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Erasmus Mundus Master's Programme in Social Work with Children and Youth

Lived experiences of young adults with Intellectual Disabilities: exploring their Social Inclusion pathways

#### **IEVA JOKSTE**

Author

#### PhD. Pablo Álvarez-Pérez

Assistant Professor ISCTE - University Institute of Lisbon *Supervisor* 

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## **ABSTRACT**

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Inclusion pathways

**Author:** Ieva Jokste

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This study was carried out to develop a more in-depth understanding of the experience of Social Inclusion among young adults with intellectual disabilities living in the community and attending formal programs. To date, this type of research on people's individual experiences and their interpretation is lacking, especially in the Latvian context- the country is undertaking significant reforms to promote the inclusion of people with disabilities in society. This research is based on the recognition of Social Inclusion as an essentially relative and subjective phenomenon that occurs as an interaction and evolving process between spending time in activities that create meaningful participation, having meaningful interpersonal relationships, and a sense of belonging.

The results of the study were obtained by interviewing ten young adults about their experiences of Social Inclusion and were analyzed by applying Interpretative Phenomenological Analysis. The themes that emerged from the participants' narratives show that despite living in the community and receiving community-based services, their social inclusion mainly occurred in segregated settings, as their interactions with mainstream society were highly limited. Nevertheless, formal programs served as Social Inclusion havens because they allowed participants to spend their time in diverse and exciting activities, were a place for socialization and meeting friends, and gave participants a strong sense of belonging.

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# LIST OF ABBREVIATIONS

#### **Abbreviations Definitions**

DI Deinstitutionalization<br/>ID Intellectual Disability

IPA Interpretative Phenomenological Analysis

## INTRODUCTION

Research on topics concerning people with intellectual disabilities (ID) is of utmost importance. Several key reasons drive this research, each highlighting its importance and relevance. First of all, in 2023, Latvia concluded a deinstitutionalization (DI) project funded by the European Union, which focused on the establishment of a service system that would provide people with intellectual disabilities with community-based services that could enable them to live in a society (mainly group flats, specialized workshops and daycare centers). Although the final results of the project are not yet available, and there are some concerns regarding the implementation process and its sustainability (Anča & Neimane 2017), it is clear that the DI (Deinstitutionalization) project has created an opportunity for Latvia, along with several other countries in Central and Eastern Europe, to significantly advance the inclusion of people with intellectual disabilities in society, finally moving away from the legacy of post-Soviet institutionalization tradition and following in the footsteps of other Global North countries in their disability policy with a nearly half-century delay.

Secondly, people with intellectual disabilities have a fundamental right to Social Inclusion, and it is recognized as one of the central dimensions of the quality of life. (Buntinx & Schalock, 2010; Jacinto et al., 2023). Given its immense influence on the overall life experience and well-being, it has understandably become one of the most important processes and goals in the lives of people with intellectual disabilities.(Grung et al., 2023). However, despite various efforts to promote Social Inclusion, people with intellectual disabilities remain one of the most marginalized groups in society, and there is a huge gap between Social Inclusion policies and the realities of daily life that people with intellectual disabilities face. (Overmars-Marx et al., 2019).

In recent years, Latvia has experienced rapid growth in terms of services available for people with Intellectual Disability that are targeted at including those individuals in the community (Ministry of Welfare of the Republic of Latvia, 2023). A considerable part of them are young adults living with their parents and attending a daycare center or specialized workshop. However, almost nothing is known about the perspectives of these people who are benefiting from those services and living in the community. Based on a framework that defines Social Inclusion as a personal and subjective experience, this study seeks to fill this research gap.

This study aims to explore how young adults with Intellectual disabilities living in a community and attending daycare centers or specialized workshops experience and make sense of their Social Inclusion based on their individual and lived perspectives. Specific objectives of this study are to first investigate the structure and involvement level of community participation among young adults with intellectual

disabilities and explore the subjective meaning of significance they derive from various activities in diverse settings shaping their Social Inclusion experience; secondly, to investigate, among young adults with intellectual disabilities, the structure, function, meaning, and significance of interpersonal relationships in regard to their inclusion experience, and thirdly, to correlate and categorize ways of belonging in regard to the Social Inclusion of young adults with Intellectual Disability.

Social Inclusion is a contested concept. Even though it has been one of the central themes in disability studies for a long time, when it comes to people with ID, it has focussed mostly on objective measurements and proxy informants that alone do not capture the phenomenon. Currently, there is a growing body of research acknowledging the subjective character of social inclusion, defining it as something that is more relative in nature and can be understood through exploring personal and individual experiences and interpretations (e.g. Bredewold & van der Weele, 2022; Hall, 2010; Merrells et al., 2019). Applying interpretative phenomenological analysis (IPA) as methodology, this research seeks to capture the subjective realities of ten young adults, closely examining and interpreting their experiences of community participation, interpersonal relationships, and sense of belonging, identifying them as core dimensions of Social Inclusion that can be understood through ecological framework.

This study consists of five chapters: The Literature Review describes the emergence of the concepts of intellectual disability and Social Inclusion, provides an overview of current trends in Social Inclusion research, and presents a broader view of the Latvian context, focusing on the recent deinstitutionalization process. The Theoretical Framework defines the concept of Social Inclusion and provides a detailed description of its dimensions; the Methodology chapter contains a general overview of the research process and provides a justification of the chosen approach. This is followed by a chapter presenting the themes identified through the Interpretative phenomenological analysis (IPA) and their analysis, and finally, the thesis ends with conclusions.

Overall, this study aims to promote a more holistic understanding of the Social Inclusion of people with an ID that can inform more inclusive and person-centered support mechanisms for people with intellectual disabilities and, therefore, contribute to the shift towards a more inclusive and equitable society.

## **CHAPTER I - LITERATURE REVIEW**

To contextualize and clarify the rationale for this thesis, the first chapter provides a concise overview of the genesis of Intellectual Disability and Social Inclusion perceptions, as well as the current state of the art. The chapter continues with a brief description of Young Adults as a specific group in society, particularly within the prism of Intellectual Disability. Further, this chapter gives an insight into current Social Inclusion research and reviews studies carried out in recent years focusing on the experience of Social Inclusion among young adults with intellectual disabilities. This review consists of three blocks that characterize the main themes in the research: firstly, the post-institutionalization era's interest in the experience of inclusion in a particular setting or context; secondly, research on the role of social ties in the experience of inclusion, and finally, Social Inclusion as a subjective experience. A separate section is devoted to contextualizing the situation of young adults with Intellectual Disabilities in Latvia.

### 1.1 Understanding Intellectual Disability

Over the last century, society has undergone several major paradigm shifts that have, among other things, transformed the way it looks at people with differences and various minority groups, including people with intellectual disabilities. To be able to talk about the experience of Social Inclusion, firstly, it is important to understand the nature of the changes that led to the concept of Intellectual Disability as we know it now.

### 1.1.1. From medical to social disability model

Disability studies, disability policies, and rights have been, to a great extent, shaped by disability models (Lawson & Beckett, 2020). The construct of disability has undergone a shift in recent decades from a focus on impairment/deficiency to a socio-ecological person-environment fit. Briefly, however, it should be noted that historically, the oldest model of looking at different types of disability is the religious/moral model; namely, the problems of disabled people have been explained in terms of divine punishment, karma, or moral failing (Retief & Letoša, 2018). In the mid-19th century, the religious/moral model was gradually replaced by the medical model, which dominated for more than a century and is still, to a certain extent, present today. Within the medical model, disability is interpreted as an individual medical problem - a pathology. It follows that disability is a condition that needs to be healed as far as possible. Within this model, people with disabilities are patients, and they are expected to avail themselves of the variety of services offered to them (Retief & Letšosa, 2018)

Calls for a reassessment of the appropriateness of such a model emerged in the 1970s, spurred by the disability rights movement. This movement criticized the over-medicalized and individualist narratives surrounding disability (Beaudry, 2016). To replace the generally accepted medical model, which is individual in nature and focuses on a person's medical diagnosis or impairment, the Social Model was proposed. The Social Model views disability not as characteristic of a person's illnesses that must be cured but rather as a form of oppression- a socially constructed phenomenon emphasizing that people are mostly disabled by societal and environmental factors and discrimination, not only by their medical condition (Shakespeare, 2006). The social model proposes to view disability as a match between a person's abilities and the context in which they function (Broka, 2017). Adaptation of this model has contributed to changes in policies and practices in many countries that promote the inclusion and rights of people with disabilities, led to a process of deinstitutionalization and development of supported employment/living and other community-based support mechanisms, and contributed to overall empowerment of people with disabilities (Giri et al., 2021).

### 1.1.2. Intellectual Disability defined

From this paradigm shift, the concept of Intellectual Disability emerged. As a concept, it was proposed in order to better understand a person's environment as well as its social interface within the environment and replace terms that only concentrate on describing particular neurobiological deficits. (Broka, 2017).

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) is a diagnostic tool published by the American Psychiatric Association. It defines intellectual disabilities as neurodevelopmental disorders that start in childhood and are characterized by deficits in adaptive functioning that significantly hamper conforming to developmental and sociocultural standards for the individual's independence and ability to meet their social responsibility and deficits in intellectual functioning —"reasoning, problem-solving, planning, abstract thinking, judgment, academic learning, and learning from experience" (APA, 2013, p. 33).

The severity of Intellectual Disability can vary widely, and individuals with this condition may require varying degrees of support and accommodations to lead fulfilling lives. The following table (Table 1) demonstrates the classification of Intellectual Disability severity as described in the Diagnostic and Statistical Manual of Mental Disorders, fourth and fifth editions, and by the American Association on Intellectual and Developmental Disabilities (AAIDD).

Severity Category	Approximate Percent Distribution of Cases by Severity	DSM-IV Criteria (severity levels were based only on IQ categories)	DSM-5 Criteria (severity classified on the basis of daily skills)	AAIDD Criteria (severity classified on the basis of intensity of support needed)
Mild	85%	Approximate IQ range 50–69	Can live independently with minimum levels of support.	Intermittent support needed during transitions or periods of uncertainty.
Moderate	10%	Approximate IQ range 36–49	Independent living may be achieved with moderate levels of support, such as those available in group homes.	Limited support needed in daily situations.
Severe	3.5%	Approximate IQ range 20–35	Requires daily assistance with self-care activities and safety supervision.	Extensive support needed for daily activities.
Profound	1.5%	IQ <20	Requires 24-hour care.	Pervasive support needed for every aspect of daily routines.

Table 1: Classifications of Intellectual Disability Severity (Boat, 2015)

### 1.1.3. Framing the "young adults" notion within Intellectual Disability

Young adulthood is a period in a person's life course between adolescence and middle-aged adulthood, which, as a concept, has taken shape in recent decades thanks to the process of societal change. It is a social construct, rather than objective reality, inextricably linked to biological age, and thus, there is no normative path or gold standard for defining what a young adult is. However, it can be understood through several social, psychological, and legal markers of this transitional period in a person's life. (Settersten et al., 2015). Young adulthood is a time of growth, transition, and preparation for full adult life. This period is distinguished by major developmental tasks that enable the young adult to engage in self-exploration in order to develop a personal identity and belief system while acquiring a sense of independence and autonomy. (Higley, 2019).

