mothers and sisters provided information on the situation of social relationships in social networks and

on social wellbeing of women with intellectual disabilities. This information is analysed below organised in issues that are grouped into themes.

## **4.2 What characteristics of social network improve social relationship of women with intellectual disabilities?**

In the first part of thematic analysis, the impact of social networks on the social relationship and on community inclusion is analysed. This part of content analysis addresses the first sub-question of research.

### *4.2.1 Theme: Family support for social relationship*

In this theme data are analysed to explore the nature of relationship within family and the support that family provides to women with intellectual disabilities to develop relationships outside family with other social network actors such as friends and neighbours.

Proxy participants informed that except for three adult women living in group-homes, the eleven others were living with their families. Women living in their family home are reported to depend on parental and sibling support for relationships within and outside family, while women living in group-homes depend more on flat-mates and assistants rather than on family for social relationships.

Mothers are reported by proxy-participants to be the most important person in family for women with intellectual disabilities, whatever the woman's age. The reasons for rating the relationship with mother as the most important are: the long time mothers have been caring and the trust women with intellectual disabilities have developed on mothers due to the care and dependency on mothers. Women with disabilities love their mothers, as is nicely expressed in MA1's words that "My daughter calls me: you are my ever-beloved mother". Half of mothers are reported to care as single mothers for their daughters, in absence of father. Even when women with disabilities have a father, the parental care for women with intellectual disabilities is reported to come mostly from mothers. Mothers



are reported to be more supportive in creating opportunities for women with intellectual disabilities for social relationships outside family, through the socialisation with mothers' friends or by accompanying women in leisure activities.

Majority of women with intellectual disabilities the relationship with fathers was reported by proxy participants to be negative. As mentioned above, half of women with intellectual disabilities are raised by mothers only, as their fathers left them at an early age, the first day they knew of having a daughter with disabilities, which is reported by a mother (MAD1) in a very significant way, saying that, "Her father did not recognise her to be his daughter, as he couldn't believe to have a child with disability". For half of fathers staying with the family after having a daughter with intellectual disabilities the comments are different, providing a dichotomist description: caring father and rejecting father. The rejecting fathers are reported in two cases. They refused to have a daughter with disability by showing constant dissatisfaction and refusing to care for them, as expressed in MA5's words: "Her father was unhappy with her; she was a burden to him". They showed more affection towards healthy children, considering the daughter with disability as harm to fatherhood pride: "He never liked her; he was proud of the healthy daughter" (MY4). Out of fourteen women with intellectual disabilities, five are reported to have caring fathers. Those having supportive fathers are the adolescents and young women with intellectual disabilities. The fathers of adolescent girls were reported to have a good relationship with their daughters and to spend time with them upon returning back home from work. Both adolescents' and young women's fathers were sharing part of the caring responsibility for their daughters and participating in domestic work. Fathers were sometimes privileged in the family relationship by the daughters with intellectual disabilities, as they were more permissive to them than mothers were. Proxy participants informed that this preference for fathers is related to the fact that fathers are more involved in home leisure activities with daughters, such as playing with adolescents. According to one respondent, "He is very good at her that little time he is home; he only plays with" (MAD3), while mothers are strict due to their instructive role. Fathers were reported to be more engaged in interacting with daughters with intellectual disabilities when at home and less involved with daughter's activities outside the home, like mothers

did. Participants reported that for mothers living in partnership, daughters with intellectual disabilities had very good relationships with the mother's partner.

Siblings' relationships were reported to be most of the time positive, with very few exceptions, only two cases out of fourteen were reported as an absent relationship. The relationship with sisters was rated as more positive than the one with brothers. Elderly sisters were more caring and authoritarian, while younger sisters to women with intellectual disabilities were more permissive, less critical, expressed affection openly and were more engaged in playing with and sharing things, probably because of similarity in cognition ability, as expressed by mother MAD4: "Although she is thirteen years older than sister, she used to play with her; they do understand each other very well, because their cognitive age is the same". Elder sisters sometimes shape the self-identity of younger sisters with intellectual disabilities who like to identify with the elder, as expressed in the statement, "The elder sister is a role model to her" (MAD3). Elder brothers were more responsible towards care duty for younger sisters with intellectual disabilities, while younger brothers were less involved with caring. Sisters were more willing to include the sisters with intellectual disabilities in their friends' networks especially when inviting friends home.

Brothers were reported to socialise more with sisters with intellectual disabilities when they were children, such as playing more together; but they became distant when grown up and after adolescence they reduced significantly the time spent with sisters. MY3 reported that "They have been going along better before; they used to play when they were children, but now he has his friends, he doesn't care about her". Elder siblings were reported as more promising to care for their sisters with intellectual disabilities in the future, substituting for parental care, as the MY3 noted, "He has promised to care for her when I will not...".

In conclusion, family support was reported to be very important to the social relationships of women with intellectual disabilities with family members. Although the main source of parental care and love comes from mothers, the relationship with fathers was reported

to be important in stabilising the self-security in parental love, care and protection. Besides parents, siblings are reported to be decisive actors in creating opportunities for socialisation of women with intellectual disabilities by sharing toys and playing (for adolescent girls with intellectual disabilities) and by caring and supporting them in doing things good, especially elder siblings. The relationship with sisters was reported to be steadier over time, while brothers' interaction was reduced over time. Elder siblings are the hope of parents for the future care of the women with intellectual disabilities. Mothers and sisters are reported to support more than fathers and brothers the socialisation of women with intellectual disabilities outside family, in creating social relationships with other people in neighbourhood or including them in their own friends networks.

#### *4.2.2 Theme: Peers' social relationships with women with intellectual disabilities*

Proxy participants unanimously reported that peers are the main source of social relationships outside family for women with intellectual disabilities. Except for two women that were staying home, all the others had friends among their peers at special schools (all adolescents and two young women), sheltered workshops and group-homes (all adult women and two young women). Women with disabilities were reported to like school and job mainly because of having their friends there, who are like them. Adolescents and young women with intellectual disabilities socialised with peers as friends not only during the school time, but at leisure time as well, especially in activities organised by parents' organisations and in sport clubs and creative work courses after school. Adult women with intellectual disabilities did socialise with their peers during the working time in the sheltered workshop and after job, by frequenting cultural and socialising events of parents' organisations. Women who were sharing a flat with other friends with intellectual disabilities were reported to do common activities after job, like domestic work and using community resources together, with staff assistance. Women living in group homes were reported to have as friends the assistant staff as well, because of the long time spent together and sharing home responsibilities. Only one woman with intellectual disabilities is reported to have peers just as job colleagues rather than friends. Another woman is reported to consider the clients to whom she delivered services as

friends, but this was just a perception the mother (MY3) said “She wishes to consider those people friends as wish to be among other people, different from her”.

In conclusion, beside the family, peers were reported to be the most important source of social relationship for women with intellectual disabilities. Peers of school, sheltered workshops and flatmates in group homes were the best and the only friends of women with disabilities. Proxy participants mentioned two factors influencing friendship of women with intellectual disabilities: similarity and the long-time they spend together in and out of school and job activities. Peers fill the day of women with intellectual disabilities. Women with intellectual disabilities go to school or job all week days and spend there from 8am-2pm. They socialise after school and job in leisure time events like going to theatre, to sport or to cultural clubs. Usually mothers and assistant staff of parents’ organisations services accompany them in leisure activities, explaining why service staff was mentioned as a source of friendship.

#### *4.2.3 Social relationship with community for women with intellectual disabilities*

All mothers and sisters unanimously reported that there is no friendship in community for women with intellectual disabilities, but only physical acceptance. Proxy participants were using the term acceptance interchangeably for welcoming, although their information can be classified more as acceptance rather than welcoming. Participants differentiated the neighbours in two groups: friendly and distant. Neighbours behaving friendly to women with intellectual disabilities were declared to be family friends. They came into relationship with women with intellectual disabilities while interacting with their families. Neighbours were nice to women with disabilities because of friendship with family and trying to be sympathetic to the family. “Our neighbours are kind to her because of us; they are our friends”, SA3 said. Mothers reported trying a lot to include their daughters in the neighbourhood, by exchanging family visits, especially on ceremonial days, like birthdays, where other young people from community would be present, in order to put their daughters in contact with them, as MY3 said: “My daughter likes to go to her age neighbours’ birthdays; she loves to meet them; they have been her friends before; they used to play together when little kids”.

Even when parents organise public events dedicated to women with intellectual disabilities, like open days for public to see the works and activities women with intellectual are able to do, neighbours come for the family rather than an interest in the work of women with intellectual disabilities. Another strategy reported by participants to create opportunities for friendship of adolescents with intellectual disabilities with neighbours of their age was inviting other children home to play or inviting them for a meal or ice-cream outside, but these strategies have not been successful so far. The mother of an adolescent reported that even when she tried to provide socialising opportunities to her daughter, by inviting other children from neighbourhood to play with her, children played with toys but not with her “This is interest-based relationship, there’s no friendship in there”, MAD1 said.

Proxy participants reported that the old neighbours, meaning those who have been neighbours to family for a long time, behaved in a more friendly way to women with disabilities than those who were new to neighbourhood. One mother, MA2, reported that “neighbours knew her since a little child, as they have always been living with them”. Women with intellectual disabilities who have been living for a long time in the same neighbourhood were reported to be more accepted than those who have moved into new settlements; for example women living in group-homes or women whose families have shifted into a new neighbourhood. Those were distant neighbours avoiding direct communication with women with intellectual disabilities and ignoring their presence. They were polite though with women with disabilities and the family that “does not like people to be polite only because of family”, MA1 said. The relationship of women with intellectual disabilities living in group homes was reported to be limited to staff and flat-mates.

