SUBJECTIVE WELLBEING IN PEOPLE WITH INTELLECTUAL DISABILITIES

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ABSTRACT

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The aim of the study was to reflect on and search for the factors and forces, which influence subjective wellbeing in people with intellectual disabilities. The study was conducted in social therapeutic workshops "Eben-Ezer" (Český Těšín, the Czech Republic). Through utilizing a narrative approach, I aimed to hear and record the ups and downs in the lived experiences of the people with intellectual disabilities. The main idea was to grasp the various views on the issue of subjective wellbeing through the listening to the stories of people and at the same time cherish the subjectivity of each story-teller.

The study follows qualitative research methodology, narrative approach for data collection, and thematic analysis for analysing the data. For the study six individuals were invited to take part in the research process. Previous contact was built with them during "Peer-Mentoring Project", which was conducted few months earlier.

The findings showed that the individuals who have experienced of being able to take care about themselves are more self-confident and resilient to life challenges. The persons with less social skills tend more to live either with the family or in the institution. Further, it was acknowledged that health aspects prevented their full participation in society. For others, it was one of the reasons why they are more dependent on their relatives or guardians. Also, research participants emphasized secure and supportive environment, as well as proper medication system as the factors for improved mental health, and consequently better subjective wellbeing. Finally, the interviews highlighted the factors and forces making positive impact on subjective wellbeing of people with intellectual disabilities strictly related to the culture (e.g. watch hockey matches) and family traditions. Social workers and the workers of social services should be aware about subjective wellbeing of people with intellectual disabilities and address it as a need of a person.

Keywords: subjective wellbeing, intellectual disability, qualitative study, narrative method

CONTENTS

1. INTRODUCTION

My experiences over recent years have resulted in the conclusion that very few people in everyday life have ever thought of the nature of intellectual disability and about the needs and concerns those people might have. I am very aware that I was one of that group until relatively recently. However, getting to know the issue in my practice and applying critical reflection on the nature of intellectual disability (hereafter ID), I soon learned that it was a complex topic which not only challenged my curiosity but, in my view, presents a pivotal challenge for practitioners in social work and the institutions which have the task of addressing the needs and concerns of such groups.

The first thought to conduct such study came to me during usual activities in the daily hospital for people with intellectual disability (severe level intellectual disability) “Eden” (the Czech Republic). In fact, I witnessed attitudes diminishing human dignity by one worker towards a service user of the agency. According to Clifford Simplican (2015) a degrading attitude is very common when it comes to the people with intellectual disability. In that particular practice the ‘worker - client’ behaviour was repeated all over again and this motivated me to search more deeply the relationships between the staff and participants in the context of services to people with intellectual disabilities. Interestingly, my future experience of taking part in the activities in the social therapeutic workshops “Eben-Ezer” (mild and moderate levels of intellectual disability) highlighted opposite attitudes. However, this contrast of different relationships in two agencies, which both work under umbrella of “SlezskáDiakonie” (the Czech Republic) influenced me to change the focus of my research interest from the ‘worker-client” perspective to the reflection on the subjective wellbeing (hereafter SWB) of people with intellectual disabilities (hereafter PwID), which actually, embraces the previous interest of mine. Therefore, the core idea of the thesis work is to let the people with intellectual disabilities to speak for themselves about their life experiences, ups and downs, and the factors which make an impact on their happiness and sadness. The discussion with the practitioners and managers of the management team of “Eben-Ezer” regarding the concept of subjective wellbeing and their support for my proposed research project influenced my next steps and, as a result, formed the substance of this thesis.

As it was mentioned above, an ‘unfair attitude’ and very little focus on human dignity towards the service users pushed me to think about researching this subject. The experience of work with PwID in two different agencies (mild, moderate and severe levels of ID) gave me the prospect for conducting the current study. Furthermore, the initial search for information highlighted the very small numbers of studies in this area. Hence, with the purpose of uncovering the topic I worked out particular questions which I wanted to research:

- What is the societal attitude towards PwID?
- How could human dignity be ensured in work and communication with PwID? What does human dignity mean, when it used in relation to PwID?
- How can the language used with and about PwID be less discriminatory and more empowering?
- How is wellbeing understood in the context of “Eben-Ezer” agency? What are the differences between objective and subjective wellbeing in relations towards PwID?
- How to make the research process inclusive and empowering?
- How can I improve the work of the agency to ensure a better understanding of subjective wellbeing of PwID?

Thus, taking into account these questions, I formulated my aim as to reflect on and search for the factors and forces, which influence the SWB of PwID. Adopting a narrative approach, which I will define and discuss later, I became interested in hearing and recording the ups and downs in the lived experiences of the people. As Kumar (2011) suggests, this should involve conducting a qualitative research process to gathering the content and making the analysis with the purpose of establishing variation in the situations without quantifying it. The idea is to listen to the stories of people and at the same time cherish the subjectivity of each story-teller. Crucially important was to grasp the various views on the issue of SWB, thus I have chosen an unstructured approach to conducting the research. After getting acquainted with various methods of qualitative research, I opted for narrative enquiry as a less structured approach to data collection, which highlights the historical knowledge and subjective viewpoint of a person (Kumar, 2011). Thus, my role as a researcher was dictated by the specifics of the method as an engaged but passive listener, providing a lot of space for people to express their own point of view in any way and as they wish.

The research was conducted in the social therapeutic workshops “Eben-Ezer” (Český Těšín, the Czech Republic). This agency is governed in a centralized way by the headquarters of

“Slezská Diakonie” in ČeskýTěšín (Czech Republic). The organizational headquarters is divided into several departments and sections, each of them focused on a specific issue. Together, they are responsible for the efficient management of “Slezská Diakonie” as a whole. “Eben-Ezer” is the residence house for people with intellectual disabilities and the provider of social services to the service users with a diverse range of activities.

As I have indicated in the early section of this introduction, working in the sector of intellectual disability has been personally challenging and this has captured my attention for almost two years. I feel that personally I am highly motivated to work with this particular group of people and the organisations who serve them. My experience of being engaged with the same user group in two different agencies has highlighted the issues related to the wellbeing of people with intellectual disabilities. Basically, due to being exposed to two related contexts I feel that it was useful for the conduct of the projects and studies directed towards empowerment and participation. However, I am profoundly motivated personally to engage in activity to make changes in situations where I see injustice towards marginalized and excluded people. PwID are in an ‘institutionalized environment’ in “Eben-Ezer”, and I feel well motivated to insure a dignified and fair attitude towards groups in such contexts.

In terms of professional development, this project and related study has been very enriching for my own growth. First of all, it has helped me to build deeper understanding of intellectual disability and in particular subjective wellbeing. As matter of fact, I have future plans to develop different studies directed towards empowerment of PwID. Consequently, the experience of conducting this research and related activity has contributed a great deal to my professional growth. Secondly, the current thesis work may be very useful for the future use of other professionals, as this topic is not developed so much in the town of Český Těšín (the Czech Republic). I have experienced front line practice in two agencies each with a major focus on the physical needs of people while less attention was given to non-discriminatory language and behaviour towards PwID. Being often in the position of a passive observer of discriminatory attitudes encouraged me hugely to study the topic hard and think about possible tools to change it on the organisational level.

According to Knight et al. (2014), for a comprehensive overview of wellbeing it is important to integrate subjective and objective elements such as family, community and the living environment. After some time, wellbeing as a concept started to change its focus to personal resilience for overcoming difficulties in life, thrive on the subjective level. Meanwhile, a person, according to McNaught (2011) may hold opposite understandings of the systematic factors of the state of wellbeing. Thus, in the modern world it’s more reasonable to take into account the circumstances influencing subjective wellbeing of a person (McNaught, 2011). Previous experience of working with the group of PwID highlighted some specifics of processing the information by them therefore, I tended to use different pictures, symbolizing the various life events. These included occasions leading to positive and negative emotions, to support people on the way in constructing the stories.

An important consideration at an early stage of the research was thinking about how best to focus on six main aspects relating to and circumscribing 'quality of life'. Skevington (1999) records that researchers focus a lot on exploring the impact of physical and mental ill health relating to and impacting on an overall quality of life. Evidenced by the literature available, considerable attention continues to be given to the conditions people experience in their lives and the impact of this on the overall quality of their life.

To conclude, theories and best practices concerning the SWB of PwID will be introduced in Chapter 2 and Chapter 3. Different stages of the research process will be presented in Chapter 4 and will include data collection, data analysis, expected outcomes, and the code of ethics. The Chapter 5 will contain explication of the research methodology. The findings and results are presented in Chapter 6. A separate Chapter will be devoted to reflection on my personal and professional development during the research process, and the prospect for future development. The last Chapter will conclude with the reflection on the whole thesis and discuss whether the initial aim and goals were met.

2. SUBJECTIVE WELLBEING AS A KEY CONCEPT

Wellbeing is a broad-based concept or area of study. McNaught in the book "Understanding wellbeing: an introduction for students and practitioners of health and social care" indicates that it has to reflect the whole complexity of 'wellbeing' and he shows its dependency upon a range of social, economic and environmental forces, which provide the resources for maintenance of wellbeing at all levels of society (McNaught, 2011). Another definition is given by the Department for Environment, Food and Rural Affairs (DEFRA, 2009) which considers wellbeing as meeting individual need, giving sense of purpose in terms of personal relations, financial reward and attractive environments. On the other hand, DEFRA increasingly conceptualises health and wellbeing, not only in terms of absence of pain and disease, but also in terms of how they are produced through individual action and wider communities. (Department of Health, 2010a; 2010b)

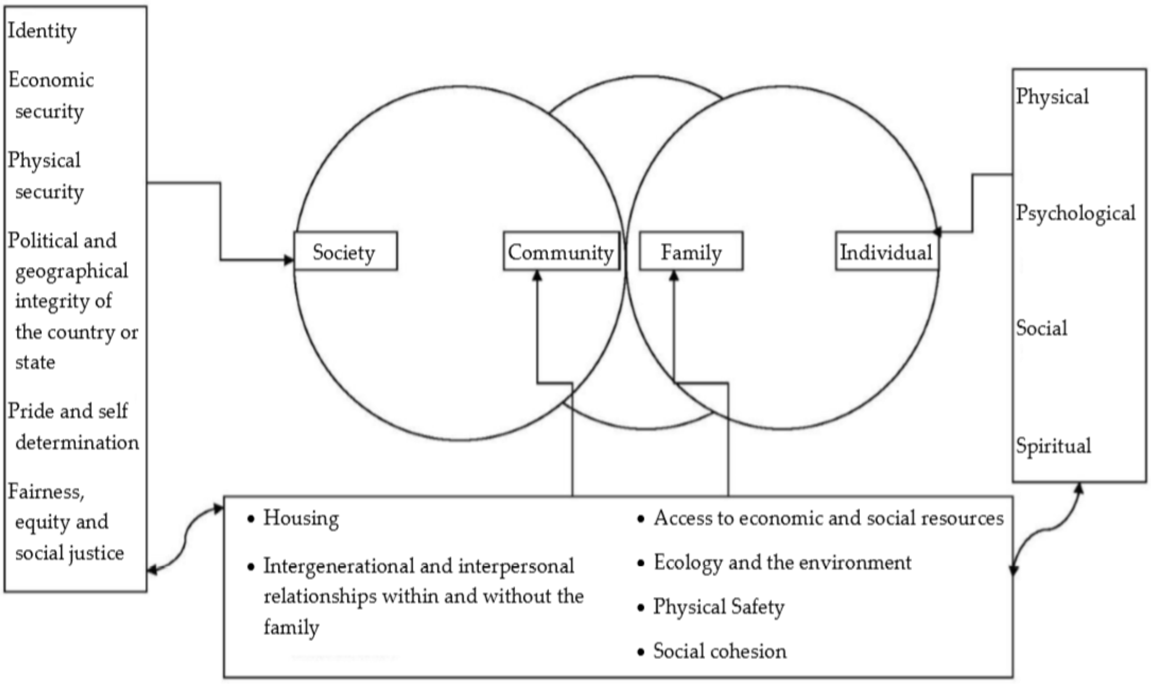
Knight et al. (2014) emphasize that psychology is inclined to integrate subjective and objective elements such as family, community and the living environment. However, a person, according to McNaught (2011) may hold opposite understanding of systematic factors of the state of wellbeing. Consequently, in the modern world it's more reasonable to take into account the circumstances influencing subjective wellbeing of a person (McNaught, 2011). Further, Knight illustrates how the exploration of personal resilience may help to overcoming difficulties of life, and in this way to thrive on the subjective level.