There is no common consensus on exactly what age group is included in the definition of young adulthood, and there is disagreement among several experts and organizations on this issue. Also, young adults are often not singled out as a separate group but considered as part of a broader youth group. Different definitions include people aged 15 to 40, but more common are definitions that define young adulthood as people aged 18 (adulthood) to 24/25 (Higley, 2019; Society for Adolescent Health and Medicine, 2017), and these age brackets vary depending on such factors as geographic, cultural, economic and other contexts

(Settersten et al., 2015). In studies of young adults with intellectual disabilities, authors have paid little attention to the details of the young adulthood age rationale; given the specific characteristics of people with intellectual disabilities, more emphasis is put on other markers so it can be that people up to the age of 35 are also included in the studies (Hall, 2017).

Although Social Inclusion has been given a very important role in disability studies, little research is dedicated particularly to the hearing voices and experiences of young adults with Intellectual Disability as a separate group (Hall, 2017; Merrells et al., 2019). It is a significant phase of life as it marks a shift towards independence and self-reliance. Maintaining social connectedness is crucial for young adults, especially as they transition from the school environment to adult life, to ensure their well-being and quality of life. (Hall, 2017). At the same time, reaching the age of majority marks a significant change in an individual's legal status and relationship with the state (thus, the support a person can receive). When researching Social Inclusion or related questions, young adults with intellectual disabilities are often part of a bigger group identified as a youth (including minors from early adolescence) (e.g. Renwick et al., 2019) Or are part of the adult group without a more narrow age specification where often it is actually young adults that make up a great part of participants. (Corby et al., 2020; Ramsey et al., 2022; Wilson et al., 2017). Another group, in which a large number of participants are typically framed as young adults, is research about the experience of Social Inclusion in a particular context, most often in an educational setting. (e.g. Robinson et al., 2020). Finally, the group that probably overlaps most with the "young adults" notion we are interested in is youth in transition to adulthood. (e.g. Scanlon & Doyle, 2021) As a longer process that also includes people younger than 18 (Garolera et al., 2021). Although these above-mentioned groups only partially cover young adults with intellectual disabilities, research on youth and adults, as well as on people with intellectual disabilities in general without a specific age bracket, makes an important contribution to a better understanding of issues related to the Social Inclusion of young adults. For example, Louw et al. (2019), in their systemic review of original empirical studies that focus on the enhancement of Social Inclusion among young adults with intellectual disabilities, include some studies where young adults are only part of the research participants, thus suggesting that issues concerning the Social Inclusion of young adults, while with their own specificities, are also to a large extent related in the context of other age groups.

### 1.1.4. Importance of Social Inclusion for people with Intellectual disabilities

Due to the change in models of disability described above and the emergence of a concept of Intellectual Disability, it is quite understandable that the idea of Social Inclusion as one of the central components of a good life is emerging. Social Inclusion for people with intellectual disabilities is important

for several reasons. First of all, its importance is clearly revealed in the key global disability document-Social Inclusion is stated as a general principle (article 3), a general obligation (article 4), and a right (articles 29 and 30) in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006). The Convention stresses that people with intellectual disabilities are equal members of society and, therefore, entitled to the full and equal enjoyment of all human rights and fundamental freedoms. Similar and Convention-derived principles related to Social Inclusion are a central theme addressed through the implementation of various policies, community-based services, and support systems in a large number of countries and communities in the Western world (Grung et al., 2023).

Secondly, social inclusion is one of the core life experiences a person has. (Grung et al., 2023). Positive experience of Social Inclusion is closely linked to improved quality of life and wellbeing of people with intellectual disabilities. (Buntinx & Schalock, 2010): it is associated with better physical and mental health outcomes (Wilson et al., 2017), a greater sense of life purpose, self-esteem, and personal development (Hall, 2010) as well as a sense of belonging (Robinson et al., 2020), to name some. At the same time, if people with intellectual disabilities are still experiencing exclusion and are undervalued in the community, they run the risk of becoming segregated and discriminated (Heras et al., 2021), experiencing shame because of their disability (Marriott et al., 2020), and having negative overall life experiences (Buljevac et al., 2022; Merrells et al., 2019; Robinson et al., 2020).

Finally, the social inclusion of people with intellectual disabilities is important not only in the lives of the individual but also in a wider societal context. Social Inclusion is identified as a highly desirable outcome by families of people with intellectual disabilities. (Simplican et al., 2015) It is important to accept diversity, reduce discrimination, and enable people with disabilities to contribute to their communities (Shakespeare, 2006) and helps people with and without intellectual disabilities to live alongside each other (Heras et al., 2021).

Despite the fact that Social Inclusion has been recognized as an important goal and process for several decades, and despite significant improvements in this area, Social Inclusion remains an unattainable dream for many people with intellectual disabilities. (Merrells et al., 2019) And the gap between the desired outcomes of Social Inclusion policy and practice and the actual experiences of people with intellectual disabilities is significant (Robinson et al., 2020; Strnadová et al., 2018). Data shows that it is people with intellectual disabilities who are among the most marginalized and discriminated groups in society (Browne & Millar, 2016; Tilly, 2019).

### 1.2. Latvian context

#### 1.2.1 Terminology peculiarities

In Latvia, it is difficult to identify people with intellectual disabilities as a group within society. Currently, different terminology exists between different sectors in Latvia for people with different mental disorders: in education, the term 'mental health disorder' is used; in the social field, 'mental illness,' in the social field, the term covering persons with mental illnesses and persons with intellectual disabilities is 'persons with mental disorders', in the health sector, 'persons with mental and behavioral disorders', in the field of education, there is no specific term that covers only these two categories of persons, in the field of education, the term 'students/people with special needs' is used to cover all types of disabilities. (Krūmiņa, 2022).

According to experts in the social field, the term "persons with mental disorders," which is currently widely used, is rather poorly defined (Anča & Neimane, 2017) and generally not successfully chosen, as it attempts to combine two groups of society - persons with mental illness and persons with intellectual disabilities, whose needs may differ significantly (Krūmiṇa, 2022). The terminological peculiarities and the fact that people in Latvia are not always diagnosed (Krūmiṇa, 2022) are the reasons why it is not possible to clearly state the number of people with intellectual disabilities in Latvia. In 2022, a total of 25 724 adults (1.4% of the population) had a disability status due to mental and behavioral disorders (The Central Statistical Bureau of Latvia, 2022); however, as already mentioned, it is not possible to clearly state how many of these people have an Intellectual Disability.

### 1.2.2. Deinstitutionalization: EU and Regional context

In order to better understand the country's efforts, progress, and challenges in including people with intellectual disabilities in society, it is important to look at the situation in a broader, regional context. Latvia is an EU member state, and for the last few years, thanks to support from the European Union, Latvia has been undergoing a process of deinstitutionalization, which is a major step towards the Social Inclusion of people with ID.

The Scandinavian countries, particularly Sweden, are often highlighted as leaders in deinstitutionalization in the region, as is the United Kingdom. In these countries, deinstitutionalization as a systemic goal has been pursued since the 1980s, leading to major legislative achievements by the end of the last century, providing people with intellectual disabilities with the choice of community-based living arrangements and the accompanying support (McCarron et al., 2019).

A very different dynamic of deinstitutionalization and its implementation can be observed in postsocialist Central and Eastern European countries, including Latvia. Due to various political, economic, and historical factors, deinstitutionalization in the region has only been purposefully implemented since the late 2000s, and this process has been fraught with challenges.

The two most important factors that have shaped this situation are the socialist legacy of states and post-social neoliberation. Until the late 1980s, these countries were under socialist regimes. Socialist State defined disability primarily as the inability to work, and such a medical-productivist framework shaped disability assessment systems and policies, emphasizing medical diagnoses over individual needs and preferences; these systems placed a strong emphasis on large institutions, the norms of the system of Soviet psychiatry ('drugging people,' 'isolating, segregating,' 'staff corruption' and stigma) were adapted in these countries, resulting in the dehumanization of people with disabilities, that included their complete isolation from society (Sumskiene & Orlova, 2015). After the collapse of the socialist bloc, Central and Eastern European countries underwent radical neoliberal reforms. Post-socialist neo-liberalisation has done little to facilitate the transition from institutional care to living and caring in the community. On the contrary, limiting resources, promoting market-oriented approaches, emphasizing individual responsibility, and ignoring the systemic changes needed to support the rights and well-being of people with disabilities often worsened the daily lives of people already in institutions (Mladenov & Petri, 2019).

Deinstitutionalization in most Central and Eastern European countries has had a top-down character as it was initiated and stimulated by legislative, political, and funding agendas set by European Union bodies and backed by human rights discourses, notably by the UN Convention on the Rights of Persons with Disabilities (Mladenov & Petri, 2019). It is shaped by a complex interplay between EU funding, the country's socialist legacy, and neoliberal policies, which creates challenges for the transitions towards community-based care.

One of the challenges faced by many EU member states, including Central and Eastern European countries where deinstitutionalization reform started only in the 2000s that hinders the successful achievement of the reform objectives is the development of a sufficient network of community-based and person-centered support services that would not only enable people to be moved out of large institutions but also prevent them from ending up there in the first place.(ANED, 2019). Currently, in Central and Eastern European countries, deinstitutionalization reforms are often superficially implemented and do not achieve their objectives, leading to re-institutionalization outcomes. Simply put, people with intellectual disabilities often end up in slightly smaller or better-equipped settings, which are nevertheless essentially institutional settings- 'the key stakeholders in the process have dismissed such re-institutionalizing trends by focusing on superficial differences and disregarding internal commonalities between 'new' services and 'old' institutions.' (Mladenov & Petri, 2019, p.1219).

#### 1.2.3. Latvia's endeavors on Social Inclusion of people with disabilities

Latvia's disability policy has been shaped by the direct influence of international disability policy and its underlying principles. Although current terminology makes it impossible in principle to distinguish people with intellectual disabilities as a separate target group in the Latvian policy context, in recent years, the Latvian state has made increasing efforts to promote the inclusion of this group in society. The aim of the national disability policy is to promote, protect, and ensure that persons with disabilities enjoy all human rights and fundamental freedoms fully and on an equal basis with others, to promote respect for personal dignity, and to take measures to mitigate the effects of disability (The Cabinet of Ministers of the Republic of Latvia, 2021). This policy framework is a direct result of the UN Convention on the Rights of Persons with Disabilities, ratified by Latvia in 2010 (OHCHR), which has created the preconditions for public policies to move towards equal inclusion of people with different types of disabilities in society. Social Inclusion efforts for people with disabilities are reflected in a number of national planning documents. The "Plan for Equal Opportunities for Persons with Disabilities 2021-2023", which aims to promote the development of an integrated support system that meets the needs of persons with disabilities, is of particular importance. It provides five lines of action: Improving the disability assessment system, developing a system of support measures targeted to the needs of persons with functional limitations, strengthening inclusive employment, ensuring accessibility of the environment and services, and reducing stereotypes and prejudices (Cabinet of Ministers of the Republic of Latvia, 2021).