Proxy participants differentiated urban neighbours from rural ones, describing the latter ones as more friendly and supportive. “Neighbours in cottage place are nice to her; they stop and greet her, sometimes even helping her; but in Prague is different” SA3 said. Neighbours in Prague are less cooperative and far more distant than neighbours in rural

areas. Participants reported that neighbours in urban area were inattentive and non-supportive because of the individual life-style in urban areas.

Participants had a tendency to justify the community behaviour towards women with intellectual disabilities by locating the problem of missed relationship mainly with the women's disability. They highly agreed that the barrier to relationships in community was their disability. They considered the inability for communication and lack of proper social behaviour (manners) as the main barriers to creating relationships. Two participants reported that even if things were organised by parents to socialise women with intellectual disabilities in the community, they would not benefit from it. As SA4 said, "She likes to be on her own, she does not cooperate, she does not support the presence of others, and she feels uncomfortable". Three participants said that when women with intellectual disabilities try to communicate with people they touch them, and this can be intrusive to other people and may incite in them wariness and hostility. As SA3 reported, "she likes to touch people while wanting to communicate with them, but they dislike this act". Some participants reported that women with intellectual disabilities do not respond to other people's interest in communication. But as a mother explained this is a misunderstanding from the side of the public rather than a lack of desire for communication from the women with intellectual disabilities. MA2 explained how it is difficult for a person with intellectual disabilities to translate symbols contained in messages: "Her teacher complained why she has not answered to teacher greeting in the bus, and I had to explain to her that my daughter needs time to understand others' messages". This mother continued to explain that not only do people with intellectual disabilities need time to understand others' messages, but they need others to take some time as well to understand women with intellectual disabilities' messages.

Participants reported that women with intellectual disabilities like to communicate with others. Although having friends like them in the segregated daily activities of school and sheltered workshops, women with intellectual disabilities are reported to like having friends in community of their age, as reported MAD2: "Our family has many friends, but she wants friends of her age". Women with intellectual disabilities who were accepted

and treated in a friendly way by neighbours were reported to have good verbal and non-verbal communication skills and to behave correctly. Neighbours appreciated very much the good personal characteristics of women with intellectual disabilities to socially relate; as MY3 said, “Our neighbours like her because she makes them happy; she is like sunshine”. Participants reported that, though loving to have friends of their age in community, adolescents especially and young women faced as an obstacle the long distance of special schools from home. They reported that if they are not socialised with children and young people of community in mainstream school, the chances to create friendships with age peers without disability are absent. A mother (MAD2) reported that her daughter “leaves early to school and comes back home late afternoon; she has no friends in community because nobody knows her; she goes in another school too far from neighbourhood. How can she have friends in neighbourhood?”

One of the highlighted environmental barriers that participants mentioned was the lack of community cooperation with women with intellectual disabilities. Participants made it clear that neighbours tolerated their physical presence, but they did not interact in a purposeful way with them. As a cause for the lack of cooperation participants mentioned the lack of understanding of intellectual disabilities. They said that the neighbourhood is not informed about intellectual disabilities and are worried about having a normal relationship with women with intellectual disabilities. As a consequence they do not trust them. A mother (MAD2) said that “Even compared to other people with disabilities, women with intellectual disabilities are less trusted by community”.

Participants stressed that women with intellectual disabilities were treated as if they were children. Neighbours did not direct conversation to them but to their family members only, and in some cases even bought candies for the women. Participants were critical toward this form of treatment, stating that even women themselves did not like to be treated like that, especially when ignored. A mother (MA2) said that her daughter does not like that people ask the mother for her; “she likes instead neighbours to ask her directly”.

Besides infantilisation, participants reported that another barrier hindering relationships of women with intellectual disabilities in the community was the over-protective behaviour of family. Fearing abuse in public, the families tried to control every opportunity of women with intellectual disabilities to create relationship outside family. Participants acknowledged that their caring has taught women with intellectual disabilities dependency, discouraging them from trying on their own to create new relationships in community. One mother, MAD5, clearly blames herself for not allowing her daughter to have friendship and relationships with neighbours in community when she says, “I am the main obstacle to her; I am always by her side; I never let her alone to try by herself”.

Despite their overprotective behaviour, participants reported that parents, especially mothers, are the main supporters of community relationships for their daughters. By organising and participating in the events of parents’ associations, parents are trying to disclose their daughters to the community and invite community members to interact with them. Yet, participants said that despite an increase in the presence of women with intellectual disabilities in the community, there is no inclusion, but just physical integration.

Therefore, to improve the situation of social relationships with the community, participants recommended that changes should occur at both the personal and environmental level. Personal characteristics of women with intellectual disabilities can be improved by cooperating more with community and having friends with and without disabilities. Communication and social skills can be improved and positively impact the creation of relationships. At the environmental level, participants mentioned as a major change the increase of public awareness of intellectual disabilities; of strengths and values that people with disabilities have for themselves and for the community. To this end, the participants as members of parents’ organisations were publishing a wealth of sensitising information targeting change in public attitudes towards intellectual disabilities.



In conclusion, women with intellectual disabilities are only physically integrated into community, lacking purposeful relationships with neighbours and friendship with their age peers in the community. Therefore relationships outside family of women with intellectual disabilities are reduced to their peers at special school or sheltered workshop. Neighbours accept women with disabilities to be nice to their families. Neighbours in rural areas are reported to be friendlier than neighbours in urban areas. Being polite to neighbours is a personal characteristic that helps women most to enter into relationship with neighbours. But the ability for communication is rated as the major barrier to relationship as well. At environmental level, lack of knowledge about intellectual disability has led to denial of cooperation with women with intellectual disabilities. The hostile neighbourhood attitude and fear of abuse has led families to be overprotective, thus impacting negatively the opportunities of women with intellectual disabilities for social relationships in the community. To safely include women in the community, participants as members of parents' organisations are working to raise public awareness about intellectual disability.

### **4.3 How does social relationship impact the life satisfaction of women with intellectual disabilities?**

To answer this research sub-question it is necessary to address the issue of activities carried out with the social network and how they impact wellbeing. Purposeful activities result in feelings of usefulness and happiness and inspire aspirations and decision making for women with intellectual disabilities. Therefore the issues addressed in this part are related to daily and leisure activities developed with support of social networks and the outcomes of these relationships for personal social wellbeing of women with intellectual disabilities.

#### *4.3.1 How domestic activities impact the social wellbeing of women with intellectual disabilities?*

Participants reported unanimously that all women with intellectual disabilities were happy to be with families and nine of them liked to participate in domestic activities. Women were reported to feel useful if helping with housework and cooking. The other

five women not participating in housework were not encouraged to do so and everything was done by the mothers. Participants reported that women participating in domestic family work felt happy if praised for good housework, especially if the praise came from mothers, who gave instructions for the work. Participants confirmed that the example of fathers participating in domestic work increased the desire for engagement in housework of adolescents and young women with disabilities. Elder sisters, committed with care and domestic labour, were sometimes serving as a role model for younger sisters with disabilities. In the interaction with family members women with intellectual disabilities were encouraged to decide on their daily routine activities and making their choices about preferred food, clothes and activities.

#### *4.3.2 How school and job activities impact the social wellbeing of women with intellectual disabilities?*

Most of the day, women with intellectual disabilities were engaged in a busy daily agenda of going in special schools - the adolescents and young women, or going to work - the adult women. All of them spent most of the time with peers like themselves at special schools, sheltered workshops or group-homes, during the formal activities of the day and during leisure time. Except for two of them who are not studying and working, the others had the best friends among peers at school and sheltered workshops. Participants informed that women with disabilities felt very useful by going to school or work. All of them were reported to feel better having a routine daily agenda that protected them from unpredictable situations and made them feel secure within known situations.

Adolescents and young women were reported to participate in leisure activities with their friends after school or in summer camps during school vacations. Together with friends they followed extra-curricular activities such as sport clubs (swimming and yoga) and cultural circles (ceramics and paintings). The young women were working to practice, as part of practical school requirements.

Adult women had a pre-determined agenda of work activities in the sheltered workshop where they were producing goods and services for the community such as painting, paper folding baking, running a café bar, etc. Although the job in a sheltered workshop is not a paid-job, as it has rehabilitative purposes, women felt very happy to go there, as work make their day purposeful. Participants reported that adult women were particularly happy when the results of their job were praised, and praise motivated them to do more work. Adult women living in group-homes were active in deciding the week's programme of their assisted semi-dependent living with the help of the staff. They felt very useful while participating in this program, by participating in house-work and buying things for the home.

#### *4.3.3 How community activities impact the social wellbeing of women with intellectual disabilities?*

Participants reported that through support of family and parents' organisation activities, women with intellectual disabilities are more present in community, using the community resources and public facilities more. Participants informed that adolescents and young girls make use of community facilities such as sport club and cultural places during their leisure time, while the adult women use more shops, with the assistance of mothers and assistants, or use the bar-cafes and restaurants with friends and parents, or frequent cultural places such as theatre and cinema. This disclosure of women with intellectual disabilities towards community is reported by participants to be an important step in getting acquainted with in the community. Although there is no friendship and meaningful relationships in the community for women with intellectual disabilities, participants reported that the situation is improving in some aspects regarding community participation, while regarding community inclusion the score is very low.