McNaught and Knight (2011) highlight the constant debates around concepts of wellbeing traditionally formed within the philosophy of ethics, in particular around how 'the person should live' and the way of looking for happiness and satisfaction (Haybron, 2008). Current debates about human wellbeing have also provided a growing number of literature and research as well as policy discourse. (Dodge et al., 2012)

It is important to notice, that modern discourse often refers to the original World Health Organisation (1946) definition that, 'health is not the mere absence of diseases but a state of wellbeing'. Whereas this definition connects the concepts of health and wellbeing, it also has a tendency to underestimate in full range the complex nature of wellbeing as a concept (McNaught, 2011). In other words, the old forms of defining wellbeing are still in use in modern society. On the other hand, wellbeing was theoretically considered as more correct in the areas of the emotional and psychological. In the outcome, we received the concept of wellbeing as differently defined and understood, divided into the range of segments. Thus, the notion that wellbeing was segregated by objective and subjective fields created the debates upon its measurement; for instance, in the idea that it is effectively measured through economic and social indicators such as income, housing and work (Diener et al., 2009). The opposite view tends more towards the subjective area, relied upon individual, emotional and psychological interpretations of wellbeing. (Felce& Perry, 1995)

Knight et al. (2014) offer a framework which provides a helpful overview of the complexity surrounding the study and research relating to wellbeing.

Figure 1. A structured framework for defining wellbeing



From: Knight, A. &McNaught, A. (Eds). (2011). Understanding wellbeing: An introduction for students and practitioners of health and social care. Banbury: Lantern Publishing (pp. 11). Reproduced with the kind permission of Lantern Publishing.

In **Figure 1** it can clearly be seen that the frame of wellbeing has to be understood as dynamically constructed by its actors through an interconnection between their circumstances, locality, activities and psychological resources, including interpersonal relations with the family (Knight, 2011). An individual might be able to change the family or start doing things differently in his own family. Thus, a person may try to get a satisfaction from life by change the situation. This can also involve moving to a new community or setting that offers economic opportunities and psychological resources different from those the individual previously had within the family. (Knight, 2011)

2.1 Underpinning theories of subjective wellbeing

Diener et al., (2009) discusses that SBW includes positive and negative evaluations regarding work and life satisfaction and affective reactions to life events, such as joy and sadness. However, it would wrong to say that an individual creates their own wellbeing standards which are obviously affected a lot by the culture and environment where they live. (Knight, 2014)

The important perspectives and ideas from Diener (1984) are that SWB measures are designed to capture information about how people experience their lives. Ideally, they are based on an individuals' self-reports. They include aspects such as whether people feel satisfied, content and fulfilled in their lives. This would also embrace a range of everyday emotions, such as happiness, worry, depression, and sadness. In this way Diener (1984) supports the move from an objective (more general) to a subjective (more specific) wellbeing. Individual wellbeing is multi-dimensional, it takes into consideration personal circumstances, financial and physical, psychological, spiritual and moral situations and experiences.

Further, my intentions are to underpin current study with two complementary theories of wellbeing, focused on overall optimism. Firstly, one is "The Hedonic Treadmill Theory" (Brickman and Campbell, 1971), which is focused on the idea of individual's fast adaptation to changes in their lifestyles and return to their baseline levels of happiness. Hereby, one aspect of high importance, is an individual's capacity to change the way of thinking about their life. Brickman and Campbell (1971) argue that an individual can learn how to be more optimistic by changing how they think about themselves. Nevertheless, it is important to remember about the limited capacity of PwID to be comfortable engaging in such reflective processes. As discussed in Chapter 3, PwID tend to repeat and 'mirror' what others think about them. In this way, their perception of self might be quite negative in exclusive and neglecting environments. PwID tend to do better development in a supportive and inclusive society. The implications of this for individuals, such as social workers and related researchers is to strive for creating and maintaining such an environment, where PwID and other marginalized groups may develop the capacity for changing their explanatory thinking style and become more optimistic.

Following theory is “Optimism” (Diener et al., 1999), based on the way how one thinks of his or her life. There are expectations of more good things to happen in the future than bad. At the heart of the theory is belief that a person has control over his or her life. In fact, current theory seems to be of a high importance and relevance when we talk about SWB in PwID. The processes of a narrative model of research highlights that individuals who think more positively about their future have fewer concerns and worries about their lives. As a result, optimistic view makes a great impact on their overall SWB. Notwithstanding, there are different circumstances and reactions reinforcing negative thinking and the attitudes of PwID towards the future. For instance, those participants who are more dependent on others can barely think in a positive way about their future, as they have limited capacity to take care of themselves. Therefore, it is a challenge for social workers and workers of social services in “Eben-Ezer” to create a range of environments where people may think more positively about the future prospects.

2.2 Implementation of subjective wellbeing of PwID

Knight et al. (2014) in the book “Wellbeing. Policy and Practice” argue that social policy could follow the strategy that allows structures that are detrimental to individuals, families and communities to be changed. In the author’s viewpoint, research practice should be flexible to be able to keep its focus on individual’s needs. The inclusion of both objective and subjective factors gives a clear guidance to researchers how to apply research methods when conducting interventions, strategies and likely outcomes. Clarity around research and frameworks also enhances more effective practice. (Glanz et al., 2008)

Smith et al. (2011) make an argument that current theoretical approach gives a chance to health and social care professionals to take into consideration how family or community is produced in combination, ensuring a framework that focuses on wellbeing on different layers. As Felicia et al. (2005) points out, professionals gain the information from their environment information that they as a result pass on further. Reflection on subjectivity provides people with an opportunity to make different interpretations of everyday circumstances. (Knight, 2011)

The personal resources and rules of an individual or community have a significant influence on wellbeing. For instance, people with poor health conditions might interpret their wellbeing in a different way, due to different cultural features or circumstances. In other words, with a developing personal resilience, an individual may also develop their own wellbeing, regardless of poor circumstances such as poverty or inadequate housing and physical disease (Smith et al., 2011). In a like manner, negative personal attitude to some circumstances or behaviour may influence person's health and wellbeing. Smith et al. (2011) make an example of over consumption of alcohol or reactions to stress depending on, for instance, personal characteristics or peers and families that may facilitate effective resilience and motivation to change.

Knight (2011) says that the definitional framework of wellbeing, given by McNaught is very broad and holistic, but, at the same time sophisticated enough for practical implementation, and suitable for modern world. The main disadvantage is that the model is small-scale, and does not explore the global domain, or the potential consequences of globalisation to establish global standards of wellbeing (Knight, 2011). Nevertheless, it suits my thesis work well, as I aimed to conduct research with a small group of people in the Czech agency and the cultural aspect pays crucial role. It can also be argued that the framework is biased towards a Western 'post-industrial' society, although that does not preclude developing similar frameworks within non-Western countries and contexts (Knight, 2011). Currently, the framework provides the ability to study and analyse wellbeing in different cultures and contexts. There is also capacity to explore how individuals in different cultures and communities adapt rules and resources according to circumstances and constraining influences.

Regarding people whose lives are shaped and influenced by ID, Skevington (1999) importantly draws attention to the subjective nature and aspects relating to an individual's 'quality of life'. This argument is that introducing the concept of subjectivity makes measuring 'quality of life' a much more comprehensive and holistic concept for the purposes of measurement and defining. Further, SBW can be highlighted as introducing a multidimensional concept, underlining and emphasising the importance of the perception of self of a human being and their state of mind (Bonomi, Patrick, Bushnell, and Martin, 2000). In the planned research with my selected individuals (all PwID) the main objective aspects relating to the quality of their lives informed my explorations and influenced the shape of the narratives. It is argued that the process of defining quality of life can be very challenging in the light of the necessary domains for encompassing the overall definition of this construct.

Nevertheless, Skevington (1999) suggests following the indicators for successful research makes it crucial to view ‘quality of life’ as a concept consisting of different social, environmental, psychological and physical aspects. On this basis, the following list of aspects was considered to be an important skeleton framework for shaping the narratives with my group of PwID:

- Financial life;
- Security in life;
- Physical health;
- Social life;
- Mental health;
- Emotional life.

2.3 Successful practices on subjective wellbeing with PwID

In this part I will refer to the ‘Guidance for social care providers and commissioners on improving health and wellbeing of people with learning disabilities’ (Public Health England 2015). A basic requirement for all professionals who work in the field of learning disability is to provide for people all necessary support and conditions, without waiting until they will experience some problems. In fact, the professionals in social care and social services are obligated to follow the suggestions of this document with a purpose of insuring the wellbeing of PwID. In accordance with Public Health England (2015) PwID have poorer health than the general population, and it is possible to avoid these problems. PwID face health inequalities in most cases starting from the childhood. It makes an impact on their quality of life and even early death. The following are suggested determinants of health inequalities:

1. Greater risk of exposure to the social determinants of poorer health such as poverty, poor housing, unemployment, discrimination and isolation;
2. Increased risk of health problems associated with specific genetic, biological and environmental causes of learning disabilities;
3. Communication difficulties and reduced understanding of health issues;
4. Personal health risks and behaviours such as poor diet and lack of exercise;
5. Problems with access to healthcare provision.

This Guidance is based on three main acts governing the field in the UK:

1. Equality Act (2010);
2. NHS (National Health Service) and Social Care Act (2008);
3. The Mental Capacity Act (2005).

The Equality Act (2010) and the NHS and Social Care Act (2008) are focused on providing rational adjustment to the practices that will make them as accessible and effective as they would be for people with no disabilities. That includes:

- Removing physical barriers to accessing health services;
- Make the changes to policies and procedures;
- Staff training;
- Organize service delivery for people with learning disabilities.

According to the Mental Capacity Act (2005) the person is assumed to have capacity unless it is clearly established the he or she needs extra help. This act is strongly based on a human dignity approach. The Mental Capacity Act (2005) includes the following recommendations:

- A person must be assumed to have capacity unless it has been clearly established that they lack capacity regarding the specific decision under consideration at that point in time;
- A person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success;
- A person is not to be treated as unable to make a decision merely because he/she makes what is considered to be an unwise decision;
- An act done, or decision made, under the Mental Capacity Act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests;
- Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

In accordance with Public Health England (2015) families usually have the best knowledge about the person, and they know their likes and dislikes, how they communicate and what to look out for if the person is unwell or in pain. There are plenty of examples of families acting as advocates for their relative. Nevertheless, families are not always listened to, and the consequences for the individual may be very serious, leading to poor care, lack of pain relief and premature death. Similarly, in "Eben-Ezer" the contact between social services and families is not well established. For example, “Eben-Ezer” aims eventually to get PwID into employment, but families discourage their relatives from this initiative. (Mihnakova, personal communication 7.10.2018)

At this point I would like to present a successful practical example of “Mencap” (the UK) on working for improving SWB of PwID. I have decided to choose “Mencap”, because for years they used to work successfully with PwID. Moreover, they involve service users in decisions making process and in making an influence on policy in the UK. A key priority for “Mencap” is to improve attitudes to PwID. It is reported that PwID in the UK are more physically integrated into the society. Nevertheless, there are still a lot of individuals who feel socially excluded and exposed to unwelcome and aggressive behaviours. The exclusion is related to the spheres of equal participation in education, employment, leisure and social pursuits. Argyle (2001) argues that these aspects are the parts of quality of life, and straightforwardly influence subjective wellbeing of an individual. In the Czech Republic, a very small percentage of intellectually disabled people have an employment in the UK this is (7%). “Mencap” suggests some actions towards tackling negative attitudes to individuals with learning disabilities. Furthermore, the organisation aims at breaking down the barriers that prevent people with learning disability from the societal acceptance, from accessing wide range of opportunities and positive experiences. These aims are based on UN Convention on the Rights of Persons with Disabilities. “Mencap” has managed following interventions for promoting the SWB of PwID:

- In collaboration with the “Foundation for People with Learning Disability” in the UK, “Inclusion International” and “Special Olympics”, “Mencap” provided education and messages designed to promote inclusion and more positive attitudes via their websites, leaflets and social media;
- Included educational approaches that attempt to challenge misconceptions by providing factual information;
- Created filmed interventions to explain what is learning disability and show people with learning disability in positive roles, while also highlighting injustices they experience.