Promoting the employment of people with mental disabilities is one of the relatively new areas that the Latvian State has decided to strengthen, and it is still at an early stage. Social entrepreneurship, subsidized jobs, supported work, and counseling support centers are among the main mechanisms through which the State intends to promote the integration of people with mental disabilities into the labor market (Krūmiṇa, 2022).

Recent national policy has been characterized by deinstitutionalization, which is part of the European Commission's EU-wide deinstitutionalization process, following common guidelines and funded by the European Union's Structural Funds (Anča & Neimane, 2017). This process is extremely important for Latvia because until now, despite the basic principles for the provision of social services laid down in Latvian legislation, binding international documents, and the investment of EU funds, the provision of social care services in institutions still dominated over family-oriented or community-based social services when it came to adults with mental disorders. (Podzina, 2019).

In Latvia, key services that are developed as part of deinstitutionalization are group apartments and group homes, daycare centers, and specialized workshops. (Ministry of Welfare of the Republic of Latvia, 2020). The deinstitutionalization project in Latvia runs from 2015 to 2023. As a result of the DI projects,

the share of community-based social services for persons with mental disorders should increase significantly, and the share of institutional care should decrease. Before the deinstitutionalization project started, the ratio was 20:80 (of all people with mental disorders receiving social services, 20% received community-based social services, and 80% received services in an institution); at the end of the project, this ratio should change to 45:55 (Baltic Institute of Social Sciences, 2020). The final reports of the project have not yet been published, so it is unclear what results have been achieved. Admittedly, the process has been subject to a lot of criticism - for being too fragmented and addressing only a few problems, for lack of clarity on whether the reforms undertaken will be sustainable beyond the end of the project, for the often lack of implementation expertise of the stakeholders involved (Podzina,2019), and for the significant delays in the implementation of the planned measures since the beginning of the project (Baltic Institute of Social Sciences, 2020).

#### Day care centers

Daycare centers for people with mental disorders are dedicated services offering daytime social care and rehabilitation services. Their aim is not only to provide the necessary care and a safe environment but also to deliver meaningful activities for those with limitations in accessing other employment services. (Law on Social Services and Social Assistance, 2023) These centers need to focus on fostering independence, cognitive development, and social skills for persons with ID, as well as providing opportunities for personal and professional growth. Activities that can be organized include crafts, cooking, physical exercises, and outdoor walks, all tailored to individual needs (Ministry of Welfare of the Republic of Latvia et al., 2019).

#### Specialized workshops

Specialized workshops are also social rehabilitation services, but unlike social care centers, they provide productive employment activities and put particular emphasis on vocational skills training for people with ID who have difficulties entering the labor market (Law on Social Services and Social Assistance, 2023). This service should enable a person with ID to acquire skills that could potentially enable him/her to enter the open labor market at a later stage. For people whose disability prevents them from participating in employment activities, specialized workshops can be a way to fill their free time with meaningful activities and creative pursuits. The service promotes the development of people's interpersonal skills and their ability to work in a team (Ministry of Welfare of the Republic of Latvia et al., 2019).

### 1.2.4. Current situation regarding Social Inclusion of people with ID in Latvia

According to the Ombudsman of the Republic of Latvia (2020), Latvia's policy is in line with the European area of rights and values; the problem is their implementation in practice. At the moment, the

risk of social exclusion for people with disabilities remains high in Latvia (Krūmiņa, 2022). People with intellectual disabilities in Latvia often face discriminatory and rejecting attitudes from the general public: one-fifth of the Latvian population believes that people with intellectual disabilities should not participate in society, and about one-third of people would "feel disturbed" if a person with intellectual disabilities lived next door. (Baltic Institute of Social Sciences, 2020). Only 14.5% of people with mental disorders work in Latvia (Krūmiņa, 2022), and it is not known how many of them are people with intellectual disabilities. According to the Ministry of Welfare of the Republic of Latvia, only three persons with intellectual disabilities were employed in social enterprises in 2021 (Krūmiṇa, 2022), which can serve as an intermediate step in a person's transition to participation in the free labor market

Although the amount of available support is increasing, health, education, social services, and employment are not sufficiently tailored to the individual needs of the person, services are often difficult to access, tend to lack diversity, and service providers often do not have enough competences to work with people with disabilities, another serious shortcoming of the existing support system is that there is no continuity of services for the person, no mechanisms to help the person move from community-based services to, for example, participation in the free labor market (Krūmiņa, 2022)

When examining the impact of deinstitutionalization on people with intellectual disabilities, it is quite clear and fairly well-researched that moving to the community generally improves a person's overall quality of life compared to an institutional setting (McCarron et al., 2019). In a literature review on the pros and cons of community living, Bredewold et al. (2020) summarise the main findings on the impact of living in the community on people with intellectual disabilities: in addition to improving quality of life, it is highlighted that people living in the community learn better adaptation skills and receive better care. As negative outcomes, the authors name more criminal behavior, victimization of the target groups, and physical health problems. Although Social Inclusion is the main goal of deinstitutionalization, research shows rather ambiguous, mixed, and contradicting results as to whether deinstitutionalization results in real Social Inclusion (Bredewold et al., 2020). It must be noted that there are very few studies that specifically investigate how such policies affect people's lived experiences, including in terms of Social Inclusion. (Šiška & Beadle-Brown, 2020).

Very little is known about the outcomes of policy efforts and the actual lived experiences, including Social Inclusion experiences, of people with disabilities and, specifically, people with intellectual disabilities in Latvia. According to the Academic Network of European Disability Experts report (2018), in Latvia, there is an absence of published academic research that focuses on questions regarding independent living and the inclusion of people with disabilities. Also, in the *Scopus* and *Science of Web* databases of scientific research published in the last decade (2013-2023), there is virtually no research on people with intellectual disabilities and their Social Inclusion in Latvia (key words "Latvia," "disability,"

"Intellectual Disability"), as a rare example Broka et al. (2017) article on meaningful employment of young adults with intellectual disabilities in the context of the deinstitutionalization process which highlights the need to move towards more effective implementation of the Social Model of Disability in Latvia, and concludes that achieving the employment-related DI goals of persons with intellectual disabilities is difficult.

## 1.3. Perspectives in Social Inclusion experience studies

As in policy making, academic research on Social Inclusion is of great interest. Over the years it has been studied in many different facets and using different methods. As outlined above, in most countries of the Global North, for several decades, there has been a large network of support for people with intellectual disabilities, with Social Inclusion as one of their central themes and goals. The accomplishments of the disability community have helped people with intellectual disabilities to become more integrated within mainstream society and recognized as equal citizens. These achievements include improved physical accessibility, increased access to employment and education, simpler access to services and information for people with disabilities, and consciousness of inclusion (Hall, 2017), and it is quite clear that these changes have also come about thanks to the extensive and numerous studies in the field of Social Inclusion. However, research also shows that young adults with intellectual disabilities still do not feel socially included in wider society(Merrells et al., 2019)- it is hardly arguable that solely physical presence in a community does not guarantee or promote Social Inclusion.

Despite being a central theme in academic research on issues related to intellectual disabilities for over 30 years, the definition, dimensions, indicators, and measurement methods of Social Inclusion are still being discussed. Such ambiguity is problematic for research and, among other things, hinders efforts to take effective steps to improve the situation. Lack of clear definition leads to that the term "Social Inclusion" is sometimes used interchangeably with other related terms, for example (Martin & Cobigo, 2011) In their study that aimed to better understand the concept and indicators of Social Inclusion deliberately used participation and integration as synonyms for Social Inclusion, saying that due to the lack of clearly defined dimensions and indicators, these terms are hard to distinguish even if they aim to express different realities (Martin & Cobigo, 2011).

Research on Social Inclusion from the viewpoint of young adults with intellectual disabilities conducted in the last few years varies significantly when defining the main objectives and purpose of the research, as measures and methods used are not unified. Therefore, it is hard to compare social inclusion outcomes without clearer indicators (Louw et al., 2020). However, even if there is little research done that would focus solely on trying to grasp the Social Inclusion of young adults with intellectual disabilities,

there are several studies where Social Inclusion is still one of the central themes while focusing on some other topics such as relationships (Garolera et al., 2021; Pallisera et al., 2022), participation including access resources and services (Byhlin & Käcker, 2018; Hall, 2017; Robinson et al., 2020) and belonging (Renwick et al., 2019) that all are core themes of Social Inclusion (Simplican et al., 2015).

Many studies that aim to understand the experiences of Social Inclusion among people with intellectual disabilities focus on people with mild or moderate intellectual disabilities. Research that focuses on the experience of Social Inclusion aims to explore, in more depth, the unique story of each individual, and therefore, qualitative methodology is applied. Such studies are characterized by small sample sizes, which makes it difficult to generalize the findings. When it comes to more specific ways of studying Social Inclusion, to hear the voices of young adults with intellectual disabilities, the main method of data collection is through interviews, sometimes complemented by focus groups and observation. Photovoice techniques also have been shown to provide valuable insights (Robinson et al., 2020).

Phenomenological research should certainly be highlighted here as it most directly explores the phenomenon from the perspective of the individual's experience and is, therefore, particularly relevant in the context of the issues we are interested in. Authors have been focused on both the experience of Social Inclusion per se (Merrells et al., 2019; Wilson et al., 2017) and phenomena that are directly associated with Social Inclusion, such as transition experiences after leaving school (Gobec et al., 2022; Scanlon & Doyle, 2021), participation (Hall, 2017) And living with support experiences (Giesbers et al., 2019).

#### 1.3.1. A bottom-up approach

The literature has begun to shift out of the mere idea of physical integration to a more comprehensive understanding of Social Inclusion. The first theme in research on Social Inclusion, when studied through people's experiences, is that Social Inclusion is increasingly seen through a personal, individual prism. It is increasingly interpreted as a subjective rather than an objective reality. Martin & Cobigo (2011) emphasize that measures of Social Inclusion should provide information on persons with ID's subjective experience and satisfaction in order for them to be meaningful to them. Research on various subjects related to people with intellectual disabilities has long been grounded on the perspectives of service providers and families (Merrells et al., 2019), and still little is known about their actual experiences (Renwick et al., 2019). More and more authors emphasize that Social Inclusion is a personal and unique experience (Cobigo et al., 2012), meaning that it is not possible to access this phenomenon based on knowledge gathered only using surveys and proxy informants (Renwick et al., 2019), but instead, it needs a strong integration of the first-person accounts (Ramsey et al., 2022). Exploration of lived experience allows to hear an "active voice of people" (Merrells et al., 2019), access personal perception and perspective on particular aspects of the life of a

person (Giesbers et al., 2019), and therefore helps to gain a better understanding of the world of people with intellectual disabilities (Corby et al., 2020). This is of great importance when developing future support mechanisms that would stimulate the process of inclusion (Robinson et al., 2020; Wilson et al., 2017), as these efforts must be centered around the perspectives, needs, and aspirations of people with intellectual disabilities (Giesbers et al., 2019; Merrells et al., 2019; Renwick et al., 2019).