#### *4.3.4 The outcomes of social networks on wellbeing*

The most beneficial outcomes of purposeful activities developed though networks are the feelings of happiness and usefulness. As participants reported women who participate in domestic work and succeed in school and job activities get praised for results and this helps in turn the feeling of being useful. Praise boosted their motivation to perform better.

Participants informed that being with family and having the right to choose the preferred things and activities made women happy. Participants informed that ten of women with intellectual disabilities felt anxious if left alone in unknown situations with unfamiliar people. Women were reported to cry sometimes, but participants could not figure out the reason of crying. One mother (MA1) said that “Probably the loneliness is the cause of tears”. All women with disabilities are reported to make choices for concrete things, but not at abstract level. Participants reported that sometimes women do contradict the choices that mothers do for them such as food or clothes and prefer to decide themselves on personal things and activities. This freedom of choice was related to the self-decision on simple things and activities, as expression of adulthood roles.

Participants reported that women with intellectual disabilities have wishes like other women do. Adolescents liked to have friends of her age in community with and without disabilities, while young and adult women liked to have an intimate relationship, to be married and to have children. But, as participants confirmed, they were told that they could not assume adult roles and parental responsibilities. Mothers and sisters were not sure whether this censure had a negative impact on the quality of life for women with intellectual disabilities, they believed that they were instructing them the right thing to do.

In conclusion, relationships and activities developed within and through social networks impact the personal social wellbeing of women with intellectual disability by making them feel happy and useful, and incite their aspirations and motivation for better performance of activities in home, school, job and relationship. These sentiments contribute to the life satisfaction which improves the status of personal wellbeing.

#### **4.4 Summary**

In this chapter the content analysis of collected data evidenced support for answers to the research questions. Social network support is considered to have a strong impact on social relationship and this late on the personal wellbeing of women with intellectual disabilities. .

Concerning characteristics of social networks that improve community inclusion and social wellbeing of women with intellectual disabilities, changes should occur in environmental level with the due support to improvement of personal characteristics for relationship. Participants have considered the social network support to be important and therefore women with disabilities are more included in social network of at least parents, siblings and peers more, through family, school/job and leisure activities. Research has evidenced that social networks can be effective in increasing participation of women with intellectual disabilities in community life, by having more relationships and doing purposeful activities. Participants see the physical integration as part of long-term process of inclusion and to this end, they as parents 'organisations members are working to prepare the conditions in community for a safe inclusion in a network of friendly neighbours in community. Being part of social network themselves, participants believe that social networks can create the social capital that will hold women with intellectual disabilities tied to the community social structure.

## CHAPTER 5

### EVALUATION

#### 5.1 Introduction

This chapter presents the interpretation of findings based on the data analysis described in the previous chapter. In this chapter, research moves from description to inference. Explanations on the situation of women with intellectual disabilities regarding their inclusion in community and social wellbeing are offered in this chapter. The evaluation of data analysis presents an attempt to answer the research questions raised at the beginning of research. The chapter starts with an introduction to the policy changes occurring in the field of intellectual disabilities in the Czech Republic, followed by the contextual situation of the educational system and employment of women with intellectual disabilities. The chapter continues with the subchapters on the impact of social network on social relationships as a precondition for community inclusion. Here the explanation proceeds with the role of family, peers and community in creation and maintenance of social relationships for women with intellectual disabilities. The next subchapter proceeds with the impact of activities developed with and through social networks on the personal wellbeing of women with intellectual disabilities. Findings are evaluated against reviewed literature and research questions. This chapter concludes a summary of discussion of the findings.

#### 5.2 Research Context

##### *5.2.1 Inclusion policy in the Czech Republic*

Contemporarily, social inclusion of people with disabilities is being targeted as a top priority objective of worldwide policy agenda aiming at full equalization of opportunities and access to human rights. The Czech Republic has ratified most major human rights instruments related to people with disabilities and has incorporated the human rights principles into the National Disability Plan, the most important policy documents in the area of disability (Šiška, 2005). The changes in social policy reflect an increase of

recognition of individual differences based on the *normalization* principle, which is achieving gradual acceptance in the Czech Republic and by which persons with disabilities are being afforded new opportunities in important areas like housing, employment, education and social relationships (Gargiulo et al., 1997). To the policy makers it is clear now that there is a strong link between social inclusion and social participation and denial of access leading to life-long dependency, poverty and social exclusion adding to stigma of disability (Šiška, 2005). Since social inclusion is primarily about belonging and participation, it is necessary to provide people with intellectual disabilities full support to create and maintain social relationships and to participate in community life. To access citizenship rights, people with disabilities must be included in people's lives as friends and companions first. Social inclusion is a monumental task to be fulfilled, asking for reversal of long held-beliefs on disability and calling for civic transformation and engagement of self-advocates (Gargiulo et al., 1997; Šiška, 2006). Many positive steps targeting improving the situation of people with intellectual disabilities are already taken in the Czech Republic, including the legislative basis for social inclusion and developing important disability policy, but barriers against social inclusion still persist (Šiška, 2005).

### *5.2.2 Context of educational system*

There is a historical and contextual difference in education systems to which the study subjects belong based on their age. Until late 1960's, education for some children with intellectual disabilities was not viable, as they were considered uneducable due to the severity of disability and to the association of it with other disorders (Mandell & Fiscus, 1981). Three decades ago, a subject of this study could not attend formal education because less was known about her autistic disorder at that time and the special educational system could not address her educational needs. Fortunately, nowadays all children with intellectual disabilities are entitled to both types of education: mainstreamed and special schooling. The majority of young girls and women of this study are in special education which has goals of socialization, normalization and emancipation in order to include them in the world of work and social activity (Černa 1994, cited in Gargiulo, Černa & Hilton, 1997, p.23). To achieve the lifelong objectives of

normalisation (Wolgensberger, 1972) and social inclusion, the reform of education has targeted teacher training as a crucial factor for change, including in the teacher training program the model of the lifespan approach to special education which emphasises the strengths and needs of the person with intellectual disabilities (Gargiulio et al., 1997). As for all young people, education is the core activity of daily life for adolescents and young women of this study. The younger girls are being educated at an auxiliary level while the younger adults are attending the practical schools and working at the same time to meet the school requirements.

### *5.2.3 Context of employment opportunities for women with intellectual disabilities*

Like majority of people with intellectual disabilities in the Czech Republic, women with intellectual disabilities are unemployed due to barriers to employment such as negative stereotypes about their employability, exclusion from disability payment schemes, and lack of implementation of legislation promoting employment and social business (Šiška, 2005). They depend financially on social benefits. Knowing that meaningful employment is important to the person with intellectual disabilities, the parents associations have established sheltered workshops as vocational rehabilitation centres to provide job training and to open the doors of the mainstream labour market (Gargiulio et al., 1997).

Most of the women with intellectual disability are mainly employed in sheltered workshops run by parents' organisations that aim at social and vocational rehabilitation rather than income generation. The working time varies from 3-5 days a week, depending on the combination of school with work for those following the practical school. The kinds of jobs women do in sheltered workshops are manual handcrafting and services for third parties. Another type of sheltered workplace, funded by labour offices, is provided by for-profit enterprises that provide a minimum wage to disabled workers under a work contract (employment service) (Šiška, 2005). In this study only one woman had a permanent contract with a private enterprise.

Although their jobs at sheltered workshops are unpaid, women like the job because it makes them feel useful, especially when praised for the results. They see at work the



possibility to be in contact with people by meeting them or producing goods and services for them. Wishing to be present in peoples' lives a woman of this study prayed that people embellish their house walls with her paintings. But above all, women wish their job is valued.

Contrary to younger women, one older woman who has worked sixteen years in a sheltered workshop did not like the job. Probably the conditions of the job in the sheltered workshops two decades ago were not the same as today. The conditions of the sheltered workshops may be improved somehow and the job activities are perhaps more interesting. Whatever the level of satisfaction with the sheltered workshops, this should not be a reason for maintaining them as the best available employment for women with intellectual disabilities, for having an unpaid job perpetuates financial dependency and economic insecurity. Therefore the government should not encourage the proliferation of segregated sheltered workshops through the state subsidies system as the best alternative for employment, but should ensure employment in the open labour market (Šiška, 2005).

Despite positive impact on economic security, a job is one of the main purposeful activities for adult people and as such is a source of life satisfaction. This more reason why young and adult women with intellectual disabilities need to be included in purposeful activity programs and need to have a life of quality, like all citizens.

Although practical implications of the inclusion policies are mainly resulting in physical integration, the aim in the long run is social inclusion. Social relationships and networking are considered a prerequisite for meaningful inclusion, as they provide the sense of belonging and conditions for social participation and inclusion through socializing.

### **5.3 Theme One: Family support of inclusion**

#### *5.3.1 Parental support to social relationship*

Social relationships are considered to be a precondition for community inclusion. Natural social ties are developed within family first which is the main source of love, care and protection. In order to protect their members with intellectual disabilities from adverse effects of exclusion and isolation, families are trying to open the doors to the community to women with intellectual disabilities. Parental and sibling roles are crucial in creating opportunities for relationships in the community for women with intellectual disabilities, either by supporting them to create acquaintances with neighbours or by including them in their existing friendship networks. The most direct way for women with intellectual disabilities to learn how to build social capital however, is through the relationship bonds developed within family with parents and siblings.

In this study, mothers are quoted as the closest person to women with intellectual disabilities because of trust and dependency on mothers as the main source of love, care and support through all lifespan. For women with intellectual disabilities living in sheltered accommodations and for their mothers the physical detachment has been a stressful event at the beginning, but mothers have convinced themselves that by living independently their daughters would develop as adults and form relationships in the community. Whatever age, women in this study count on mothers for help and advice.

