From Institutional Settings to Community Living: Enabling people with intellectual disabilities to be active citizens

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ABSTRACT

This study explored how people with intellectual disabilities who reside in different types of living arrangements in the Czech Republic can be supported in enhancing Active Citizenship.

Using the UN Convention on the Rights of Persons with Disabilities (CRPD) as a framework of reference, this research study is a pilot conducted in the Czech Republic to implement the project **DISCIT: Making people with Disabilities Full Citizens – New Knowledge for an Inclusive and Sustainable European Social Model**. Taking on the work of the larger project this study explored the experiences of six people with intellectual disabilities living in community settings and six other people living in a Training House within the institution premises as a result of the deinstitutionalization in the Czech Republic and the development of Community Living.

The study adopts a participatory approach supported by a qualitative design combining: semi-structured Interviews, focus group interview, aided by Visual Aid Mediation tool, as data collection methods, and qualitative data analyses.

The approach allows the opportunity to reflect on, explore and disseminate the views, concerns, feelings and experiences of research participants from their own perspective. A service provider in the Czech Republic offering services to both people with intellectual disabilities living in community and people living in the institution was identified to elicit the participants.

In the last few years the philosophy of care of the service provider has changed from a medical approach to encourage and promote independence by the introduction of the In House Training Programme to the opening of the Community Living. By referring the findings to the UN CRPD participants were impede to be active citizens due to discriminatory legislation and entitlements. However without legal infrastructure to support participants to become active citizens findings shows that providing individualised services in community empowered participants to be active citizens.

ACKNOWLEDGEMENTS

CONTENT LISTS

CHAPTER ONE

1.   INTRODUCTION

This study explores the views of adults with intellectual disabilities from different residential arrangements in the Czech Republic, herein Community Living and In House Training Group[1] settings, regarding their status from the perspective of Active Citizenship. Within such a perspective, instead of being stigmatized patients (Goffman, 2009), people with intellectual disabilities are ordinary citizens living in ordinary houses (Morris, 2005; Evans, 2001).

Seven years after the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2008), which recognizes the need to promote and protect the human rights of all persons with disabilities, the implications of the citizenship perspective for adults with intellectual disabilities remains to be fully explored. The majority of individuals with intellectual disabilities continue to be housed in institutions in EU Member States without much choice and control over their lives (Mansell & Ericsson, 1996; Evans, 2001; Vann & Šiška, 2006; FRA[2], 2012). Recent European studies on deinstitutionalization and community living confirm that nearly 1.2 million children and adults with disabilities continue to live in long-stay residential institutions in Europe, and that more than one-half of public care expenditure goes towards institutional care (FRA, 2012; Mansell et al., 2007; Power, 2013). A wide gap can be seen between the everyday experiences of people with intellectual disabilities in Europe and the demands of CRPD regarding their rights as active citizens. The Active Citizenship perspective continues to be ambiguous and ignored by public services organisations (Mansell & Ericsson, 1996). This haziness is upheld by obstacles arising from national legislation, eligibility criteria, accountability, inadequate training for social

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[1] A group of adults with intellectual disabilities being prepared within a comprehensive Individual Plan, moved to a less restrictive facility within the premises of the institution to be soon moving out in community living arrangements as part of the deinstitutionalization process

[2] Fundamental Rights Agency (Choice and control: the right to independent living; Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States)

services professionals and poor organization and procedures in reviewing and monitoring the impact of the CRPD implementation for people with intellectual disabilities (Evans, 2003; Šiška & Beadle –Brown, 2011; Mansell et al, 2007). Consequently the welfare state support becomes stigmatizing by definition, and therefore an obstacle in itself (Tøssebro, 1996). To pursue the goal of a society in which all people with disabilities are able to participate as equal citizens, a cultural environment that places the needs of the many on the same level with those of the few must be created (Barnes, 2005; Biggeri et al., 2011).

1.1 Active Citizenship and People with intellectual disabilities

More than twenty years ago the buzzword in the political discourse was something called citizenship (Young, 1985). The imagery of the citizen is imbued with hegemonic normalcy and as such excludes disability, as we can see later in this chapter. Many research studies reveal that due to this imagery people with disabilities are lacking control over their lives and are excluded from society, leading researchers to label them invisible or 'socially dead' (Morris, 2005; Miller & Gwynne, 1972; Vann & Šiška, 2006; Ratzka, 2007; Power et al., 2013).

Within the citizenship debate the perspective of people with disabilities in Europe as well as in other Western democracies is absent (Morris, 2005; Meekosha & Dowse, 1997). As Bert Massie said 'society still sees its best response to disability as care welfare and charity – rather than equal rights, opportunities and citizenship' (Massie, 2006[3]). To achieve such a transformation within the social services a reconfiguration of the traditional welfare structures is necessary in ways that will remove the barriers to participation (Zarb, 2004). The concept of Active Citizenship embraces all aspects of life (e.g. education, employment, transport and leisure). The existence or absence of obstacles in engaging in these areas of life will determine the ability of people with intellectual disabilities to be active citizens (DRC[4], 2007; Zarb, 2004). Karan goes even further calling the citizen approach for people with ID nothing less than a revolution for traditional providers (Karan et al.,1992). This reform must build the capacity amongst

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[3] Bert Massie, January 2006, cited in Disability Rights Commission, 2007

[4] Disability Rights Commission

people with intellectual disabilities to work against the marginalization they experienced. While all citizens might face barriers restricting their freedom of choice at some point, like freedom of choice over the type or location of housing or financial insecurity, there are some essential rights such as freedom to develop social relationships or engage in family life that people with intellectual disabilities are confronted with more often (Zarb, 2004). Even though the CRPD ensures recognition of the civil rights of people with disabilities, effective inclusion and the manifestation of those rights in community will only take place with adequate support in various settings. Support must be provided within a framework directed towards full participation, inclusion and autonomy as opposed to dependence, segregation and paternalism. This means fostering the full and active citizenship of people with intellectual disabilities (Power et al., 2013).

1.2   Active Citizenship Concept

As mentioned earlier, the concept of citizenship has been contested as governments have given different definitions of what a "citizen" is at various points in time. Definitions have changed due to the social, economical or political problems of the moment. Often, the emphasis of the definition of "citizen" was on the individual's behaviour or on the obligations that must be fulfilled to assure the health and stability of communities and less on the rights of the individuals (Morris, 2005). While governments are concerned that certain groups are not fulfilling their role as active citizens and thus undermining the state of democracy, people with disabilities may be more concerned that they are denied the opportunity to be active citizens and that their human and civil rights are being undermined (Morris, 2005). For example, from a conservative perspective a citizen is a consumer, and within a liberal concept an autonomous citizen. From the communitarian perspective citizenship is cultural solidarity amongst individuals that creates social stability, therefore the community identity is the basis of citizenship, encouraging individuals to assume responsibility for themselves and for their family (Etzioni, 1995). This kind of interpretation led to governments' lack of care or public responsibility (McCloughry and Morris, 2002). Within the different political views the debate is whether rights are separate from, or contingent upon responsibilities.

A different starting point is Marshall's citizenship model, rooted within communities and society and status for all its members. All community members are equal and their rights and duties are bestowed in their status (Marshall, 2006). Three elements emerge from

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Marshall's definition of citizenship; civil, political and social rights. The civil element (e.g. right to own property, right to justice) is the necessary right for individual freedom, the political element is the 'right to participate in the exercise of political power' as a voter or as a member invested with political authority, and the social element is ranges from the right to security to the right to share social heritage and to 'live the life of a civilized being according to the standards prevailing in the society' (Marshall, 2006, p. 30). These elements are establishing concurrently with the CRPD perspective the three domains within the analytical framework of this study. **Social Security** - the civil element, **Personal Autonomy** – the social element and **Political Influence** – the political element will be reviewed in more detail in the following sections of this chapter using the CRPD as a lens for evaluation.

1.3   Aims of the study

The present study uses Marshall's three domains, Social Security, Personal Autonomy and Political Influence, as the starting point for shaping a new Active Citizenship paradigm where 'individuals with intellectual disabilities are capable of making choices about their life' (Walmsley & Johnson 2003; Walmsley 2004)

The aims of this study are:

1. To examine how elements of active citizenship (Security, Autonomy and Influence) might be achieved by people with intellectual disabilities
2. To explore the experiences people with intellectual disabilities from both In House Training and Community Living arrangements in the Czech Republic have had related to security, autonomy and influence, and
3. To identify the impact Community Living has on people with intellectual disabilities,
   - What has changed, to ensure active citizenship?
   - How does community living impact feelings of security, autonomy and influence
   - What factors help avoid creating new mini-institutions? (Mansell & Ericsson, 1996; Power et al., 2013).

1.4 Background of the study

The year 2013 is the European Year of Citizens focusing on the rights of every EU citizen. The better people of Europe understand their rights the more informed their decisions will be.

To achieve the full and effective participation of persons with disabilities in society and the economy, a cross – European consortium of research organizations called DISCIT[5] embarked on the study *'Making people with Disabilities Full Citizens – New Knowledge for an Inclusive and Sustainable European Social Model'* funded by EU Seventh Framework Programme.

The study investigates the social and political conditions of eight European countries, including the Czech Republic using the CRPD as a framework to identify more effective ways to prevent and remove physical, attitudinal, social and organizational barriers to Active Citizenship (DISCIT). It comprise a number of inter-related 'work packages' each targeted at a specific aspect of active citizenship including the theory of Active Citizenship, operationalization and measurement, active citizenship and social inequalities, labour market participation, community living, using new technologies, fiscal innovation and political participation.

Charles University Prague Universita Karlova, where I am conducting my research as a requirement and as a contribution to the scholarship of the MA/Mgr. SIE Erasmus Mundus to which I have been entitled, is leading the community living work package[6].

This present study is a pilot conducted in the Czech Republic to implement the project **DISCIT: Making people with Disabilities Full Citizens – New Knowledge for an Inclusive and Sustainable European Social Model.** It will take on the work of the larger project to explore the experiences and the impact that relocation had or has on people with mild and moderate intellectual disabilities from the Czech Republic.

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[5] http://discit.eu

[6] http://www.pedf.cuni.cz

1.5 Purpose of the study and its contribution

When it comes to disability, full and effective social citizenship proves to be the precondition of having access to economic, political and cultural dimensions of citizenship. People with disabilities do not need basic rights only; they also depend on the accessibility and accommodation as pre-conditions of being able to exercise citizenship (Shakespeare, 2000). Most of the deprivation endured by people with intellectual disabilities stems from and is perpetuated by their invisibility. People with intellectual disabilities can be rendered visible through sound data collection and analysis. Participation in research by people with intellectual disabilities can be very useful for the development of user-involvement, citizenship and consumer participation (Zarb, 1995; Šiška, 2006). This study is carried out with the participation of people with intellectual disabilities.

European efforts such as the United Nations Declarations of the International Year of Disabled Persons, The United Nations Convention on the Rights of Persons with Disabilities (CRPD), EU Disability Strategy 2010-2020 and The European Year of Citizens 2013, to name few, are milestones towards the realization of the rights of persons with disabilities in all life aspects including community living. The study will explore the experiences of people with intellectual disabilities from the two different arrangements of residential services in the Czech Republic**,** herein Community Living and In house Training,[7] related to the three domains from the Active Citizenship framework as well as revealing disabling and enabling barriers to active citizenship.

1.6 Terminology

1.6.1 PEOPLE WITH INTELLECTUAL DISABILITIES: TERMINOLOGY AND DESCRIPTION

The language of disability is always complex, controversial and evolving and hard to define (Stevenson, 2010; Jenkins 1991). The term 'people (person) with intellectual

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disability' is going to be used in this study as a people first-language over 'disabled people' albeit there exists some inconsistency with the social model of disability[8]. In the Czech Republic, intellectual disabilities are described as 'mental disabilities', people with intellectual disabilities continues to be referred as 'mentally retarded' (Vann & Šiška, 2006).

1.6.2 DESCRIPTION

The operational definition of Intellectual disability states that an intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills, and that these impairments originate before age 18 (Schalock, et al., 2007; Schalock et al., 2010).

For the purpose of this study 'people with intellectual disabilities refers to a condition where skills in areas of cognition, language, motor and social abilities can be permanently impaired due to an incomplete development of intelligence and faced with significant difficulties in learning and understanding (Freyhoff et al., 2004).

1.7 Relevant Concepts

In order to understand the Active Citizenship perspective, concepts respected as relevant will be discuss below such as the medical model, the social model of disability and its criticism, effects of institutionalisation and deinstitutionalisation processes.

1.7.1 THE MEDICAL MODEL

The core of medical model is the presumption that disability is a problem that is experienced by an individual as a deviation from an assumed state of normality (McCloughry and Morris, 2002). Rehabilitation of people with disabilities was suggested in order to *normalize* the person so that nondisabled people will accept them. This lead to

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[8] This project concerns a Participatory Approach, which is underpinned by the Social Model of Disability (Upias, 1976; Oliver, 1990). The term disability describes the 'social oppression that all disabled people face'. The model recommends that in terms of disabled people as a group, irrespective of impairment, we should use the term 'disabled people'. However, self-advocacy groups prefer people-first language. In UK self advocacy groups are using the term 'people with learning difficulties' while in Australia and America the preferred term is 'people with intellectual disabilities'.

the separation of people with disabilities from the natural family being only tolerated, not socially accepted (Creamer, 2008). Due to the medical model, people with intellectual disabilities were placed in residential institutions since the early 19th century in Europe. Hence disability was seen as a social consequence of a person's biological or psychological deficiency.

1.7.2 SOCIAL MODEL OF DISABILITY

Challenging the dominant attitude of the medical model, the Social Model of Disability was formulated by a group of people with disabilities in the United Kingdom in the early 1970s as a manifesto[9] for social action and change (Evans, 2000; Barnes & Mercer, 2006; Barton, 2006; Shakespeare, 2008). The model sees disability as a socio-political category; in other words to be disabled is to be discriminated against (Barton, 2006).

According to the International Classification of Functioning Disability and Health 2001 (ICF), disability is a universal human experience as every human being can experience some degree of disability by a decrement in health at some point. Moreover disability impacts a wide range of individuals and families that are either born with or acquired disability over their life course, establishing that it is more about the 'temporarily able and the disabled rather than them and us' (Stuart, 2000). According to Priestley, the number of people with disabilities is between ten and twenty per cent of the global population (Priestley, 2003). Disability is an evolving concept (CRPD, 2008) and the experience of people with disabilities is too complex to be rendered within one unitary model (Creamer, 2008). The social model is not without flaws as scholars and activists have realized (Shakespeare and Corker, 2002). Telling people with disabilities that they must embrace their impairment, the social model leaves out the physical and emotional reality of impairment.