Taking into account subjective experiences when designing policy for a particular societal group is important as it ensures that policies are informed by real-life challenges, helps identify gaps in policy as well as promotes dignity, respect, and empowerment of people with Intellectual Disability. As Thill (2015) points out in her analysis of the involvement of people with disabilities in policy-making, "People with disabilities should not simply be surveyed, as individual consumers, about their satisfaction. Instead, people with disabilities must participate at the design stage in decisions about how to evaluate the policy so that the evidence base for future development reflects their concerns, interests, and experiences as well as those of other stakeholders such as government agencies, service providers, carers and families." (Thill, 2015, p. 19)

By listening to the voices of young adults with intellectual disabilities and trying to understand their experiences, researchers can get a unique understanding of this particular group and shed light on how meaningful present support systems aiming to promote Social Inclusion are. "Researchers may find they gain more insight about a person's ability to meet the needs of and socialize with family and friends if they ask the young adult with Intellectual Disability directly."(Espiritu et al., 2022). Many people with intellectual disabilities are able to be participants and informants in the studies without their guardian or staff oversight.

Young adults with intellectual disabilities state that they want to be treated and accepted as individuals, not according to their disabilities (Byhlin & Käcker, 2018); therefore, they recognize the need for Social Inclusion. Through examining personal experiences, researchers are trying to answer questions regarding how Social Inclusion feels. Young adults with intellectual disabilities in various studies have shared that they feel included when they have a sense of belonging to a place or people (Robinson et al., 2020). Hall (2017) draws a conclusion about the sense of belonging as a key reference point that determines whether a person subjectively experiences Social Inclusion, thus shifting the focus away from the discussion about what kinds of groups and settings are included in the definition of Social Inclusion, calling for a greater focus on the subjective experience and the meaning that people give to it. When it comes to how young adults experience belonging and a strong sense of identity, it grows from being acknowledged and valued, where one's potential and agency are recognized. (Robinson et al., 2020). Another study's results support this, revealing that for young adults, social inclusion means belonging to a community of peers specifically crafted for and according to the needs of people with intellectual disabilities (Bredewold

& van der Weele, 2022). This closely relates to one of the core insights that permeate recent research on young adults with intellectual disabilities, namely that Social Inclusion and its experience cannot be captured only through objective indicators but must be seen through the prism of individual human experiences to the way how young adults are making sense and interpreting their experiences. Social Inclusion cannot, therefore, be achieved only by objective improvements in living conditions and opportunities alone, as research shows this does not always directly tackle inclusion problems. "While formal support and assistance are provided for young adults to participate within their community, results show there may be a significant gap between the desired outcomes of a social model of disability and lived experiences of young adults with Intellectual Disability. As disability policy rapidly moves towards increased choice and control, it is critical that the impact on the participation of people with disabilities is understood from their perspective, and formal services are achieving what they purport to do when articulating Social Inclusion outcomes." (Merrells et al., 2019, p.20)

#### 1.3.2. Contextualisation

The experience of Social Inclusion is most often studied within a particular setting. When it comes to young adults, authors have taken a particular interest in Social Inclusion in educational settings, at work, and in the home/neighbourhood. A lot about Social Inclusion can be found in studies researching related topics such as transition experiences after leaving school (Gobec et al., 2022; Scanlon & Doyle, 2021), participation (Hall, 2017) And living with support experiences (Giesbers et al., 2019). The authors are interested in whether and how being present in a particular context or setting is or is not inclusive and how this Social Inclusion experience can be fostered.

Research shows that while broader concepts such as access to services and public goods and the ability to form extensive social networks are often given great weight in defining criteria for Social Inclusion, people with intellectual disabilities themselves attach more importance to micro-level aspects and everyday participation in society as a photovoice study done by Overmars-Marx et al. (2019) shown, exploring neighborhood Social Inclusion among adults with Intellectual Disability. People with intellectual disabilities attach great importance to public familiarity as participants specifically value opportunities to go shopping by themselves, perform (small) social roles, attend neighborhood activities, and meet family and neighbors in the street. Young adults with intellectual disabilities (similar to people at other ages) indicate that meaningful participation in society is important to them; thus, education (Corby et al., 2020) and work (Kruithof et al., 2021; Merrells et al., 2019) is central when it comes to the desired inclusion outcomes. Such participation is important because it helps to experience and feel interconnected with others, thus feeling like a valuable part of the wider community (Kruithof et al., 2021); through such

activities, they can contribute to society (Carnemolla et al., 2021; Corby et al., 2020). Even when facing difficulties in the workplace, young adults value the opportunity to work and see it as an important positive aspect of their lives (Merrells et al., 2019).

Despite the willingness to get involved, these desires are rarely satisfied. Participants in a study done by Merrells et al. (2019) revealed that young adults with intellectual disabilities often feel segregated from their peers and community, which leads them to see themselves as rejects of society. At the same time, there are contradictory data that suggest that young people with intellectual disabilities have a generally good level of satisfaction with their participation and are not particularly behind the general public (Espiritu et al., 2022).

Through participatory research, Robinson et al. (2020) were able to get a better understanding of young people's experiences of connections to place, space, and people in small-town communities. Their study revealed that the willingness of young people to engage in social spaces and relationships is significantly dependent on the way systems respond to them and their disability. Receiving positive or negative responses from others was crucial in how young people felt able to engage (or not) with a wide range of people and settings (Robinson et al., 2020).

Negative attitudes towards people with intellectual disabilities lead to experiences of social humiliation, bullying, and employment rejection, and overall make young people with intellectual disabilities feel as radically different and excluded (Merrells et al., 2019). A study done by Hall (2017) on community involvement of young adults with intellectual disabilities in which 14 participants shared their involvement in work, recreation, and leisure activities shows that in a mainstream setting, such as the workplace, young adults with intellectual disabilities rarely have a feeling of being included and fail to form closer personal relationships with people in such settings (Hall, 2017). Without meaningful ways to participate in the community and lack of social connections, young people tend to spend more time alone, with family, or in segregated settings; therefore, they become more and more separated from the rest of the community.

In recent years, one of the rare attempts to understand the phenomenon of Social Inclusion holistically, rather than within specific settings or contexts, among young adults with intellectual disabilities was undertaken by Merrell et al. al (2019), who conducted a phenomenological study on Social Inclusion experience whose participants have been lifelong recipients of individualized community-based coordination and services focusing on inclusion and participation. The findings revealed that despite the extensive set of services focused on Social Inclusion, young adults' actual experiences and progression towards Social Inclusion are much slower than previously thought and expected – young adults reported having limited social circles, few friends, feeling alone in their community outside of their immediate families, frequently becoming bored, being turned down for jobs, and viewing themselves as different by

referring to people without disabilities as "mainstream people." Young adults in this group had a strong experience of exclusion and segregation from their peers and community (Merrells et al., 2019).

#### 1.3.3. Through strengthening social ties

A number of studies trying to understand Social Inclusion from the perspective of young adults with intellectual disabilities are concerned with the amount and quality of Social ties these people have and how they make sense of them. People with ID name the lack of meaningful relationships as an important issue and consider acquiring long-term social connections as one of the main goals that they want to achieve through participation, for example, in educational programs (Corby et al., 2020; Plotner & May, 2019). Research focusing on the relationships of young adults with intellectual disabilities clearly shows that they usually have very limited social circles that usually consist of family members and paid staff (e.g. Pallisera et al., 2022). Young adults with ID struggle with relationships; they often do not have any friends, or their number does not exceed two or three people (Merrells et al., 2019) and their social network is much smaller and more restricted than for people without intellectual disabilities (van Asselt-Goverts et al., 2015). Lack of opportunities for meaningful and various participation in the community is a significant obstacle to forming relationships for youth with intellectual disabilities (Garolera et al., 2021) as their relationships are often formed in leisure or work settings (Hall, 2017). When it comes to obstacles to having meaningful relationships, Merrells et al. (2019) shown that young adults with intellectual disabilities have limited skills to maintain relationships and lack initiative in forming them due to people's ideas of how their relationships are often formed in formal settings, with strong prompts, where the initiative does not commonly comes from them (Merrells et al., 2019).

When it comes to how young adults are making sense of relationships and defining them, often the way relationships are built demonstrates "aspects of children's friendships including describing it as "play." (Merrells et al., 2019, p.19) and they are strongly connected to the place where interaction is occurring. For example, only a few people keep in touch with their friends from school after graduating (Scanlon & Doyle, 2021) or meet their friends from formal support programs in other settings (Merrells et al., 2019). Corby et al. (2020) study on the experience of young adults with Intellectual disabilities in post-secondary or higher education showed that even though participants referred to their non-disabled peers as friends, the descriptions of these relationships were more centered on interactions with them rather than specifically friendships.

### 1.3.4. Enhanced and supported

It is also important to mention how research on young adults' experiences contributes to efforts to promote Social Inclusion. Therefore, it is important to mention studies that seek to understand the

effectiveness of support systems and how to stimulate the Social Inclusion experience of young adults with intellectual disabilities.

It is through listening and responding to the viewpoints and aspirations of persons with intellectual disabilities that inclusive practices become relevant and can contribute significantly to Social Inclusion and its promotion (Carnemolla et al., 2021). The systemic review of empirical studies conducted by Louw et al. (2019) vividly shows that there is a growing body of evidence suggesting that structured, guided social activities that promote social relationships and participation are crucial to improving the results of Social Inclusion. Young adults taking part in such activities have a better chance to build stronger social bonds and have meaningful access to the wider community (Louw et al., 2020). This is a particularly acute issue in young adulthood, as the person leaves the educational context and, consequently, if the support system is not prepared for this change, the person's level of Social Inclusion can suffer significantly (Renwick et al., 2019).

Research done by Wilson et al. (2017) on outcomes of Structured social groups for people with intellectual disabilities showed that targeted support and encouragement in building and maintaining positive relationships for people with intellectual disabilities can help to move from social exclusion towards supported inclusion and experience richer lives (Wilson et al., 2017). For young adults to fulfil their goals regarding their Social Inclusion they need to acquire information, know their options, have confidence and some of the hard and soft skills. There is strong evidence that specially dedicated support in order to achieve these issues is essential, and they have a high impact on participation outcomes. (Scanlon & Doyle, 2021). It is clear that to ensure greater involvement and inclusion of young adults on their own terms, it is important that they are in a permissive environment where opportunities for participation are given (Byhlin & Käcker, 2018). Research on experiences of Social Inclusion in a sheltered living institutions show that people living in these places, unlike mainstream society, consider these places to be socially inclusive not because their values per se are different, but because there participation is not only an important part of their lives, but it is defined on their own terms unlike in mainstream society. (Bredewold & van der Weele, 2022).

Even though there is no doubt that people with ID would benefit from the support that would enhance their Social Inclusion, there is no clear answer on how to reduce the gap between these two realities and promote it. One of the promising directions is building bridges between segregation and striving to "fit in" into the mainstream world. For example, concerning employment, integrated settings have proven to be, in some cases, a suitable compromise, such as through volunteer work (Kruithof et al., 2021) or internships (Hanson et al., 2021) as they have more room for personalized approaches and are appreciated by young people (Hanson et al., 2021).