Despite the more egalitarian family of today, mothers still perform most of the essential care and housework in the family and hold part-time jobs when young mothers. They return to full-time job only when their daughters are grown, while others have never worked because they are single mothers. Despite having good qualifications and wanting to be economically active, mothers were not free to work as the responsibility of care outweighed the need for a job. The sacrifice is done to provide their daughters permanent care and support their social connections.

The majority of women have been raised by mothers only as fathers left them in their first days. Fugitive fathers could not reconcile the self as a father of a child with disabilities,

while some questioned the fatherhood. As a mother testified (MAD1), 'He didn't recognise her to be his daughter, as he couldn't believe he could ever have a child with disability'. A remorseful sentiment leads few of them to come into rare contacts with daughters. Negative fatherhood is reported for some fathers who remain as well. Those did not interact and clearly expressed no satisfaction for having a child with disabilities, as one mother (MA5) described: 'Her father was not happy with her; she was a burden to him'. These fathers even did some injustice to daughters with intellectual disabilities, by caring only for the non-disabled children, with whom they preferred to be identified as fathers. As one mother (MY4) desperately expressed "He never liked her, he refused her, he was proud of the other healthy daughter". The preferential attitude for the healthy children has contributed to an unpleasant relationship tension between family members by creating factions within it.

There is an interesting difference regarding fatherhood between two generations. Contrary to fathers of older women who left, the younger fathers are more likely to stay and have other children. Those fathers have very good relationships and are very cooperative with daughters and wives as well. As a mother (MAD5) explains, "He is very good to us; he shares the care for her and responsibility for housework". Younger fathers have interiorised the cultural changes occurring in the post-modern society related to the domestic labour division and share of care for children. As role models they inspire daughters to participate in the housework. Lastly, mothers' partners as well have good relations with women with intellectual disabilities.

Despite positive cultural changes, the traditional family model of man- bread-winner and wife-carer continues to prevail. As a consequence fathers spend more time out of the home – working, and mothers in home - caring. When fathers are present at home, they engage more in leisure activities rather than providing substantial care; therefore the relationship with them is more relaxed sometimes compared to mothers who are stricter because of instructional responsibility. This is expressed in MAD3 words: "He is too permissive that little time he is at home, he only plays with the daughter with intellectual disabilities".

### *5.3.2 Siblings support*

Elder siblings are authoritarian, but they show responsibility of caring and are influential for the role modelling for younger girls with intellectual disabilities, confirmed by a mother (MAD3): “The elder sister is her model”. Seemingly promising carers, elders siblings are a big relief to parents’ worries about future care for women with intellectual disabilities, as a mother (MA1) said: “He will look after her when I will not...” Younger siblings share more time and things with women with intellectual disabilities as confirmed by a mother (MAD4): “although thirteen years difference they are very well together because of same cognitive age’. When younger, siblings use to play a lot, as the gender differentiation is not yet internalised as a central social value in little children. Growing up, the siblings of opposite gender cope with differentiated social roles leading them to adulthood. When grown up, sisters continue to be nearer to their sisters with intellectual disabilities, while younger brothers keep some distance, as referred by a mother (MY3): “They went very well before, they used to play together, but now he has his friends”. Getting older, especially sisters’ relationships become closer. This is widely supported in previous studies suggesting that siblings, particularly sisters, tend to stay more in touch and ready to help when grow older (Papalia & Olds, 1992).

## **5.4 Theme Tow: Peer relationships contributing to inclusion**

### *5.4.1 Friendship for adolescent and young women with intellectual disabilities*

One of the main reasons that women with intellectual disabilities liked school and job is that they have their friends there. The adolescents and young women with intellectual disabilities in this study were attending special education schools. Besides friendship, they liked school because school kept them active. Their friendships developed at earlier stages of their education when going to special school and have continued to adolescence, having chances to continue throughout the life-span. This is fairly consistent with other studies that found that the increased satisfaction with friendships and relationships for people with intellectual disabilities is associated with having friends like them in their social networks (Gregory et al., 2001).

Despite school friends, adolescents and young women with intellectual disabilities like to have friends of their age in the community to socialise with after school, but the special schools' distance from home acted as an obstacle to having acquaintances in the community. In order to be able to create acquaintance and interact with community adolescents and young women with intellectual disabilities need to be in their natural environment, in their neighbourhood. This is especially important given the long history of alienation of people with intellectual disabilities from society. In the near past, as a result of segregated education in faraway special schools, non-disabled children did not interact with their peers with special needs and a majority of healthy adults had very little contact with their fellow citizens with disabilities. This heritage provided a firm foundation for the development of negative attitudes towards people with disabilities (Gargiulo et al., 1997). Knowing that school has a huge power in creating and maintaining social relationships within the community, mothers believe that is better for their daughters to attend the neighbourhood mainstream school. Mainstreamed education is at an early stage and benefits regarding friendship have not yet been fully attested. For the time-being the promising indices are that children with intellectual disabilities like to be among other children who are not necessarily like them. Liking can be the first step towards acquaintance and relationship (Papalia & Olds, 1993; Myers, 1993).

The study yielded an interesting result in the positive correlation between disliking the school and not having friends. The girls not having friends in schools did not like school activities either, considering them unattractive. Besides the ghetto effect of keeping children way from community, thus impacting friendship opportunities, the special schools provided a few socialising activities. In such conditions, to compensate for missed relationships, parents' organisations organised leisure activities comprising cultural and sport programs aiming both at rehabilitation and socialisation after-school in the community. Besides the impact on health and social wellbeing, participation in leisure activities positively influences the social participation and inclusion in community. This is supported by previous literature informing that as for other citizens, participation in sports, cultural events and other leisure time activities is an important part of a normalized life style for persons with intellectual disabilities serving as a primary means

for allowing integration with the non-disabled population (Gargiulo et al., 1997). However, being among people without disabilities does not imply that the women with intellectual disabilities are automatically accepted and have friends (Cummins and Lau, 2003).

#### *5.4.2 Friendship for adult women with intellectual disabilities*

Despite the gains in working experience to access the labour market, the sheltered workshops are the main socializing place for women with intellectual disabilities working there, as their friends work in the sheltered workshops as well. Workshop friends were rated as the most influential factor to their wellbeing. This is largely supported by literature that identifies friends as the source of emotional support helping foster both mental and physical health (Emerson & McVilly, 2004). Women placed a significant value on their friendships with people like them. Nonetheless, sharing personal characteristics such as age and gender similarity, women felt closer to other women. This is supported by studies suggesting that similarity of individual characteristics determines friendship among people with intellectual disabilities (Dangan et al., 1998; Ager et al., 2001; Whitehouse et al., 2001; Emerson & Mc Villy, 2004; Arvidson et al., 2008).

Some of the women share a flat with friends from the sheltered workshop and socialise with them after work as well as share responsibilities of housework and buying things for their home. Leisure activities consist mostly of common attendance at cultural events such as going in theatre or cinema with their friends and assistants, with whom women socialise after work as well. Working and living with flat mates and being similar to them, women with disabilities considered them as their closest friends. That people with intellectual disabilities tend to choose friends like themselves is widely supported by other studies on friendship (Dangan et al., 1998; Cummins and Lau, 2003, Gregory et al., 2001).

Sometimes assistants are identified as friends, but staff relationships toward women with intellectual disabilities are framed in terms of a professional ethic of service provision. Instead of friendship, staffs have a rather professional relationship with clients (Ager et al., 2001; Gregory et al., 2001; Hundert et al., 2002; Dudley, 2008).

Whereas women with intellectual disabilities living in group homes depend on staff for relationships, women staying with families depend on mothers and parents 'organisation events for socialising after work. They usually socialise with friends of workshops after job during the activities organised by parents 'organisations.

However, it should be stated that workshop colleagues are not always perceived as friends, put in a mother's (MA5) words: "To work with someone does not necessarily mean that he or she is your friend" and only a few times people without disabilities can be instead seen as friends. For example a woman called friends the clients to whom she delivered services. That she desired to have them as friends does not mean that they really were; it was just her perception, as the mother (MY3) said: "A wish to be with other people different from her". This is consistent with the existing literature which indicates that few people with intellectual disabilities, wishing to have friends different for themselves, have meaningful relationships with people who do not have intellectual disabilities (Myers et al., 1998; Felce, 2000., Gregory et al., 2001). To create relationships and a friendship bonds beyond the day-care centre and workshop area women with intellectual disabilities depend largely on their families and on parents' organisations.

#### *5.4.3 Importance of similar friends for well-being*

The most important social bonds outside the family are those with friends in school and work. Girls and women with intellectual disabilities expressed considerable satisfaction with friendship between them. Having friends similar to themselves is important for self-identity and belonging. Friendship formation both structural and process factors have been shown to have an impact (Gregory et al, 2001). Structural factors include physical attractiveness, similarity in appearance, personal characteristics and attitudes. Girls and women place a high importance on friendship with people like themselves. Sharing common structural characteristics, this is quite understandable, as girls and women are surrounded by friends who are similar to them everywhere, in schools and work-shops, in

cultural circles and sport clubs, in indoor-activities of shared accommodation and outdoor activities of leisure time.