This chapter can be summarised as follows. The intention was to illustrate the complex nature of the concept of SWB and its relation to PwID. I have concluded that ideas from Dienar et al. (2009) about positive and negative evaluation of life satisfaction are particularly important. SWB measures are designed to capture information about how people experience their lives; aspects such as life satisfaction and embracing a range of everyday emotions, such as happiness, worry and sadness are acutely significant and important. Knight's ideas (2014) are also of importance and sit comfortably alongside Denier et al. (2009). Knight (2014) emphasises the significance of cultural and environmental factors which make a huge impact on people's lives. Thus, it can be concluded that a wide range of different arguments and viewpoints helpfully illustrate a comprehensive and holistic picture for the understanding of SBW. As McNaught (2011) argues, it is sensible in modern world to consider different circumstances (factors and forces) which may make an impact on the SBW of a person. In a later chapter I will critically reflect on some of the different circumstances to which McNaught (2011) refers.

3. INTELLECTUAL DISABILITY

In an earlier chapter I indicated some of the motivating factors encouraging and inspiring a deeper understanding about ID and its impact on the lives of people. Recent practice involvement in social welfare organisations responding to the needs and concern of PwID has also sharpened my attention to the actual and potential role for social work and social workers engaging with people for whom such a disability is their lived experience.

For a working definition of the term, ‘Intellectual Disability’ I found it useful to refer to the UK based “Mencap” organisation, which focuses its work and innovative projects on PwID. According to “Mencap”, ID is a reduced intellectual ability and difficulty with everyday activities; for instance, household tasks, socialising or managing money, the disability affects someone for their whole life. This group of people incline to take longer time for learning and may need extra support to develop new skills, understand complicated information and interact with other people” (“Mencap”). Nevertheless, Braddock and Parish (2002) argue that society defines and interpret disability and impairments. Disability can be seen as social construction, when impairment is a physical fact. Environment does not see disabilities differently, as well as the treatment of disabled people. Further on I will write more about the perception of disability in society.

From the literature search I noted that ID is not a static disorder, but it is dynamic condition. The adaptive behaviour of PwID is impaired, so any factors which might cause stress are very unsafe. Thus, the society, which is more supportive can reduce stressful factors, and the integration of PwID will be smoother (Gil and Harris, 2005). Accordingly, individuals with ID need different levels of support. For example, those persons with a mild disability may have a need with support to find a job and appropriate employment. Someone with a severe or profound ID may require fulltime care and help with different things at the different stages in their life. Moreover, it is possible that some individuals may additionally have mental health concerns or physical disabilities too. It is important to acknowledge here that people with Down’s syndrome and some people with autism may have a reduced intellectual ability. The philosophy of “Mencap” and their practice model is to adopt a positive approach which is helpful, encouraging and appropriately demanding for their user groups – some of their project work is quite inspirational. Essentially, according to “Mencap”, proper assessment and appropriate support and resources, can lead a person, depending on the level of ID, to a reasonably independent and resourceful life.

In accordance with Braddock and Parish (2002), society defines and interprets disability and impairments. Disability can be seen as a social construction, whereas impairment is a physical fact. Different contextual environments and various cultures also see disabilities differently. Such perceptions also may affect the response and where appropriate treatment of people with a disability. At a later point I will discuss more about perceptions and responses to disability in society.

3.1 The concept of human dignity

As illustrated above, it is important to understand that intellectual disability affects the people for their whole life. Based on this, it is inevitably important to ensure that PwID are related to and treated with respect and their dignity preserved at all times and in all situations. For example, Clifford Simplican (2015) argues that PwID are far more often likely be interrupted or 'corrected' when expressing their opinion, compared to 'normal people'. During my own practice experience, in one of the agencies working with a group of PwID, I repeatedly witnessed such behaviours and attitudes of disrespect.

From a wider societal perspective there is evidence that human dignity is a concept still in the process of being defined (Addy, 2011). To illustrate this, we can observe in our world the tensions and 'clashes' regarding the distribution of power. In such situations we can witness the putting of the value of one group of people against and over another with little thought for respect or dignity regarding their lives. In accordance to Dorling (2011) as human beings can move very quickly from being feudal to being cooperative and, hence, to being competitive or totalitarian. People with weaker ability (such as PwID) are more than others under the threat of being treated with little or no respect. Dorling also adds that prejudice justifies the actions of those who consider themselves more deserving than others. (Dorling, 2011.)

In the context of European Union (the Czech Republic is one of the member-states) safeguarding of human dignity is considered as a human right (Addy, 2012). Nevertheless, the concept was not precisely defined, and mostly is understood by people intuitively. For me it means that people in different countries and cultures across the EU have their own understanding about human dignity and how it should apply to others. Addy (2012) argues that human dignity concept nowadays strictly relates to performance of a person and is understood from the perspective of the enlightenment (secular understanding). In other words, dignity has a strong link with autonomy and to a person's ability to make rational decisions. In this way, PwID due to their incapacity don't fit well to current 'model', being unfortunately perceived as the 'residue' of a mainstream society. Secular understanding of human dignity also put the guilt on people themselves for their failure, such as they have not shown sufficient effort of building up their own future. Bauman (2011) considers current model of dignity to be a justification of government policy in the European context for neglecting the other people, who are less able to fit into the 'mainstream'.

From Theological perspective, first and foremost, human dignity is considered as a God-given gift, and God's mercy is available for every human being regardless of abilities, capabilities or disabilities; in other words, everyone ought to be treated with respect and honour due the human creature (Addy, 2012). If secular understanding of dignity emphasizes personal autonomy - Christian and Jewish traditions, on the contrary, view human being in the relational way as a part of society. The foundation for such thinking is that all human beings have been created in the image of God. (Gen. 1:27.)

Recently, the Holy and Great Council of the Orthodox Church revealed their position on human dignity. First, their mission has been defined as a contribution towards realizing peace, justice, freedom, fraternity and love between peoples, and in the removal of racial and other discrimination. Finding some inspiration in this and a foretaste of the Kingdom of God, the Church can't stay away of the troubles of humanity in all times. Rather, the Church shares people's problems, as the Lord taught - our sufferings, which are caused by evil in the world and, like the Good Samaritan, pouring oil and wine upon our wounds through words of *comfort* (Rom 15:4; Heb 13:22), and through love in action. The unique dignity of every human being, which stems from being created in the image and likeness of God and from our role in God's plan for humanity and the world, inspired the Church Fathers to action. The purpose of the incarnation of the Word of God is the deification of the human being. Christ, having renewed within himself the old Adam (Eph 2:15).For just as the entire human race was contained in the old Adam, so too, the entire human race is now gathered in the new Adam. This teaching of the Church is the endless source of all Christian efforts to safeguard the dignity and majesty of the human person. (HGC 2016)

In this way, it is appropriate to comment on human dignity mostly from a Christian perspective (as “Eben-Ezer” is a Christian organisation) where it states that each person being made in the image of God. Dignity is innate to being human and this innate dignity should be recognised in practice and form the basis for development. In my view it is important that “Eben-Ezer”, with its faith connections, explores ways of developing such a perspective in its work with PwID. This will involve changing the perceptions, understanding and practice of social workers and management and in turn the service user. Such an approach is crucially important for the service users in “Eben-Ezer”, as many of them are ‘locked up’ in the institution with no chance of proper interaction or critical engagement with the environment. In my opinion, it is a great challenge for social workers and workers of social services in “Eben-Ezer” to be able to position themselves ‘in-between’ the ‘system world’ and ‘life world’ of the service users. In most cases the workers prefer or are influenced to follow the requirements of a ‘system world’ and place more emphasis on care and control of PwID. The result is that only a very small focus is on the idea of making a change in the life of service users. From my viewpoint, the dignity of PwID can be preserved in the commitment of social workers and workers of social services in striving for creating similar possibilities, life conditions and treatment of ID as ‘mainstream’ society. Addy (2012) states that marginalized people tend to ‘mirror’ the assumptions about them. Similar point of view was held by previous placement supervisor, who argued that PwID are often told by the family member that they are ‘unable’; it shapes how PwID view themselves (Michnakova, personal communication, 22.01.2019). By using narrative method to data collection , I gave people a chance to define their own understanding of proper treatment and mistreatment by other people. In other words, I paid proper respect to the contextual perspective of this group of people, aiming at preserving human dignity throughout the research process.

3.2 Understanding intellectual disability

It is broadly accepted that there are three different levels of intellectual disability (Gil and Harris, 2005):

- Mild;
- Moderate;
- Severe.

“Mencap” emphasizes that it is crucially important to recognise that in every case of ID is for a person’s whole life. It is accepted that there could be some difficulties with diagnosing a mild intellectual disability, for example, a person may often fit well in to a group of other people and will not find it too difficult to manage with most necessary tasks. However, for each person there are likely to be some challenges which they may need extra help in some areas of their life. Individuals with a moderate or severe learning disability or profound and multiple learning disability (PMLD), may obviously require more care and support with areas such as mobility, personal care and communication.

There are plenty of reasons which may cause ID. These include wide range of etiology. For better understanding the nature of the topic, I will focus on the book, called: “Intellectual Disability. Understanding its development, causes, classification, evaluation and treatment”, written by Gil and Harris (2005). It’s suggested that ID can be caused by genetic and biological factors:

- Downs Syndrome;
- Prader-Willi Syndrome;
- Angelman Syndrome;
- Williams Syndrome;
- Fragile x Syndrome;
- Phenylketonuria;
- Substance use/abuse: illicit drugs;
- Foetal Alcohol Syndrome;
- Lead-based paint;
- Rubella;
- Birth trauma;
- Other injuries.

According to “Mencap” some people in society do not see the difference between mental ill health and intellectual disability. “Mencap” and similar service organisations helpfully address this concern in their webpages and accessible literature. The explanations offered discuss the differences between mental health problems and ID, and of course the possibility of a combination of both. It is normally emphasised that a mental health problem is a term used to cover a range of emotional, psychological or psychiatric distress experienced by people. It is usually acknowledged that a mental health problem may affect anyone at any time and may be overcome given appropriate medical/social work support and treatment.

3.3 Societal attitudes towards intellectual disability

Epson and White in their book “Intellectual Disability: ethics, dehumanization and a new moral community” argue that the ability and capacity of PwID are often underestimated. PwID should be seen as people first (treated with dignity and respect with no reference to their capacity) and as ‘handicapped’ in some way after that. Further, relating to this aspect, important to refer to the book “Capacity Contract: Intellectual Disability and the Question of Citizenship” (Clifford Simplican, 2015). It is discussed that, PwID are often undervalued in many cases, and as a result they tend to do and repeat what they are told. Instead of cherishing subjectivity, we often put our own expectations on PwID, and we impose our viewpoint on them (Clifford Simplican, 2015). Given the theme and concern of this thesis work the literature was a very useful resource.

I can see the connection between the topics of SWB and ID. Thus it helped me to make a proper transition from one part of thesis work to another. Clifford Simplican (2015) challenges ideas such as thinking that disability might impact on erosion of human capacities that are essential for the flourishing of human beings and their relationships. The author argues that our anxiety about ID is manufactured, and it has long roots to the history of segregation and discrimination. Consequently, society tends to underestimate even the positive outcomes of work with PwID.

The presence of ID in a human being often results in a dismissive and derogatory attitude from other people, including caregivers (Clifford Simplican, 2015). “Mencap” and one or two UK university learning programmes in social work and nursing have recruited PwID to play a formal educational teaching role engaging directly with students in professional training. Recognition, through these examples, that PwID have the capacities and skills to play such roles.

3.4 Rights of PwID in the Czech Republic

As a final section of this Chapter it is relevant to note that, as a part of European Union, the Czech Republic has signed the “Convention on the rights of Persons with Disabilities” (CRPD) which was adopted by the United Nations (UN) on 3d of May 2008. The Czech Republic has confirmed its validity in other legal system on 28th of October 2009. The Convention imposes on the states that have accepted it what they should do to ensure that people with disabilities enjoy the same rights as other people. By confirming the Convention, the Czech Republic has committed itself to do everything to ensure that people with disabilities can do the same thing as others, in order to enjoy the same rights as non-disabled people. It includes following principles:

- People can make decisions for themselves;
- No one should become the victim of discrimination;
- Everyone should be respectedfor who they are and accepted among others;
- People with disabilities should have the same opportunities as others;
- Everyone has the right to access buildings, transport and information as others (CRPD).

PwID for the purpose of experiencing full integration into society need not only to have access to important information from the state, public administration and the private sector, to public and private services (authorities, medical institutions, banks), but also to the public space. PwID need more accessible websites, more accessible labels, easy-to-understand contracts, modified buildings prepared for mentally handicapped people, etc. The state of the Czech Republic guarantees accessibility and intelligibility of information, services and public space to PwID through the adoption of the Convention on the Rights of People with Disabilities. (SPMP)

Article 9 of the Convention on the Rights of People with Disabilities invokes actions to ensure that people with disabilities have an equal access to material living conditions, transport, information and communication, public services and facilities, anywhere in the city and the village (CRPD). The Czech Republic has undertaken the actions to remove obstacles and barriers related to: buildings, transport networks, transport and other indoor and outdoor facilities, including schools, residential buildings, health facilities and workplaces.