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[9] The UPIAS manifesto (Union of the Physically Impaired Against Segregation) document Fundamental Principles of Disability (1976) states that 'it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society' (UPIAS, 1976, p., 14)

1.7.3 INSTITUTIONALISATION AND ITS EFFECTS

Symbol of devaluation and exclusion, the medical model's legacy institutions are defined by its culture and organisational structure rather than its size. Institutions are restricting choice and control by depersonalisation, rigidity of routine, block treatment of people, and significant social distance between staff and residents (Barnes & Mercer, 2010; FRA, 2012). Dominated by staff, people with disabilities were experiencing lack of privacy and constant staff surveillance, rigid schedule, control and punishment, different forms of being bullied, harassed and abused (Goffman, 1961; Morris, 2003).

1.7.4 DEINSTITUTIONALIZATION PROCESS

Deinstitutionalization itself is the practice of moving people (regardless of their disability – that is, mental or physical) from institution into community based environments (Castellani, 1992). Thus deinstitutionalization is a prerequisite to enable people with disabilities to become as independent as possible and take their place as full citizens with the opportunity to access education and employment, and a whole range of other services (Power, 2013). In other words people with intellectual disabilities become ordinary citizens whose needs are met through services available to the general population (Mansell & Ericsson, 1996). Moving people from a large institution to community settings is a necessary condition but not sufficient to make people with intellectual disabilities active citizens without the appropriate support (Šiška & Beadle-Brown, 2011).

Research findings support Mansell's statement that people with intellectual disabilities benefit from deinstitutionalization (Mansell & Ericsson, 1996) having significant life quality improvements by moving into community (Larson & Lakin, 1991; Rotergard et al., 1985; Emerson & Hatton, 1994; Kozma et al., 2009; Mansell, 2006; Mansell & Beadle-Brown, 2009; Mansell et al., 2007; Šiška & Beadle-Brown, 2011).

1.8 Deinstitutionalisation process in the Czech Republic

Since 1990 the Czech Republic experienced a significant shift in social care provision for people with intellectual disabilities, moving from an institutional era towards community living arrangements (Vann & Šiška, 2006; Šiška & Beadle-Brown, 2011; Evans, 2003). Despite having European and national policy supportive of community living and a

direct payment scheme, progress towards community living in the Czech Republic remains slow and faces many barriers (Šiška & Beadle-Brown, 2011; FRA, 2012).

Since 2007 the Czech Republic embarked on a pilot project at a national level to transform the institutions. During the major shift to the community living implementation, only thirty-two facilities were from hundreds of institution around the country (Alternative Report, 2011). The Czech Republic ratified the UN CRPD in September 2009 and is also a signatory country of the major human rights instruments. However, since 1990s the country had few national disability plans serving as guides but failed to turn theory into practice (Šiška & Beadle-Brown, 2011). Although major changes inside the financing system occurred by the introduction of the direct payments, no significant improvements of choice and control could be identified for people with intellectual disabilities (Šiška & Beadle-Brown, 2011).

The lack of data that are unavailable or inaccessible due to the fragmentation between different government bodies is also holding back the process of deinstitutionalization (Mansell et al., 2007; Alternative Report, 2011). Monitoring continues to be ineffective since inspection reports are not accessible to all stakeholders but only to providers (Šiška & Beadle-Brown, 2011) making choice intangible.

According to a report from 2007, it seems that neither a comprehensive anti-discrimination legislation for people with disabilities nor a definition of disability was yet created in the Czech Republic (Šiška, 2007). The process of deinstitutionalization in the Czech Republic needs to be sustained since a large number of people with intellectual disabilities continue to live in institutions regardless the significant developments (e.g. direct payment scheme, social policies in favour of deinstitutionalization, the right to choose social services) (Šiška & Beadle-Brown, 2011; FRA, 2013). Closing an institution is more or less easy, but it is much harder to replace it with community living arrangements that offer the support and opportunities needed by people with intellectual disabilities to be active citizens (Mansell & Ericsson, 1996).

To conclude this chapter, an outline with the content of the remainder of this dissertation will be presented.

Chapter Two - the analytical framework will introduce the three domains and their elements, drawing on the UN CRPD regulations to explain their importance. It also looks at relevant literature in the field within the three domains to analyse the data.

Chapter Chapter Three - describes the methods used to generate and analyse the data including reasons for which they were selected and challenges of the tools. Ethical considerations are also part of this chapter.

Chapter Four – presents the research findings according to themes and sub-headings.

Chapter Five – the research findings will be evaluated and interpreted by referring to the literature review for validation. Findings will be summarised and conclusions drawn. A brief evaluation of the whole project will be at the end of this chapter, followed by the presentation of the limitations and areas to look at for future research.

CHAPTER TWO

2. LITERATURE REVIEW

2.1 Analytical framework

The analytical framework of this study entails three domains: Social Security, Personal Autonomy and Political Influence as seen from the perspective of the UN CRPD and the perspective of citizenship (Miller, 2000). These three domains have basic elements that are analytically different, but in practice interrelated aspects of what active citizenship is (Morris, 2005). The framework will be expanded by referring to the CRPD and other empirical research within each of the three domains. Moreover it will be used as a starting point to generate sub-questions, develop the project's design and prompts, present and discuss the data as well as conduct data analysis. The development of the framework will inform the reader and future researchers concerning the current state of knowledge about the active citizenship of people with intellectual disabilities living in different residential settings.

2.2 United Nations Convention on the Rights of Persons with Disabilities

A mentioned above the UN CRPD is used as a framework for this study. It is an international legal instrument that recognises the absolute rights of people with intellectual disabilities as full citizens (Evans, 2011). The Convention marks a paradigm shift that acknowledges the link between disability and human rights (Lawson, 2007[10]), and is the vehicle for establishing living in community as a basic and universal human and civil right (Zarb, 2004).

The framework with each domain and its elements are presented in Table 1 (see **Appendix A)** and briefly explained in the following sections.

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[10] Anna Lawson, Disability Rights Commission 2007.

2.3   The use of the analytical framework

The framework was used to:

- o Generate three research sub-questions and prompts, one for every domain
- o Create the research design, interview and research prompts within each domain
- o Organize the data presentation in three domains by coding and sorting
- o Relate the data to the current state of knowledge and discuss and draw conclusions accordingly

The framework will be further developed by submerging into the three domains Social Security, Personal Autonomy and Political Influence as well as their elements in order to create a view of how community living situations for people with disabilities have evolved.

Most of the studies reviewed focused on one or two out of the three domains, which makes this presentation of the results within one domain cross-over to other domains as they are strongly related and contingent on each other (e.g. free access to personal budget and the right to make budgetary decision is related to personal assistance and derives from the right to independent living (Evans, 2003).

2.4   The three domains

2.3.12.4.1   SOCIAL SECURITY

According to the CRPD, Art. 28, people with disabilities are entitled to social protection. Defined by the need of an individual, and indicating the support and assistance that is needed to live where and how one chooses, the social security domain is of particular interest when it comes to the wide range of support for individuals within the context of life and personal capacities (Mansell et al., 2007). People with intellectual disabilities should have access to the same range of options as everyone else, receiving the support they need as they choose (Mansell et al., 2007; Zarb, 2004).

2.3.22.4.2   AUTONOMY

The fundamental principles of autonomy are grounded in the Art. 19 to 21, 26 and 27 of the CRPD, which outlines that State Parties, must respect a person's dignity, individual

autonomy and independence, including the freedom to make their own choices. Autonomy received increased international visibility and utilization in the field of intellectual disability (Wehmeyer & Bolding, 2001).

2.3.32.4.3   INFLUENCE

Influencing own life through decisions that aim to promote the common good, together with legal capacity in all aspects of life on an equal basis with others appear in Art. 29 of CRPD.

2.42.5   The three Domains and their elements

2.5.1 SOCIAL SECURITY

2.4.1.12.5.1.1 Having the adequate accommodation and a secure place to live

Few systematic reviews point to a better material and standard of living as well as acceptance from the community for persons with intellectual disabilities (Walsh et al., 2010; Kozma et al., 2009). However, a recent European study reveals that respondents were satisfied with their living arrangements but strongly dependent on their previous living conditions (e.g. meal times). People who moved out from the institution were pleased with group homes even if they had to share the facilities such as bedrooms and day rooms (FRA, 2012). The research on services for people with intellectual disabilities shows that they encountered discrimination, rejection and lack of safety in community, which undermined independent living, especially for women (Cobigo and Hall 2009; Hall, 2005; Hendey & Pascall, 1998; FRA, 2012; Morris, 2005).

2.4.1.22.5.1.2 Access to a barrier free environment and accommodation

The environment plays a significant role in promoting autonomy, a high level of physical activity for people with intellectual disabilities, and the amount of choices available to them (Mithaug, 1998). In more restrictive settings (e.g institutions) they have less choice opportunities than in community based settings (Stancliffe, 1997; Stancliffe & Wehmeyer, 1995; Stancliffe & Abery, 1997; Wehmeyer & Bolding, 2001).

Access to cultural heritage and participation in cultural life is an integral part of the National Plan in Czech Republic. The plan offers discounts and a free guide to people with disabilities, as well as recreation and leisure-time activities which are led by few independent unions partially supported by state funds (Alternative Report, 2011). According to Hayden a significant number of people living in community arrangements than people in residential care settings went grocery shopping, shopped for personal items and did banking (Hayden et al., 1996), but new findings of the FRA reveals limited access to community life and independent living (FRA, 2012). To make participation a reality in cultural and leisure activities the possibility to travel independently is vital, but most people with intellectual disabilities experience difficulties (FRA, 2012). They find transport to be unmanageable, while hinders their equal opportunities to be mobile. This is a real barrier to participation according to Verdenschot (Verdenschot, 2009).

2.4.1.32.5.1.3 Being protected against arbitrary and unlawful interference with own privacy, family or home

A person's right to a family life and to privacy is denied if resources are only available to support them in a residential setting. In the Czech Republic, persons restricted in legal capacity can marry only with court consent, and all persons that are deprived of or have restricted legal capacity lose their parental rights automatically without given the opportunity to demonstrate their capabilities (Alternative Report, 2011; Šiška & Beadle-Brown, 2011). Accessing support for parenting without having their parenting capabilities being called into question or having their children considered at risk is another obstacle (Morris, 2003). There is also stigma attached to having child protection and social workers assessing parenting capability of parents with mild and moderate intellectual disabilities. Children of those with intellectual disabilities are more likely to be removed from their parents' care than the children of people without intellectual disabilities (Morris, 2004). Research suggests that this is happening in around 50% of the cases involving a parent with intellectual disabilities. From banning the right to start a family (Latvia) to the removal of children from families with parents with intellectual disabilities (UK), the stakeholder and carers are concerned with the answers they should give to people with intellectual disabilities on the issues of sexuality and marriage (FRA, 2012).

2.4.1.42.5.1.4 Barrier free access to public housing programmes

Housing is the platform from which people with intellectual disabilities establish participation in community life, care for their health and well-being, and take part in cultural and recreational activities as well as social relations and community involvement (Mansell & Ericsson, 1996). A systematic review concluded that dispersed housing appears to be superior to clustered housing for the majority of quality indicators studied (Mansell & Beadle-Brown, 2009). However, despite the CRPD entitlement for the right to live independently and be included in community, international trends towards larger group homes and congregation were identified in Norway and Australia (Tøssesbro et al., 2012). By 2010 the number of residents within group homes in Norway doubled and in some cases are larger than 25, while in Australia an institutional redevelopment program has clustered together residents on one site adjacent to a hospital (Bigby, 2012). A study conducted in America in five states in 1993 revealed that agencies did not own or lease the individual's home, they acted as a guarantor in some cases but in majority people with intellectual disabilities were the owners (Allard in Mansell & Ericsson, 1996). A more recent study from Europe showed lack of autonomy and private space and only a small number of individuals with disabilities had their own house. Lack of information about their entitlement to social housing and community support services was also identified within the same study (FRA, 2012).

2.4.22.5.2   AUTONOMY

2.4.2.12.5.2.1 Having the right to choose own place to live on an equal base with others and to choose with whom the person wants to live

The place where people with intellectual disabilities are to live remains a point of debate: should it be where the services are already available to offer support, or where the person comes from (Mansell & Ericsson, 1996). If they receive support from other people they can live in community, if not than their experience of a life in community will be limited (Ericsson in Mansell & Ericsson, 1996). Findings of FRA show administrative barriers in accessing the right to choose where to live, such as eligibility for benefits or availability of assistance in the new location. Moving from one part of the country or from a different municipality to another can prevent the exercise of choice and control when the source

does not follow the user and community living seems to be more of a 'postcode' lottery (Morris, 2004; FRA, 2012; Ratzka, 2004).

Choice in living arrangement, as expressed in CRPD, refers to the choice and control that people with disabilities should have over their place of residence and where and with whom they live. At present the special services that arrange housing for people with intellectual disabilities are the owners of the property (Ericsson in Mansell & Ericsson, 1996). A house can be developed into a home, where the person can create a life for themselves where recreation, friends are also part of the home life (Ericsson in Mansell & Ericsson, 1996). Findings from an American study stated that progress in supported employment influenced how and where people with disabilities lived in community (Allard in Mansell & Ericsson, 1996).

Despite progress, lack of choice and control over where and with whom to live remains a significant problem. The alternative housing and support options for living in community within the EU Member States remains limited due to lack of offers but also due to lack of financial resources that would allow people with intellectual disabilities to live in community (Holman, 2002; FRA, 2012).

2.4.2.22.5.2.2 Having the right to decide the type of living arrangement ones wants to live in and having the right to leave the institutional living arrangement on one's own will

For most people with intellectual disabilities, entry into an institution became a 'point of no return' or a 'social death sentence' (Barnes & Mercer, 2006). On one hand the lack of entitlements in combination with rationing leads to the decision of placing someone in residential care as the only option. On the other hand, the pressure to move people out of residential care quickly by certain deadlines makes things worse by not having enough time to explore and establish alternatives to residential care (Morris, 2004). When only one alternative to institutionalisation exists, the person cannot make any real choice, as it is often the case (Holman, 2002). Once a person has entered residential care it is considered a final decision, as one study regarding disabled women concluded (Smith, n.d., cited Morris, 2004). Moreover in the Czech Republic the law does not recognise the obligation for deinstitutionalisation or the obligation to provide services and support in a less restrictive environment as social care services are mostly provided in institutions (Alternative Report, 2011)

2.4.2.32.5.2.3 Having access to community support services (residential, in-home service, etc.) including personal assistance

As long as the medical model of disability dictates the contact between social services professionals and people with disabilities, the entitlement to resources will be determined by level of dependency rather than an individual needs-led assessment (Oliver & Sapey, 1983; Zarb, 2004). Access to services could become a reality and resources required to meet the needs of people with intellectual disabilities could be identified if the community care system was driven by assessments based on the needs and disabling barriers (Zarb & Nadash, 1994). The needs of person with intellectual disabilities often span more than one service provider, and many different agencies must be involved in community living care (e.g. health, housing, education, employment, transport, leisure, social security) (Mansell et al., 2007).

Personal assistance is the key to living independently (Ratzka, 2004), where funding of services follow the person and not the service provider. Barbuto and colleagues in their study using the capability approach found that stakeholders believed that competencies, professionalism and coordination of efforts can play a fundamental role in improving the well being of persons with disabilities and their families (Barbuto et al., 2011). Research findings about the transition from institution to community living pointed out that family members were concerned about the support available after the transition and therefore opposed to community living. This brings to light the importance of having people with disabilities and their families play a supported leading role in the development of services (Mansell et al., 2007; Barnes, 2005), and know that they have played an important role in service provision, service innovation and policy formulation (Gillinson et al., 2005).