Process factors include displaying reciprocity, gradually increasing self-disclosure over time, and both verbal and non-verbal communication behaviours indicating liking for the other person (Gregory et al., 2001). All participants agree that girls and women communicate with and understand better people like themselves to whom they feel closer and in whose presence they display a more affirmative self-confidence. Sharing almost all of their time and activities with people like themselves they feel comfortable in their presence. The 'staying together' with friends like themselves has developed in them a sense of reciprocity and mutual liking for each other. This has definitely strengthened their sense of self-identity and belonging to the group of people to whom they are similar. This is highly supported in previous studies confirming that given the structural and process factors necessary for friendship formation, it is not surprising that people with intellectual disabilities report greater satisfaction with friendships with people more similar to them in their social networks (Myers et al., 1998; Dangan et al; 1998; Felce 2000; Gregory et al., 2001; Emerson & Mc Villy, 2004; Arvidsson et al., 2008).

### **5.5 Theme Three: Community relationships**

The community is the social network of which people feel a part. In order to provide a feeling of belonging, the community has to take into account the different identities of people as valuable assets for the social capital of the community, which is a derivative of trust-based relationships. As predicted, the neighbourhood has a powerful role in providing relationships that lead to both personal wellbeing and to social cohesion. Given this quality of solidifying the social ties among individuals and groups, the neighbourhood is analysed to explore whether it facilitates or hinders social relationships and participation of women with intellectual disabilities.

#### *5.5.1 Neighbourhood characteristics influencing relationships*

This study produced an outline of two kinds of neighbourhoods: the friendly neighbours of women with intellectual disabilities and distant ones. The friendly neighbours are



those considered as family friends, with whom family has created a stronger bond compared to other neighbours, based on shared values and similar attitudes. However, being friends of families does not mean that neighbours are friends of women with intellectual disabilities too. The relationship they have with women occurs when they come in contact with the family and they behave positively to them because of respect for family, as a sister reports (SA3): “Neighbours are nice to her because they want to please us, as our friends”. Given the frequency of contacts with families of women with intellectual disabilities, those neighbours may become familiar with the difficulties associated with intellectual disability.

Unlike friendly neighbours, the distant ones are far less cooperative. They do not go further than physical acceptance of women with intellectual disabilities and show a superficial courtesy for the family, as a mother (MA1) said: “people are polite to her only because of me...” The superficiality of urban neighbours in Prague is in striking contrast to the friendliness of the rural neighbours with whom many women with intellectual disabilities and their families spent their holidays. In villages, the collectivist spirit prevails over urban individualism, as a sister (SA3) stated: “Neighbours of cottage place are nice; they stop to talk and help her, but in Prague is different”. The smaller community of the village is more accepting and supportive for women with intellectual disabilities, while urban neighbours are far more distant and less cooperative. This is supported by previous studies suggesting that small homogenous communities are rooted in shared values and characterized by a natural propensity to display solidarity toward its members, while in post-modern individualised society this solidarity is assumed to be in decline (Komter, 2005).

A positive factor contributing to social acceptance in the community is length of time the family and neighbours are known to each other. In the urban neighbourhood the demographic shift is more frequent as people shift settlements over time. The short amounts of time new neighbours spend in the community do not allow them to come closer to existing neighbours. This contributes to the erosion of social cohesion in neighbourhoods. The same old neighbours seem to accept and interact more with women

with intellectual disabilities than those in new settlements, as “they know them ever since” a mother (MA2) said. Women who were living in supported living arrangements were less known to community and their social relationships were limited to flat mates and assistants. They had no relationships beyond these although using the resources of the community. This indicates that people with disabilities who are placed in a new neighbourhood do not automatically develop interpersonal relations and the wider community does not readily accept previously marginalised people moving in next door (Whitehouse et al., 2001). This is explicitly supported by previous studies which suggest that proximity and frequency are necessary conditions for the formation of superficial acquaintances, but not sufficient for the formation of deeper friendships (Gregory et al., 2001).

Lastly, assertive personality is considered to be a determinant factor in communicating with others. For example, apart from knowing families, neighbours react nicely to women with intellectual disabilities when they behave friendly and politely, as confessed in a mother’s (MY3) statement: ‘our neighbours like her because she makes them happy; she is like sunshine’. It is prevalent in the literature that personal characteristics are very important in creating and maintaining relationships (Dangan et al., 1998; Arvidson et al., 2008).

### *5.5.2 Physical integration*

Clearly the community tolerates their physical presence but does not involve women with intellectual disabilities in purposeful cooperation or genuine friendship. Although an increase in use of community resources and services provides for a higher presence in community this is evidenced to be more a physical integration rather than social inclusion which is about relationships in community. Accepting is important, but creating meaningful interaction is the core of social relationships. Despite being physically integrated women with intellectual disabilities remain socially outside the community. Therefore the opportunities for social relationship and friendship, beyond family ties, are restricted to social contacts with staff and clients of social services offered mainly by parents’ organisations. This study evidenced the gap between being physically within and

socially excluded in community. Community presence is a necessary but not sufficient precondition for social participation. This is firmly supported by studies indicating that enhanced community presence contributes to integration, but does not guarantee social participation (Myers et al., 1998; Emerson et al., 2000; Ager et al., 2001). Although physical exposure is considered to be an important initial step towards creation of the sense of community, sometimes it can create adverse results such as the sense of alienation and otherness, if not followed by social inclusion. This result is clearly indicated in the research findings suggesting that it is social not physical integration that has a reliable positive influence on wellbeing and participation (Young et al., 1998; Hundert et al., 2002; Spreat & Conroy, 2002; Emerson & Mc Villy, 2004)

#### *5.5.3 Obstacles to relationship and friendship*

The obstacles to relationship and friendship in community are grouped into two categories, obstacles at the personal level and obstacles at the environmental level. This division is consistent with the theory of social psychology that ascribes significant importance to the interplay between personal and situational factors for creation and maintenance of social relationships (Myers, 1993; Papalia & Olds, 1993).

#### *5.5.4 Obstacles at the personal level*

At the personal level, the major obstacles identified are personal characteristics and learnt dependency. Personal characteristics, such as the inability to communicate are considered a significant barrier to relationships for women with intellectual disabilities. Understandably, the impairment of cognitive ability has a role in communication which is important for social relationships. Additionally, high relevance is ascribed to the social skills in creation and maintenance of relationship. Having communication as one of the major barriers for expressing themselves, women with intellectual disabilities face extreme difficulties in creating social relationships. This is fairly consistent with literature which suggests that besides communication, personal skills are as influential in the realm of friendship creation as in maintenance; thereby improvement in adaptive behaviour is strongly recommended (Meyers et al., 1998; Emerson & Mc Villy, 2004)

Surprisingly, the study found that the community is not held responsible for failing to create conditions for social relationships and public attitude is justified by focusing the problem greatly on the intellectual disability. Even if the community would be more 'tolerant', pessimist opinions declare that environmental changes would not bring about any change for women relationship. The intellectual disability is considered to be the major problem. Still, environment is considered to play a role in the social relationships of women with intellectual disabilities.

#### *5.5.5 Environmental barriers*

Besides personal characteristics, environmental factors have a much more significant contribution in facilitating or hindering social relationships by influencing adaptive behaviour. The environmental obstacles highlighted in this study are: the low level of community cooperation, lack of understanding, individualistic life style, infantilisation and overprotection. Let's explore each of them.

#### *5.5.6 Low level of cooperation of community*

As mentioned above, women with intellectual disabilities are polite, nice and friendly to neighbours, thus communication may not be an insurmountable barrier. Furthermore, the ability to socialize with others does not depend only on personal characteristics; it depends on environmental factors as well such as community availability and support to include women with intellectual disabilities in existing social structures. This is supported by previous studies indicating that community life participation goes both ways from individual's adaptation to community responsiveness (Myers et al., 1998). Admittedly, the task of welcoming, meaning to have supportive friendly networks within which to form social bonds, rests with the community rather than women, who from what is witnessed, like very much to be with people. So far, the friendliness of community is evidenced to be superficial as there is no indication that people really mean to create relationships with these women beyond acceptance of them. This is consistent with studies suggesting that the low level of social participation and absence of increase in relationships may be caused by inconsistent community efforts to provide conditions for both participation and relationships (Whitehouse et al., 2001; Arvidsson et al., 2008).

Surprisingly, changing environmental conditions seem to some highly inconvenient as it would be counterproductive for the happiness of women with intellectual disabilities, as expressed by a mother (MAD4) wondering: “Why to change things, she is happy with!”

#### *5.5.7 Lack of understanding*

Other environmental barriers for women with intellectual disabilities are the attitudinal barriers and prejudices enhanced by the low level of knowledge about intellectual disability. Even though people accept the women among them, they do not fully understand the difficulties related to intellectual disabilities. Given the impaired cognitive ability, women with intellectual disabilities need time to translate a message coming from a waving hand or a smiling face, but this does not mean that they do not understand it. For example, a teacher complained to a mother that her daughter did not answer to a greeting and the mother (MY2) “had to explain that the daughter needs time to recognise people and translate other’s messages”. Having identified the lack of understanding of intellectual disability as a major barrier to social relationships, parents’ organisations have targeted the raising awareness as the strongest mechanism for changing people’s attitudes against women with intellectual disabilities.