Such legislation obviously poses many challenges for the Czech government and Social Work and Welfare Organisations. It is encouraging to note that “Mencap” and its partner organisations, in their context, are seeking ways to demonstrate the changes that the above legislation infers and desires.

Some conclusions can be asserted from the different sub-sections of this chapter. The evidence presented by “Mencap” illustrates that the concept of ID is often misunderstood and confused with mental illness. Further, the importance of ID, as a lifelong experience is important to be understood. It is not something that might be ‘cured’ or treated as with mental ill health issues or concerns. As I have illustrated, there is a working definition of the concept of ID, presented by “Mencap”, which is broadened and sharpened by Braddock and Parish (2002), who additionally emphasize the societal responsibility for defining and interpreting disability. Thus, it was concluded that intellectual impairments together with societal attitudes often shape the outlook and life circumstances of PwID. For the purpose of better understanding of the concept of ID different reasons for causes of ID were presented. Very importantly, not least from a social work perspective, I have drawn attention to the likely discrimination and injustices which PwID may experience throughout their life from a range of formal and informal structures and sources. It was shown how such experiences may deny them respect and human dignity. There is evidence across the literature that PwID are often denied and undervalued due to their capacity and weaker functioning in their societal context. Based on my own practice experience and current research findings I propose in Chapter 6 to critically discuss further the evidence gathered and conclusions, I have reached relating to the concept of human dignity. This evidence and analysis will be based on the in-depth narratives of the participants themselves with whom I have been engaged in the research process. It will also draw on critical evidence of the organisational and professional values of the agency context where the participants were involved and the research was based.

Finally, indications were given of wider positive societal responses and legislative policy and practice measures relating to the rights of PwID at an international level. The chapter also drew attention to practices innovations and imaginative responses to some of the above concerns and aspects in practice organisation in the UK and other international context.

4. RESEARCH METHODOLOGY

As it was outlined in previous chapters, ID can be described as a multidimensional concept, which includes intellectual ability, adaptive behaviour, the level and nature of a person’s participation in relationships and social contexts. Schalock et al., (2010) contributed a report about the potential of a specialized approach to classification within the field of ID towards understanding the complexity and the likely paradigm and parameters of support that may be required. Thus, providers of services might be encouraged and able to understand more about the structures, resources and the systems, and how they impact on the lives of people (Emerson, Baines, Allerton& Welch, 2012). Clearly, it can be argued, a better understanding of the influencing factors on SWB in PwID is a high level of importance. This will also include other significant factors such as identifying the social discrimination and inequalities which may be experienced by this group of people; their likely socioeconomic status is much more likely to be lower. The literature indicates higher incidences of both physical and mental health difficulties (McGuire, Daly & Smyth, 2010) and they may have a vastly reduced social network (Faust & Scior, 2008). In this way, there are many factors, which make a great impact on the wellbeing of PwID. Among these, as can be noted, there is likely to be mixed objective and subjective features of wellbeing, including family, community and living environment (Knight, 2014). Hence, the designing and planning of research with a group of people with intellectual disabilities requires careful consideration, and, to some extent, exceptional methods and sensitive approaches with the purpose of making it less harmful and more useful for the participants.

This chapter is devoted to the methods and approaches, which were used as a part of my proposed qualitative research. The intention in what follows is to critically assess these approaches regarding their relevance and appropriateness for use with a selected group of PwID.

4.1 Narrative enquiry as a part of qualitative research

As it was pointed out several times above, the main aim in my thesis work was to research the factors and forces which make an impact on SWB of a selected group of PwID. In other words, through the narrative approach I wanted to collect and record the ‘ups and downs’ in the lived experiences of a selected small groups of people. At a later point I will discuss how I selected those participants, their particular social context and my relationship with them.

Kumar (2011) argues that qualitative research should be used when the intention is to reflect on the variation in a situation, phenomenon or problem without quantifying it. Therefore, a qualitative research method seemed the most appropriate for the purposes of my study, as I planned to collect different views and perspective on wellbeing by PwID. My major consideration of crucial importance was to be able to grasp the various views on the issue of SWB – this more open and somewhat less structured approach to research seemed to be the most suitable for the current study. As literature illustrates narrative enquiry is considered to be a less structured method of data collection, but also as an approach of study for collecting historical knowledge, in the subjective viewpoint of a person (Kumar, 2011). Consequestnly, my personal role as a researcher could be described as a passive but attentive listener, who gives a lot of space for an individual to express their own point of view in his or her own words. Nevertheless, according to Kumar (2011) current approach has to be modified, as the PwID are a group with special needs and capacity. As a matter of fact, I was prepared with extra appropriate sensitive enquiry type questions if the participants were less forthcoming in their communication. In addition, together with the usual approaches to narrative enquiry I aimed to use alternative communication strategies such as symbols and picture cards. This was used to encourage and assure a more productive transmission and communication to the researched person and the reverse of this process.

The literature review was very fruitful relating to thinking about the narrative and qualitative research model. Kumar (2011) argues that the oral history is a process of receiving, recording, presenting and interpreting the information, grounded in the experience and viewpoint of an individual. So, it is simple in design and flexible in its usage. Likewise, Atkinson (2004) explains the oral and life history approaches with PwID as the means of hearing their accounts – their ‘lost voices’. The approach used was to facilitate and empower PwID by enhancing their knowledge and understanding of the world and his/her place in it (Atkinson, 2004). Throughout the research process I held in mind the idea of narrative enquiry being to enable PwID to recall, recount and review their lives, valuing them as expert witnesses rather than mere sources of data (Atkinson, 2004). Atkinson (2004) also adds that narrative enquiry is a means for systematic gathering, analysing and representing the stories told by people, which provokes traditional understanding of truth, reality and personhood. Consequently, to draw a conclusion out of listed above, narrative enquire is an approach, which was well suited for research on SWB with the group of individuals in "Eben-Ezer".

4.2 Analysis of qualitative data

Etherington (n.d.) suggests two different forms of narrative analysis, focused either on the content of stories or meaning. Taking into the account the specifics of a group with ID my intent was to keep the focus on the meaning of stories told by people. Etherington (n.d.) also emphasizes the importance of analysis of 'meaning making' happen as a part of data collection, instead of breaking it into two different activities.

Complementing the immediate reflection done during the interviews, I did further data analysis from ready-made transcripts (I obviously also had the additional challenge of translating the text from Czech to English). To offer some framework, given the anticipated range of information received I considered that some open-ended themes would be useful and likely to be appropriate. The following topics were used: financial life, security in life, physical health, social life and relationships, mental health and emotional life. The narratives can bring the complexities in people's thoughts and talking, thematic analysis was used to make sense of qualitative information received. This also helped in building the system in gaining knowledge and empathy about a person and interaction with him or her. In accordance with Howitt and Cramer (2007), such an approach and method enables researchers to develop deeper insights for the people or particular situation, which they research.

Furthermore, Josselson (2006) states that narrative research is always interpretive at every stage. Thence, the data analysis always involves interpretation. Following the suggestion of Josselson (2006) I used analysis of data (objectivity) and interpretation (subjectivity) in tandem. It was done with a purpose to develop an understanding of the meaning which the participants give to themselves, to their surroundings, to their lives, and to their lived experiences through telling the stories (Josselson, 2006). According to Spence (1986) the researchers, through subjective interpretation (narrative smoothing) tend to write a nice story more than the truth. He argues that it is used to make a story more coherent, engaging and amusing to the reader. Therefore, I had a goal to bring the stories and their meanings close to the original as much as possible. I held in my mind the importance to enrich the process and being able to bring up different viewpoints and perspectives of SWB, which I may not fully understand. Thus, I aimed at proper use of data without distortion of reality.

4.3 Methodological challenges

- Gaining of trust

In accordance with Whitehurst (2006), I understood that there are many challenges related to communication with PwID, and they occur right from the stage of gaining informed consent; also, they might appear again during the data collection and data analysis processes. One of the suggested approaches, in cases where communication challenges escalate for researchers, is to use a person who knows the participant well to gather and interpret the information (Whitehurst, 2006). However, the group of people which I interviewed was involved in the earlier "Peer-Mentoring Project", which I designed and conducted in "Eben-Ezer". An adequate level of trust and understanding was achieved and maintained. Therefore, there was no necessity for extra assistance to help me to understand and interpret the research participants. In the literature it is suggested that proxies could be professional workers (e.g. speech therapists) acting as the experts, or people with close relationships who know the person well, or someone else with ID (inclusive and empowering approach). Emancipatory projects clearly showed some of the benefits here; Townson et al. (2004, 73) for instance said: "People who are not in the same boat as us don't understand what it is like to be us, they have not had our experiences…Because of this people will want to talk to us. We know what they are talking about and understand them". However, being an active practitioner for more than two semesters in the social therapeutic workshop "Eben-Ezer" provided me with the opportunity to develop the necessary understanding of people with intellectual disabilities.

- Data collection

It is important in this chapter to reflect on the aspects of data collection. Cambridge and Forrester-Jones (2003) suggests using augmentative and alternative communication (AAC) in research with PwID. This could mean informal and non-symbolic (e.g. gesture), symbolic and low-tech (e.g. sign language), symbol systems and photographs or symbolic, and high-tech such as voice synthesisers. This necessitates finding out the AAC ordinarily used by the participant, whether this be a specific system or a combination of communication strategies as part of a total communication approach. Such individualized communication approaches are essential when participants do not communicate through speech but they may also increase response/inclusion rates with those with some speech (Cambridge & Forrester-Jones, 2003, cited by Brewster, 2004). I have considered the previous experience of working with this a group of PwID and the specifics of processing the information by the participants. I tended to use different pictures, symbolizing the various life events. It was helpful in terms of staying focussed on specific aspects of life and not getting distracted by different unstructured thoughts. It included the occasions leading to positive and negative emotions, with the purpose of supporting people on the way in constructing the stories.

- Data analysis: relevant key perspectives

As it was mentioned earlier, the data analysis stage may bring the challenges of misusing or misinterpreting the information (Spence, 1986). The desire to write a good story might mislead the researcher from the way of presenting the real findings. A small amount of data or insufficient answers may become a trigger for the researcher to transmit in the stories his own reality and subjectivity. Nevertheless, Spence (1986) suggests the researchers to try to stick to original experiences of the participants and appreciate the stories which were told.

Another problem on the stage of data analysis is to use the wrong order chronologically or conceptually in the stories (Spence, 1986). Data may be presented in an inconsistent way without a clear focus. It is suggested that researchers should make sense of stories during the listening and to rearrange the stories told from interviews into chronologically or thematically coherent material. There are always are larger landscapes in stories with a personal meaning.

In conclusion, regarding this chapter I was confronted with many challenges in the research process and hopefully have reflected above the purposeful use of the literature which was accessed. A particular challenge was obviously the aspect of engaging with the participants and thinking about their lived experiences through the accounts they offered and through their reflections and memories of social experiences and relationships.

5. RESEARCH PROCESS

The intention of this chapter is to describe, comment on, and highlight the process of the research. This will include the aim and goals of the study, the selection of methods and approaches used, recruitment of the participants to be involved in the research, processes of data collection and data analysis, ethical considerations and validity of research.

5.1 Aim and goals of the study

The main aim of the study was to make a search for the factors and forces, which influence SWB of PwID. All in all, the plan was to listen and to let the participants speak about their life experiences, including positive and negative aspects, making an impact on their SWB. The decision was made to focus on and follow the methodology of qualitative research, with the purpose of creating a space for open conversation with the participants. One of the goals was to learn how to find a way to collect different viewpoints of PwID about the phenomenon of SWB.

5.2 Recruitment of the participants

Given the envisaged limited scale and time limits of the project the decision was made to involve six adult services users of “Eben-Ezer” agency – five males and one female. The selection of particular participants was also influenced by the relationship I had developed with service users in an earlier “Peer -Mentoring Project” which I had planned and implemented at “Eben-Ezer”. Taking into account the fact that I am a Ukrainian by nationality, and not a native Czech language speaker, and I have never experienced intellectual disability; based upon these aspects the decision was made to continue collaboration with group of people from “Peer-Mentoring Project” in thesis work too. Moreover, the advantages of that choice were the trust, understanding and good relationships which had been built up between me and the project’s participants. The levels of ID of the participants was mild and moderate. Earlier contact with them during “Peer-Mentoring

Project" had highlighted their actual and potential ability to communicate well and to process received information. Moreover, they were selected for "Peer-Mentoring Project" based upon different capacity, skills and experiences. Thereby, in my opinion it was an appropriate group for conducting such a study with them. As indicated, I wanted to get various viewpoints on the question of understanding SWB. Further, the lived experiences of the group were helpfully varied. Some of the participants live independently, some were institutionally based, or with a family. All in all, it was very rich and diverse group of people.