2.4.2.42.5.2.4 The right to choose personal assistance

This right is made unproductive when finding skilled and suitable staff is a main obstacle within the growth of community living (Mansell et al., 2007). One way of solving the dilemma was by transferring staff from institution to the community but not everyone wants to move, and often they are not the right people (Mansell et al., 2007). However there is also evidence that some of the staff practices found in institutions were replicated at times in community living with negative consequences for users.

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Personalisation is about the whole system being changed not about changes at the margins (Power et al., 2013).

2.4.2.52.5.2.5 Non discriminated access to residential property that is accessible and affordable

Cost-effectiveness plays a discriminatory role in accessing residential property. People with intellectual disabilities struggle to maintain their independence in community due to the high costs, which force them to stay in institutions. In this manner people's freedom has a price (Zarb, 2004). The right to own property, while guaranteed by the Constitution, is limited in the Czech Republic for people that are deprived or restricted of their legal capacity. Their property is partly or totally handled by the guardian (Alternative Report, 2011). Upon loosing or having restricted legal capacity people with intellectual disabilities in the Czech Republic are automatically deprived of other rights such as access to loans, financial credit or mortgages.

2.4.2.62.5.2.6 Non discriminated access to private insurances (health, invalidity, care needs, old age)

The new reform of social benefit system from the Czech Republic adopted measures limiting the rights and freedom of people with disabilities by introducing the 1st degree of disability with a lower pension, abolishing the benefits for transport, flat and garage (Alternative Report, 2011). In health care, respondents from FRA complained of lack of understanding coming from professional staff. Negative attitudes, inaccessible information and focus only on their impairment were the main problems they were facing (FRA, 2012). Essential health care is often denied to people with disabilities due to the professional judgement about a person with disability's value and quality of life (Zarb, 2004). People with intellectual disabilities from Sweden expressed complaints about lack of coordination between the different bodies (FRA, 2012). According to the Disability Rights Commission health services can help a person to live independently, work, be a parent and participate in the local community (DRC, 2007).

2.4.2.72.5.2.7 The right to decide regarding the use of personal budget and barrier free access to it

Access to public money is essential to allow people with intellectual disabilities to live as independent citizens (Rioux, 2002). The assumptions about 'capacity' expressed through the legislation and the negative attitudes applied to anyone identified as 'vulnerable' are a key reason for the low uptake of direct payments. For example people living in residential care are not able to access direct payments, payments that cannot be used to pay the residential care but could give more choice and control if they could gain access to (Morris, 2004). Stakeholders (e.g. Germany) highlighted that personal budgets are an invaluable form of support enabling people with intellectual disabilities to achieve greater self- determination and self-esteem, yet personal budgets and uptake of direct payments continue to be low for this category in comparison with people with physical disabilities (FRA, 2012). Direct payments are an important instrument to challenge the 'culture of welfare' across social service department (Sapey, 2001). Access to cash payments is not in itself enough to secure independent living (Power et al., 2013). Experiences from Sweden and UK have shown that demand amongst people with disabilities for managing all the responsibilities involved with the direct payments and hiring personal assistants themselves remains low, and this kind of expectations could be unrealistic and harmful (Power et al., 2013). Burwell's study from 1993 found that persons with intellectual disabilities could control their own housing but the service provider was still managing their money. As a solution the support came from hiring or asking bank personnel to assist (Allard in Mansell & Ericsson, 1996).

2.4.32.5.3   INFLUENCE

2.4.3.12.5.3.1 Access to legal capacity on all aspects of life on an equal base as others

Article 12 of the CRPD recognises that people with disabilities must 'enjoy legal capacity on an equal basis with others in all aspect of life'. Access to justice is restricted because of lack of awareness about their rights or how to file a complaint but also because of fear of reprisals or that the situation will worsen (FRA, 2012).

The common law assumes that everyone is capable of making decisions for themselves. When it comes to people with intellectual disabilities it is often the reverse, as they are required, up front, to prove that they are capable of making decisions (Morris, 2004).

Substitute decision-making in the Czech Republic means that a person is deprived from her/his legal capacity and has a court-appointed guardian that is responsible for everyday matters. Czech Republic people under plenary guardianship are legally 'dead,' and their human rights (e.g. access to justice, property, right to marry, right to vote) denied. There are 5,741 with restricted legal capacity and 26,520 are deprived of legal capacity in the Czech Republic (Alternative Report, 2011). The new Civil Code terminology for legal capacity is stigmatising and the courts are not even using the Convention articles. Disabling attitudes held by social services professionals, about 'risk' and 'capacity', are major barriers. For example a proceeding in the Czech Republic concerning legal capacity and involuntary placement in an institution disregards the person with intellectual disability from the proceedings (Alternative Report, 2011).

In most of the east European countries and the ones from the former communist block, a majority of people with intellectual disabilities residing in institutions are under the guardianship of the social worker or directors of the institutions where they live. The guardians exercise control over financial affairs, but in some cases, as the findings of FRA show, they also take over other aspects of people's lives.

Furthermore there is no legal mechanism in the Czech Republic to monitor for possible abuses of the guardian (Alternative Report, 2011). Many people with intellectual disabilities are deprived of their legal capacity often leading to forced institutionalisation (Alternative Report, 2011, Zarb, 2004).

Research reveals that users are not aware of the implications of guardianship (FRA, 2012). Most of them came across the issue in establishing their own families (Hall et al., 2005).

2.4.3.22.5.3.2 Access to supported decision-making without conflict of interests and being influenced

Being labelled as 'mentally incapable', people with intellectual disabilities are subject to other's decisions ' in their best interest,' often without guidance or supervision (Edge, 2001, cited in Morris, 2004). For people who have been institutionalised for some time,

access to advocacy services is crucial in negotiating the challenges of moving into the community (Power et al., 2013). Living in institutional settings left people with intellectual disabilities with little, if any, control over their life and life decisions such as transfers to other institutions and future living arrangement. These decisions seem to be controlled by the institution's administrative personnel.

Financial consideration plays a significant role in determining if a person with intellectual disability will continue to live with their families for their adulthood. Financial incentives lead family members to prevent such members to leave home for fear of loosing what could be identified as a source of additional family income (FRA, 2012). Stakeholders note that a guardianship law plays a restrictive role in entering or leaving social care homes.

A facilitator role is essential to enable people with intellectual disabilities to manage their responsibilities in designing their support arrangements. A system of self-directed support must exist and be monitored in the same way as conventional services, to ensure that neither people nor the staff fall between cracks, or are left isolated or vulnerable to abuse (Power et al., 2013).

2.4.3.3 2.5.3.3 Access to adequate personal assistance

Not linked to the physical or intellectual capacity to care for oneself without assistance, independence is created by having assistance when and how it is required (Brisenden, 1989; Zarb, 2004). Assistance is only guaranteed if there is a substantial risk to people's health and functioning (Zarb, 2004). For example assistance for travel might be available, but not for work, to go shopping or for participating in social or leisure activities, meaning that people with intellectual disabilities often receive minimum support which does not guarantee much more than simply being able to stay alive (Zarb, 2004).

Parents and relatives are a vital source of support. Combined with accommodation, parental support seems to be the effective support as many research findings are recording within Europe (Mansell et al., 2007; FRA; Power et al., 2013). Findings of a recent comparative study show that new support structures based on the principle of personalisation have led to improvements in people's lives. State evaluation in USA, Canada, France, Sweden, UK and Northern Ireland reveals that self-directed support can enhance choice, control and flexibility when compared with direct service provision (Power et al., 2013)

> 2.4.3.42.5.3.4 The right to: choose the personal assistance service staff, if using any; control their performance and instructions; control the budget; control the execution and the implementation of the services given and; to choose the place where the assistance is taking place

The uniqueness of personal assistance resides in the fact that people with disabilities can choose who they want to work for them, organising support and scheduling the times when they need it. This means controlling and managing the whole process (Evans, 2003; Zarb, 2004; Finkelstein 1999; Morris, 2004). Choice and control over personal assistance support services is usually non-existent when operating under organisations who have little understanding of the principles of independent living, and using direct payments in ways that do not give choice and control to people with intellectual disabilities (Morris, 2004). Poor payment of personal assistants who can support individuals with disabilities limit the quality of service provided (Morris, 2004; Zarb, 2004).

> 2.4.3.52.5.3.5 Access to influence public decisions regarding services or professional agencies with direct impact on personal well-being

Regarding the right to political participation, the FRA report confirmed that in most EU Member States, people with intellectual disabilities are deprived of their legal capacity, with the result of being denial of their right to vote. Judges are deciding the right to vote on a case-by-case basis (e.g. Germany, France). A breakthrough in this area is the recommendation of the Council of Europe Committee from November 2011 stating that 'all persons with disabilities, whether they have physical, sensory or intellectual impairments, mental health problems or chronic illnesses, have the right to vote on the same basis as other citizens, and should not be deprived of this right by any law limiting their legal capacity by any judicial or other decision or by any other measure based on their disability, cognitive functioning or perceived capacity' (Council of Europe, Committee of Ministers, 2011). Findings of the FRA recommend that greater consultation and participation of persons with disabilities and the presence of their representative' organisations in policy making is needed. Results from Sweden shows that self-advocacy agencies were crucial in channelling the views and needs of people with intellectual disabilities (FRA, 2012). People benefited greatly from peer support organisations' role in providing free legal support. These peer support organisations and

self-advocacy partners are either nonexistent or at different stages of development among the Member States.

A broad-ranging strategy embracing capacity in managers of providers, including the voice of people with disabilities at the policy table, and adopting a strategic financial approach to transition from institution to support in the community is required for successful implementation with clearly defined responsibilities among different stakeholders for each task (Power et al., 2013). Having people with intellectual disabilities at the centre of the decision-making process and seeing them as crucial actors will help in rethinking both policy objectives as well as the implementation of services with direct impact on personal well-being (Barbuto et al., 2011). Other findings point to practical ways in which people with intellectual disabilities can influence public decisions regarding services provided, including discussions with the provider when moving into the community about all possible problems, and site visits to the new place as part of the move.

2.52.6   Summary

Throughout this chapter citizenship was examined from different political and cultural stands using Marshall's definition of citizenship to highlight the importance of his three domains. By using the UN CRPD as a framework the three elements of Marshall's definition could be identified within the CRPD as foundational principles. I focused on the importance of the living arrangements through the lens of the social model and deinstitutionalisation process. The complexity of the two shifts (e.g. social model and deinstitutionalisation) is evidenced by the outcomes of the medical model and institutionalisation.

CHAPTER THREE

3.   RESEARCH METHODOLOGY

3.1   Introduction

This chapter sets out the research approach, data collection and how it was managed and the methods of analysis. A short description of the participants along with the methodological dilemmas and how they were reconciled are included in this chapter. A final section is dedicated to ethical considerations and how they were met.

The realisation of disability equality cannot happen away from the full participation of person with disabilities themselves (Power et al., 2013). Regardless of the fact that research experience has been enriched through the inclusion of people with intellectual disabilities as participants in the research process (Stevenson, 2010), involving people with intellectual disabilities in research is often viewed as too complex and therefore marginalized (Richards, 1984; Aspis, 1997 in Barton, 1997) In other words, the development of citizenship rests on the participation of people with disabilities in research (Zarb, 1995).

The importance of including people with intellectual disabilities in research has been widely debated within academia (Barnes & Mercer, 1997; Beresford & Evans 1999).

For this study the core belief in choosing the participatory approach lays with what Stevenson has said:

> *'in creating services to provide assistance to people with intellectual disabilities, should I not try to find out from them how, what, when, where and so on such services should be provided (Stevenson, 2010, p., 12)?*

3.2   Study Approach

This present study adopts a participatory approach supported by a qualitative design. The study uses individual interviews and focus groups as its data collection method. The approach is most suitable given the research aims. A qualitative approach allows the opportunity to reflect on, explore and disseminate the views, concerns, feelings and experiences of research participants from their own perspectives (French & Swain, 2004; Morris, 1992; Stone & Priestley, 1996; Mercer, 2004).

This study is empirical as it 'collects data about people and their social contexts' (Somekh et al., 2005, p., 1) to test or generate social science theories.

Employing a participatory approach the research is controlled both by research participants as well as the researcher (Cornwell & Jewkes, 1995; French & Swain, 2004). This means that research is with people rather than on people, and a way to promote ethical research (Heron & Reason 2006). Lloyd uses the term 'partnership research' (Lloyd et al., 1996) to highlight that power relations and control are less likely to be exploited in a sincere participatory research (Heller et al., 1996; Balandin & Raghavendra, 1999; Chappell, 2000; Kellett & Nind, 2001). Participants of this study had control over the method of data collection. Participants from the In House Training (IHT) preferred individual/pair interviews while participants from Community Living (CL) preferred a group interview. The method prevents the study from being oppressive. As a result, data was collected by means of four face-to-face interviews of which two were in pairs and a focus group.

3.3   The Participatory Approach

Participatory research is a prerequisite to emancipatory[11] research as Zarb pointed out (Zarb, 1992), 'enabling people to assert choices and have control over their daily lives' (Lindow & Morris, 1995, p., 5). Promoting understanding of disability rights we must understand the importance of treating others, as we want to be treated. That is, to consider in research practice the preferences and needs of people with intellectual disabilities in order to promote respect and accountability (Kitchin, 2000; McDonald,

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[11] Mark Oliver coined as 'emancipatory disability research' a radical new approach focusing on the environmental cultural and social barriers that exclude people with impairments from mainstream society, and prioritising people with disabilities' knowledge and experience (Oliver, 1990; Oliver 1992).

Kidney and Patka, 2012). One way to achieve this goal is to use the participatory research, which reflects the disability rights mantra of "Nothing About Us Without Us" (Ham et al., 2004; Nicolaidis et al., 2011).

A participatory approach is not only an ally to the social model, but also takes on a radical critique of traditional 'scientific' research claims such as impartiality and objectivity (Mercer, 2004; Priestley 1997). It has been associated with qualitative rather than quantitative data collection strategies and emerged as a response to the shortcomings of the positivist and interpretative paradigm in contesting the social exclusion of people with disabilities (Mercer, 2004).

3.4   Qualitative Research

Primarily concerned with meaning and interpretation (French & Swain, 2004; Creswell, 1994; Robson, 2011), qualitative work gives us a window into the struggles of those silenced and marginalised (Creswell, 1993; Moore et al., 1998; Punch, 2005; Robson, 2011). It provides in depth understanding of the research problems that embraces the perspective of the participants and the context in which they live (Hennink, 2010). Data is generated and analysed using qualitative methods. In a broad sense qualitative research is defined as 'any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification (Strauss and Corbin, 1990:17).

Within qualitative work the researcher accepts that she cannot be independent of her own values and perspectives while engaged in the research process.