Summarising the findings of this literature review, we can draw certain conclusions, as well as point out gaps in current research and questions that should be answered in future research. In recent decades, the understanding of people with intellectual disabilities as a group has undergone a significant transformation, and the notion of Social Inclusion as a central goal has been strengthened. First, while the number of studies on the experiences of Social Inclusion and the lived experiences of people with intellectual disabilities is increasing, there is a lack of studies that specifically analyze the Social Inclusion experiences of young adults. Although there is a growing awareness of the importance of individual, personal experiences in the context of Social Inclusion, there has been a lack of research analyzing the life of the individual as a whole rather than in a particular setting or context, thus looking only at a particular aspect of life, a particular role (student, worker, neighbor). Finally, in the Latvian context, it is clear that, in recent years, with significant changes in public policies and support offered to people with intellectual disabilities, Latvia is trying to follow the example of many other countries in promoting Social Inclusion, the voices of people with intellectual disabilities themselves are still virtually unheard. Research on the Social Inclusion experiences of young adults in Latvia would provide a more in-depth understanding of the situation of this population group, would give one of the components for a better understanding of the effectiveness of current Social Inclusion efforts, and would help to find ways to promote better Social Inclusion of both young adults and other age groups of people with intellectual disabilities

## **CHAPTER 2 - THEORETICAL FRAMEWORK**

This chapter introduces the Theoretical Framework of this study that will allow to conduct research and analyse the Social Inclusion experiences of young adults with ID. This chapter explains how the phenomenon of Social Inclusion is defined in the context of this study. It goes on to provide an in-depth explanation of the core categories of Social Inclusion experience that also emerge in the Literature Review - interpersonal relationships, meaningful participation, and belonging. The chapter concludes with an explanation of the usefulness of the ecological model when mapping the experience of Social Inclusion.

#### 2.1. Social Inclusion defined

As noted in the previous chapter, there is no single clear definition of what constitutes Social Inclusion. The literature review done by Simplican et al. (2015) is the key study of the last decade, bringing together the existing literature on the subject and trying to provide a clear understanding of what is Social Inclusion for people with ID- it revealed that most Social Inclusion definitions contain two major themes: interpersonal relationships and community participation. Their interaction is a constantly evolving process where the level and kind of participation directly create soil for the experience of social relationships and the other way around (Louw et al., 2020). However, this definition does not include processes that may enhance social inclusion and the subjective feelings that may result from inclusion. These are the aspects that Cobigo et al. (2012) highlight in their definition, which is also based on an extensive analysis of the available literature- they define Social Inclusion for people with ID as a series of complex interactions between environmental factors and personal characteristics that provide opportunities to access public goods and services, experience valued and expected social roles of one's choosing, be recognized as a competent individual and trusted to perform social roles in the community, and belonging to a social network within which one receives and contributes support. (Cobigo et al., 2012) This definition adds a personal aspect to the concept of Social Inclusion: a sense of belonging and recognition as a third core component of Social Inclusion.

### 2.1.1. Depth, Setting and Scope of Social Inclusion

As pointed out by Simplican et al. (2015), although most definitions of Social Inclusion consist of similar themes, researchers are mainly divided on the matter of depth, setting, and scope of Social Inclusion. Defining these aspects is of utmost importance in order to later identify the dimensions of Relationships, Participation, and Belonging to be analyzed as core themes of Social Inclusion. They can be construed through the broader sameness-difference debate when it comes to the Inclusion of People with ID in society.

Until the second half of the last century, people with intellectual disabilities were often categorized as abnormal and deviant, and policy of institutionalization was the most common practice. This process of negative categorizing is known as "othering" (Bredewold, 2021). From the 1960s onwards, movements came into force that argued for the right of people with intellectual disabilities to live with dignity and opposed the dehumanization of this societal group as well as promoted deinstitutionalization and normalisation-right to be empowered to take valued roles in society (Bigby et al., 2015) meaning that full equality is the goal-people should have full access to mainstream society and services available to others regardless their disability (Simplican et al., 2015). Thus, the idea of sameness and having a "normal" life was established and promoted. In accordance with this framework, research then has focused on how able individuals are to blend into the wider society, taking into account factors such as their involvement in productive or leisure activities in the community and the size of their social networks. As extensively described in the literature (for example (Cobigo et al., 2012; Hall, 2010; Meys et al., 2021)) this approach often prioritizes conformity to traditional societal values such as work and independent living over personal preferences and individual needs. There is more and more evidence that shows that Social Inclusion purely on the basis of normalization – in which sameness is emphasized – is difficult to achieve (Bredewold, 2021). If Social Inclusion is based on normalcy, it fails to include those who do not fulfill regular societal norms; at the same time, these normality norms are dictated by people who do not have a disability and might lead to the requirement of conformity in order to be included and accepted, rather than aspiring to co-create a society where everyone belongs (Bredewold, 2021; Renwick et al., 2019).

When it comes to the depth of Social Inclusion, as clearly shown in the previous chapter, In recent years, more and more researchers tend to put emphasis on subjective rather than focus on objective measurements alone, emphasizing such aspects of Social Inclusion as belonging and having valued social role in the community as crucial in order to get a full understanding of Social Inclusion (Fulton et al., 2021; Reeves et al., 2023). Martin & Cobigo (2011) emphasize that Social Inclusion is always personal and unique. Therefore, understanding of phenomena should also be rooted in the perceptions, feelings, and experiences of a person.

As previously described, this research tries to shift away from the principle of normalization and aims to analyze Social Inclusion from the perspective of individuals with ID and, so when it comes to the scope of Social Inclusion, it would not be reasonable to limit the scope by imposing a condition, for example, that Social Inclusion occurs only when a person with intellectual disabilities participates in society and builds social networks with people who are not employees, their family members or people without intellectual disabilities. (Bigby & Wiesel, 2019; Šiška et al., 2018). That is because subjective and personal experiences are not "contingent upon the 'nature' of the space, activity or people but instead upon the 'moral culture' that is produced within that space" (Reeves et al., 2023).

Finally, before examining the experience of Social Inclusion, it must be established in what settings it can occur: private or public. When speaking of Social Inclusion, historically, most definitions put emphasis on access to community facilities and community participation, emphasizing the importance of the public dimension of Social Inclusion. However, there is a significant research body indicating that semi-segregated or even segregated settings as well can enhance Social Inclusion as they might promote belonging, friendship, and safety, which is often hard to achieve within the mainstream community (Bredewold & van der Weele, 2022; Hall, 2010). The results of these studies allow us to see that Social Inclusion cannot be tied to a specific setting or context. As it comes to this study, since Social Inclusion is defined as a broad concept in depth and scope, it follows logically that setting strict limitations cannot be drawn and must be explored from the participant's point of view.

In order to capture the range of the scope, depth and setting of Social Inclusion that have just been positioned, and to incorporate the categories of Social Inclusion that have been described in the literature, Social Inclusion is defined in the context of this study as interaction and evolving process between spending time in activities that are creating meaningful participation, having meaningful relationships and sense of belonging.

This definition positions Social Inclusion as a relative rather than an absolute phenomenon - the level of inclusion may vary across roles, environments, and over time (Martin & Cobigo, 2011). The emphasis on the relativity is a common when it comes to exploring the Social Inclusion experiences of people with ID. (Hall, 2010; Merrells et al., 2019).

### 2.2. Categories of Social Inclusion

#### 2.2.1. Meaningful participation

Participation is of crucial importance when trying to understand and achieve the goal of Social Inclusion. (Gray et al., 2014). Meaningful community participation is the involvement of a person in social interactions and activities with others in their community that are valued by themselves (Louw et al., 2020).

Community participation consists of several types of activities: productive activities, recreation& leisure activities as well as consumption activities (Hall, 2017; Simplican et al., 2015; Verdonschot et al., 2009). Productive activities refer to engagement in income-producing work or in work that contributes to a household or community (Verdonschot et al., 2009). Participation in paid work has been one of the central goals of Social Inclusion for a long time (Melbøe & Hardonk, 2022); as described in the Literature review, other forms of productive activities, such as volunteering and sheltered workshops, also play an important role in the Social Inclusion experience. Recreational & leisure activities include hobbies, socializing,

sports, arts, and culture (Simplican et al., 2015; Verdonschot et al., 2009), and finally, consumption refers to the use and access to goods and services (Simplican et al., 2015).

After identifying in what activities exactly a person does engage, in order to understand the level of inclusion across roles, time, and environments, it is important to examine the structure and involvement (Simplican et al., 2015). The structure here refers to where activities that are important to a person are taking place and with whom. Participation can be divided into segregated, semi-segregated, and integrated contexts. (Simplican et al., 2015). Segregated activities are those in which only people with disabilities and staff are involved and are happening in segregated facilities, e.g., special education classrooms, specialized workshops, day centers, and group homes. Immediate family members and home also refer to a segregated context of participation.(Simplican et al., 2015). Segregated participation is the dominant structure of participation in which people with ID spend their time(Merrells et al., 2019). Even though in the light of normalization and sameness movement, participation in segregated settings has often been excluded from the definition of Social Inclusion as it is not part of the "mainstream" society, as described earlier in this chapter, nevertheless there is data suggesting that within segregated contexts Social Inclusion can be enhanced. Results of a study done by Louw et al. (2020) on segregated institutions show that in such places, social contact and participation are encouraged in the same way as that would be done elsewhere, however contrary to integrated settings, participants of research believed that "these values and goods were defined on the terms of the people with disabilities themselves" (Louw et al., 2020, n.p.). On the other hand, Merrels et al. (2019) argue that segregation leads to isolation, and even though various forms of formal programs for people with ID aim to help build friendships and increase independence, they most often fail to do that.

Opposite to segregated are integrated settings. That means participating in the mainstream society and activities. This, in many definitions of Social Inclusion, is prioritized over other contexts (Cobigo et al., 2012), however it is mainstream settings where people with ID experience rejection and exclusion more often than elsewhere (Robinson et al., 2020)

Activities that mix the elements of segregated and integrated activities are semi-segregated and can take various forms. Firstly, activities in which only people with intellectual disabilities, staff, and their families are participating, but they are accruing in the mainstream settings; secondly, activities in segregated settings but involving community members (Simplican et al., 2015). Participation that has a semi-segregated structure can promote the Social Inclusion of people with ID (Bigby & Wiesel, 2019; Hall, 2017) as they provide "a basis and stepping-stone to even more involved participation in the future" (McCausland et al., 2022). Another point of interest is a degree of involvement: whether a person with intellectual disabilities is participating, having encounters, or is merely present. Mere presence means that a person is not taking part and interacting with others, however, such participation or rather community presence has its place when considering Social Inclusion as "presence may be an important component for community

activities that require minimal involvement and because presence is likely a precursor to participation" (Simplican et al., 2015). On the other hand, a high degree of involvement means that a person, through participating in an activity, is able to develop interpersonal relationships (Simplican et al., 2015). Studies show that people with ID struggle with such involvement (McCausland et al., 2022) As an example, the inability of persons with ID to form meaningful relationships might be caused by their reliance on others to facilitate interaction (Merrells et al., 2019), therefore its important to pay attention to how involved people are in activities they engage in as it is directly linked to their Social Inclusion experience.