#### *5.5.8 Individualistic life-style*

“People don’t have time for my daughter”, a mother (MAD1) said. It is true to some extent that nobody would have plenty of time for others and sometimes even for the significant ones. In post-modern society the needs and the interests of individuals prevails over those of collective society. A century ago Durkheim (1897 [1951]) foresaw that in modern society social cohesion and bonds of individuals with society would weaken. The individualisation process renders social ties more transitory and weakens community solidarity for those in need. In accordance with self-reliant personality, people identify more with communities of individual interests not necessarily located in the neighbourhood and feel less committed to neighbourhood concerns. Studies in sociology and psychology identify the individualistic life style, referred to as the paradigm of selfishness, as the main factor responsible for diminishing community capacity to provide

meaningful support and opportunities for social relationships (Karp et al., 2004; Cummins & Lau, 2003; Myers, 1993; Papalia and Olds, 1992; Komter, 2005).

#### *5.5.9 Infantilisation*

Contrary to what women wish for, neighbours communicate with parents about them instead of directing the conversation to them. They treat them as if they were children, ignoring that they are adult. Rightly, women do not like neighbours to make them feel belittled and devalued as persons, as a mother clearly stated: “She does not like people to ask me about her; she likes people to be introduced to her”. By interacting with adults they feel as adults too. For example, wanting to be recognised as an adult person by an elected official who was participating in a community event for people with intellectual disabilities, a young woman, to the surprise of her mother, stepped courageously ahead and initiated and concluded the discussion by asking him for his business card. Surely, the treatment of women as eternal children is a major attitudinal barrier against relationships with adults. This finding is anticipated in other studies suggesting that infantilisation as a core component of paternalism and dependency disqualifies women with intellectual disabilities for adult friendship (Clements et al., 1995; Traustadottir, 2000; Smart 2001).

#### *5.5.10 Overprotection*

Although scoring participation in community as the best way to disclose to other people, familiars fear that girls and women with intellectual disabilities can be exposed to abuse from outsiders if familiars do not check their relationships, as expressed in a mother’s (MAD%) words that: “If a women with intellectual disabilities is alone, bad things may happen to her and she does not understand the others’ intention”. The fear of abuse has led to an over-protective attitude which in turn has resulted in learnt dependency. By considering women with intellectual disabilities as their ever-child, many families police their relationships without allowing women to provide acquaintances to themselves or to take the risk to assume the responsibility to attempt friendship, with the full right to fail as well. Subsequently, women with intellectual disabilities are limited in their choices for relationships and are highly dependent on family friendship and day-care centre clients.

Adding to familiars' lack of trust the usual wariness of neighbours on the presence of people with intellectual disabilities in general, the opportunities for women with intellectual disabilities for social relationships and participation are at stake. As the literature confirms, deprivation from opportunities to meet people and to take advantage of opportunities places them in a difficult position for developing relationships (Dangan et al., 1994; Myers et al., 1998; Ager et al., 2001; Whitehouse et al., 2001).

#### **5.6 Theme Four: Social network activities that improve social well-being**

The domains of social inclusion and personal wellbeing are closely interrelated. Social relationships, which are a core indicator of social inclusion, lead to increased emotional wellbeing, while purposeful activities enhance the quality of social relationships and participation. People interact based on assumed role stereotypes. Even if it seems natural to have a social role, it is given by society to those who are qualified as role bearers. Each social role has a set of expectations to be fulfilled. Depending on fulfilment of social expectations, individuals gain praise for success or rejection for failure. Obviously, successful fulfilment of social expectations accredits to individuals social status, which is the essence of social value. Admittedly, social roles are a precondition for social status. Social status is gained through belonging and participation in community. As suggested by previous studies, the more people experience community living and social integration the better their lives will be and friendship plays a vital role in this by improving social wellbeing (Cummins & Lau, 2003; Emerson & Villy, 2004). Purposeful activities carried out in social networks make life meaningful to women with intellectual disabilities and strengthen their self-esteem and feelings of usefulness and happiness. The life satisfaction originating from useful and purposeful activities is a step towards social wellbeing

##### *5.6.1 Personal satisfaction*

Women with intellectual disabilities in this study feel generally happy with their lives. Family care and love is the main source of their happiness, even to those living in sheltered accommodation. Younger women with intellectual disabilities feel useful going to school whereas adults feel useful to working and having their job valued.

#### *5.6.1.1 Adolescents and young women with intellectual disabilities*

Adolescents and young women with intellectual disabilities feel happy to be with their families and to go to school, enjoying mostly being active and having friends in school. A predetermined routine agenda of studying and leisure time, which is familiar to them, helps them to be less anxious. They are able to decide on their free time and routine activities such as the time of study or watching preferred programs. They feel useful when they are praised for following conventional instructions of parents and teachers. Participation in domestic work makes them feel useful in the house and that they have a value for their parents, especially mothers. They particularly enjoy the cultural and sport activities of leisure time with friends organised by parents' organizations such as ceramic creative courses and swimming and yoga clubs. Being with friends in school and leisure activities, acts as a buffer against loneliness for them. Although they like their school-peers, they wish for friends of their age in the neighbourhood as well. Some adolescents were going through an adolescence crisis and felt less happy than when they were children.

#### *5.6.1.2 Adult women*

Generally women are happy to share life with family or flatmates in supported living arrangements. They are satisfied with having an active daily agenda to which design they contribute in participation with familiars and assistants. Women can decide on daily activities and ordinary things such as choosing the preferred food and dress or TV program. Usual activities of the self-determined program comprise going to school for the younger adults and working for the older adults. Feelings of usefulness as a result of working and being of valued for their work motivates them more. They participate in housework activities together with families or flatmates. Sometime over-responsive mothers cover everything and do not allow their daughters with intellectual disabilities to carry out things for themselves, thus impacting their sense of usefulness and teaching them dependency. In some cases they disobey by choosing something different from what their mothers decided for them. Except for self-decision in daily routine things and activities, women with intellectual disabilities are not considered to be able to make



decisions at an abstract level, such as what to do in life, pursuing an activity of interest or establishing an intimate relationship.

They do actively participate in leisure programs after school and job by attending cultural activities organised by parents' organisations or by themselves in cooperation with families or assistants. They enjoy dancing, singing, listening to music or watching preferred movies. Obviously, if left alone in unfamiliar environments they feel anxious and uncomfortable. Most of time they are happy, but sometimes they experience feelings of loneliness and prefer to be left alone in their own world. Presumably, they feel happier for being active workers and for living on their own sharing life with other adults, which makes them feel as adults. Despite enjoying the companionship of families and friends like themselves, they express an overt desire to be in friendship with other people and to participate in community life. Being with others helps them overcome loneliness and fosters the meaning of coherence in life. This is well supported by studies suggesting that social relationships with friends enhances mental and physical health, while emotional support helps to minimise the effect of stress and loneliness (Emerson & Mc Villy, 2004; Felce, 2000; Papalia and Olds, 1992).

Young and adult women with intellectual disabilities wished for being married and having children. The wish to create a family originates in their self-perception of being adult. As adults, people engage in marriage and family formation. This is strongly related to the social role of adult as reproductive agent of social capital and fulfilment of the social expectations on family formation. Women with intellectual disabilities are hampered in realising this wish by being considered as the 'eternal child' of the family who can never have adult roles nor a sexual self either, so they are not entitled to intimate relationship, as other adults are. They are told by parents that they are unable to assume a parental role. The hindrance to having adult-roles is called social disabilism and impacts quality of life (Smart, 2005).

### *5.6.2 Social value contributes to wellbeing*

As mentioned above, girls and women have engaging daily agendas that keep them active in school activities or in job relations. Whatever the activity they carry out, they like to be valued for what they are doing. For example, girls like to be praised for scoring well in school and conforming to instructions for behavioural adjustment to social conventions, while women like especially to be valued for their job results such as goods and services produced by their hands. Being accepted for who they are and valued for what they do makes them feel happier. Above all, productive activity allows women to fulfil adult role expectations as productive members of society. By doing something useful for others they feel valuable as human beings and that society grants them social status for fulfilling social role expectations. By occupying socially valued roles women get social value which can rescue them from the effect of devaluation as persons with disabilities and as women. This is well grounded in the theory of Social Role Valorisation (SRV) of Wolfensberger (1995) and in gender and disability studies (De Beauvoir, 1949 [1972]; Oliver, 1986; Katovil, 1996; Black Well Stratton et al., 1998; Smart, 2001; Finkelstein, 2002; Martin 2003; Ridgeway & Corell, 2004; French and Swan, 2004; Kelly & Traustadottir, 2005; Thomas, 2004; Barnes & Mercer, 2005).

Like everyone, girls and especially women with intellectual disabilities like their presence to be noticed by people as a signal of social acceptance and as a condition for commencement of social relationships. By expressing the wish to be recognised by other people they are just showing a natural inclination to be welcomed and accepted. It is commonly accepted that social relationships provide wider access to community and more opportunities for social participation. Additionally, social relationships are considered to be the main source of emotional wellbeing and conveyer of a sense of belonging. This is fairly consistent with literature reporting that social relationships with others provide a sense of self and belonging and impact positively both mental and physical health (Papalia & Olds, 1992; Myers, 1993; Reinders, 2002; Emerson & Mc Villy, 2004).

## **5.7 Theme Five: Changes for inclusion**

This study has found that although girls and women with intellectual disabilities are more present in the community they have no meaningful relationships and friendship within the community. Previous literature has presented similar findings suggesting that people with intellectual disabilities exposed to community have found effective social integration extremely difficult to achieve (Whitehouse et al., 2001; Hundert et al., 2002; Cummins & Law, 2003). Women and girls with intellectual disabilities need to feel socially accepted, welcomed and considered as valuable persons. In order to address the absence of social relations networking for women with intellectual disabilities and establish relationships and friendship in community, this study has identified that changes should occur at four levels: personal, environmental, policy and self-advocacy.