The qualitative approach entails the 'face-to-face' semi-structured interview, or an equivalent focus group, on the grounds that these are located in non-hierarchical relationships (Mercer, 2004).

3.5   Process of data Collection

3.5.1 GAINING ACCESS

In gaining access to the physical setting various steps were taken. The researcher's supervisor identified the initial contact. After visiting the residential setting and the community setting and meeting with the gatekeeper, the process of gaining access went

unhindered. The gatekeeper introduced the study and the researcher to all interested in participating and facilitated the process.

3.5.2 METHODS OF DATA COLLECTION; SEMI-STRUCTURED INTERVIEWS AND FOCUS GROUP INTERVIEW

This research study uses qualitative interviews as a method for data collection to capture people's individual stories, their beliefs and perceptions, the meaning they attach to their experiences and the context surrounding their lives (Hennink, 2010). The focus group interview is a way of collecting qualitative data engaging a small number of people, six in this study, in an informal group discussion focused around a particular topic (Wilkinson, 2010). The format of the interview is a combination of a standardized open-ended interview proposed by Patton (Patton, 1990) and Visual Aid Mediation[12], a tool designed by the researcher to facilitate different ways of communication and understanding to enable participation (Davis, 2004; Morris, 2003). The Visual Aid Mediation tool helped to address the barriers both for participants (e.g. the possible abstract nature of the researched problem) and researcher who did not speak Czech. This tool consists of images representing the three domains to be researched and its elements with a short definition (Appendix D). Participants were first asked to identify the images, define when needed, and transposed its concept to real life situations in their narration.

3.5.3 SAMPLING

In this study the opportunity to participate in a research was brought to the participants attention by the service provider manager, the gatekeeper in this study.

In recruiting the participants, the scientific community is in disagreement whether this should be done by a person who is known and trusted by the participant, by researcher or by a neutral party or advocate (Becker, Roberts, Morrison, & Silver, 2004; Clegg, 1999; McDonald et al., 2009). For this study due to the circumstances related to the researcher not knowing the participants, the service provider manager, a trusted person within the participant's social network, acted as a recruiter. People in the CL arrangements as well as the ones in the IHT were given the opportunity to volunteer, and a potential group of

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[12]Presenting visual information acting as an intervention to dismantle barriers to participation.

participants was identified without any interference or criteria set by the researcher or by the manager beside availability and wanting to participate.

3.5.4 PARTICIPANTS

TABLE 2: PARTICIPANT'S CHARACTERISTICS

* Names have been changed to protect identity.

[**] Instead of a classification of intellectual disabilities (e.g. mild, moderate, severe) a level of ÷dependenceø was chosen as it is strongly connected with the entitlements[13] meaning the support and services the participants receive and their legal capacity.

Name*	Gender	Age	Present living arrangements	Level of dependence **	Time living in institutional care
Simon	M	56	2 years in the IHT	Third Degree of Dependence	41 years in institutional care
Jacob	M	49	2 years in the IHT	Second Degree of Dependence (moderate)	37 years in institutional care
Joana	F	32	One month in the IHT	No dependence	26 years in institutional care
Andrew	M	35	2 years in the IHT	Second Degree of Dependence (moderate)	18 years in institutional care
Philip	M	45	2 years in the IHT	Second Degree of Dependence (moderate)	28 years in institutional care
Paul	M	45	4 years in the IHT	Second Degree of Dependence (moderate)	27 years in institutional care

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[13] http://www.mpsv.cz/en/12955

Mathew	M	47	2 years in the CL	Third Degree of Dependence (heavy)	16 years in institutional care
Thomas	M	39	2 years in the CL	Second Degree of Dependence (moderate)	29 years in institutional care
James	M	48	2 years in the CL	Second Degree of Dependence (moderate)	27 years in institutional care
Tabitha	F	57	2 years in the CL	Second Degree of Dependence (moderate)	Since birth
Joseph	M	57	2 years in the CL	Second degree of dependence (moderate)	Since birth
Judith	F	59	2 years in the CL	Second Degree of Dependence (moderate)	

From a number of twenty-three people living in a clustered[14] home consisting of sixteen apartments situated in the middle of the town, six participated in the in-group interview.

From a total of seventeen possible participants in the In House Training[15] program six participated in individual interviews

Potential participants were given letters explaining the research proposal in an informal meeting (Appendix B), and were asked for interest in involvement (Appendix C). A separate informal meeting was conducted with one user who wanted to participate but could not attend the meeting on the day due to illness.

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[14] A number of living units grouped together, separated from the surrounding community (Bigby, 2012)

[15] A less restrictive facility, a separate building within the premises of the institution (own room or sharing room with one more person, with a small kitchen) for the training and preparation of the users to be soon moving out in community living arrangements by 2015 as part of the deinstitutionalization process.

All male participants lived together in the same institution. The three women lived in separate institutions for women with intellectual disabilities (see Table 2).

This was a large institution that was to care for almost 150 men with intellectual disabilities with a strong medical approach to its services. The institution is currently in a process of transformation and relocating the users in community living. The word 'nurses' was still used by the IHT participants referring to staff members, although they were not nurses.

3.5.4.1 Participants from the In House Training

Joanna moved a few weeks before the study took place to live with her boyfriend Andrew in IHT. They are one of the pairs interviewed. Joanna is the only participant from the IHT group that enjoys full legal capacity.

Simon and Jacob were sharing a room and also planning to move together to CL. They both have a part time jobs at the institution within the cleaning sector. Simon is visually impaired.

Philip also had a part time job as a receptionist at the institution and hopes to move to CL, closer to his place of birth, in less than two years.

Paul has been in the CL within the first group who moved but 'failed' due to heavy drinking. He is back to IHT. He has a job at the local bakery. Paul uses a wheelchair for mobility.

3.5.4.2 Participants from the Community Living

Tabitha lives with her partner James in the CL after living in an institution for women with intellectual disabilities. Both have full time jobs at a local bakery.

Judith lives with her partner Joseph in the CL. Although she is the only one that is local she also lived in an institution previous to the CL move.

Thomas lived in the community in a sharing apartment with someone else that is not participating in this study, and he works a full time job.

All five participants have six hours of personal assistant support per week.

Mathew lives by himself and has a personal assistant support for four hours a day. He could not use verbal communication due to an accident. Because of high literacy skills, he was able to communicate through the use of an electronic device. He uses a wheelchair for mobility.

From these two groups, three women and nine men participated in this research study. .

3.5.5 CONDUCTING THE INTERVIEWS

For the IHT interviews as well as for the CL group the choice of method, date and time was left to the interviewee to decide. During the informal meeting, the IHT group voiced concerns about privacy and anonymity for the group interview method. It became apparent than some would be less likely to speak freely about their lives or the institution's practices within earshot of service provider staff and other residents. For that reason all participants from the CL group agreed to a face-to-face interview in their rooms.

All interviews lasted from fifty to 60 minutes resulting in almost seven hours audio material. Interviews were conducted in the Czech language with the help of a translator. Permission for recording was asked and background, ethical considerations and the topic were mentioned. Each person received further opportunity to decline participation at the beginning of each meeting. Four face-to-face interviews were conducted in one day with the IHT participants, and the focus group interview took place the next day. After the period of fieldwork was completed I visited the place once more to keep the participants informed of the project progress and to discuss internal policy and regulations with the service provider in order to frame the study.

All face-to-face interviews were translated from Czech into English and fully transcribed. Answers were recorded on the day in writing . Participants were told what was written as part of the next question in order to validate, which Stalker suggests is a respondent validation (Stalker, 1998).

The CL group was all in favor of having a group interview and were in an informal discussion about how they would like to be involved and by whom (if anyone) they would like to be supported. The participants needed a trusted support person to register

their in writing during the data collection. Two supporters[16], people familiar to them were chosen by participants. The focus group interview took place at the CL block building.

Respondents from both groups answered questions that followed a uniform pattern covering the three main areas (e.g. Security, Autonomy and Influence). Each domain was color-coded and participants' answers from the CL group interview were added to this conceptual level after they were given the option to change or amend their answers and after they were read back to them (Mercer, 2004).

Enquiries were guided by basic questions stemming from the research aims:

1. What are the things that make you feel safe in your place of living?
2. What are the things that make you independent/autonomous?
3. What are the things that allow you to influence the decisions in such a way that will help you experience independence and better protection in your living place?

The three domain's elements were used as specific topics for questions increasing the comparability of the responses and facilitating coding and analyses of the data.

3.6   Method of Analysis

The CRPD articles used for this study not only help to understand the research findings, but also provided the framework for analysis, which supported and directed the research (Carey, 2013). Thematic analysis approach was used to conduct the analysis. It is common and widely utilized for qualitative methodologies that involve empirical research. In order to connect the data to the analytical framework, interpretational analyses was used. The introduction of the analytical framework, already pre-coded at the beginning of the study, alongside the visual prompts of the three domains helped the preliminary analysis by sorting data into themes and categories of the framework.

Data was closely examined in order to find constructs, themes and patterns that could be used to describe and explain (Boyatzis, 1998) the Active Citizenship domains that are being studied in relation to people with intellectual disabilities. Using the domains and associated elements from the analytical framework, data was compiled in the computer

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[16] A personal assistant of one of the participants and a paid worker from the Community Living

and categorised, which took on developing a set of categories that summarized and encompassed the data. For coding, each element from the three domains was assigned a number (see Apendix A, the framework table) while the corresponding domain was assigned a letter (e.g. S1 – security, having the adequate accommodation and a secure place to live). However as mentioned before, the elements of the three domains are interrelated and contingent on each other, therefore information about one domain or element was sometimes provided during the discussion about some other domain of element.

Conclusions were drawn by initially identifying the patterns, and then consulting the analytical framework.

3.7 Addressing Methodological dilemmas

Human enquiry cannot be supported by traditional natural science approaches due to the involvement of free will that cannot be preempted (Blaikie, 2007).

From a positivist perspective qualitative methods are unreliable due to the more subjective manner in which data is gathered and analyzed. According to Silverman the methods of a study must be valid, 'truthful' and reliable or consistent over time to ensure rigor (Silverman, 1997).

Within the interpretative paradigm the trustworthiness criteria of **credibility** are stressed paralleling internal validity, **transferability** versus external validity, **dependability** paralleling reliability and **confirmability** paralleling objectivity (Guba & Lincoln, 1994). As mentioned earlier during the research process the researcher cannot be independent of her own values and perspectives, and a claim to objectivity within both positivist or interpretivist paradigm remains spurious.

3.7.1 CREDIBILITY

As Lincoln and Guba suggest there is a different way of supporting qualitative research rigor (Guba & Lincoln, 1994) . Looking for **credibility** instead of validity they refer to how believable the research is from the perspective of the participants. This study was one way to provide a vehicle to collect and disseminate information important to people

with intellectual disabilities such as Social Security, Personal Autonomy and Political Influence in relation to their status as citizens.

Within this study, the methods employed respected individual preferences and opinions whenever possible. It was also hoped that the subject of Active Citizenship would be one of wider interest and practical use, to those who took part in the research.

3.7.2 TRANSFERABILITY

Transferability is refers to how generalizable the results may be across situations. This research takes place in one location within the Czech Republic and is focuses on how people with intellectual disabilities living in different settings such as Community Living (after being relocated from institutional settings) and In House Training (within the institutional grounds being prepared to move into Community Living as part of the deinstitutionalisation process) are achieving elements of Active Citizenship (i.e. security, autonomy and influence). Although this study was conducted in one community area in the west of the country, it has an analytical framework grounded in the UN CRPD articles designed to 'promote, protect and ensure the full and equal enjoyment of all human rights and freedoms by **all persons with disabilities**' (UN CRPD, Art. 1). The findings of this study will refer directly to the stipulations of these articles (19, 21, 26, 27, 28, 29). The findings could be extrapolated across the lives of other people with intellectual disabilities and also between different socail service providers caring for people with intellectual disability in the Czech Republic.

3.7.3 DEPENDABILITY

Dependability refers to the researcher's reflexivity in considering all angles and circumstances within the research.

The knowledge of people with intellectual disabilities has been generally dismissed on the basis of their perceived intellectual deficiencies (Beresford, 2000), however as Walmsley said, participants possessed experience and knowledge but resist theorising (Walmsley, 2001). To aid access to the research process and discussions, a clear language and pictorial multiple-choice questions were designed to facilitate responsiveness without introducing systematic bias (Sigelman et al., 1982). An information sheet was provided with the aims and objectives of the study (in plain text and pictures) that was also read to

the participants in advance to the focus group or the interviews to enable participants to be prepared for the meeting. In this study, facilitating the inclusion of people with intellectual disabilities in research required a skilled supporter to enable participants to articulate their views (Walmsley, 1997). The group discussion as well as the interviews followed the same pattern, providing an opportunity to talk about emerging issues and concerns.

3.7.4 CONFIRMABILITY

Lincoln and Guba suggest **confirmability** instead of objectivity. According to them confirmability should be one of the objectives of auditors (Bryman, 2008). However, this study is explorative and thus the data produced will contribute to the general knowledge of what may have happened in the life of people with intellectual disabilities as a result of the deinstitutionalisation process and the Community Living relocation in the Czech Republic. My findings will then be confirmed by existent knowledge.

3.8 Ethical considerations

Consent issues from vulnerable groups, such as people with intellectual disabilities are particularly sensitive. Although, when using a participatory approach, it is less likely to exercise power relations and control (Emerson et al., 2004). An outline of the present research including the purpose of the research, aims of the study, methods, and time frame was given to the Supervisor of this project from Charles University and to service provider gatekeeper. Informed consent was sought to maximise participants' control over the research project, namely data collection. Through interviews and focus group informed consent was sought (Appendix E). A time convenient to the interviewees was arranged and consent was given either verbally or in writing before the face-to-face interview and focus group interview took place.

A minimum requirement for consent is the ability to communicate a preference that is whether to participate or not. All participants in this study exhibited the capacity to decide.

The consent form was written stating the purpose of the research, its methods and demands on participants, the potential benefits to the participants or others, procedures of ensuring confidentiality and the voluntariness of consent and the right to withdraw

(Iacono & Murray, 2003). For one participant with visual impairment the consent was tape –recorded after the separate consent session where a verbal agreement was given (Griffin & Balandin, 2004). The participants were assured that all information received would be treated with confidentiality and would not be attributed to any individuals. These techniques not only inform, but also build trust between researcher and participants (Freedman, 2001). While many researchers are focusing on how to improve comprehension in order to promote inclusion of people with intellectual disabilities in research (McDonald and Kidney & Patka2012), in this study the focus was on altering the environment[17] to promote the same inclusion rather than on individual deficits (McDonald and Kidney & Patka, 2012). For example after an informal meeting and discussion in which the aims and objectives of the study were outlined, participants were given the opportunity to ask questions and clarify their roles.

My research practice was not adversely challenged due to ethical considerations as participants had a degree of control over the process. Participants decided the level and the method of their involvement (Carmichael, 2004). However, due to the timescale it was not possible for participants to comment on the researcher's final analysis.