In order to expand the understanding of participation in the context of Social Inclusion of people with Intellectual disabilities and seek a way how to provide an opportunity to engage with differences without trying to eliminate them, several researchers are suggesting the concept of "convivial encounters" that originally comes from Urban geography. (Bigby & Wiesel, 2019; Bould et al., 2018; Bredewold, 2021). It is suggested that it be a pathway toward understanding what places, activities, and practices promote the social inclusion of people with intellectual disabilities. Urban life is centered around having encounters with strangers, and these are more than just anonymous free mingling, but it is also not a formation of strong relationships; it is rather bridging simple community presence, and full community participation-encounters are brief or continued interactions between neighbors, clients, and service providers, passengers and cab drivers, strangers waiting in a queue or sitting at a cafe, etc.(Bigby & Wiesel, 2019). While participation is more concerned with the act of getting involved in a particular activity, event, and context, convivial encounters are more concerned with the quality of the interaction between people (Bigby & Wiesel, 2019). Convivial encounters are modernizing the concept of community participation, transforming the understanding of Social Inclusion as something rooted in a particular place or setting, but rather suggesting that it can happen anywhere and is accruing between strangers(Simplican & Leader, 2015).

Finally as explicitly stated and described earlier, it is crucial not only to understand participation through identifying various categories, their structure and involvement level, but also to explore what of all that is important for person, what meaning person attaches to activities they are engaging in, whether they are satisfied with current situation and what they would like to change.

### 2.2.2. Interpersonal Relationships

Positive and meaningful relationships are one of the most fundamental human needs, and people with intellectual disabilities are no exception to this. (Fulford & Cobigo, 2018). There is a growing body of research on how having a wide range of interpersonal relationships contributes to having a "good life" for people with intellectual disabilities (Friedman & Rizzolo, 2018; Wilson et al., 2017). It is clear that people with intellectual disabilities want friendships and meaningful relationships, and they are important for their

social inclusion experience (Brown & McCann, 2018), as other studies mentioned earlier have shown. Studies that center around the experiences of people with intellectual disabilities reveal that it is of crucial importance to pay attention to the unique ways in which individuals make sense of their social connections (Fulford & Cobigo, 2018), and support is necessary to promote and strengthen them to increase their Social Inclusion. People with whom relationships are built can be divided into several groups: family members, staff, friends, acquaintances, and romantic partners (either with or without a disability) (Simplican & Leader, 2015), and one person could also be in two categories (Callus, 2017). In this respect, it is certainly worth mentioning that researchers are divided on whether all relationships that are important in the eyes of a person with ID can be linked with better Social Inclusion. Numerous studies have indicated that people with ID often see staff as their friends and closest people in their lives (Giesbers et al., 2019; Merrells et al., 2019). Giesbers et al.(2019) propose to look at support staff and the support system as a whole from an individual perspective, without trying to categorize the relationship with staff as a monolith structure that can be definitely categorized as inclusive or not, but rather looking at the functionality of each individual relationship acknowledging the importance of staff in facilitating meaningful relationships in person's with intellectual disabilities life underlining that the support system is a vital and continuous pillar of life for people with intellectual disabilities. This also reflects the considerations addressed earlier regarding the scope of Inclusion. To develop an understanding of the importance of interpersonal relationships in the context of Social Inclusion, Simplican et al. al (2015), like in the case of participation, suggest that the attention needs to be focused on the structure of relationships. When it comes to specific relationships, structure refers to how often contact occurs, the dynamics of how these relationships develop, and the contexts in which these relationships emerge and are sustained. (Simplican & Leader, 2015). Reciprocity is another important structural component of Relationships(Fulton et al., 2021) it means the mutual exchange of help and support between friends, which is seen as a marker of friendship and enables valued interactions with others (Callus, 2017). Bredewold et al. (2016) point out that reciprocity can occur in different relationships, both with people with and without intellectual disabilities, but that the common notion of what constitutes balanced reciprocity may need to be expanded to include different or seemingly smaller return gifts such as 'happy smiles' (p. 547) or 'expanded horizons' (p. 545)

Finally, Simplican et al. (2015) suggest that it is also important to understand the different functions of relationships, whether they are emotional (caring, trust, love), instrumental (service and help), or informational (providing support, advice, counseling).

#### 2.2.3. Belonging

In an effort to reframe the concept of Social Inclusion, moving away from a normative ideal emphasizing the importance of "fitting in," several authors suggest a broader view that accommodates

differences and places individual needs at the center. They propose belonging as a concept through which Social Inclusion could be "reimagined" to better capture the diverse reality of this phenomenon (Hall, 2010; Reeves et al., 2023; Renwick et al., 2019; Robinson et al., 2020; Strnadová et al., 2018). As a response to the fact that Social Inclusion goals are still far from being achieved, some authors suggest that the experience of Belonging is a more crucial dimension of Social Inclusion than previously thought. Reeves et al. (2023, p. 326) call belonging a radical concept that 'helps us see Social Inclusion differently, shifting Social Inclusion towards relationality and fluidity, expanding Social Inclusion to encapsulate a felt experience and intimate, informal inclusion.' Looking at Social Inclusion through the lens of belonging centers Social Inclusion experience around persons with Intellectual disabilities, giving voice to each person's opinion and individual needs so that becomes a foundation for further action towards achieving Social Inclusion goals in the broader context as they should be achieved on terms of people with intellectual disabilities (Merrells et al., 2019).

Even though Belonging is an important dimension when thinking of Social Inclusion, it should be seen as the third component of Social Inclusion alongside Participation and Relationships, not as a replacement for the concept as such, due to its subjective character because, on its own, it does not provide knowledge about the actual level of involvement of people with disabilities in their communities or their social networks.(Simplican & Leader, 2015).

Belonging is an ongoing process through having social relationships, interacting with people who are similar, negotiating meaningful roles in the community, and navigating norms and expectations – finding a good fit (Renwick et al., 2019). As such, belonging refers to the subjective feeling of being valued, needed, important, comfortable, respected, and "at home" towards other people, locations, or activities (Hall, 2010; Reeves et al., 2023).

#### 2.3. Mapping social inclusion within the ecological perspective

The interactions of all three components, participation, interpersonal relationships, and belonging, create an experience of social inclusion, and one of them should increase and strengthen others (Simplican & Leader, 2015). The proposed theoretical framework that focuses on in depth analysis of a person's experience to understand Social Inclusion will help to avoid potential risks that Cobigo et al. (2012) identify among Social inclusion research: there is a risk of seeing inclusion as ideology, and that might lead to potentially wrong strategies, it tends to still often be seen as aiming to achieve the dominant societal values and such approach may lead to moralistic judgments, it tends to be measured by productivity and independent living, that is not reasonable for some people with ID, and finally it often excludes from the

definition of social inclusion activities and relationships that are not experienced in the community (Cobigo et al., 2012).

The social inclusion experience of young adults with intellectual disabilities can be grasped and understood through an ecological perspective as it helps to better understand how three components of Social Inclusion: participation, relationships, and sense of belonging interact on different levels.

Looking at Social Inclusion through an ecological perspective is beneficial because the earlier proposed theoretical framework not only describes Social Inclusion as relative but also shows that it is not dichotomous-level of inclusion can be different across roles, environments, and change over time (Cobigo et al., 2012). For example, a person can feel included in their family or among closest friends but experience rejection when trying to access some services. It is also possible that a person who values their privacy or autonomy may also decide not to join a group or to try to belong. Instead of focusing on particular aspects of interpersonal relationships and community participation, the ecological perspective gives an opportunity to look at all factors that affect social inclusion at the same time (Meys et al., 2021) and provides a broader and more nuanced picture of experience.

Five different levels are distinguished when mapping Social inclusion through Ecological model: the individual level (e.g. level of functioning), the interpersonal level (e.g. relationships with staff, family members, friends, etc.), the organizational level (e.g. access to communication services), the community level (e.g. type of living accommodation) and the socio-political level (e.g. laws). (S. C. Simplican et al., 2015). It shows how processes influence and resonate with each other and points to the need to take a broad view of Social Inclusion without dismissing certain types of relationships or activities as *a priori* irrelevant (Meys et al., 2021; Simplican et al., 2015).

## **CHAPTER III - RESEARCH METHODS**

## 3.1. Objectives

The research's general objective is to explore how young adults with Intellectual disabilities live in the community and attend daycare centers or specialized workshop experience and make sense of their Social Inclusion based on their individual and lived perspectives.

Specific objectives are:

- To investigate the structure and involvement level of community participation among young adults with intellectual disabilities and explore the subjective meaning of significance they derive from various activities in diverse settings shaping their Social Inclusion experience.
- To investigate, among young adults with intellectual disabilities, the structure, function, meaning and significance of interpersonal relationships on regards of their inclusion experience.
- To correlate and categorize ways of belonging in regard to the Social Inclusion of young adults with Intellectual Disability.

## 3.2. Research design

This research will use qualitative research design as it is appropriate for the exploration of the topic 'Lived experiences of young adults with intellectual disabilities: exploring their Social Inclusion pathways.'

The meanings that people give to their experiences are studied within qualitative research design (Corby et al., 2015) Qualitative research is based on post-positivist and constructivist beliefs (Teherani et al., 2015) therefore, such study design allows the investigation of the complexity of the social world and gives an opportunity to better understand meanings of human experience that are less perceptible, giving attention to questions like 'what,' 'why,' and 'how' rather than 'how much' and 'how many' that are central in quantitative studies (Tuffour, 2017).

## 3.2.1. Interpretative phenomenological analysis (IPA)

Qualitative research can have many approaches linked to several epistemological and theoretical positions. The most commonly used are phenomenology, ethnography, and grounded theory (Teherani et al., 2015). Phenomenology as methodology is inductive and, in general, is concerned with the study of phenomena—"things themselves": how we experience things, how they appear in our experience, and thus what meaning people prescribe to them (Flick, 2014).

This study is done by using one of the phenomenological methodologies- Interpretative phenomenological analysis. IPA is a relatively new method but already has gained significant popularity among researchers that is developed and theorized by J.Smith (Smith et al., 2009). IPA is a blended approach that grows out of two main categories of phenomenology- descriptive phenomenology, which follows the philosophical traditions of Husserl, and hermeneutic/interpretative phenomenology, which follows Heidegger's approach.

According to J. Smith, "The aim of interpretative phenomenological analysis (IPA) is to explore in detail how participants are making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences, events, states hold for participants" (Smith et al., 2009, p.53). Similar to the wider phenomenological tradition in opposition to an attempt to produce an objective statement of the object or event itself. (Tuffour, 2017) IPA seeks to integrate the works of Heidegger, Merleau-Ponty, and Sartre "to illuminate phenomenology as a singular and pluralist endeavor existing in a continuum" (Tuffour, 2017, p.3). It differs from other phenomenological approaches because of its emphasis on meanings that are attributed to experiences, and it focuses on understanding participants' subjective interpretations and personal narratives. (Giesbers et al., 2019).