Firstly, changes at the personal level should tackle personal characteristics such as social skills, self-dependency, self-confidence and ability for communicating in order to maximise behavioural adjustment. While improving communication ability and social skills, changes at the personal level only are insufficient prerequisites to address the absence of social relationships and friendship in the community. Therefore the second set of changes should occur at the environmental level.

At the environmental level changes include increase in the level of cooperation with community and reducing of overprotective family behaviour in order to provide women with intellectual disabilities the opportunities to enter into relationship with others. An increase in people's knowledge of intellectual disability would produce changes in the attitudinal barriers put toward people with intellectual disabilities as unworthy members of the community and can increase the chances for more respectful treatment of women as persons with dignity and values. An openness of community towards relationships with these women is crucial to creation of friendship networks. To this end, the community should offer more available support in establishment of social networks of appropriate age as a mother (MAD3) recommends "My daughter needs friends of her age in neighbourhood with and without disabilities". This is highly recommended by previous literature suggesting that success of inclusion into community is determined by the characteristics of the environment that support improvement of personal characteristics

for adaptation (Emerson, 1985; Young et al., 1998; Dangan et al., 1998; Felce, 2000; Whitehouse et al., 2001; Hundert et al., 2002; Baker, 2007).

A third change targets policy, implying that social policy should be more inclusive and should not provide only for services within institutions. As inclusion urges, community-based social services should increase the opportunities for social relationship and enable women with intellectual disabilities to establish friendship networks as means for social inclusion and participation. Policy changes are extensively explained in previous studies critical to social policy which state that although community-based services may promote proximity to community (hence promoting acquaintances), they have not tackled the necessary issue of development of more meaningful friendships for people with intellectual disabilities with people without intellectual disabilities (Gregory et al., 2001).

To their good luck, girls and women of this study have very active mothers who fight for their right of social inclusion, but to achieve this goal, mothers should encourage self-advocacy, so that women with intellectual disabilities, like other citizens, are able to participate in the decision-making process and thereby assume greater control over their lives (Gargiulo et al., 1997; Šiška, 2006).

## **5.8 Summary of findings**

### *5.8.1. On family support*

Family is the main source of stable relationships and support for creating relationships with others in neighbourhood and family friendship networking. Mothers are still the main carer and often the only carer. Fathers are more involved with care and leisure at the present time, as the analyses showed. Siblings remain a crucial factor for socialising the person with intellectual disability through the life-span. The analyses found that elder siblings, both brothers and sisters, felt more responsible towards younger sisters with disabilities, with elder sisters especially more involved with caring and sharing. The relationship with younger siblings was particularly good when they were smaller as they played together. Younger sisters were found to be more comfortable in relationships than elder sisters who were more critical and authoritarian. The relationship with younger

brothers was good until brothers' adolescence, after brothers became distant and did not like to be identified as brothers of a woman with a disability.

Families, especially mothers are the main support for creation of opportunities to form relationships in community by exposing women with intellectual disabilities to community acquaintance or including them in family friends' networks.

#### *5.8.2 On the friendship presence*

Beside the family, peers were reported to be the most important source of social relationship for women with intellectual disabilities. Peers from school, sheltered workshops and flatmates of group homes were the best and the only friends of women with disabilities. Two factors influencing friendship of women with intellectual disabilities are the similarity and the long-time they spend together in and out school and job activities. Peers fill the day of women with intellectual disabilities in school and sheltered workshops and leisure time events. Girls and women with intellectual disabilities have expressed considerable satisfaction with friendship between them. Having friends similar to them is important for self-identity and belonging.

#### *5.8.3 On the community acceptance*

Although women with intellectual disabilities are living in community they still are outsiders within it. They have no purposeful relationships and friends in the community. The only ties they have with it are through family relations with neighbours and friends. The recognition of the physical presence of women with intellectual disabilities in the community is translated as acceptance and sometimes as welcoming tolerance by familiars. Usually neighbours behave politely to women with intellectual disabilities because they want to please the family and not because they genuinely accept them as neighbours and friends. Yet there is a huge difference between neighbours' attitudes in urban areas compared to rural: for example, people in Prague were reported to be more distant, inattentive and overlooking the presence of women with intellectual disabilities in their neighbourhood, while people in rural areas were friendlier and more responsive towards needs of women with intellectual disabilities.

With regard to the obstacles to relationship and friendship in community, the personal characteristics of women with intellectual disabilities were highlighted as the main obstacle, especially cognitive ability related to the incapacity of communicating and creating relationships, therefore the majority of recommendations relate to the improvement of communication. Environmental characteristics were found to present persistent barriers as well, such as superficiality of neighbours in communicating with women with intellectual disabilities, lack of understanding the communication difficulties associated with intellectual disability and mistrust of neighbours regarding social abilities of women with intellectual disabilities for socialisation and relationship. Finally, infantilisation and degenderisation of women with intellectual disabilities are the major barriers to relationship opportunities, for both intimacy and friendship.

Regarding changes that the community should undergo to be more inclusive and friendlier for women with intellectual disabilities, so they can develop trust in community and self-confidence to disclose to others. Four levels at which change must occur are: personal, environmental policy and self-advocacy.

Recognising the relevance of both personal and environmental factors in creating relationships, social policy should develop inclusive programs for enabling women with intellectual disabilities to have a life of quality among friends, as a sister (SA3) recommended: “Assistants should not only teach relationships, they should help persons with intellectual disabilities to create and maintain relationship beyond the group home inhabitants”. To this end, social policy should not be limited to assistance within social institutions; it should be more inclusive and develop social networks as part of enabling services and government should fund these kinds of services. Most importantly, social relationship is a basic human right, a precondition to live in society. For sure, people with intellectual disability need access to citizenship rights but to conduct a life of quality they need friendship first.

#### *5.8.4 On the social well-being*

In relation to social wellbeing, both groups, young and adult, are happy to be with their families, and some adult women were happy to share their home with flatmates like

themselves. The activities making women happy are different for young and for adult women. For young girls education was the central activity of the day whereas for adults the job was the main activity. Young girls felt happy to be praised for academic scores and instructional guidelines achievement, while adult women felt useful if their job results were valued by others. Regarding leisure activities, young girls were more involved with peers like themselves in special school activities, while adult women's leisure time consisted of common cultural activities with job colleagues after work, or flatmates and assistants or with family friends. Both groups were well served with day programs targeting both rehabilitation and socialisation of women with intellectual disabilities.

## CHAPTER SIX

### CONCLUSION

#### **6.1 Introduction to the research findings**

At present, a humane-based approach promoted by the social model of disability has placed a strong emphasis on social relationship as a precondition for social participation and as an indicator of quality of life, contributing to the wellbeing of persons with intellectual disabilities. As a quality indicator social relationships and participation are used to monitor social exclusion and to contribute to reduction of inequalities and injustice while purposeful activities measure level of satisfaction which contributes to psychological wellbeing (Felce, 2000; Walsh et al., 2007). In this study the quality of life indicators examined are social relationship and purposeful activities as preconditions for social inclusion and wellbeing. They are subjectively assessed through analysis of the information captured in perceptions of mothers and sisters who described the situation of girls and women with intellectual disabilities.

Family support, friendship and neighbours social relationship quality are evidenced in this study to be the core factors influencing the domains of social inclusion and personal wellbeing. Social inclusion is indicated by the existence of relationships such as social networks and friendship while wellbeing is indicated in personal satisfaction in conducting a purposeful life of meaningful activities that results in feelings of happiness and usefulness and increases the capacity for decision-making.

Current social policy in the Czech Republic places considerable emphasis on the empowerment of people with intellectual disabilities to participate in community life and to be socially included (Šiška, 2005). The ultimate goal of social inclusion philosophy is to improve the quality of life for people with disabilities which results in increased wellbeing. The growth of awareness about social inclusion is reflected in efforts of parents to involve friends and neighbours in creating and supporting opportunities for participation for women with intellectual disabilities.



The full exploration of the situation of social inclusion and wellbeing of women with intellectual disabilities in the Czech Republic was not possible within the limits of this study due to its scope and time-limit. However this study has investigated the characteristics of social relationships that influence both social participation and life satisfaction, which are indicators of social inclusion.

## **6.2 Main research findings**

The study found differences in between age cohorts regarding social relationships and participation, as those activities are age-bound and conditioned by specific social roles and societal expectations ascribed to the age. Regarding opinions of mothers and sisters, the study found a high consistency between them in describing the perceived rate of social relationships and activities participation.

Finally, four general conclusions can be drawn from the findings which address the issue of social relationships and their impact on community participation and personal well-being of women with intellectual disabilities.

Firstly, well-being of women with intellectual disabilities is expressed in high levels of satisfaction with social relationships with their family and with friends like themselves, while social participation and social relationship with community provide less satisfaction. This is consistent with studies indicating that family ties (Spreat & Conroy, 2002) and friendship among people with intellectual disabilities are of high importance for their well-being (Emerson& Mc Villy 2004), and studies that have found social integration difficult to achieve in larger community settings (Withehouse et al., 2001; Hundert et al., 2002; Cummins & Lau, 2003; Arvidsson et al., 2008) although there is good evidence of greater participation in smaller community settings (Young et al, 1998; Dangan et al., 1998; Ager et al., 2001; Kim et al, 2001; Hundert et al., 2002; Baker, 2007).