5.3 Research methods and data collection

Given that the main aim of the research was exploring the factors and forces which make an impact on SWB in PwID, I adopted and utilized a narrative approach. In defence of selecting this approach a qualitative research method seemed the most appropriate for the purposes of my study, as I planned to collect different views and perspective on wellbeing by PwID. I have considered the importance of grasping the various viewpoints on the phenomenon of SWB – unstructured approach to research was the most suitable for this study. Narrative enquiry is considered to be a less structured method of data collection, but also as an approach for collecting historical knowledge, from the subjective viewpoint of a person (Kumar, 2011). Nevertheless, according to Kumar (2011) current approach had to be modified, as PwID is a group with special needs and capacity. As a matter of fact, I was prepared with supportive questions if a person found communications and understanding difficult. In addition, together with the usual approaches to narrative enquiry I aimed to use alternative communication strategies. Such considerations would be used for assuring a better transmission of the information from a researcher to the researched person and the reverse of this process.

Kumar (2011) argues that the oral history is a process of receiving, recording, presenting and interpreting the information, grounded in the experience and viewpoint of an individual. In this way, it is simple in design and flexible in its usage. Similarly, Atkinson (2004) explains the oral and life history approaches with PwID as the means of hearing their accounts – their 'lost voices. Thus the approach used was with a purpose of empowering PwID by enhancing the knowledge and understanding of the world and his/her place in it (Atkinson, 2004). Throughout the research process I held in mind the idea of narrative enquiry for enabling PWID to recall, recount and review their lives, valuing them as expert witnesses rather than mere sources of data (Atkinson, 2004). Atkinson (2004) also adds that narrative enquiry is a means for systematic gathering, analysing and representing the stories told by people, which provokes traditional understanding of truth, reality and personhood. All in all, the narrative enquire is an approach, which was likely to prove well for the purposes of the research on subjective wellbeing with the group of individuals at “Eben-Ezer”.

5.4 Data analysis

Considering the specifics of PwID, I followed the suggestion of Etherington (n.d.) to keep the focus on the meaning of stories. Moreover, I did some of the analysis of ‘meaning making’ as a part of data collection, instead of breaking it into two different activities.

As a second stage after immediate reflection which was done during the interviews, I did further data analysis from ready-made transcripts (translated from Czech to English). Because of the reason of different topics for the interviews, thematic analysis was considered the most appropriate for current study. The following topics were used: financial life, security in life, physical health, social life, mental health and emotional life. In a later chapter I will illustrate the usefulness of this approach and framework.

5.5 Reliability and validity of the study

In accordance with Tuffrey-Wijne et al., (2008), it is crucially important for credibility of overall results to have the viewpoints of other people. In my case it is great to have the discussions with other students and teachers during thesis seminars. Thus, I received a lot of critical feedback on every stage of thesis process. Also, the responsible teacher was involved in giving me the guidance about theoretical background and its practical adoption. My own personal and professional backgrounds certainly make an impact on data analysis and its interpretation (Tuffrey-Wijne et al., 2008). Listening and interpreting the narratives shared by people put me into special moral position. As researchers, we may critically confront with attitudes, opinions and behaviours, other than our own (Tuffrey-Wijne et al., 2008). In addition, I was aware of high probability to over-interpretation of data and a desire to draw out theoretical issues or practical recommendations. Hereby, in sharing the thesis work with other students and the teachers, I minimised my own bias.

5.6 Ethical considerations

According to Harris (2003) during the research process it is very important to give the space for PwID to make the decisions for themselves. Further, Harris (2003) suggests that meanwhile attention is usually paid to a person's intellectual capacity, social and environmental factors are also vitally important. People with intellectual disability often live in such world where there is no chance to make a choice, or they are highly restricted. Moreover, PwID may be quite often unaware of choices denied to them, and that with poor information and little help in communication they have incredibly small experience of choosing (Harris, 2003). Therefore, my aim was to highly respect the right to make a choice by the participants of the study. From the very recruitment stage to story-telling the individuals were asked whether they were willing to participate, share the information so on and so forth. In the first place, people were verbally asked about their willingness to take part in the research. Before the interviews every member was informed about the aim and purposes of the research, and the ways how I am going to use received information. Moreover, as a researcher I communicated and asked people whether they do not mind if I use digital recorder.

As a first step, I received the consent to conduct the research from the host organisation "Eben-Ezer". After this, each person signed the written consent, where they agreed to be participants in the study. As I was well aware that I was going to interfere the life of another person, and I have to be careful not to do any harm. I did set for some boundaries for myself. There were a lot of sensitive topics about the family and childhood, different issues in life. Therefore, I tried to be as careful as possible do not go to the topics and issues which are not comfortable for participants to discuss.

Goodley (1996) advices researchers to treat PwID as the experts, not just the source for data. By encourage them to tell the narratives – they bring together insights and empathy; moreover, we acknowledge the subjective meaning of the story teller. It also involves a high commitment to listening, to make the interpretations of both, communications and silences, and to support the reflection process (Goodley, 1996). Thus, being empathic towards the researched people helped me to be less harmful.

6. RESEARCH FINDINGS

In this chapter you will find my reflection on the outcomes of the interviews made in accordance with the methodology previously described. The section is divided into six main themes which I identified in the Chapter 2. Each interview is allocated a number from W1 to W6 with a purpose of preserving confidentiality.

6.1 Financial life and personal sustainability

The evidence suggests that service users benefit from a person, playing the role of a guardian. Such a person can encourage and support the user regarding development of self-discipline. The role includes taking care of financial management, and response to physical needs of the PwID. The guardian may also explore the factors and forces that seem to motivate the service user best. For example, the guardian may also be an important person in the process of connecting and linking the service user to other institutions and services. Helping the service user to consider how these services might enhance or improve their lives. Trying to grasp and gain insights into experiences that capture the attention of service users – the danger, of course, is that the guardian may think that they know what is best for service user and, at worst, become too controlling. (Learning diary 30.11.2017)

In fact, the interviews proved the dependence of the majority of participants on their guardians. In most cases this was either state guardian or family member. To a large extent, such dependency is manifested in the management of finances. The evidence seems to suggest that PwID do find it very difficult to manage budgeting and the proportional use of money and sustain this over a whole month.

> *My guardian (from the city of Třinec, 15-20 km away from ČeskýTěšín, the Czech Republic) manages money: food, accommodation, cloth, pocket money, etc. It's expensive for me to visit my granny and mom more often than once in a month. Now the government want to up the amount of social benefits (600CZK more) and it's very fine with me. If I have a lot of money, I am able to spend all of them during one day. In fact, I use it for some 'crap', e.g. mobile phones, computers, so on and so forth. It has already happened to me, so I needed to ask my guardian for help (she is managing my*

> *money now). I tried to manage money myself, but it did not work out. So, I did not have money for food and other things almost for a month (W6).*

Nevertheless, in a few cases the participants have expressed an opinion of importance regarding managing their finances independently. Moreover, those who are employed can combine social benefits and salary, which is enough in the context of Český Těšín (the Czech Republic). In the cases when people are able to manage such tasks on their own, I could notice higher self-esteem. Still, the positive attitude was shown by the person living in the institution of "Eben-Ezer" (the Czech Republic), and not taking care about the finances on his/her own. Thus, it would be wrong to generalize, but very important to look at each case differently and cherish the subjectivity of research participants.

> *With the combination of working salary and social benefits I am able to manage money independently. I can buy something to myself, some things for the flat. I do my best to manage with money and it works well for me. It is not a problem for me. I pay the bills by myself at the post office (W1).*

> *I think that I have enough social benefits. My mother receives and sends the money to "Eben-Ezer". Assistant puts the money to the book (collect the money). I receive pocket money for myself (he said first 50CZK/day, and then he changed his opinion and mentioned 100CZK/day). I use this pocket money when my assistant takes me to bowling, or to the restaurant. I buy there some beer, I like it so much; I am so happy when I go there and buy some beer. We also go sometimes to candy store to have some coffee. Other money goes for paying for accommodation (W4).*

Some participants, who are less independent, during the interviews expressed a worry about the pressure of the future for them, for example, when the guardians will not be able to take care of their finances, etc. Furthermore, some had regrets about their lack of skills to take care of themselves. More developed skills would mean that they would rely less on others and having more assurance for the future.

6.2 Security and feelings of safety

My personal experience of communication with PwID and observation of a group and individual behaviour highlighted many issues related to security and personal safety. These include repetitive conflicts with other service users, staff workers, family members, and themselves. Often, PwID may become the victims of inappropriate communication, abusive phone messages, stealing of material goods, or being mistreated by the relatives, so on and so forth. The issue of security is even more relevant when the service users live in the institution like "Eben-Ezer". Repeatedly individuals complained to me about the cases of abuse, when the workers have less power to control the situation. Due to inability to solve the problems and lack of tools to make an impact on the situation, PwID look for help from the outside. Nevertheless, frequently the workers of social services or police do not take seriously the complaints from PwID, as they can barely give an explanation to what really happened. It oftentimes results in a bad mood and depression. Stereotypical thinking continues to characterize PwID as pitiful ones (Clifford Simplican, 2015). He argues that the society does not perceive the PwID as equals; thus, their security is at risk, as their problems are not taken seriously. According to Gil and Harris (2005) PwID are at great risk for exploitation, physical or sexual abuse. It is explained that due to impairment of their adaptive behaviour social stress is at great concern. (Gil and Harris, 2005)

The interviews underlined the different attitudes towards security, as a part of life, depending on either person lives independently or not. In this way, the individuals who experienced of being able to take care about themselves are more self-confident and resilient to life challenges. From one side, the participant on independent living indicated some strategies to be able to cope with security issues; e.g. emergency numbers, reaction to the conflicts on the street and so on. From the other side, these people who live with the relatives or in the institutions showed less potential to be resilient to different life events and situations. In addition, extra support for some participants is crucially important, as there are some daily routine things which they can't manage on their own. The reasons for this widely vary from physical inability to mental problems. Moreover, the participants who depend more on others have a fear about the future prospects and survival. Such thoughts make an impact on people's wellbeing and their happiness. Therefore, more dependent individuals are motivated to find the partner who can take care of them when caregivers won't be around anymore.

> *I live independently in Svibice (part of ČeskýTěšín, the Czech Republic) and for me it is much better than to live in "Eben-Ezer".* ***Why?*** *It is not so bad there, the clients are good too, but I do cherish independence. It is better for me to be able to take care about myself. I do not need any extra help from other people. I manage OK to go for shopping to the city. In my opinion, there in therapeutic workshops live only those who need extra help. It can happen that someone will get sick, or people on the wheelchairs. The person should understand that today you feel OK, but tomorrow you might turn sick, or you will be hit by the car (W1).*

> *I live with my family. In fact, I would not be able to take care about myself, because everywhere where I go I have to have a person supporting me on the way (in transport etc.). My family prepare the breakfast for me. They also help me with time management. They watch the clock for me, what time do I have to go to the bus stop. I do not know what is going to happen when my mom and dad will die. I do not know who will take care of me (W2).*

> *I live in "Eben-Ezer". As I mentioned, stealing is a big problem here in "Eben-Ezer". One man has stolen from me 50 Czech Crowns.* ***Did you tell anybody about that situation?*** *Yes, I told my assistant about this. As it turned out, assistant asked this man about the money and he lied that he has already given it back to me. But, in fact he did not. At the moment we are with my neighbour lock all the goods in the room. I lock it when I go to pedicuresessions too (W4).*

Furthermore, from the interviews I can notice stealing as a factor which makes an impact on the subjective wellbeing of people with intellectual disabilities. Participation in "Eben-Ezer" during practice placement period proved that the current issue is problematic for many service users. My perception is that it happens due to inability and lack of skills of people with intellectual disabilities to problem solve, and, added to this, disrespect amongst themselves. Again, if PwID try to bring up this issue to workers in social services, the possibility, perhaps indeed, indeed likelihood, is they will be ignored. Clear evidence here of disrespect and absence of human dignity values.