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[17] see the design and purpose of the methods used to collect data

CHAPTER FOUR

4. DATA PRESENTATION AND DISCUSSIONS

4.1 Introduction

This study has been exploring the experiences and views of people with intellectual disabilities, regarding safety, autonomy and influence, by living in Community or by being in a Training program with a less restrictive environment, soon to be relocated in community, as part of the deinstitutionalisation process. The subjective evaluation was sought to provide more valuable information about the impact, that different living arrangements of people with disabilities living in the Czech Republic, has on their feelings of security, autonomy and influence. Moreover it was to identify if people with intellectual disabilities, living in community and living in the training programme, within the institution premises, achieved elements of security, autonomy and influence, from the perspective of active citizenship.

4.2 A brief historic of the participants

Prior to the relocation of the two groups of participants, the institution in which the majority of the participants lived for most of their life, had been controlled by professionals and by routines and regulations of a medical approach (Evans, 2001; Vann & Šiška, 2006). Although the philosophy of care has been changed since 2006 when the Training Programme started with assisting users to be more independent, signs of the medical institution have lived to present trough the terms participants who were living at the IHT within the institution premises were using in calling the staff.

Further steps taken by the service provider brought a new approach to the life of people with intellectual disabilities by the opening of the first community apartments in 2009

and continuing the Training Programme as a way to prepare more users into successfully transit to community living arrangements.

A significant change in the lives of all people with intellectual disabilities, as a result of the deinstitutionalization process, is their living environment. This is the platform from which people with intellectual disabilities establish participation in community life (Felce et al., 1985). In line with the UN CRPD people who were part of Institutions are to 'live in ordinary streets with ordinary people as citizens in the community' (Evans, 2004).

Mathew, as well as the other five participants from the CL group are now living in the community, having their own apartment, while the other six from the IHT group, are in a preparation stage, to soon be relocated, in the community. This change theoretically supports the opportunity for establishing active citizenship.

The following section reflects on findings of the three domains, **Security, Personal Autonomy** and **Political Influence** and their elements, to see how changes in the environment appear to facilitate these elements and therefore citizenship. The findings from the two groups will be presented in parallel, in the following sections, to maintain the united character of the study. Also the three domains and elements are strongly interrelated and causational upon each other. As a result some of the elements from the three domains merged as one.

4.3   Social Security

4.3.1 HAVING ADEQUATE ACCOMMODATION AND A SECURE PLACE TO LIVE

Reports from around the globe were largely consistent, regarding the positive changes in the life of people with intellectual disabilities, after relocation into the community (Conroy & Elks, 1999, Kosma et al, 2009).

Findings of this study confirm these global reports, as participants involved from the CL group, enjoy ownership over personal items (e.g. furniture, electronics), having a job and a 'regular salary,' all contributing to an increase in self-worth.

In terms of living arrangements, both CL as well as IHT allows easy access by wheelchair where needed. All participants of the IHT have their own room, apart from two, who

were sharing. They have control over the rooms (e.g. keys) and only people that are invited and staff, who must knock first, may enter. This provides the participants with privacy, which often was equated with safety during the interviews.

For people at the CL, within the first months from the relocation, access seemed to be challenging, as a new locking system, that users were not familiarized with, raised obstacles. Although access to the physical place seemed to be challenging at the beginning, privacy was highly enjoyed and appreciated. This suggests that equipment should be explored with the residents, prior to the move.

Opportunities of choice, involvement in a variety of leisure activities (exercising, cultural events, open-air cinemas), interaction with staff and other residents, participation in outings (e.g. pubs, restaurants, meeting with others, visiting friends from other community livings or institutions from the surrounding area) were all part of the life of people living in community. Not sharing spaces such as kitchen and hallways with others and leaving whenever and to where one wanted was fully enjoyed by the participants living in CL, but limited or non-existent (e.g. no kitchen facilities for cooking) for people living in IHT.

For those in IHT, receiving visitors lays with the assistant's decision more than with the user. Moreover the building becomes a barrier for visitors, as being too restrictive, as one of the participants said (at the time he was in the medical block building following an accident). Going to visit other people, requires the user often to first fulfil chores that were assigned or good behaviour. Although the participants had free access to the environment, going where they wanted and when they wanted, except the time fulfilling their daily duties (e.g. cleaning) isolation was experienced by many in the IHT, confirming Barnes findings that isolation was experienced where choice opportunities over personal time was missing (Barnes & Mercer, 2006).

> *I like to talk and discuss but I miss that sometimes.*

> *Yes, we don't have that chance.*

The perception that the CL group had about the local community as a whole, was one of a safe environment, therefore participants engaged themselves in first aid and fire safety training in the community, as a way of influencing public opinion or gaining visibility. Developing citizenship means that the community will facilitate the inclusion of people

with intellectual disabilities, by inviting them in and by being invited within the CL settings (Mansell, 2005). Despite the positive attitude of the participants from the CL arrangements, there was little evidence of the outside community coming into the homes (Nunkoosing & John, 1997).

Amongst the IHT group, the common theme was that even acts of generosity were to be questioned by the participants and interaction with 'strangers' was seen as getting in trouble. This confirmed the findings of people with intellectual disabilities still not feeling part of the community, twelve years after the relocation (Forrester-Jones et al., 2002). However considering that they were to be moving soon and to different towns within the Czech Republic, it would be premature to make a final statement. Discussions with the manager revealed that the Czech community in general is not prepared to live together in the community with people with intellectual disabilities, as obstacles to opening community living arrangements appeared from their inception.

While all the participants from both groups expressed a general satisfaction with the living conditions, a level of dependency on the service provider was also evident for both groups (FRA, 2012) but more so for the IHT group, regarding meals, shopping for personal items and daily tasks.

> 'We are protected from all sides, which makes us dependent.'

> 'I was depending on the assistants to help me wake up all the time.'

The feel of the place as a home was strong amongst participants from the CL, attributed to personal assistant support and the personalised services.

> 'It's a home not an institution, where the staff was changing so often as if they were on a magnetic band'

While in the IHT, participants were general in their descriptions, such as feeling good or having the staff treating them nicely.

4.3.2 ACCESS TO A BARRIER FREE ENVIRONMENT AND ACCOMMODATION

A concern within the relocation process is that a more restrictive setting will lead to less choice opportunities (Stancliffe, 1997). When it comes to disability, full and effective

social citizenship proves to be the precondition of having access to the economic, political and cultural dimensions of citizenship. Visits into the community were taking place daily to shops, post offices, walks in the neighbourhood or to a café, for all the participants, from CL or IHT, but there was no evidence or little evidence of the outside community coming into the homes. Forming relationships in the community was also low. It is vital to the community integration, for people with intellectual disabilities to form these relationships (Hogg, 1998). To support relationships being formed, the service provider facilitated meetings, but without any positive impulse from the local community. A more positive response came from the local associations and services, such as the local football team or the fire fighter department, to interact with the service users. These strategies of raising social awareness, or rendering people with intellectual disabilities visible within the local community, were initiated for people in the IHT, but it was expected that participants in the CL would do this on their own.

Access to cultural events was something that participants from the CL liked to be part of, by regularly checking the town hall programme, as well as going to an open-air cinema. Only one participant from the IHT was interested in attending different cultural or sportive events, mentioning a few names of rock bands or the hockey and football teams he would like to see performing. In general for both groups, such participation and access was due to distance, time frame, possibility to travel and or finances. The preferred events were the local or close ones, that did not involve long distance traveling and the ones that were free entrance or low cost.

Traveling for CL participants happened more often, to visit friends from another CL arrangement, or friends from an institution, within less than an hour traveling by bus.

Participants from IHT saw free access to the environment as being directly influenced by having access to a personal budget and personal support, which releases the individual to participate in social events and visit family members. A free access to the environment, as in going where, when and with whom ones wants, increases the opportunities of choice, which led to what one of the participants defined as 'being independent'.

When buying personal items, people from CL were able to go grocery shopping once a week, having support from a support assistant and almost daily for smaller things, needed within their homes. When purchasing from another town the support assistant

will accompany on request. On the contrary, shopping for people in the IHT was more occasionally and involved small things, such as treats (e.g. ice cream, buns).

In the CL settings, conventional social activities were emphasized, whereas in the IHT settings, the emphasis was on order, cleanliness and safety.

> *We go out to buy things, a bucket, or mop, so that we can be ready,*
>
> *or things for washing our hands…*

Findings presented in this paper are consistent with the hypothesis that in a more home like arrangement, staff emphasis is on conventional social activities, while in an institution the emphasis is on cleaning and safety (Egli et al., 2002).

Within the two groups, only one participant from the CL was doing banking and handling all the payments through Internet banking. All the other participants from CL or IHT were relying on the support assistant for managing finances, twice a month, for the CL participants and once a month for the IHT participants.

4.3.3 BEING PROTECTED AGAINST ARBITRARY AND UNLAWFUL INTERFERENCE WITH OWN PRIVACY, FAMILY OR HOME

The difficult situation, in which people with intellectual disabilities are, due to the legal capacity interpretation and applicability, leaves more than 5,741 people with intellectual disabilities with restricted legal capacity and 26,520 deprived of legal capacity in the Czech Republic (Alternative Report, 2011).

Lack of awareness, regarding the implications of guardianship, amongst the two groups of participants, is confirming previous findings (FRA, 2012).

A secure place to live in the community, together with a person centred-plan, direct payments and a personal assistant, are key elements in achieving security, autonomy and being influential; in other words being an active citizen. Achieving active citizenship remains an illusion for people with intellectual disabilities, when legal capability is called into question regarding legal contracts and parental rights (Šiška & Beadle- Brown, 2011). The service provider revealed that this state of affair affects and influences service delivery for both groups; people living in IHT and people living in community. Due to

the complicated procedures, unavailability of the authorities and no monitoring body of the possible abuses within the guardianship (Alternative Report, 2011), despite the evidence of capability during the training programme, any efforts made by the service provider to lift the restriction, regarding the capabilities of the users, remained fruitless. This situation is affecting both groups of participants, but again, as mentioned above, participants were not aware of the implications of the guardianship.

> *If I have money, I mean, lots of money, I can buy an apartment.*

The staff helping with data collection, later on commented that the residents of the CL do not have full legal capacity in exercising this right.

4.3.4 BARRIER FREE ACCESS TO PUBLIC HOUSING PROGRAMMES

People with disabilities do not need basic rights only; they also depend on accessibility and accommodation, as pre-conditions of being able to exercise citizenship. Within Europe the situation of people with intellectual disabilities appears to be similar regarding access to public housing. Being assigned full or partial guardianship, the right to public housing, that people with intellectual disabilities have, is made redundant. Although the right to own property is guaranteed by the Czech Constitution (Alternative Report, 2011) participants of this study have restricted capacity, except one who has full legal capacity (see Participant Table), and so are deprived of this right. Under such guardianship, a person with intellectual disabilities cannot decide where to reside, or sign any type of contract, nor be heard during court procedures, being deprived of this legal capacity.

Regardless of the legal capability obstacle within the legal sphere, significant developments concerning the independent living were found in the Czech Republic, as Evans mentioned (Evans, 2003). The CL project and the IHT programme being studied here, is a development within the independent living, in the Czech Republic. Started at the institution six years ago, following the international transformations of the social care system, the service provider hoped 'to offer people with intellectual disabilities as much support as they could to encourage independence' as one of the workers said. First steps were taken by introducing the use of computers and some work possibilities, in sheltered

workshops outside the institution. It was to 'prepare some of the users who were willing to develop, capabilities for managing an independent living' as the manager recalled. These individuals with mild and moderate intellectual disabilities were able to estimate their self-sufficiency in daily activities, confirming the findings of Heller (Heller et al., 2000), which played a role of removing barriers to a less restrictive environment, as in IHT arrangements and eventually to the CL arrangements that came only in 2009, when the first apartment in the community was opened.

These efforts were later strengthened, when the service provider joined the implementation of the pilot programme '*Support for the Transformation of Social Services,*' in the Czech Republic, which assists thirty two social care institutions, mainly for people with intellectual disabilities (Alternative Report, 2011).

We could say that this particular social service provider from the Czech Republic took a step ahead of the national legislation, in ensuring the people with intellectual disabilities, for which they were caring, of their right to live and have access to a house in the community. Although the community living residents are not the owners of the houses in which they live, due to the implications of being under guardianship, participants were feeling secure and as if they are the owners of the place.

> *I feel good in my apartment, it's homely!'*
>
> *I feel safe here, I can just go inside and rest'*
>
> *When we got the apartment here I also received the key for it. After we moved we had to sign that we take full responsibility for it'*

In terms of security and feeling safe, both participants from the CL, as well as the ones from the IHT, mentioned that having their own house would safeguard that. This data also points out to similar findings, where people with intellectual disabilities are not aware of their entitlements[18]. The introduction of the 1st degree of invalidity, from 2010,[19] not only adds to the barriers (guardianship) to access to public houses, but it also

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[18] The personal payment in the Czech Republic is determined by the disability level/ dependency. The top-level amount is approx. 330 Euro. The personal payment to purchase social services is in 4 levels determined by the level of disability: 1- approx. 29 Euro; 2- approx. 146 Euro; 3- approx. 293 Euro; 4- approx. 440 Euro.

[19] 1st degree of disability from 2010 introduced lower amount of pension and changed in 2011 with no evident improvements.

causes material poverty for persons with no other source of income (Alternative Report, 2011).

> *If I have money left, then I can go and have my own more equipped apartment, but first I have to find out if I have money to purchase and then I have to go to see where will be cheaper and more convenient for me'.*

> *Saving money somewhere will protect us from being poor, but not just saving money but to have your own property.*

For people with intellectual disabilities in the Czech Republic to be active citizens, it is crucial that a transformation of the social services will continue, regardless of the austerity measures, and a more progressive guardianship legislation, that will support decision making, will be soon introduced. Such an initiative has been already approved in the Czech Republic and it will enter into force in 2014. It is a much-waited document by people with intellectual disabilities and their supporters (Šiška, 2006). However the success and implementation, and more so the access to public housing for people with intellectual disabilities in the Czech Republic, relies on the hard-won understanding of the problem and pitfalls that have to be faced to do the job properly as Mansell said (Mansell & Ericson, 1996) and on the commitment to the principles of independent living (Burwell et al., 1993).

Regarding the **Security** domain, two themes were predominant with the IHT participants such as: 1) **Savings** that will diminish major life uncertainties and will help avoid constant worries about the future and protection against poverty (see Appendix F); and 2) **people** that would genuinely care and look after (see Appendix G).

For the CL group three themes were predominant for the security domain such as: 1) **earning and savings** constructing future projection and ensuring self-sufficiency and self-determination; 2) **the place of living** where privacy, stability, familiarity and responsibility constructed a safe environment; and 3) **people** as in a personal assistant, social worker and life partner, providing the right assistance to maintain personal autonomy (see Appendix H).