The IPA recognizes the role of the researcher in shaping the analysis, taking into consideration their own perspectives and interpretations. This subjectivity is used to develop a better understanding of the participants' views. Also, IPA incorporates both empathic understanding and critical questioning, which allows for a more balanced exploration of participants' experiences. It involves two stage interpretation-participants interpret their experiences and researchers interpret participants' interpretations. (Smith et al., 2009).

When it comes to Intellectual Disability studies, IPA is currently one of the most used phenomenological approaches as it is suitable for small samples, it is practical in application, allows exploration of subjective perceptions (Corby et al., 2015) and it is suitable when dealing with complexity, process or novelty (Smith et al., 2009). Moreover, this approach "provides an opportunity to hear the concerns of research participants and to understand these concerns in the context of a more interpretative "birds' eye" view from the researcher; this is a domain where there is much to learn about the development, needs, and preferences of people with intellectual disabilities, in a different context" (Rose et al., 2019, p. 1008).

# 3.3. Data collection methods

## 3.3.1. Research participants

One of the things that characterises IPA is its dedication to scrupulous and detailed interpretive accounts of the participants of the study. Therefore, in such research, a small sample of participants is necessary. According to the IPA developer Professor Jonathan Smith, "This allows sufficient in-depth engagement with each individual case but also allows a detailed examination of similarity and difference, convergence and divergence" (Smith et al., 2009, p. ). A systemic review of phenomenological studies in which people with intellectual disabilities are participants conducted by Corby et al. (2015) reveals that sample sizes in such studies vary significantly - from 1 to 28 participants; however, most of the time, the sample size is not bigger than 11 participants and when IPA was used average number of participants is eight people (Corby et al., 2015).

For this research, participants were chosen using purposive sampling as for such study, a homogenous group of participants is necessary. (Smith et al., 2009).

The following criteria were used to select the study participants:

- -participant is a young adult (18-35)
- -participant has an Intellectual Disability
- -participant has sufficient verbal communication skills to provide in-depth information about their thoughts and experiences.
  - -participant is attending a formal program: daycare center or specialized workshop in Latvia
  - -participant is living in the community

Potential participants were found by approaching several daycare centers and specialized workshops in Latvia. Representatives of these institutions identified potential participants who met the criteria and gave them a brief overview of the research. Those who were interested in participating in the study were given a more detailed overview of the research process and their role as a participant (Appendix A). A face-to-face meeting was arranged with those candidates who had expressed an interest, during which the researcher again ascertained the participant's understanding of the research and his/her willingness to participate. Once this was confirmed, the participant was asked to sign an informed consent form. Respective institutions confirmed the legal capacity of participants.

In total, ten young adults with mild or moderate Intellectual Disability from six different cities located in various regions of Latvia (none of them from the capital) took part in the present study. The age of the participants varied from 25 to 35. Nine participants were living with their parents, and one participant had only recently (1 month) moved to a group home. No prospective participants living independently were

found during the participant selection process. There were five male and five female participants; three of them were Russian speakers, while the rest spoke Latvian. Eight people attended daycare centers and 2-specialized workshops (Appendix B).

#### 3.3.2. Data collection instrument

In order to collect necessary data, semi-structured conversational interviews were conducted as it is the most suitable data collection method for IPA because this form of interviewing allows "the researcher and participant to engage in a dialogue whereby initial questions are modified in the light of the participants' responses, and the investigator is able to probe interesting and important areas which arise" (Smith et al., 2009, p.).

Semi-structured interview enables the researcher to follow pre-prepared guidelines in order to delve as deeply as possible into the social world of the interviewee through the questions. However, the way the interviewee responds and conducts the conversation plays an important role, which may reveal aspects unforeseen by the researcher and provide more of the information needed.(Smith et al., 2009). The semi-structured interview helps the researcher to create a rapport with the interviewee and allows them to share experiences and their interpretations in a meaningful way (Rubel & Okech, 2017)

In IPA, a very specific and detailed interview guide is not necessary as it focuses on a more organic exploration of participants' personal experiences and perceptions. Flexibility is, therefore, of utmost importance in the interview process. Nevertheless, the interview schedule still plays an important role in guiding the interview. It allows one to explicitly list topics that need to be covered and and to identify some possible difficulties that can occur during the interview (wording, sensitive areas, prompts, etc.) (Smith et al., 2009).

When designing interview questions for people with intellectual disabilities, the interviewer should be particularly aware of the characteristics of this group, as this is the only way to expect reliable and relevant results (Hollomotz, 2017). As A. Hollmotz (2017) emphasizes- when interviewing people with intellectual disabilities, one must acknowledge how diverse this group of respondents might be. She points out that when formulating questions, it is important to adapt the depth of questioning regarding an individual's abilities as well as create a concrete frame of reference to make it more accessible for less articulated responders because obtaining views about abstract issues, time, and frequency from people with intellectual disabilities is a complex challenge. (Hollomotz, 2017, p. 157-158) In light of this guidance, previous research (Merrells et al., 2019), and recognizing that Social Inclusion is a complex and abstract concept, no direct questions were asked of respondents about their experience of Social Inclusion. Instead, more simple and concrete questions were formulated and grouped based on the three core categories,

belonging, community participation, and interpersonal relationships, that were selected in the theoretical framework (Appendix C). Following the suggestions of Smith et al. (2009), the interview schedule was organized in a way that it began with trying to put respondents at ease with simple questions about themselves and then moved to the areas of interest of the research, starting with more general and then went to more detailed questions (Appendix D), alongside, few possible prompts where noted.

#### 3.3.3. Data collection

In- person interviews lasted from 18 minutes to 49 minutes (Appendix B). Interviews were held in a environment that is familiar for the respondent i.e. day care centre or specialised workshop that respondent attends in language that is most comfortable for the participant (Latvian or Russian). To ensure discretion, the interview took place in a separate room from other people. All interviews were audio-recorded, transcribed, and translated into English. Notes were also taken during the interview and later added to the transcript.

## 3.4. Ethical considerations

Ethical considerations are key to maintaining trust, credibility, and dignity in research; they are guidelines and principles that protect the rights, dignity, and well-being of participants throughout the research process. This includes obtaining informed consent, preserving confidentiality, minimizing any harm, and respecting the integrity of the research. (Hesse-Biber, 2016). When doing research with participants who have Intellectual Disability, additional ethical considerations arise that need to be addressed. It is extremely important to make sure that the research participant has the capacity to consent to take part in the research and then to make sure that the participant is able to fully grasp the purpose of the research and is able to give informed consent. To ensure this, the researcher should offer the information and consent form in a way that the potential participant is able to comprehend (Harding, 2021).

Only participants with legal capacity participated in the study. All participants were given detailed information about the research and their respective roles in it. Before the interview, each participant had to be presented with and sign the document for the informed consent, which was written in plain language (Appendix A). Participants were informed that they were free to stop the interview at any time and that they did not have to answer a question if they did not wish to do so.

To ensure the anonymity of all participants, each person was given a pseudonym. Also, pseudonyms were used for other people mentioned during the interview, and the names of specific places and organisations were replaced by more general terms. The audio recordings of the interviews were deleted after the transcripts had been written.

# 3.5. Limitations

When choosing Interpretative phenomenological analysis as a methodology in research some limitations are posed due to the specifics of this methodological approach as such. Most importantly, this method is fundamentally subjective and has an idiographic focus; therefore, it does not allow broad generalisation of results; it operates with a small sample size, and it provides less standardization than other qualitative methods.

Conducting research with people with intellectual disabilities is also challenging as all data collection process needs to be specially tailored and adopted for this particular groups needs and abilities. To ensure a more diverse group of participants and to find the most appropriate candidates for the study, young adults from different services were interviewed for the study. However, there were disadvantages to this, as the interview was also the first meeting with the interviewee and so there was not always the opportunity for a more in-depth understanding of the contexts of the person's life, which would allow questions to be asked in a more targeted way receiving more in depth data. Additionally, the service provider limited the time for a few interviews.

# 3.6. Overview of analytical process

In order to improve the quality and make the data analysis process more efficient and transparent in this study, qualitative data analysis software MAXQDA 2022 was used. The data analysis process was conducted in six phases, as described by Smith et al. (2009,2021).

First of all, interviews were transcribed and re-read several times in order to familiarize oneself with the text. This was followed by the creation of initial notes and comments. After that, the content was uploaded to MAXQDA. After that, initial comments and notes were turned into initial codes-experimental statements that express the essential quality of what was revealed in the data. Analysis of data was done based on theoretical categories that were chosen and justified in the theoretical framework.

The next step was grouping the codes into subordinate categories, looking for trends that illuminate the commonalities among statements that would create personal experiential themes- in this phase, some experiential statements were dropped, renamed, or merged, and subthemes were identified.

This process was repeated for all transcripts. After those personal experiential themes identified earlier in all transcripts were analyzed and consolidated in order to create group experiential themes. The analytical process was concluded by writing up the results.

# CHAPTER IV - FINDINGS, ANALYSIS AND DISCUSSION

This chapter discusses the study's findings in relevance to the main aim of the study, which is to explore the social inclusion experiences of young adults with intellectual disabilities living in the community and how these experiences are perceived. Using Interpretative Phenomenological Analysis, the data collected from the interviews were analyzed based on the concept of Social Inclusion constructed in the Theoretical Framework, which consists of three key dimensions: community participation, interpersonal relationships, and sense of belonging.

The chapter is structured to address the three specific objectives, meaning each of the dimensions of social inclusion will be addressed separately.

Given the phenomenological perspective of the research, the chapter also presents direct quotes from the participants' interviews, which complement and support the analysis. Including these quotes is essential as it allows a direct insight into the participants' experiences and how these experiences are given meaning and significance by the young people themselves, offering rich and authentic data that enhances the depth and credibility of the analysis.

The results of this study have been analysed and interpreted in the context of existing knowledge and research which was outlined in the first chapter.

# 4.1. Participant vignettes

Amanda is 29 years old and lives in the countryside with her mum and adult brother. She enthusiastically attends a daycare center in the nearby town since she had to leave school due to her health condition a few years ago. Her hobby is knitting socks. Outside the daycare center, she spends all her time at home and occasionally joins her brother at work (he is a woodcutter). She struggles with loneliness and has no friends.

Andris is 25 years old and lives with his parents and brother. At home, he often feels bored; therefore, he likes coming to the daycare center. He particularly enjoys designing and making various objects out of wood with the support of his teachers. Before he started attending the center, he used to work as a cleaner. He has a group of seven friends with whom he likes to go for a walk or ride a bike: some of them are attending DCC just like him, and some are still in a special school. Grandmother and her friend often take him to different events and concerts, which he greatly enjoys.

Edijs is 26 years old and lives in a small village with his parents, grandmother, and brother. He comes to the daycare center four times a week to spend his day but hopes to find a job one day to earn some money. He regularly attends the village's community center, but his biggest and most important passion is being part of the village theatre group. Although he struggles to connect with his peers, he finds solace in his theater group, where he regards the members almost as friends.