6.3 Physical health

ID is not a specific illness or disease, but it is a developmental disability (Clarke, Clarke, and Berg, 1985). It refers to adaptive functioning and cognition. Moreover, ID is not a static disorder, but it is a dynamic condition dependent on its etiology and support from the environment which is available. There is a strong association between intellectual impairment and visual impairment (Prasher, 2002). Twenty to thirty per cent of PwIDhave moderate visual impairment and 1– 5% have severe visual impairment or blindness (Prasher, 2002). In people with severe and multiple physical and intellectual impairment the prevalence rates are greater than 50% (Prasher, 2002). As with the general population, the problem increases with age. Nevertheless, in the case of the interviewed group at "Eben-Ezer" the age of people is from 22 to 38 years old. In this way, I did not notice from the interviews any increase of health problems of participants.

During the interviews the concern regarding physical health of the participants was opened up many times. Most of them expressed some problems relating to their health. For some, it was acknowledged that health aspects prevented their full participation in society. For others, it was one of the reasons why they are more dependent on their relatives or guardians.

> *I had some epileptic convulsions in my sleeping time during childhood. Also, I have the problems with walking, and it's difficult for me to go up and down the stairs…I have to give attention when I am on the road. I remember I was scared, when my brother disappeared after the hockey match. I got lost amongst strangers, but in ended up well. I can't walk well without assistance. Then, it was dark outside, and my brother was walking quickly somewhere. He walked with his friend. I should have had asked security services from the hockey arena to walk me to the car, but I was scared (W3).*

> *I like to go to bowling. But it doesn't work well for me, because I can use only one hand. It is very good that I am able to take a shower by myself, to shave. It is important for me to smell good (W4).*

> *I do not see very well. But, generally I feel good. Sometimes I had the difficulties with health. I felt very tired. From time to time I do some physical exercises at home. It is crucially important for me (W5).*

6.4 Social life

There is no full description of objective standards for assessment of quality of life, and it is likely that some individuals are quite happy (a subjective characteristic) in some objective circumstances that others would find not suitable for them (Hensel, Rose, Stenfert,Kroese, & Banks-Smith, 2002). However, what is clear is that social connections are of crucial importance especially for PwID. Individuals who are 'locked' in the institutions like "Eben-Ezer" do not get too many visitors or go to visit their relatives. Thus, they cherish even very little moments of socializations with somebody from the outside. Previous personal communication with one service user over Christmas holidays highlighted very negative mood of this woman, for a reason of received news that her relatives were not going to come for a visit to "Eben-Ezer". I can't fully understand their feelings, as I have never been locked in any institution. However, there are always visible features in person's mood that are very visible how they feel. Moreover, my participation in two different agencies emphasized that PwID due to mental impairments can barely hide their emotions. Surely a very 'normal' response in the context of anyone's SWB.

From the interviews I have learnt about the importance of the family in the life for all participants. Vital factor which influences SWB in PwID is the presence of supportive relatives (especially during childhood). Again, a very normal behavioural response. However, from another perspective, if a family member is conflictual, aggressive, and non-accepting it makes negative impact on person's wellbeing. Again, it can be argued a very normal response. Personal communication with a placement supervisor also has highlighted huge importance for the wellbeing in PwID and their relationships with the family. Those service users have good and stable relationships are generally more positive, and often it reflects on their health and life expectancy. (Michnakova, personal communication 30.10.2017)

Some of the interviewees have pointed out that when they can't handle particular situations – they do look for and appreciate external support. The support may come from the workers of social services, volunteers, friends, or familiar people. Thus, having someone 'on their side' can increase the level of person's resilience to life challenges. As it was already mentioned above in the text, due to social stress PwID are at great risk for exploitation, physical or sexual abuse (Gil and Harris, 2005). I could see the reflection of the statement of Gil and

Harris that some participants are the victims of physical and psychological abuse by their relatives. Consequently, it is often transmitted to the mood of people.

> *As a child I was often in the hospitals and institutions. I could not sit in one place. I was always running everywhere, not sitting at home. Now it is much better than it was in my childhood. I remember the situation when I was small and together with my granny we went out for groceries. I stepped to the road and did not look to the left and to the right – I felt that the car hits me. My granny ran to me, and I said: "Hi, granny, I am on that side of the road". I think that I was always lucky, when I was a child. I was staying on the other side and smiled. My granny is very good. I also remember the situation when it was cold outside, snowing, and I went to swim in the water. My granny punished us with a rod. I remember in one institution (educational institution for youth) we were jumping to the river in January. We were hardened with friends. Our educators watched us. We could not go there by ourselves. I had some understanding with people over there. From the beginning I was nervous, throw the things, but later on the doctor gave me some medicines which made me calm. And, now I am calm; probably, I should be thankful to these medicines (W6).*

> *I remember the time when I was 4 years old and I was with my grandma and grandpa. It was very good time and I have nice memories. Grandpa and grandma were looking after me, and my mom was working. My dad died when he was 69. I saw him, and then I was with my mother (W4).*

> *My brother behaves aggressively towards me. I don't understand why my brother behaves this way. My brother also behaves badly with my mom. He calls her an alcoholic in front of all the family. Together with my dad we get so upset because of this situation. I didn't want even to tell something to him. I think personally that there is nothing wrong with drinking the wine – it's not alcoholism. The family asked my older brother (he is 20 years old) to look for new accommodation. One friend of my father supported me. He said that my brother should not behave with me that way as he does. Also, sometimes my older brother comes and scares me. And then laugh. He is happy about scaring me and to leave (W3).*

Parts of the conversations with the interview participants about their family experiences during childhood are presented above. It is important here to critically reflect on the part when the interviewees' perception of the family in their adulthood was revealed. As it was illustrated through subjective viewpoints of participants, the relatives may reflect both positive and negative factor of wellbeing. Notwithstanding, each person underlined the importance of having their family and some ‘lived experience’ of being part of such a group. However, the relationship between PwID and their relatives might fluctuate between good and bad; but those who still have the family are much more open to share their experience. On the other hand, the participants who are not in touch or lost the relatives seemed to be more negative and ‘bottled up’.

> *I have two aunties and one uncle. But they think only about money, and they are not good people. I understand that people need money, but they are like: “Give them a million, and they will want more”. I think that the person needs money to pay the bills and to buy some food. I have bad relationships with my family. I don’t see them very often, because I don’t care about them (W1).*

> *Unfortunately, I don’t have any relatives anymore. I have only a brother. I live with my brother and his family. I have good relationships with my brother. We communicate with him about everything sometimes, if he has some time. My brother is happy, of course, that I live together with him. He helps me with something, if I need help. He is also my guardian. If I need some cloth or look for something in the computer, he helps me and suggests something – with different things. He helps me with managing the finances. He takes me to hockey matches sometimes. I have good relationships with brother’s family too. We communicate well together which it’s important for me (W5).*

In the narratives, the majority of the participants touched the topic of friendship and relationships with other people. In connection to what was said before, the friends are inevitably important in terms of support and for good feeling. Moreover, behind the talks regarding the topic of friendship I managed to observe that for some people it is necessary to be able to be of help to someone, ‘to love and be loved’, ‘to give and receive’. Wider social networks are also helpful in terms of better access to resources and information. The narratives with the participants evidenced, for some, the interest in the possibility romantic relationships. The sexual health of PwID is an area that has received little attention or research. Taboos and prejudice regarding the sexuality and sexual behaviour of this group have resulted in both increased vulnerability and denial that abuse can occur. They also lead to limited access to sexual health services. For some people the relationships are about survival, and for others it is a wish to love, and to take care of another human being.

> *I have many friends. There are more tolerant and less tolerant friends. I had good friendship with previous international volunteer in "Eben-Ezer". I have some people around me who need my help, and some people who manage by themselves. I know that there some homeless people too, but we all should understand that we might end up in the homelessness. I can also help to elderly people, who carry heavy bags, if they accept my help. I do not impose myself to other people, it is not the type of my character (W1).*

> *I have a friend, with whom I was coming to kindergarten and school. My mother asks him to visit me at home during Christmas time. I have another friend in "Eben-Ezer". Friendship is very important for me. I do not want to lose this friend, because I know him from the very beginning in "Eben-Ezer". In the beginning I liked another service user (woman), when we lived together in "Eben-Ezer". She had yellow hair. She wanted to be with me and said that she loves me. We were coming to the same activity in the agency (making screws). We kissed each other before the activities every morning. But, eventually she was gaining some weight more and more. I stopped liking her (W4).*

6.5 Mental health

According to Borthwick-Duffy (1994) there has been a gradual realization and acceptance that PwID experience the same range of mental disorders as do the rest of the society. However, here is now a general consensus that not only do people with intellectual impairments experience the same mental disorders but also the prevalence of mental disorder in these individuals is significantly higher. (Borthwick-Duffy, 1994)

In the interview conversations very, little evidence was mentioned or indicated about mental health issues. Therefore, it was difficult for me to make and analysis of mental state of the participants. However, I tried to critically reflect on any identifiable factors and forces which might influence, positively or negatively, the mental health of people. As was illustrated earlier, impairment of adaptive behaviour of the PwID is often results in poor response to social stress (Gil and Harris, 2005). Information was shared by one participant which evidenced the experience of a seriously dysfunctional family due to mental ill-health concerns. The view was shared that this had seriously impacted on their upbringing and experience of managing and coping with their own life experiences and challenges. Some suggestions were made that some mental health concerns, for which medication had been prescribed, had resulted or were accentuated from his earlier experiences.

> *It is very difficult for me to identify stressful situations in my life. I do not have any fears, but I do not like when people behave badly towards each other (argue and behave aggressively). I cope with it by ignoring such people, and then they can do whatever they want. It can be possible also to support those who are the victims of aggression. I can take those people aside of the conflict. It's said that we do not have the system in "Eben-Ezer" to get rid of the conflicting persons or to solve the conflict. I do not like when people complain on each other (W1).*

> *From the beginning I had a family. But I spent a big part of my childhood in the institutions. In the early childhood I was living together with my parents. Eventually, it did not work out, so my grandmother decided to take us to her place. It happened when we were little. My parents behaved aggressively towards us (me and my brother). Father used to throw some plates at us, mother defended us. My dad had some mental problems. Then, they have left us at the railways. Grandmother was following them to have a look and decided to take us to her house. Then I started to come to the institutions. At the moment, my mother lives together with a grandmother. Granny takes care about my mom. My mom has some mental problems. Now I have good relationships with granny and mother (W6).*

6.6 Emotions

In accordance with Davis et al., (2013) ID is more about social response and its perception, rather than the fact of physical or mental impairments. PwID struggle more due to unsecured, exclusive and discriminative environments; whereas acceptance and support in more sympathetic surroundings lead PwID to independent living. ("Mencap")

The interviews emphasized the difficulties of the respondents to react in the correct way to social stress, which they face in everyday life. Thence, there are many emotions, which are often mixed up and may be showed in the wrong way. People expect from others to behave logically in accordance to particular situations; nevertheless, it was proved by my practical experience that PwID may behave and show emotions not in the proper sequence. In my opinion, it often results in ignorance of the complaints by the workers of social services to PwID. Due to inappropriate demonstration of the emotions group of PwID are misinterpreted and misunderstood. Personal communication with a coordinator of social services of "Eben-

Ezer" pointed out that such institutions in the Czech Republic do not formally gather or hold any data about mental or emotional health of their 'clients' (Tomanova, personal communication 26.10.2018). Consequently, social service workers have to make an assessment about emotional state of service users by themselves. Strong focus on physical needs of PwID and miscomprehension of the emotions triggers negative impact on SBW of some service users. During the interviews critical comments were made a few times about the deterioration of the activities and lived experiences in the "Eben-Ezer" agency. Probably, the respondents saw me to be in the position of power, thinking that I am able to influence the situation in some way; even though I gave full explanation to the participants beforehand about my aim and goals. I have learnt from the conversations about the activities that people are not empowered to share their opinion with the management team of the agency. There are many things which they dislike or not satisfied with, but they can't give a proper feedback to the agency and its staff.