4.4 Autonomy

4.4.1 HAVING THE RIGHT TO CHOOSE OWN PLACE TO LIVE ON AN EQUAL BASIS WITH OTHERS AND TO CHOOSE WITH WHOM THE PERSON WANTS TO LIVE

The deinstitutionalisation process is at the beginning in the Czech Republic and social services in the community are not developed in a way that will help people with intellectual disabilities to exercise their right to choose their place to live without no repercussions. Such ramifications could be loosing their personal assistant, if choosing a different location than the one in which the social service provider is, or the right to move into the community, if the place desired to live in, has no community living arrangements. In this case the person will be transferred to a different institution, rather than providing a home in the desired locality. So moving from one part of the country to another prevents people with intellectual disabilities to exercise this right, when the source is not following them and community living is more of a 'postcode' lottery, as Morris has said (Morris, 2004).

In this study all participants have spent long years in institutions and having the service provider going through a transformation process, building community living arrangements for its users, is what cause participants to consider themselves 'lucky,' as one of the participants said. Different clustered houses in different towns have been and will be built by the same social service provider, in the next two years, to offer a place in community to all of its users.

Everyone in this study has a comprehensive person-centred plan. By talking with the manager of the CL and IHT programme, the users of the services must want to go through the training programme, so that community living will become a reality to them. On one hand this could be viewed as an obstacle for the user, when the right of choosing is conditioned, but on the other hand the service provider's requirement could be seen as a facilitator towards a successful transition. As one of the interviews from the IHT reveals, the readiness that users must exhibit at the end of the training programme is essential, but not sufficient to secure a successful transition into the community living, where the person could create life for self. One of the participants now in the IHT failed to live in community and had to come back to the training programme. Findings of

Ericsson show that when people that moved to community receive support from other people, they can live in community, if not, their experience is going to be limited (Ericsson in Mansell & Ericsson, 1996). In this case the staff from the CL attributed the failure to the user's shortcomings and insisted on more training.

Knowing the users, the IHT programme is to develop stronger social skills, to support the relocation in the community and due to the high costs of CL, the person enrolling in the programme must develop work 'capabilities' so they could take on a job, as they move in community, to contribute to the costs.

According to the manager, choosing where one wants to live is very hard, or even impossible to achieve, when high costs of living, within the big towns for example, will restrict individual choice. Instead of being the way to independence, it is the way from institution to another institution, knowing that only thirty two institutions within the Czech Republic want to be changed and transformed. The entitlements that people with intellectual disabilities have are not sufficient to cover the costs of living in a bigger town, when it hardly covers the costs of living in community in a small village. Having said that, the right to choose one's own place to live, in this study amounts to where the social services are already available to offer support, confirming previous findings of Ericsson (Ericsson in Mansell & Ericsson, 1996).

Then again participants of this study were happy about having a place in the community and having the perspective of being relocated.

> *Everything changed for me, institution was for me like a prison. Now I have my home.*

> *Here, we've been prepared for life…*

> *I can tell people that they should try this community living (referring to the IHT programme) to learn things.*

> *We could move there right now, we are ready!*

At present the service provider, who is arranging the housing for the participants of this study, is also the owner of the property, confirming Ericsson and Mansell's findings (Ericsson in Mansell & Ericsson, 1996).

The environments, namely CL and IHT positively support autonomy, as in choosing the place to live, but this evidently is confined to the available places, or who the person can

live with. For example no one from the CL or IHT went to live with someone that was unacceptable for them. While in the training programme, participants decided who to live with, as well as deciding if they were going to move together, or on their own.

After deciding on the location, visits were made to the place and short and long-term goals that will help the transition were established, within the personal-centred plan. The person-centred plan enables individuals to draw up a personal plan, describing their aspirations with respect to housing, employment and leisure (Redley, 2009). The service provider took the person–centered plan and used it for people from IHT and CL, as a tool in promoting choice. For example leisure time is managed with the support assistant.

For the CL group, decisions on where to live were also narrowed down by the employment availability, determining where participants were to live and thereby confirming findings of an American study (Allard in Mansell & Ericsson, 1996). Employment will continue to challenge the opportunity of living in community, as the law is discriminatory for people with intellectual disabilities. Only a few months ago the law changed to stop the discrimination that people with disabilities in the Czech Republic were facing through the payment[20] rates.

Data suggest that everyone from the IHT and CL can make choices at some level, confirming Stalker's finding (Stalker & Harris, 1997). These choices include, buying individual items, deciding on who to live with, where they will be moving, savings, what to have in their rooms, visits and free time, although the last two have some control exercised by the staff for the IHT group.

Participants from the CL benefited from the changes in the environment to be included in ordinary tasks, such as cooking, while participants from the IHT were waiting for the opportunity to be explored when moving.

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[20] People with intellectual disabilities were paid half of the amount that nondisabled were paid (27 cronners) while one hour is paid 48 cronners/hour.

4.4.2 HAVING THE RIGHT TO DECIDE THE TYPE OF LIVING ARRANGEMENT ONE WANTS TO LIVE IN AND HAVING THE RIGHT TO LEAVE THE INSTITUTIONAL LIVING ARRANGEMENT ON ONE'S OWN WILL

Interrelated with having free access to housing programmes, the right to choose the type of living arrangement one wants to live in is determined once again by the legal capacity one has and is also undermined, when the national law does not recognise deinstitutionalisation as an obligation, as happens to be the case in the Czech Republic (Alternative Report, 2011). Plus only a few institutions within the Czech Republic (thirty two) took on the transformation programme, if we consider that there were 143 institutions for people with intellectual disabilities in 1998 (Vann & Šiška, 2006) housing 15, 000 individuals. Social support services in the community are either in an incipient form or don't exist, leading to no choice of the type of services people with intellectual disabilities can opt for, which means that being institutionalised remains often the only option. No alternatives to institution, no choice for people with intellectual disabilities! The vicious circle of guardianship, lack of entitlements caused by the guardianship and determined by the level of dependency, looks unbreakable and maintained, when there is no obligation to provide services and support in a less restrictive environment. This can be seen in one participant failing to remain in CL, not having the support needed in the community and no other alternative accommodation.

The only alternative for participants of this study is the clustered houses where they presently live. Supporters of cluster housing have invoked low costs (Cox & Pearson, 1995), and the possibility that cluster-housing schemes will promote increased chances of socialization by creating a sense of community. Housing that is physically comfortable and provides private space, helps to meet people's basic needs for security and, in so doing, reduces negative affect (Nelson et al., 1998). Privacy and security were identified already, within the two settings, under the security domain. From the CL group, only one person said that having his own apartment, as in owning the place, in a small town where he grew up as a child, would make him feel fully independent. For that he was continuing to pursue the service provider manager, who gave him hope, as the place was in a small village and costs were lower. The other five participants found that the CL arrangements empowered them to live the life they wanted.

The goal of services for people with disabilities is to provide a flexible range of help and resources to enable all people with disabilities to live their life in the way they wan, but with the support and protection that they need, having the choice and control over how their needs are met (Barnes, 2005).

From twelve participants only one person in this study has a personal assistant.

Social support from living companions, staff, and people living outside the residence is very important in these situations to the participant's positive affect and life satisfaction (Hall & Nelson, 1996).

As said before, the involvement of the people living outside the residence, while important for people who were relocated to feeling they belong to the community, was almost absent for those living in the CL. Combined with lack of community involvement was lack of entitlements, as a result of resources being allocated based on the level of dependency, rather than the needs of the residents. Due to these circumstances, participants from the CL were deprived of some activities that could assist with their social integration (e.g. birthday celebrations). The one participant living in CL, entitled to a personal assistant for a few hours a day, achieved a high level of independence, as a result of the CL apartment, personal assistant support and use of new technology (e.g. internet banking).

> *'Everything changed for me…, now I have my home… Praise God for European Union! Without it there will be no community living here! I have my own assistant. Thanks to her the apartment flourished. Internet banking is a big help for me. I can administrate everything this way. I manage everything myself what I need to. I pay what I have to and the rest is my business!*

At the same time, the other five from the CL group were benefiting from the CL assistant's support. Although one assistant was assigned to four to six people in the CL, the support is individualised. The assistant support consists of two hours per day, as the participants are quite independent, according to the manager. Usually, at weekends, users are assisted with weekly shopping. When travelling, they can receive support, if they

request to, going to the doctor, if they wish to be accompanied and can receive assistance with laundry, cooking or shopping. Shopping for special items that are not in the local shops, usually involves the support of the assistant with travelling and signing the warranty certificates. The support of the CL assistants was also for municipality appointments, regarding the participant's pension and benefits.

Staff of IHT arrangements supports people from the IHT in different ways, from shopping for personal items, to the person-centred plan in establishing and achieving goals. In the absence of self advocacy groups and parental involvement, the staff supported the users in decision-making, regarding the location where they would like to be living, as well as whom to live with, if that was something the user wanted to do.

Achieving independence for the CL participants was attributed directly to the community living arrangement, personal assistant support and use of new technology and to freedom to choose when and how one wants to care for self.

For the IHT participants achieving independence was attributed to the ability to carry out activities independently and on the capacity to learn and acquire social skills (e.g. cooking, washing, budgeting and being able to save money). The responses of the IHT participants were future projection (e.g. having own job to earn enough for a living, when moving to CL, doing house-hold chores, cooking, saving enough money for emergencies) rather than present experiences.

4.4.4 THE RIGHT TO CHOOSE PERSONAL ASSISTANCE MERGED WITH ACCESS TO ADEQUATE PERSONAL ASSISTANCE AND THE RIGHT TO CHOOSE THE PERSONAL ASSISTANCE SERVICE STAFF, IF USING ANY; CONTROL THEIR PERFORMANCE AND INSTRUCTIONS; CONTROL OF BUDGET; CONTROL OF EXECUTION AND THE IMPLEMENTATION OF THE SERVICES GIVEN AND CHOICE OF THE PLACE WHERE THE ASSISTANCE IS TAKING PLACE.

We are all constructed by relationships and this idea has been defended within the Disability Studies. Along this line some authors are stressing the fact that sometimes we feel autonomous and independent and other times we feel dependent of others (Ratzka, 2007).

This idea is supported by participants of the IHT.

> *When others listen to my needs to encourage me, that my needs are fulfilled, then I am independent, but on the other hand it doesn't mean that I don't need anybody…*

The more people with disabilities believe in the authority of the helping professions, the less they will do for themselves (Ratzka, 2007). This dependence was identified by the participants from the IHT in becoming often disempowered in the name of protection, and security:

> '*We depend too much on the staff knowing that they are there all the time and they are…*

Participants from the CL on the other hand were valuing the support of personal assistants and social workers, as crucial in achieving independence.

> *I was not able to cook simple food, but with the assistant help I learned how to cook and now I can do it on my own. Now I can bake cakes for my boyfriend and myself…*

> *I am thankful for my assistant; she is the one that made it all possible.*

Although the participant from the CL group, who is entitled to have personal assistance, did not personally choose the assistant, the independence he has achieved was in part credited to the assistant's service and support. This is reinforcing what Ratzka has said, that most people with disabilities are not helpless or dependent because of their disabilities, but rather they are made dependent and helpless, due to lack of individualised support, lack of access to a barrier free housing and lack of personal assistance services in the community (Ratzka, 2007).

As well as access to public free housing, the right to chose own place, decide the type of living arrangement, and to choose personal assistance are made unproductive, as community living is new in the Czech Republic and community support services, residential and in-home services are not developed or inexistent in rural areas, where most of the institutions are located. The solution, found by the service provider for the participants in the CL, was to transfer staff from the institution to the CL. For some of the staff of the CL, the transfer was due to a set of circumstances, that contributed to the transfer (e.g. proximity to their place of residence, position availability, knowing the residents) confirming what Mansell has said, that the transfer of staff from institution to

the CL could solve the dilemma of unskilled and suitable staff, although not everyone wants to move or is the right person (Mansell et al., 2007).

Assistants at the CL were assigned to support between four to six individuals from the CL apartments, as the manager said, although the present situation, at the time of this research study, was that only two assistants were presently working, supporting twenty two individuals. Who was going to assist or offer the support needed was not necessarily a choice. The assistant that received the call from the user may have been called, because the user felt more at ease with that particular assistant, or maybe the one who agreed with another assistant to take the call. User's preferences or affinity with one or another assistant were not taken in consideration, when offering the support as the decision lay with the assistants. However good relationships and trust were developed between the assistants and the service users (e.g. seeing the decision of the participants to invite one of the assistants to support participation in this study, the other assistant appears in data related to the person, as someone to ask for advice and help whenever needed).

For the IHT this element is non-existent due to the living arrangements they are living in. Although, the staff is offering a whole range of support, are committed to facilitating choice opportunities and achieving a higher level of autonomy (e.g. assisting with decision making, individual plan, shopping), their mediator role within decision-making often was found to be hindering personal autonomy by most of the IHT residents (see Appendix I).

4.4.5 NON DISCRIMINATED ACCESS TO RESIDENTIAL PROPERTY THAT IS ACCESSIBLE AND AFFORDABLE

In addition to what has been listed under the element **barrier free access to public housing programme** from the Security domain, this section will present the participants perspective on the matter of accessibility to property that ensures autonomy and phases out the second-class citizen stigma. For both groups earning and savings was the top priority, in order to secure their living in the community, revealing that participants were aware of the discriminatory cost-effectiveness implications of living in the community. This aspect appeared across the three domains researched and their elements. Within the security domain, participants from the IHT mentioned poverty, as a result of not having

the financial resources to cover the costs of living and basic needs. Within autonomy, having their own property will guarantee their independence (see Appendix E).

For the CL group, within the Security domain, the financial resources were often mentioned as safeguarding their living in the community. Measures to ensure that all expenses were covered included the responsibility of having and keeping a job to earn money, savings and using the assistant's support to decide on a weekly budget, so that unnecessary expenses will be avoided. Within the autonomy domain, the only difference from the IHT group, in relation to the same findings, as in owning property will secure independence, is that it doesn't have the same regularity as it does for the IHT group (see Appendix H).

Having access to accessible and affordable property will make active the right to choose one's own place to live on an equal basis with others, for people with intellectual disabilities, who are deprived of exercising both rights. This present situation is impoverishing the communities of origin of the people with intellectual disabilities, as it is not supporting the integration and life in the community of those they know.

4.4.6 NON DISCRIMINATED ACCESS TO PRIVATE INSURANCES (HEALTH, INVALIDITY, CARE NEEDS, OLD AGE)

New findings of a European study (FRA, 2012) revealed that people with intellectual disabilities were facing discrimination, while accessing the health system. The element of health care was identified under the security domain, denoting that participants equated with safety, having a state of good health and needing to be protected or to receive an intervention to remedy, when the state of good health is disrupted temporarily by accidents (see Appendix D), rather than equating this with autonomy, as something to acquire or attain. This view challenges once again the normality interpretation through the two models of disability. However participants of this study both from CL and IHT, as mentioned earlier when discussing the findings about **adequate accommodation and a secure place to live**, were still dependent on the service provider in many situations, this particular point of health care being often mentioned but more so by the participants of the IHT. Living in the institution for most of their lifetime, participants were relying on their understanding of the roles played in the institution (e.g. department of health taking care of emergencies that were not requiring admission to hospital).

Where to go and who is the person to contact in such situations were described in detail by the IHT participants.