Secondly, the majority of women with intellectual disabilities identify as friends their school peers, service users and assisting staff of the day-care centres and group-homes; nonetheless they express a clear preference for relationships and friends other than people with intellectual disabilities. This is well evidenced in previous studies indicating that people with intellectual disabilities have friends in segregated social services (Myers et al., 1998; Felce 2000) and identify staff as friends (Dudley, 2008; Cummins & Lau, 2003), while desiring other friends without intellectual disabilities as well (Gregory et al., 2001; Emerson & Mc Villy, 2004; Reinders 2002).

Thirdly, the research findings link the rate of social relationship and participation with personal social skills and environmental characteristics with an increasing emphasis on environment, to booster the facilitating aspects. This is consistent with studies referring that personal characteristics are important, but highlight the environmental factors playing a crucial role by teaching behavioural adjustment (Emerson 1985; Donnelly et al., 1996; Yong et al., 1998; Arvidsson 2008; Dudley 2008).

Fourthly, a range of positive and negative factors have been identified which appear to be associated with increased levels of social relationship and participation. Positive factors at the environmental level include friendly neighbourhood, while at the personal level are assertiveness, engagement in purposeful activities such as studying, working and leisure time, participation in housework, use of community resources and having friends. This is found in previous research suggesting that participating in domestic tasks (Gregory et al, 2001), sharing community facilities (Donnelly et al, 1996) and being with friends (Myers et al., 1998; Felce 2000) are important for social participation and personal well-being. Factors relating negatively to relationship and participation include personal characteristics such as lack of communication abilities, while the environmental is comprised of superficial community acquaintance, lack of community cooperation due to individualistic life style and non-understanding of intellectual disability, infantilisation, fear of abuse and overprotective family behaviour. This is highly consistent with findings of other studies ,suggesting that isolation and harassment by people in local communities (Donnelly et al., 1996), community constraints on social exchange (Cummins & Lau,

2003) poor relations in community (Myers et al., 1998) and reduced social solidarity (Komter, 2005) are critical barriers to social relationship and community responsiveness.

### **6.3 Limitations of research**

The research used a qualitative strategy for data collection and data analysis. The sampling and issues of this study has been informed by theory. For exploring the patterns influencing social relationships, the theory of social psychology and the literature on social networking and friendship were extensively consulted. Semi-structured interviews were employed to explore the situation of women with intellectual disabilities through the definitions offered by their mothers and sisters, participating in the study as proxy participants. The data were analyzed in-depth and theoretically saturated in order to give justice to each single participant's opinion. In order to increase validity of the research triangulation was used by employing constant comparison. However, the study has inherent limitations at methodological and findings levels.

#### *6.3.1 Language barrier*

Although I found some cultural similarities with Czech society, due to the past analogous history of communism, still I was a foreigner to the country's culture and language, which conditioned the research procedure by requiring use of mothers and sisters as proxies instead of women with disabilities themselves. Even though the information from mothers and sisters was very useful, it is not the same thing as information that would have been yielded from women with intellectual disabilities themselves. For this reason the opinions of mothers and sister are not assumed to be the perceptions of the women themselves.

#### *6.3.2 Sample and site limitations*

Being a purposeful sample, the subjects constitute a limited number of women with intellectual disabilities that are clients of services of parent's organisations. Firstly, their characteristics do not apply to all women (however generalisation is not the scope of qualitative research like this) and secondly, as social services beneficiaries offered by parents' organisations, they represent the most active group of women with intellectual

disabilities. As very active members of parents' organisations, the participants of the study may not be a representative of mothers and sisters who are not active in associative life.

The research investigation included women with intellectual disabilities from Prague who came from parents' organisations; therefore its findings may not be relevant to other geographical areas of the Czech Republic and even to the whole area of Prague, for at least two reasons. First, it is not known whether the organisations participating in this research are providing services to the whole population with intellectual disabilities in Prague and secondly, even if so, the study did not research all clients of all organisations.

This research is guided by feminist epistemological interest and has investigated only the situation of women with intellectual disabilities, making use of cross-sectional analysis between age cohorts. The study is limited in investigating the situations of women versus men, thereby missing information on the gender differential of the two populations.

### *6.3.3 Instrument construction*

The research employed as the central method for data collection semi-structured interviews, not complemented by observation of subjects. The issues investigated in the interview questions were informed by theory. While theory-informed issues have reliability and a constant comparison across the participants is economical, this choice can sacrifice the depth and broadness of information and the integrity of individual responses, as well as de-contextualisation of data.

## **6.4 Implications for policy and practice**

This study has found that although girls and women with intellectual disabilities are more present in community they have no meaningful relationship and friendship within community. Yet, women and girls with intellectual disabilities want and need to feel socially accepted, welcomed and considered as valuable persons. Therefore changes should occur at both the individual and environmental level in order to address the absence of social relations networking for women with intellectual disabilities.

First, changes at the personal level should tackle personal characteristics such as social skills, self-dependency, self-confidence and ability to communicate in order to maximise behavioural adjustment. At the personal level, the communication ability and social skills should be enhanced. Changes at the personal level only are insufficient prerequisites to address the absence of social relationship and friendship in community.

Therefore the second range of changes should occur at the environmental level, targeting community readiness for cooperation, policy improvements for effective social inclusion and self-advocacy of women with intellectual disabilities.

At the community level, changes include increased level of cooperation with community and reduced overprotective family behaviour. The upgrade in people's knowledge about intellectual disability will create a more trustful atmosphere and increase chances for respectful treatment of women as persons with dignity and value. An openness of community towards relationships with these women is crucial to creation of friendship networks. To this end, the community should offer more available support in establishment of social networks in neighbourhoods with friends of appropriate age with and without disabilities.

The third change targets the policy level, by imposing changes to social policy to be more inclusive. Social policy should not provide only for services within institutions, but should enable the community-based social services to increase the opportunities for social relationships and to establish friendship networks as means for social inclusion and participation. Person-centred plans can be an effective means to help create social relationships and friendship.

To their good luck, girls and women of this study have very active mothers who fight for their right of social inclusion, but to achieve this goal, mothers should encourage self-advocacy, so that women with intellectual disabilities are able to participate in the political decision-making process by assuming greater control over their lives.

Albania has a similar history of former communist regime to that of the Czech Republic; therefore, to a major extent, the findings of this research are relevant to the situation of women with intellectual disabilities in Albania. During the transition years, Albania has elaborated social policies targeting the deinstitutionalisation of persons with disability and development of community-based services, but the policy is not yet enabled. The development of social policy in the field of social services should provide opportunities for a radical transformation of institutional care into an enabling system that responds to users' needs (ESPD, 2007). But the emergence of a capitalist system has introduced a market-based approach to welfare policy (Esping-Andersen, 1990), which, mixed with remnants of the communist regime, is producing conflicting social care policies and is rendering community living for people with disabilities a difficult mission. The research findings on the Czech context related to the role of community living and social networks on social inclusion, will recommend improvements to the social policy and practice in the field of disability for Albania as well.

### **6.5 Implications for professional development**

I have both a personal and professional interest in doing this research. I am an activist of human rights for people with disabilities and women, and I teach Gender Studies at the Faculty of Social Sciences in Tirana University. I am doing this Master on Special Educational Needs with the aim of gaining a deeper understanding of barriers to inclusion for women with intellectual disabilities in education and beyond, in order to work, when back in my country, to dismantle them. Since the last decade, I am witnessing the transition of the institutionalised system into a community-based care system in Albania. I am involved in advocacy projects aiming at facilitating access for people with disabilities into mainstreamed services and community living. As an activist of both disability and the women's movement, I am going to advocate for mainstreaming both disability and gender social policy in order to create conditions for social inclusion of women with intellectual disabilities in my country. Recently, I am working with parents to close down the residential institutions and to build community-based services, in order to bring people with intellectual disabilities back into their families and community. The deinstitutionalization process places the responsibility for care on the neighbourhood and social networks in the community. I consider the social

networks as a major force in ensuring meaningful and dignifying social participation for women with intellectual disability, therefore, working with parents and self-advocates, I will continue to support enablement of social networks of friends for women with intellectual disabilities at the community level in order to improve their living conditions and civic participation. The data presented here were collected in the context of a MA thesis.

### **6.6 Implications for further research**

As the ultimate goal of social inclusion is to increase the level of well-being levels for people with disabilities, including women, research should explore what environmental characteristics facilitate the improvement of quality of life for women with intellectual disabilities as for the rest of the population.

Since inclusion goes beyond formal rights of citizenship and implies a more responsive willingness from the community to find a place for women with intellectual disability within it, further research should address the moral aspects that influence social solidarity with the aim of strengthening it.

Although relationship depends on the interplay between personal factors and environmental characteristics, research should emphasize more the environmental factors given their power in facilitating or hindering social adjustment.

Given the tremendous impact the neighbourhood has on boosting relationship, more inquiry should be conducted on effective ways to reduce community relationship deprivation that impact social capital with the aim of engendering community response for relationship and enhancing the sense of community belonging.

Because friendship formation beyond people with disability is important for social inclusion, research should pay attention to the conditions that lead towards stable friends' networks in community, without reducing the value of friendship among people with intellectual disabilities.

As it is broadly explained, social roles and societal expectations relate to the respective stages of age cohorts, therefore research should focus more on the subjective aspirations of women with intellectual disabilities throughout the lifespan that correspond to given roles and social status.

For a long time research in the field of intellectual disabilities has ignored the gender differences between men and women, by considering them as a homogenous group, perpetuating this way the widespread societal belief that people with intellectual disabilities are gender-free. Therefore further research should take into account how gender differences impact the needs, experiences and aspirations of men and women with disabilities differently.



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