> *When I come for the first time to "Eben-Ezer" in 2009, I wanted to have a look around the workshops with the social worker. When my assistant did not want to make me a coffee, I have broken the cup. I was stressed and upset because of that. After, I was forced to stay in the hospital in Albrechtice. The doctors used to give me the shots and other medicines. I was tied to bed. It made me very angry (W4).*

> *I would like that something in workshops would be changed. For example: time and days when I should come. I asked today my guardian that she would allow me to have a day off on Fridays, and she would sign new contract with "Eben-Ezer"; it would result in that I don't come on Fridays. The management team of the agency want me to come 5 days a week. I don't get a pleasure from "Eben-Ezer" anymore, we argue with the workers that I don't want to do this or that. I like so much to work in glaze activity. Workers put me to do the activities which I do not like. I would love to communicate more with people and improve the relationships (W6).*

> *Sometimes I am not happy. It happened from time to time here in "Eben-Ezer". We had more activities in "Eben-Ezer" before, and now less. I am not happy about that. I mean the activities outside of "Eben-Ezer". For example, we travelled somewhere out before or after lunch, but now we do not have a lot of such travels. I become angry when people behave badly towards each other in "Eben-Ezer". Sometimes I try to help to a victim, and sometimes I ignore such situations. If I want to help, I ask a person: "Why do you that?" (W5).*

From the other side, the narratives pointed out the situations and factors which make a positive impact on their SWB. These things are strictly related to the culture (e.g. watching hockey matches) and family traditions. Immediate reflection has shown that the factors are different depending on whether a person lives independently, with a family, or in the institution. Moreover, subjective viewpoints may also very between different levels of person's freedom; e.g. those participants living in "Eben-Ezer", who are able to go to the city only once a month cherish small things and excited about something which other do not. It would never cross my mind that the cup of coffee or glass of beer in the local pub can bring big amount of joy to somebody. The narratives helped me to begin to appreciate more the subjective aspect of wellbeing of each person.

> *I like the hockey, when Třiněc (one of the local teams) plays. My assistant takes me to the hockey matches (mostly he takes me there in winter). But, I have a fear of stairs in the hockey stadium – an assistant holds and supports me on the stairs (W4).*

> *I am happy if the things work out well for me; e.g. all in general and art and crafts in "Eben-Ezer". When I do something for someone, it makes me happy. I am happy to support people. I like sports. Listen to music. Watch movies. Sometimes I visit other people. It is nice to visit other people, or when someone comes to visit me. Good to communicate with others, and to ask them such questions: "How are you?" etc. (W5).*

> *I like to take apart the computers and mobile phones, and other electronics. It is my hobby. I have learnt how to work in "Eben-Ezer", I do like computers and I do not want to change anything in my life…I like sports. I like horses, to have a ride on the horse. When I was little, my grandmother and grandfather were taking me to have a ride on the horse, and I like it. When I seat on the horse, it makes me calmer. I like also swimming and ride the bikes (W6).*

7. RECOMMENDATIONS TO “EBEN-EZER” AGENCY

In the above, I have identified a range of conclusions based on the narratives, and my analysis of these, relating to SWB and ID. The findings, in my view, based on my research findings identify some challenges and considerations particularly for “Eben-Ezer” agency. A reminder here that I have direct experience of being on the staff of this agency albeit for a short period of time. The intention is to structure these challenges as recommendations for the ”Eben-Ezer” agency. The recommendations aim to suggest ways that the agency might consider to enhance, improve and develop the service it offers to its user group of PwID.

7.1 Consider use of language and externalizing conversations

Society tends to see PwID as an issue themselves (White, 1991). Each of us lives a life in accordance with the stories which we tell ourselves and are told by others. In this way, if we hear and feel bad attitude towards ourselves, we usually do not step outside of these dominant stories. Supportive and encouraging environments influence very positively SWB not least for PwID. Some of the stories which we tell ourselves and are told by others promote competence and wellbeing, while others serve as constraint, marginalize, or pathologize ourselves (White and Epston, 1990). From my research and findings, previous experiences and the interviews’ outputs highlighted the issues of the participants in terms of the language used towards them. Continuous conflict situations with other service users, family members and the workers of social services can be a risk and have a negative impact on SWB in PwID. Therefore, the professionals who work in the field of social services and ID should be aware of the consequences of discriminatory language used towards service users. PwID should be seen as people first and as ‘handicapped’ in some way after that (White and Epston, 1990). Clifford Simplican (2015) argues that PwID are often undervalued in many cases, and as a result it makes an impact on their overall mood.

Addy (2011) states that people ‘on the margins’ tend to ‘mirror’ the assumptions of other people made about them. PwID most of the time are viewed in a ‘negative light’ by the rest of the society. Personal experience and the results of the narratives proved that current aspect makes great impact on SWB in PwID. Thus, human dignity of PwID is under the threat. Based on this, I would recommend that the workers of social services ("Eben-Ezer") at all levels, consider how the assumptions, language and communications are used to ensure that it does not reinforce any negative reputation. Instead, more positively and constructively they can locate the problem in the context of the wholeness of people's lives. As an example, White and Epston (1990) suggest instead of saying: "David is depressed", say: "David struggles with depression". It can give a chance to a person with intellectual disability to view the problem and themselves differently. (White and Epston, 1990)

7.2 Create the projects for empowerment of PwID

From my experiences of involvement in "Eben-Ezer" agency, and the results of interviews in particular, have confirmed the impression that the service users have a little opportunity to engage in decision making. As it was presented in findings chapter, the participants have a lot of ideas for improvements of the services and the activities. Unfortunately, they often feel that there is nobody who will listen to them and take them seriously. The emphasis in "Eben-Ezer" seems to be placed on management control and support, and a highly structured programme. As it was underlined in the section on Human Dignity in Chapter 2, social workers and the workers of social services place themselves closer to 'system world', rather than to 'life world' of the service users. As a result, PwID in "Eben-Ezer" feel disempowered in terms of decision making and giving feedback. Staff routines are quite formalized and tend to be repetitive and not have the response to users' needs concerns and interests. Overall, in my opinion, such an environment makes PwID more dependent, less participative and certainly not experiencing positive engagement and social integration. The narratives proved that the people with the skills necessary for independent living are more resilient and positive about the life challenges. Due to my experience, the situation described above is perhaps not surprising in the Czech context. Bynner's research shows that PwID are not encouraged to participate in the economic, social and cultural life of the society in which they live, as a consequence of a range of factors (Bynner, 2003). In day to day situations PwID are often ignored by others, and, certainly discouraged to participate in decision making processes. Instead, they are taught to think less and follow the rules (Michnakova, personal communication 6.12.2017). In my opinion, staff in "Eben-Ezer" (as Christian based organisation) should make a commitment to ensure human dignity of each service user by launching the projects directed to empowerment and inclusion. The idea can be based on theological perspective on human dignity that the main focus should be made on relational concepts and common grace for all as a foundation of life in community.

During practice placement period in “Eben-Ezer” agency I developed and conducted the “Peer-Mentoring Project”, which was focused on aspects and elements of empowerment of the participants - personal development of service users, capacity building, mutual sharing of skills and talents, human dignity, and respect of the rights of a person. The project was helpful in the way of recognizing potential, enhancing growth and encouraging discovery of personal strengths. I recognised that many of these ideas were very close to the practice approaches a community development worker might use when building up confidence and collective capacity in a community group. The main idea of the project was to use the strengths of the more experienced person to improve the strengths of less experienced individual. The results and success of the project were recognized by both the participants and the management team of “Eben-Ezer”. The service users enjoyed the experience of participating in the current project and they wanted to take part in further similar initiatives. Every participant showed the signs of development and admitted revolutionary nature of this initiative which made an impact on their lives. My suggestion would be to create and run in “Eben-Ezer” similar initiatives, which can positively influence SWB of the service users and empower them for decision making. It is important to record that the management team at “Eben-Ezer” were supportive of the “Peer-Mentoring Project” – perhaps a little hesitant in the beginning, but certainly encouraging as the project progressed and concluded. Hereby, whilst the evidence is that practice at “Eben-Ezer” would benefit from improvement, hence the recommendation, the agency response to the “Peer-Mentoring Project” was encouraging indicating the potential for change given encouragement and a lead.

In this section I would like to present an example of successful practice which could apply to the context of “Eben-Ezer”. The British organisation “Mencap” focused on work with PwID and one or two UK universities learning programmes in social work and nursing have recruited PwID to play a formal educational teaching role engaging directly with the students in professional training. Recognition, through these examples, that PwID have the capacities and skills to play such roles. As it was mentioned above, the service users in “Eben-Ezer” for the first time in their life got a chance to experience themselves in the role of teachers or providing ‘learning support’ in the “Peer-Mentoring Project”. In my opinion, these ideas can be picked up by social workers in “Eben-Ezer” and be brought to the practical level.

7.3 Work on changing the attitudes towards PwID

As highlighted in the Chapter 3, more critical consideration of our understanding and the attitudes towards ID may help to negate the stereotypes that erode human capacities that are essential for the flourishing of human beings and their relationships (Clifford Simplican, 2015). There is present an argument about manufactured nature of these negative attitudes, and it has long roots to the history of segregation and discrimination. Therefore, positive effort of PwID is often underestimated. Throughout the interviews, with a usage of the method of data analysis, called “interpretation of suspicion”, behind the words of the participants I could feel the presence of negative societal attitudes towards them. The examples were presented in the Chapter 6 “Research Findings and Results”, and these include the workers of social services, the guardians in some cases, and other people. These attitudes exist despite the legislative base of “Convention on the rights of Persons with Disabilities” (CRPD), which was accepted and signed by the Czech Republic on 28th of October 2009. The document strictly forbids any sign of discrimination towards the individuals with disability and calls to respect human dignity of each person.

As it was mentioned in Chapter 2, there are successful practices by “Mencap” (the UK) on working for improving SWB of PwID. In my opinion these practices could be implemented in the context of “Eben-Ezer” (the Czech Republic). As a key they have an idea of promoting good attitudes towards PwID. Similar to the Czech Republic, there are still a lot of individuals in the United Kingdom who feel socially excluded and exposed to unwelcome and aggressive behaviours. The exclusion is related to the spheres of equal participation in education, employment, leisure and social pursuits. Argyle (2001) argues that these aspects are the parts of quality of life, and straightforwardly influence SWB of an individual. Also, similar to the Czech Republic, very small percentage of PwID have employment in the UK (7%). “Mencap” suggests some actions towards tackling negative attitudes to PwID. Furthermore, the organisation aims at breaking down the barriers that prevent PwID from the societal acceptance, from accessing wide range of opportunities and positive experiences. These aims are based on UN Convention on the Rights of Persons with Disabilities. “Mencap” has managed the following interventions for promoting SBW of PwID, which can be implemented in the context of “Eben-Ezer”:

- Provide special education designed to promote inclusion and more positive attitudes via the websites, leaflets and social media;
- Included educational approaches that attempt to challenge misconceptions by providing factual information;
- Create film interventions to explain what intellectual disability is and show PwID in positive roles, while also highlighting injustices they experience.

To conclude, all these recommendations are supported by the theory and practices useful for promoting better SWB of PwID. Moreover, necessity for such actions can be justified by the conclusions made upon the interviews during the research process. In my opinion, “Eben-Ezer” agency and its service users would benefit greatly if these recommendations would be taken seriously at an operational level.

8. REFLECTION

In this section I will present the reflection on the process of the research and feedback received from the agency. Furthermore, I will reflect on my personal and professional growth throughout the study.

8.1 Reflection on research process

The current study has been very enriching for my own growth. First of all, it has helped me to build deeper understanding of ID and, in particular, SWB. Secondly, current thesis work may be very useful for future use to other professionals, as this topic is not so well developed in Český Těšín. During working on the research I gained many new skills. This was the first big experience of using qualitative research and the narrative method for data collection. I got familiar with new methodology on analysing the data through “interpretation of faith” and “interpretation of suspicion”, and I have learnt how to use these two in tandem.

Through reviewing the literature, I became acquainted with the new concept of SWB and its connection to PwID. Different sources gave me the chance to be able to compare a variety of definitions, and to choose some of them which are the most suitable for my context. Rich previous experience of practicing in the field of ID supported me on the way to conduct the current study. Literature review was also very supportive in terms of finding correct methods and approaches, which suited the best for the chosen concepts and group of researched individuals. For example, I have learnt that there is a danger in narratives that a researcher will hear what he wants, instead of listening to what people actually say. Consequently, it could lead to a way of writing a ‘nice story’, rather than the ‘true reality’.

Furthermore, aiming at the factors and forces influencing SWB in PwID supported me on the way of cherishing the different opinions and viewpoints of the participants. Basically, such an exercise helped me to become more open-minded and look at the same issue from different angles. The narrative approach to data collection involved me into the process as a passive listener who gives a lot of space to researched individuals. Usually it is not very common for me to be in such role; rather, I am more active in terms of giving the questions and leading the flow of the conversations. Nevertheless, through this study I have learned how to provide the necessary space for people to be involved in the research as participants.