The CL group focused on what they could do at first as preventive measures, self-reliance (e.g. checking body temperature, rest, take anti-inflammatory pills, call the ambulance). One participant from this group took a first aid course. Access to community health programmes, like first aid in this case, for individuals with intellectual disabilities, supports what the Disability Rights Commission has said, that health services have the potential to help a person to live independently and participate in the local community (DRC, 2007).

4.4.7 THE RIGHT TO DECIDE ON THE USE OF PERSONAL BUDGET AND BARRIER FREE ACCESS TO IT

The assumptions about people with intellectual disability's capacity, expressed through the internal law, were reflected in the way people with intellectual disabilities are assessed[21]. By questioning their ability, rather than looking at their capability, their right to decide on the use of personal budget is restricted. A 'high level of dependency' as recognised through the entitlements for a person with intellectual disabilities, means a good source of income to social service providers , while for the professionals will be a hopeless person (Ratzka, 2007). In a context like this choice and control, emerging from access to direct payments, is revoked by guardianship regulations together with low rates of payments that hardly cover the living expenses.

However participants of this study, mindful of the opportunity to live a life in the community, or on the contrary to be expelled [22] from it, committed themselves to saving and budgeting, as well as acquiring the social skills needed (e.g. cooking).

Their efforts were orientated towards securing a future, as in a place in the community living, leisure time and avoiding poverty. Ensuring savings and a good budgeting system secures independence and choice as in when, how and on what to spend. Securing

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[21] Assessment of people with intellectual disabilities consists of IQ tests plus a list of social skills where the individual is asked if he/she has the ability to do it.

[22] Poor budgeting and stewardship of the resources allocated weekly led to exclusion from the Community Living for one participant.

independence through savings, allows one to have free access to participate in cultural and leisure events.

> What do you mean by saving money helps you to make decisions?

> *When I go home, I can visit the disco place in the village with my sister and that is my choice!*

> *Yes it is my choice to go to visit my sister and go to the disco where they have country music.*

> *I feel independent to do things on my own, nobody thinks for me…*

As mentioned previously there are four categories of personal payments,[23] depending on the level of dependency, which indicates the legal capacity in most cases that the person is entitled to. Living in the IHT, participants of this study were paying for the social services they were receiving. Everybody at the IHT had a personal account from which payments were made to the service provider. In addition, each participant had a monthly allowance for food and other personal items (e.g. clothes), decided by their guardian. The participants living in IHT saw this situation as favourable.

> *We have here an advantage; we have social services and we have the pension.*

Although the right to decide for the personal budget and the way in which it is used was not fully enjoyed by the participants living in the IHT, as it is transferred directly to the service provider, participants had access to payments that were not used to pay for the residential care, encouraging choice and control as Morris suggested it would (Morris, 2004). For the CL group, the situation was not too different from that of the people living in the IHT, regarding the right to decide on the use of the personal budget and free access to it. Although not in a residential care, social services and accommodation in the community had to be managed, using the same personal payment. A monthly budget was decided by the guardian and managed with the help of the support assistant.

For the participants of this study, handling finances and regular expenses required support and assistance, except for one participant from the community living group, who was using internet banking and handling financial matters.

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[23] 18

4.5   Influence

The domain of Influence was hard to grasp by participants from the IHT, as the power to decide, in order to promote the common good. Questions were phrases back, revealing unbelief, regarding their ability to influence decision:

> You know the most about your life and what you want, much more than anyone else could say…so, if you speak about your needs and wishes with the assistants you can influence the decisions…

> *Is it so? About everything? About going out?*

Referring to the influence domain and its elements, participants from the IHT were pointing to the day-to-day life situations (e.g. visiting and being visited), where influence was a form of persuading or negotiating with the staff, in order to obtain a barrier free access to the environment, rather than the ability and knowledge to influence decisions.

4.5.1   ACCESS TO LEGAL CAPACITY ON ALL ASPECTS OF LIFE ON AN EQUAL BASIS WITH OTHERS

Legal capacity for people with intellectual disabilities has major implications for their status as active citizens, affecting their social, economical and political role in society. This is the element that triggers all domains involved in this study. In addition to what was said under the element of **being protected against arbitrary and unlawful interference with own privacy, family or home**, where the legal capacity element was tackled, some information directly linked to the participants will be listed here in this section, regarding their legal capacity.

From the previous elements of the Active Citizenship framework examined in this study, it appears that people with intellectual disabilities, that are having plenary or restricted legal capacity, face obstacles in fully achieving any of these rights (e.g. access to accommodation; being protected against unlawful interference with own privacy and family; access to public housing; the right to choose own place of living; access to residential property; access to personal budget).

Ten out of twelve participants in this study have restricted legal capacity and only one person enjoys full legal capacity. All eleven participants, listed as having a level of

dependency (see Participant's Table), have a substitute-decision making and therefore a guardian appointed that is responsible for everyday matters. Participants from both groups identify the guardian by using the name 'judge,' although they were not aware of the guardianship implications (e.g. access to justice, the right to enjoy and inherit property, the right to marry, the right to vote). One participant from the IHT was fully aware of the role of the guardian in managing the budget and establishing the monthly allowance.

> Who makes the decision about how much money you get as pocket money?
>
> *According to the psychologist and according to the person appointed to deal with the money, the judge,*
>
> *I have one half legal liability and one half I have not.*
>
> Ok, so it can be different for various people?
>
> *Yeah, a little bit different!*

Responsible for the financial matters, the guardian submits a report to the court judge twice a year. The person for whom the 'service' is carried out receives no report on how his/her money has been spent or what are the resources available. To receive this kind of information the participants from the CL group were using the social workers as intermediaries.

> *Not to be afraid I check how much money I have with the social worker.*

4.5.2 ACCESS TO SUPPORTED DECISION-MAKING WITHOUT CONFLICT OF INTERESTS AND BEING INFLUENCED

Self-advocacy groups are playing a key role in supporting people with intellectual disabilities to make responsible decision that will benefit them and impact their personal wellbeing. Although a training programme for self- advocates was started in 2004 in the Czech Republic, using findings from the European Commission, in most of the rural areas around the country self-advocacy groups don't exist (Šiška, 2006). This could have been a person providing suitable support to participants in the CL, as life challenges can

destabilize their security and independence, and an adviser to assist the ones from the IHT with the transition to the CL (Power et al., 2013).

For the IHT group, support for decision-making was described as being influenced, rather than being supported to influence public decisions. One participant mentioned how disabling attitudes, held by the social services about risk and capacity, could easily become major barriers and influence decisions that will deprive the individual of their right to decide.

> *The person that wants to protect me, sometimes uses power to influence me,… if someone here will tell me that I am not good to…* what? *Nothing! But that person can drag me down, cause is it from the heart?*

Similarly security measures, taken by the service provider staff at the IHT, could not only facilitate independence, but will also limit someone's independence and make him/her to become dependent through the things that were meant to secure.

> *This side of safety is just one side of the coin, one condition to be independent… yes, it can help us but it can also limit us'*

Access to support for decisions, as mentioned in the **access to community support services,** was to use the support of the staff, who were the ones who had a relationship with the participants, and knew them best and who were their trusted person.

Some interference with participants' decisions from the IHT appeared, when the physical characteristics of the place stopped visitors or stopped participants from involving themselves in social activities and when presumptions were made by the staff, as to what would be best for the user (Morris, 2004).

Lack of control (influence) over the decision-making of a person with intellectual disabilities creates the opportunity to be taken advantage of, leading to arbitrary interference with own privacy and wellbeing.

> *When there's no one to conduct* [24] *people make use of other people…*

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[24] Referring to the influence prompt used to illustrate, see Appendix D

Another aspect of influence from the IHT participants involves the collaboration between three elements; one from the security domain, one from the autonomy and one from the influence. Access to a secure and adequate accommodation becomes a supported decision that is shaped by the quality of the service, empowering the user to choose the place of living.

For the CL group supported decision was part of their life and they enjoyed this through direct consultations with their support assistants. Rather than being influenced, the participants felt free to make use of the resource.

> *I influence my life by discussing my wishes and ambitions with my assistants.*

> *I attend our common meeting with the assistants.*

> *Whenever I need help and advice I most often talk to Mrs (staff) or the manager.*

4.5.3 ACCESS TO INFLUENCE PUBLIC DECISIONS REGARDING SERVICES OR PROFESSIONAL AGENCIES WITH DIRECT IMPACT ON PERSONAL WELL-BEING

A democratic society is based on the principle of citizens' freedom of choice as voters. In most areas of life, our society trusts in its citizens' ability to make decisions in their own best interest (Ratzka, 2007). For people with intellectual disabilities this right is absent. Having restricted legal capacity, the participants of this study were not able to exercise their political right, to vote.

Some positive ways of influencing the public decisions were emerging from the CL group. Going to work in community was one of the ways in which participants from the CL group were hoping to influence the public decisions, confirming what Sprague and Hayes found, that people need opportunities both for achievement and reflection, to develop skills and explore identity, to respond to expectations and being able to contribute as well as to benefit from relationships within the community (Sprague & Hayes, 2000). Using cultural events to meet other people was found to be so important towards the successful integration.

Participants from the IHT were finding influence in the way in which they were supported, guided and advised for their wellbeing by staff. The ways identified as

exercising influence, were by voicing their needs and preferences within the Individual Plan.

The Individual Plan was indeed used as a support for decision making, where users could invite family members or friends to participate in the discussions with the key person, but only a small number, between fifteen to twenty families, are really involved and want to cooperate, from a number of 150 users, for which the service provider is caring.

Within the CL, participants expressed desire to control their life to maintain their wellbeing.

> *I discuss my wishes and ambitions with my assistants.*

> *I plan my own goal and wishes.*

Within the IHT, the well being of the participants was mentioned in relation to safety, as a result of the trust that was built between the user and the service provider.

4.6   Summary

This chapter explored the evidence in relation to security, autonomy and influence due to the living arrangements in which participants were living. The evidence found here suggests that, the group living in community was experiencing a higher level of security than the group in the in house training due to the change in living arrangements. Autonomy was given by an increase in choice opportunities for a day-to-day living experience for the group living in community while for the participants living in in house training autonomy was a future projection. Influence was linked with the assistant support that was empowering and promoting independence and with social participation for the group living in the community while for the group living in the in house training influence meant the use of the individual plan in expressing needs and a way of negotiating with the staff in gaining access or approval. There are also some losses. The absence of a self-advocacy group leaves both groups of participants to be informed and support decision making by the staff and assistance support of the service provider, which is a clash of interests.

CHAPTER FIVE

5. EVALUATION AND CONCLUSIONS

This pilot study explored the lives of six people with intellectual disabilities, who had been relocated two years ago from institutional care and accommodated in a clustered home in Community Living and the lives of six people with intellectual disabilities, who are being trained, within the premises of a institution, to be moving into Community Living arrangements.

By employing a participatory approach (Zarb, 1992), supported by a qualitative design (French & Swain, 2004) and combining qualitative interviews, as in Semi-Structured interviews and a Focus Group Interview (Hennink, 2010), with Visual Aid Mediation, a tool designed by the researcher, to facilitate different ways of communication and understanding to enable participation (Davis, 2004) the project aimed to:

1. **To examine how elements of active citizenship** (Security, Autonomy and Influence) **might be achieved by people with intellectual disabilities**
2. **To explore the experiences people with intellectual disabilities from both In House Training and Community Living arrangements in the Czech Republic have had, related to security, autonomy and influence,** and
3. **To identify the impact Community Living has on people with intellectual disabilities,**
    o **What has changed, to ensure active citizenship?**
    o **How does community living impact feelings of security, autonomy and influence**
    o **What factors help avoid creating new mini-institutions?**

The reduced number of participants undoubtedly restricts the breadth of the findings. The research study used alternative criteria of credibility, transferability, dependability and the ability to confirm, to address challenges of research rigour. The qualitative analysis method met the aims of the research. The answers drawn out are not the only

'truth' that may be found, however, as alternative methods and other participants could provide differences.

5.1   Main Findings

This section will provide a cross-analysis of the three domains and elements of Active Citizenship highlighting the main findings.

Within the security domain participants identified having a place to live, having access to personal budget and adequate support, as key in achieving security.

Improved living environments allow for more individualized and dignified lifestyles, yet there are significant differences of life lived in the two settings.

These differences are about the environment and support provided.

The In House training participants equated their present accommodation with privacy, during the study, but it seemed that *adequate accommodation and a secure place to live* was restrictive to social interaction and choice opportunities, leading to feelings of isolation. Participants were experiencing feelings of mistrust of the outside community and maintaining a culture of otherness (Hall, 2010).

Community Living participants were establishing social roles in the community, shifting from mainly benefiting to contributing and searching new opportunities for involvement in social activities, in which they get to know and be known.

A strong interdependent relationship, causational between elements of the three domains, was identified from data collected with the In House training participants. This was expressed as a desired stage, not as something that was already achieved. The relationship is between *free access to the environment*, as being directly influenced by *having access to a personal budget* and *support*, which releases the individual to participate to social events. It must be mentioned here that for participants from the In house training, access to personal support was not exercised. *Free access to the environment*, as in going where, when and with whom one wants, increases the opportunities of choice, which led to this becoming the definition of being independent.

The Community Living group enjoys a barrier free access to the environment, due to the free access they have to personal assistant support.

The arbitrary and lawful interference with own privacy, family or home is a negative outcome of having restricted legal capacity. As I said before, access to legal capacity is the element that triggers all the others. The existence of this ensures the individual of the right to exercise civil, economic and political rights; the absence of it devalues the individual and raises barriers to exercising civil, economic and political rights, on an equal basis with others. Participants from the In House training were aware of being assigned a guardianship, but not aware of its implications. The same lack of awareness about the guardianship implication in one's life was found amongst the participants from the Community Living.

People with intellectual disabilities living in the Czech Republic once deprived of their legal capacity, were deprived of civil, economic and political rights, such as access to a barrier free environment and accommodation; being protected against arbitrary and unlawful interference with own privacy, family or home; barrier free access to public housing programmes; having the right to choose own place to live on an equal basis with others and to choose with whom the person wants to live; having the right to decide the type of living arrangement one wants to live in and having the right to leave the institutional living arrangement on one's own will; non discriminated access to residential property that is accessible and affordable; non discriminated access to private insurances (health, invalidity, care needs, old age); the right to decide on the use of personal budget and barrier free access to it; access to supported decision-making without conflict of interests and without being influenced and access to influence public decisions regarding services or professional agencies with direct impact on personal well-being.

Although Community Living participants, by having restricted legal capability, were deprived of the same rights as participants from the In House training were, people living in the community had less interference with own privacy, due to the Community Living arrangement and due to the individualised support. They were able to enjoy a much higher level of self-determination and independence, compared to participants in the In House training.

Barrier free access to public housing programmes, as listed above, is one of the elements triggered by legal capacity and made ineffective by depriving the individual of his rights, despite that security and autonomy was safeguarded and achieved for both groups of participants, if having their own house.

Findings are showing that the introduction of a more progressive guardianship legislation, that will support decision-making, is crucial for people with intellectual disabilities, to enable them to be ordinary members of the community, without being stigmatized, and to be active citizens.

The Community Living in the Czech Republic is at its beginning, therefore we cannot say that '*the right to choose own place to live on an equal basis with others*' could be fully achieved. However this particular service provider, committed to transformation and to deinstitutionalisation process, opened the road to live an independent life to its users. Findings are pointing to two criteria, in order to qualify for a place in the Community Living, that the participants were mindful of: 1) willingness to embark on the training programme and 2) readiness given by the acquisition of social and capability skills.

The barrier to access the right to decide where to live is created by the limited offer of places, from the service provider, due to the location's availability of Community Living arrangements, and to high costs. Regardless of the limitations given by the social provider's options, as in the choice of where to live, staying local and having staff being transferred to the new service helped participants to achieve elements of security (e.g. barrier free access to the environment). Also staying local, could support the move to the community, by receiving support from others (Ericsson in Mansell & Ericsson, 1996), otherwise the success of moving into the community could be limited, as findings of this study reveals. High costs on the other hand of living in community have a restrictive effect on the realisation of choice opportunity, when job availability is absent in the chosen area. Therefore job availability in the community of living plays also a determining role in achieving the right to decide on the place to live.

With a limited availability of community living arrangements and obstacles to choice of location as mentioned earlier, *the right to decide the type of living arrangement* one wants to have is impossible to achieve, as only a small number of institutions for people with intellectual disabilities have committed to the deinstitutionalisation process and transformation of services. Restricted choice of where to live continues to support the institutionalisation of people with intellectual disabilities in the Czech Republic, as people could be transferred from one institution to another, due to lack of community living arrangements around the country.

Barrier free *access to community services* contributed tremendously to achieving independence and self-determination for one participant entitled to have a personal assistant. However, the allocation of resources has a discriminatory character, due to the level of dependency criteria in the allocation. A shortage in support assistants for people living in the community could easily become a threat to the individualised support.

The right to choose personal assistants and to control their performance, budget and the place could be identified only within the Community Living. Only one participant used personal assistant support. The right to exercise any of these rights was challenged in the first place by the restricted legal capacity, that participants had, correlated with lack of skilled staff and lack of poor understanding of what individualised support is. Moreover participants attributed some daily routines as signs of dependence, due to an assistive support, that is often embedded with protective measures, rather than encouraging choice opportunities.

To have *non-discriminated access to residential property that is accessible and affordable*, people with intellectual disabilities in the Czech Republic must have *barrier free access to a public housing programme.* Then again people with intellectual disabilities will not achieve this element, as long as they will continue to be under the present guardianship legislation. Even more so the cost effectiveness of living in the community can undermine the opportunity to live in the community, if necessary funds are not secured to support continuity, leading to exclusion, as findings of this study suggest.

There were no strong indicators within data to confirm or refute, whether people with intellectual disabilities achieve the element of having *non discriminated access to private insurances (health, invalidity, care needs, old age),* although the national legal framework reveals that people with intellectual disabilities are denied their basic rights (e.g. not consulted or even present regarding being placed in institutional care). Having said that, the general view of participants, regarding the health element challenges for people with intellectual disabilities, was seen as being hopeless and passive receivers. By placing the health care element within the security elements rather than autonomy elements, participants from both groups support the social model of disability. Identified within the security elements, the health care element was equated with safety, requiring protection through personal or medical care attention, when needed, rather than something to own or acquire, in order to maintain good health (e.g. relying on self care rather than professional care, except in cases of injuries or accidents).

Another element that was made ineffective for people with intellectual disabilities, due to the legal capability restriction, is *the right to decide on the use of personal budget and barrier free access to it*. Although not achieved as a full right to be exercised, some creative ways exist to encourage choice and control, by the barrier free access to payments that were not used to pay for the residential care.

Findings of this study show that restricted *access to legal capacity on all aspects of life on an equal basis with others* is the main cause of the present situation in which people with intellectual disabilities continue to be second class citizens.

Having control over decision making without being influenced was not identified in this study as not being achieved, but rather as fragile, as self- advocate groups and lack of family involvement in the life of people with intellectual disabilities left the *decision making support* resting on the personal assistant, support assistants and staff that knew the participants well. As one of the participants said, 'when there is no control people make use of other people'. This is a clash of interests as all people involved in supporting the decision-making are the service provider.

One more element that was not achieved by people with intellectual disabilities, as a result of restricted legal capacity is *access to influencing public decisions regarding services or professional agencies with direct impact on personal well-being.* Two different aspects of influence corresponding to the two different groups emerged: 1) to influence decisions that pertains to them, people with intellectual disabilities living in the community involved themselves in different social and cultural situations, being aware of their social invisibility, with the hope to be acknowledged and, 2) to influence decisions regarding the social services, people living in the In House training were using the Individual Plan as tool in negotiating with the service provider.

5.2   Limitations of the study

This research was conducted as part of an academic project, and as such was subject to limitations. The communication barrier acted as a constraint on the fieldwork (Mercer, 2004) leading to the inability to establish relationships of sufficient familiarity.

The inference of conducting the research by translation was that the methodological desired could not be realized and this is a source of difficulty. The difficulty in relation to

phrasing, or the amount of time dedicated to posing a question can influence the response obtained. However there were no mismatches as a product of Czech/English. Due to the language barrier, the design, as in the three themes with the specific indicators, using the prompts could be said to not have allowed the participants to select the topics, therefore it might seem intrusive, although the participants constructed a great fluency in linking the domains.

5.3   Concluding remarks

Any reform aiming to improve the well being of people with intellectual disabilities must focus on their potential and opportunities. Such policies will ensure not only the enjoyment of rights, but also will reduce the costs of services, which are not required by people with intellectual disabilities (Barbuto et al., 2011).

The findings of this study show that people with intellectual disabilities from the Czech Republic are not achieving most of the elements of active citizenship that will enable them to be active citizens, due to discriminatory legislation and entitlements. However the example of the service provider taking a step ahead towards deinstitutionalisation and to Community Living (an example of commitment to good practice) for people with intellectual disabilities, regardless of the absence of legal infrastructure to support the process, proves that a bottom up transformation, rather than top down can help empower people with intellectual disabilities to live independently in the community and to be active citizens.

5.4   Recommendations

The long awaited legislation, to enter into force in 2014, is hoped to introduce elements of supported decision-making that will recognise the deinstitutionalisation of people with intellectual disabilities and provide the legal support for a successful implementation of Community Living. As Community Living grows in the Czech Republic, to avoid recreating mini institutions, personalisation has to be the heart of the whole system, not just changes at the margins (Powers et al., 2013). International cooperation is more than just an obligation, as Art. 32 from CRPD stipulates, rather it is imperative and crucial to examining the lessons being learned within other countries.

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Appendix A

TABLE 1: ANALYTICAL FRAMEWORK

Active Citizenship Dimensions		
Freedom of Choice and Community Living		
Security	Autonomy	Influence
1. Having the adequate accommodation and a secure place to live	1. Having the right to choose own place to live on an equal basis with others and to choose with whom the person wants to live	1. Access to legal capacity on all aspects of life on an equal basis with others
2. Access to a barrier free environment and accommodation	2. Having the right to decide the type of living arrangement one wants to live in and having the right to leave the institutional living arrangement on one's own will	2. Access to supported decision-making without conflict of interests and being influenced
3. Being protected against arbitrary and unlawful interference with own privacy, family or home		3. Access to adequate personal assistance
	3. Access to community support services (residential, in-home service, etc.) including personal assistance	4. The right to: choose the personal assistance service staff, if using any; control their performance and instructions; control the budget; control the execution and the implementation of the services given and choose the place where the assistance is taking place
4. Barrier free access to public housing programmes	4. The right to choose personal assistance	
	5. Non discriminated access to residential property that is accessible and affordable	5. Access to influence public decisions regarding services or professional agencies with direct impact
	6. Non discriminated access	

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	to private insurances (health, invalidity, care needs, old age) 7. The right to decide on the use of personal budget and barrier free access to it	on personal well-being

Research Proposal – Information sheet

From Institutional settings to Community Living
Enabling people with intellectual disabilities to be active citizens

Following my enrolment on the Erasmus Mundus Master Degree on Special and Inclusive Education and being allocated at Charles University to carry out my dissertation, I would like to work with few people from 'Name of the institution/ Community Living address' to explore the experiences of people with intellectual disabilities living in different types of residential services in the Czech Republic regarding their status as active citizens.

This letter is to say that I would like to consider you as one of the participants in this project.

I intend to work with you over a period of about 2 days during August 2013. During this time I will use an interview as a method of collecting data (direct questions, written activities, etc.) to enable you to share your personal experience about:

- o   Things that makes you feel safe in your living place,

- o   Things that makes you independent and

- o   Things that allows you to influence the decisions that secures your safety and independence.

The topic and the research aims will be explained explicitly in our previous meeting to the formal meeting. Your views are very important and would be disseminated and kept anonymous.

I hope my findings will be used to encourage you to express your needs and wishes regarding your freedom of choice and the right to have an adequate accommodation and access to legal capacity on an equal basis with others in all aspects of life.

Please be assured that my reason for doing this project is in your best interest and potentially for the best interest of those with whom I could not work.

My findings will be available from December 2013.

If you have any further questions about my project please do not hesitate to contact me at (**Phone number included)**, or my supervisor whose details are below.

Dissertation Supervisor,

Charles University

Jan Šiška – jan.siska@pedf.cuni.cz

Many thanks!

<div align="right">

Lenu a Vintil

Email: lenutavintila@gmail.com

Erasmus Mundus MA student in Special and Inclusive Education

</div>

Hello!

My name is Lenuta Vintila.

I am a student and I am doing a research.

I want to find out how is life for you in the place you are living.

I want to see if you are happy.

I want to know if there is anything you do not like it.

You do not have to participate if you do not want to.

Best wishes,

Lenuta Vintila

SECURITY – BEZPECI

Something that protects or keep you safe

Freedom from financial failure

Freedom from financial cares

Property – it is yours

Free from injury

AUTONOMY/ INDEPENDENCE – NEZÁVISLOST

Freedom/Independence – Celebration

Power of making free choices

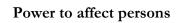**To decide your own life**

INFLUENCE – VLIV

Experience det

Cause someb
position, belief

Power to affect persons

To influence somebody's opinion

Appendix E

The goal of this study is to find out how people with intellectual disabilities experience protection (security), independence (autonomy) and influence.

You should know that the interview is anonymous and your involvement is completely voluntary, which means you can withdraw or stop participating at any time.

If you agree to be in this study, you will be asked to respond to few questions on a piece of paper by providing you with paper and pencil or verbally, having someone from the research team writing down your answers.

This will take you about one hour.

If you have questions or concerns about the study, please contact Lenuta Vintila at: Mobile phone: (?)

Email: lenutavintila@gmail.com

I hope our findings will be used to encourage you to express your needs and wishes regarding your freedom of choice.

Thank you for your help!

This study has been approved by Charles University.

If you want to participate to this study, read this, then sign your name

Any questions I had about the study had been answered and I understand that:

- o I agree to be in this study, which asks questions about my experience regarding my security, autonomy and public influence.

- o My answers on the interview are anonymous, so no one will identify my answers with my real name

- o My answers given in the interview will be kept strictly confidential (private)

- My participation in this study is completely voluntary, meaning that I can stop or withdraw at any time for any reason.

- My answers will be grouped with other participant's answers, and published for academic purpose.

Name: Date:

_____   _____

Appendix F

So what makes you feel safe?

How can money protect you?

If I buy something today I have to think if I have enough to buy things tomorrow and the day after tomorrow and so on

Does it mean that you cannot do everything at once?

No, I cannot spend it all.

What we are discussing here we don't want you to tell Mrs A or Mrs B we don't want you to tell them.

What do you mean by saving money? How is that going to protect you?

When we are going to be outside in those houses and when we will be moving there we should put money aside in case something happens! You know, to have money in case something breaks down, so we always keep money aside… we should do that!

Saving money somewhere will protect us from being poor, but not just saving money but to have your own property.

If we have money, we don't have to worry about tomorrow because we know that we have money tomorrow if we don't spend it all and that is protecting us in a way, so that we don't become homeless people, someone who does not have a home…

We have here and advantage, we have social services and we have the pension.

í í

So what makes you feel safe here?

We are lucky here with the social worker that helps us to save money!

í í

So what makes you feel safe?

We can save money

When we have money we are able to make choices!!

We can decide when we want to save it!

We can put our money aside or spend them, we can make a decision!

This money we save for future, maybe for holiday, yeah, yeah … saving money for the future…

í ..

So what makes you feel safe?

Having a salary and having my savings!

í í

So, how is money protecting you?

Money doesn't mean everything…People makes me feel secure

For me safety means to be with … Security means a lot of things…

I know... It can mean somebody we can turn to,

Someone like in your girlfriend, or a friend…

A roommate, a friend in general.

í í

What makes you feel secure here in the IHT?

This example with the umbrella protecting the house that we spoke about we can imagine that is Mr… (*the manager***) and the director is here doing everything possible to protect us…**

We feel well here because they (*staff and administration from the IHT*) **protect us…They come and take care of us if we are sick or something happens.**

í í

I feel safe because I have my friends visiting me here!

í í

Well… A will be moving with me to the same place, he will be looking after the place, he will have it under control, so everything will be good…

Appendix G

What are the things that make you feel secure here, in your place of living?

We have to earn money to be able to live and shop

If I have money left than I can go and have my own apartment more equipped but firs I have to find out if I have money to purchase and then I have to go see where is much cheaper and more convenient for me'.

I feel safe because I work and have a regular salary

Twice a month I receive pocket money from which I can buy what I need of what I want to have

I have a certain amount of money per week for food and I have to manage within this budget. I buy food and drinks and give receipts back to the assistant.

Internet banking is a big help to me. I can administrate everything this way. I manage everything myself what I need to, I pay what I have too and the rest is my business.

I have saved money for being able to buy an exercise bicycle

If I have money, lots of money I can buy an apartment

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When we got the apartment here I also received the key for it. After we moved we had to sign that we take full responsibility for it'

It's a home not an institution, where the staff was changing so often as if they were on a magnetic band

I feel good in my apartment, it's homey!

I feel safe here, I can just go inside and rest!

I have my own keys to my apartment

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We have a social worker and we receive our money week after week not to spend them all at once.

If I have health complication I can call my assistant. I can call from the fixed phone to the numbers saved in the phone.

I have somebody who I can ask for help if case there is a problem

I have my own assistant. Thanks to her the apartment flourished.

I feel safe because I have my guy here, we live together.

Appendix H

What are the things that makes independent or feel independent?

I feel free and independent when I can go out and have my walks. If I am nice to the nurses (referring to the staff**) and behave I can go out only with permission and if I finish my choirs.**

We can go everywhere we want to go in the weekend, as we don't have much to do, but only after we finish our morning cleaning… you know, doing our bed and all that!

When I was there, the educator (staff**) though that I could not be there and asked the director to bring me back to the Institution.**

When the nurses (referring to staff at the IHT**) are there all the time to help makes us so dependent because we know they are there.**