As I mentioned in the previous chapters, I have managed to build on earlier contact with a group of the researched individuals. All of them took part in “Peer-Mentoring Project” which was conducted a few months earlier. Due to this positive experience and successful outcomes of the project people agreed to become the participants of the current study. This helped me to anticipate and properly organize the flow of the research, as I knew personal traits of those individuals. For instance, some persons preferred to talk more; thus, they did not need a lot of effort from my side to support the conversations. On other hand, there were the service users who prefer to be quiet and guided in thinking and answering to the questions. Nevertheless, I had unexpected events during the interviews, and I have learned how to be more flexible. One of the participants could not come for the interview, so I needed to organize it in other time close to the place where he lives (due to the surgery he could not walk very far). Eventually, I conducted the interview with one participant in the local pizza house. Moreover, during some interviews we were distracted by other service users, or the wind and cold weather was a distraction for the participants when meeting in the room upstairs. Therefore, I should have been prepared and have extra tools for organizing the interviews in such conditions.

In addition, there were participants who are not confident or had experienced some abuse in one way or another throughout their life. The interviews aimed to discover different life events and conditions which people experienced in different age and stage. I was very interested to collect as much data as possible, to be able to use it for my research and look for the factors and forces which influence SWB in PwID. The current study taught me to be respectful to the personal space of people, and not being pushy if a person is not willing to share this or that information. Unfortunately, not being very good in Czech language played against me, and sometimes I could not understand very well the moment when I have to stop asking the questions and change the topic. Later on, during listening to the recordings I recognized some of the mistakes which I have made, and I decided to change the style of leading the conversations in the following interviews.

Furthermore, I have learnt from the studies how to use less discriminatory language. I was very careful in terms of situating a person and the problem separately from each other. It was good learning to use externalizing conversations, which is a helpful method suggested in the literature as a way for a person to view himself or herself separately from the problem/issue.

Moreover, I have made an effort to be empathetic towards researched individuals; in other words – ‘try to walk in their shoes’. I realized that many of them speak about very painful experiences and looked for support and understanding from my side. This attitude was helpful in terms of creating secure and trustful atmosphere during the story-telling for research participants. They were more able to be open to sharing their life events, ups and downs etc. We agreed with the service users that they can express their viewpoints and positions in any way they like. One participant asked me whether she can use swearwords for expressing herself, and I answered positively. Generally, I tried to involve PwID into the conversations in the way that doesn’t make the participants wrong, I considered different opinions without being defensive or intrusive.

As previously mentioned, being a Ukrainian student who never experienced intellectual disability can be a problematic in terms of fully understanding the issues and problems which are expressed by researched individuals. Nevertheless, current study influenced the way I now now‘see’ and ‘hear’ PwID.

8.2 Reflection on feedback to “Eben-Ezer” agency

In the early project planning stage, it was agreed that I would offer a structured feedback to an agency representative, regarding my project including any possible recommendations. It was subsequently agreed that this would in the form of a presentation (PPT) to a social worker in the social therapeutic workshops “Eben-Ezer”. It was envisaged that time would be available for some discussion in response to the presentation concerning her understanding and any feedback to me, relating to the research. I concluded that my presentation, be although a little structured and formal, also would include the developments and logic of thesis work as follows:

- Aim and goals;
- Research questions;
- Key concepts;
- Findings;
- Recommendations to the agency.

Here I would like to present summative comments on the discussion and dialogue with the social worker following the presentation. Firstly, the social worker was very interested to hear overall results of the study and the suggestions for improvement of SWB in PwID. As I have reported earlier, the agency had always been very receptive to my suggestions and ideas. I have always been encouraged by this and it gave the feeling that management team of the agency is very open for new initiatives and changes. Thus, the idea of conducting a current research was warmly welcomed by the staff from the beginning of my involvement with the agency.

The social worker in this feedback discussion was complimentary about how the research had been progressed and about such a positive response from the user group participants. However, I noted a protective and defensive attitude on the part of the social worker relating to the feedback about the agency's norms and ways of working. I had obviously been very careful and sensitive about how the feedback was expressed. For example, the social worker tried to assure me that the agency was taking all the possible steps to make a positive impact on improving SWB of PwID. The limitations of "Eben-Ezer" agency, as a part of bigger organisation "Slezská Diakonie" were also highlighted. Further, another cautious response was shown towards 'good' suggestions arising from the research findings, and how these might be considered for their possible implementation in the future. For instance, the social worker agreed on the importance of utilizing externalizing conversations towards PwID. At the same time, she has highlighted existing internal policy on use of more positive and motivating language in the direction of service users. Furthermore, the suggestion of launching new projects based on empowerment of PwID was understood well (through the "Peer-Mentoring Project" launched earlier), and, as mentioned before, the management team are considering organizing something similar. I realized from her comments and reflective feedback that perhaps during the stages of data collection and data analysis I had misunderstood some agency processes. That included the mechanism for feedback from users which, basically, exists in the agency and, to certain extent, functions well in the context of their system and organisational culture. To conclude, this feedback to the agency was another learning process for me to understand what ways of functioning of the agency, and to compare it with what was found in the research, and what I could improve. We concluded with some of the dilemmas and challenges for implementation of the findings and suggestions offered based on my findings and analysis. We briefly discussed how the Czech Republic at the state level seeks to implement new social policy on the inclusion of all people without perhaps fuller consideration of the special needs of PwID. It was mentioned that in the "Eben-Ezer" context an individual approach to PwID and SWB would continue to be a specific challenge and be important for ongoing staff development and evolution of the activities. It was acknowledged that the “Peer-Mentoring Project”, despite the limitations of time, had acted in a small way as one ‘sign post’ or ‘indicator’ with the potential for further development in the future.

We both agreed that for ensuring human dignity of service users staff should have a long-term commitment to work with PwID individually and relationally, taking into account specific needs. All in all, the recommendations were considered seriously and taken for further consideration in the light of existing internal and external policy. In addition, the aim, goals and possibilities of the agency, as a part of bigger Christian organisation “Slezská Diakonie” were discussed. Finally, we concluded that that discussion and reflection had been useful and important critical sharing of thoughts and ideas.

9. CONCLUSION

Overall, the research project has been fruitful and productive. As indicated in the introduction the aim was to critically reflect on and search for the factors and forces, which influence SWB in PwID. Essentially, the main idea was to gather evidence and views from research participants, selected from the "Eben-Ezer" agency, and, through listening to their life stories cherish the subjectivity of each story-teller relating to their lived experiences. Some broad conclusions can be identified as important starting point to consider for service providers and social workers.

9.1 Value and ethical base line

Engaging in research relating to and involving PwID requires critical reflection on one's own personal values, assumptions and perceptions. Also, it is crucially important to remember how these have been influenced by one's own life experiences and social background. The narratives from participants highlighted a complicated picture of different life conditions and evidence of a personal level of resilience relating to each participant. This makes it inappropriate and impossible to generalise what is the best for everyone. The research illustrated clearly that some PwID have the capacity to enjoy independent living and to take care of themselves. Others, however, require extra support to feel secure and happy in accordance with their aspirations, personal capacity, needs and abilities.

9.2 Issues of human dignity of PwID

Society in general, the social structure systems and the professionals working in social services must address the challenge that their attitudes and practice may be undermining the respect and dignity of PwID. Concerns relating to the undermining of respect and dignity were experienced and observed in some of the practices in the organisation where the research was conducted. I draw the evidence from the narratives, where it has been highlighted that some of the participants have not been listened to and understood. Further, the interviews brought to my attention some thoughts that PwID experience being viewed by the rest of the society as unable and not equal. Family life for some may also prove from time to time to be oppressive and not respectful towards their own family members.

9.3 Empowerment and inclusivity

The project findings underline the importance of recognising that each person with ID is someone who has a biography that is unique to them. Basically, the challenge for professional carers is to explore and share with them a critical reflection on their lived experiences and the impact of this on their lives. The research process adopted narrative process which was helpful in providing PwID with the necessary space for thinking and remembering different aspects of their lives, embracing positive and negative moments and different emotions. It can be concluded, as reported in previous chapters, that this has been done with the use of externalizing conversations and empathetic approaches; with the purpose of grasping the various subjective views of the participants' understanding of SWB. Indeed, some participants acknowledged the role of narrative method as an interesting learning opportunity for them. Also, it can be concluded that the process helped others to set properly and chronologically different events in their life and make some critical reflection on these. Overall, the research process and narrative approach had proved been empowering and constructive regarding making sense of the lives of participants. In fact, there was not a single question which required a simple answer like 'yes' or 'no'; rather, most of them were shaped in the way with a purpose of make a person to think and analyse the range of events and feelings. Consequently, the narrative method was empowering in the process of the research towards PwID.

9.4 Family relationships and social networks

It can be concluded that family life and regular contact with relatives is an important aspect for SWB in PwID. The analysis of the interviews substantially supported this view. Close relationships with their family members in most cases makes a very positive impact on the lives of the participants. However, important to draw attention to some evidence which suggest that neglect and negative attitude showed by the relatives may also be an ill-disposed force for SWB. For example, I have drawn attention in earlier chapters how a family may discourage their family members with ID to participate in employment activities and how this has the potential to contradict some of the aims and objectives of agencies such as "Eben-Ezer". I have also drawn attention to how this might be influenced by a family's economics which are over-dependent on social benefits gained through one of their members being intellectually disabled. Taking some of these aspects into account I came to conclusion that it is crucially important for the "Eben-Ezer" agency, and other agencies responding to the concerns of PwID, to find ways of collaborating with their families. More consideration should be extended to sensitively supporting and encouraging families to critically reflect on how they relate to their family members who have ID. In my view, supported by evidence from this research, it should be considered as an important potential role for social workers and the agencies like "Eben-Ezer".

Finally, I can conclude that the current research project has been an interesting and challenging experience. It has always been clear that the research would have its limitations regarding the producing of evidence and in-depth insights relating to SWB in PwID. However, it has proven to be a substantial and significant personal and professional learning experience for me, as a researcher. This type of research and model of using narratives was new and demanded skills and careful consideration in how work was progressed. The ethical and value aspects were particularly challenging – engagement and relationship with individual participants with ID was difficult and at times emotional in their open response to my involvement in their lives. Unfortunately, due to time limitation I did not manage to bring the results of the research to the participants themselves. In fact, sharing the feedback with the service users could be empowering process for them. Nevertheless, I believe that the agency will take seriously some recommendations and apply them to the working process in the future. In this way, the participants will benefit from my cooperation with the social worker of the agency. In the future practice I will consider deeper involvement of the service users into the process of the research. The focus of the research has drawn attention to wider societal and structural concerns and how these can be so discriminatory and disrespectful to human dignity of the ordinary people who, unfortunately, have a disability.

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ABBREVIATIONS

ID	Intellectual Disability
PwID	People with Intellectual Disabilities
SWB	Subjective Wellbeing

APPENDIX 1: Supportive questions

As it was mentioned in the Chapters 4 and 5 the narrative approach to data collection was utilized. Thus, any preliminary questions were not prepared for the interviews. Nevertheless, the conversations were shaped around six areas of a life of a person: financial life, security, physical health, social life, mental health, and emotional life. In looking for the factors and forces making an impact on SBW of a person, during the interviews I followed the suggestions given by Etherington (n.d.), to make the conversations as much open as possible. For this purpose I prepared the set of questions which meant to enhance the conversations. Such questions were also helpful to interviewed individuals, as they could build some chronology and logic of the events in their head.

Real life experiences

- What could you see/hear? How did it look to you?
- What was your sense of what was going on?
- How did you cope with that?
- How did that affect you? Make you feel/think?
- How did you feel about what he/she did?

Significance of other people

- What did your family think of that?
- Who told you?
- Did you ask anyone for help?
- Was anybody else aware of what was happening?
- Where were your friends?

Choices and actions

- What made you decide to go there?
- Why did you want to do that?
- What were you intending?
- What did you want to happen?
- When did you decide that?

Historical continuity

- What was happening in the rest of your life at that time?
- What year was that?
- How old were you?
- Were you still at school then?
- Did you get there eventually?

Metaphors and symbols

- What was that like?
- Do you have an image of that?
- Did that put you in mind of something?
- Could you draw me a picture of that in words?
- Can you say a bit more about that?

Cultural contextual (values, beliefs, habits)

- How did you know that?
- Why do you think that happened?
- What did you think about that?
- Was that something you usually did?
- Was that OK with you

APPENDIX 2: List of figures, tables and pictures