Elza is 31 years old and has lived with her parents since they helped her move away from an abusive relationship. She attends specialized workshops, where she particularly enjoys helping staff to clean up after the sessions. Besides that, she also attends theatre classes for youth with disabilities and enjoys attending concerts and events in the city herself. Elza's current boyfriend is also attending the same specialized workshops. She considers all the people in the specialized workshops to be her friends; their communication is exclusive to the context of the workshops.

Ilmārs is 31 years old and moved to a group home a few weeks ago. He preferred not to talk about his family situation. Attending a daycare center is extremely important for him. The biggest adventure of his life was a trip to a sports festival abroad, organized by the daycare center team. Ilmārs is friends with everybody in the center. He particularly values his friendly and warm relationship with the staff. He spends all his free time at home.

Jana is 28 years old and lives in the countryside with her mother, younger brother, and sister. She attends specialized workshops in a nearby town and calls that place her second home. She has two childhood friends and neighbors with whom she still keeps close contact - her cousin and her friend. She has had a boyfriend for six months who works in Riga and has no disability. Thanks to this relationship, she has a very active life: she attends events, travels, and goes to parties with her boyfriend.

Kristīne is 35 years old and lives with her mother and brother. She attends a daycare center on weekdays, and in the summer, she takes the opportunity to work as a cleaner in a nursing home. She goes to church every week, and it is very important to her. She has one friend who she has been friends with since she was at special school. She also considers all the clients of the daycare center as friends, although she does not meet them outside the center.

Leons is 31 years old and lives on a farm with his parents, grandmother, and younger brothers. He enjoys attending the daycare center. He has established close friendships with two of the center's clients. In their free time, they meet regularly and spend time together. In his free time, Leon also likes to do sports with his dad.

Ojārs is 27 years old and lives with his brother. He attends a day-care center, and his main hobby is playing the accordion. Every week, he attends church with his father, but besides that, he spends most of his time alone at home. He tries to be friends with everybody in the daycare center.

Viola is 29 years old and lives together with her parents, grandmother, and boyfriend. She has to come to the daycare center when the rest of the family is off to work, even though the daycare center is a rather boring place in her opinion. She is strongly affected by society's negative attitude towards her and tries to prove that she is an equal to them. In her free time, she writes poetry and spends time with her family. She has no other friends.

# 4.2. Meaningful participation

The first specific objective of this study was to investigate the structure and involvement level of community participation among young adults with intellectual disabilities and explore the subjective meaning of significance they derive from various activities in diverse settings shaping their Social Inclusion experience.

Results are presented in the following way: First, community participation was divided into categories defined in a theoretical framework, and within the category, several themes were identified that provide an in-depth analysis of structure, involvement levels, and significance of the category of community participation in the lives of participants. After that, a discussion on those themes is provided.

Dimension of Social Inclusion explored	Category of community participation	Emerging themes capturing lived experience through structure, involvement level, and subjective meaning attributed to the category of community participation
Community participation	Productive activities (formal programs)	Opportunity to lead an active and interesting life  Participation in formal programs as job  Platform to develop skills  Beyond work  Chance to socialise  Willingness to participate
	Recreation&leisure	Regular participation in integrated settings  Staying at home

	Depending on others
Consumption	Life being managed by someone else
	Attempts to engage

Table 2: Emerging themes of Community participation

## 4.2.1. Productive activities: formal programs

All ten participants who took part in the study were attending a daycare center or specialized workshop several times a week, and this was an important part of their normal routine. One participant worked as a cleaner during the summers (a National Employment Agency project offered the job), for all the others, attending formal programmes was the only form of productive participation. Participants varied in the importance they attached to attending the program and the impact it had on their overall experience of Social Inclusion. For two participants, attending formal programs was, in fact, the only regular occasion where they went out of the home and met people other than their family members, while for several others, although important, it was only a certain part of their Social World.

## Opportunity to lead and active and interesting life

Participation in a diverse set of activities within Day care centers and specialized workshops participants perceived as an opportunity to lead an interesting and active life. It was a very important theme that was present in the accounts of 9 out of 10 participants. Only in Viola's experience was going to the day center a necessity that she couldn't really avoid, a place where the activities were monotonous and not in line with her interests. All the other participants emphasized with great certainty that it is thanks to the formal program that they can engage in varied, meaningful, and enjoyable activities in their lives.

Regular participation in formal programs gave young adults motivation and the opportunity to get out of the house on a daily basis and engage in activities that they were interested in. Several participants drew a contrast between being at home and attending formal programs.

<u>Ilmārs</u>: That's why it's important for me to come here because it's not interesting at home. Life has to have a routine; life has to have a meaning. Here, there is work, learning, and some fun. There is a little bit of everything. Put together, it makes a good whole. (..) It is NEVER boring here. That's why it's a pleasure to come!

Such repeated comparisons indicate that participants' lives outside formal programs are much more monotonous and inconsistent with their aspirations and needs, lacking meaningful participation.

#### Participation in formal programs as job

Participants' narratives revealed several different aspects of ways how engagement in activities of formal programs was perceived. When asked to share about the importance of attending formal programs, Jana and Elza emphasized their sense of commitment toward attending specialized workshops:

Jana: It is important. I take it very seriously and responsibly. It's like a job for me.

Elza: It's my job to come here and work."

In the light of the realization that there were no opportunities available for them in the job market, Andris, for example, saw formal programs as a good replacement for the jobs. Although several participants saw formal program attendance as a substitute for work, no one called it a "real" job, pointing out that they do not receive any salary for attending the formal program. Several participants expressed that they would like to earn money themselves but did not see the opportunity to do so.

Andris: Since I cannot find a job, it is good that I can come here.

### Platform to develop skills

Some participants talked about how it was particularly important for them to have the opportunity to learn different skills that are useful also outside formal programs. Leons highlighted the importance of learning everyday independence skills, Ilmārs -social competencies, while Kristīne emphasized that it was at the Centre that she had fully developed a variety of work skills.

<u>Leons</u>: But here is another thing! Here we learn to do everything ourselves, we have to do everythingthe dishes have to be washed, the floor swept <..> We do all the household things here, we are learning to be independent here."

<u>Ilmārs</u>: "Here you become smarter and more skilled. <..> You improve everything and then it's easier when you are out and about in society, your fears disappear, you feel more secure and confident in communicating with other people. I feel safer now.

<u>Kristīne</u>: here you can learn so many things, sewing, for example. I didn't learn this craft before. Well, we learned a little bit at school, but here I REALLY learned."

#### Beyond work

Participants' experiences highlighted that participation in a formal program means more than a job or skills development. It is within the formal programs that participants have the opportunity to be engaged in a diverse range of leisure activities that they do not have a chance to do beyond the context of the formal programs. For example, for Ojārs Daycare centre is the only place where he can perform on accordion for others, for Amanda it is only context where she can attend a party.

Ojārs: Well, I feel good here. Most of the time, I am happy here. I come here to relax. <...>I like singing here the best, playing the accordion. We organise concerts... I really like performing. This is an interesting place overall."

<u>Amanda:</u> Well...it is fun here. And we have parties here sometimes, then we can dance. We have both work and leisure here! It is very nice to have these both things."

#### Chance to socialise

Throughout interviews, 7 out of 10 participants spoke about ways they value the opportunity to meet and spend time with other people within the context of formal programs and how it contributes to forming and sustaining closer friendships with peers.

Socialization and the opportunity to build personal relationships with peers were, for most participants, directly dependent on participation in formal programs. Only three participants had close personal friends outside the day-care center; for two of them, it was a friend from the specialized educational institutions they used to attend, and for one participant, it was a cousin with whom they had been friends since childhood.

Given that the formal program is almost the only opportunity for many young people to be outside the home, it is understandable that the opportunity to be in the company of others was important to them in itself. Leons and Ilmārs, describing the importance of the day-care center in their lives, said that the opportunity to socialize was the primary motivation for them to attend the day-care center. The formal program serves as a platform for daily encounters with other people and allows them not to be alone and, in Ilmārs' words, to experience "life."

<u>Ilmārs</u>: Here you are in the community, among people. <..> Also-cool people. There's life here, that's the most important thing. <..> You can laugh, you can make new friends - that's a big plus for life.

#### Willingness to participate

In the interviews, when asked about the level of involvement in the Daycare Centre and Specialised Workshops program, almost all participants indicated their willingness to participate actively and fully. However, it must be noted that the responses suggested that, at least in some cases, they might not fully understand the meaning of the question or are not able to fully reflect on their experiences. Nevertheless, those answers show that participants are looking for active participation in their lives, and filling days with diverse activities that are specially tailored to their needs are, to a great extent, contributing to their Social Inclusion experience.

Leons: "I do everything; I like EVERYTHING, EVERYTHING, EVERYTHING here!"

#### 4.2.2. Recreation and leisure

An important aspect of the study participants' community participation experience is a way how they spend their time beyond formal programs, what is their experience regarding recreation and leisure.

There was quite a lot of variation between participants in the way they managed their free time, ranging from very full and varied participation to cases where the young person spent all their free time at home. Despite the diversity of experiences, the young adults' answers allowed us to identify three themes that characterize the participants' leisure and recreation experiences.

#### Regular participation in integrated settings

Only three out of ten participants engaged in structured, regular activities in integrated settings in a community in their free time. Kristīne and Ojārs attended church every week and were actively involved in the parish life, while Edijs attended the theatre group every Friday and visited the community centre organised workshop in his village every month. This experience, especially in the lives of Edijs and Kristīne, who attended these activities independently on their own initiative rather than with their parents, was extremely meaningful for them. Even though participating in a theatre group and being a member of a parish are quite different activities in themselves, in both young adults' narratives, it could be heard that they attach quite similar meanings and functions to these activities.

Both Edijs and Kristīne emphasized that attending church and theatre enables them to meet and interact with others beyond the context of formal programs. They valued this experience as it gave them the opportunity to be actively involved in activities that they enjoy.

<u>Edijs</u>: I go there by myself, without my parents. We have this collective. It's mostly pensioners. And I REALLY like it. Yes, there, I can say that I am truly part of society! When I am there, I can say with certainty-Yes, that's an example of social inclusion in practice! You can have fun there; you can meet people there. And I like it very much. I like to have fun and spend my time in an interesting way!

<u>Kristīne</u>: I feel better immediately when I go there; it's such a peaceful and good place to be in. Everybody prays a lot there. People talk about Jesus there. I have a lot of friends there too.<..> I like to come to prayers and then spend some time with people. I am an active member of the congregation.

#### Staying at home

When asked to share how they spend their free time, the majority of participants said that they mostly just stay at home. Some had personal hobbies, such as knitting or drawing, while others could not clearly describe how their time was filled.

Compared to their experiences during formal programs, where activities are organized and facilitated, their unstructured free time is perceived as less fulfilling or active.

Amanda: "Nothing special; I spend most of the time around the house."

When talking about their participation in formal programs, several participants indicated that they enjoyed attending various places in the community, such as a libraries, museums as well as various events as part of their program. However, in most cases it did not lead to such participation in their free time. For example, Ilmārs, although he was very enthusiastic about the opportunity to visit different places in the local community as part of a formal program, never did it on his own initiative.

<u>Ilmārs</u>: No, I don't visit many places on my own, only in the context of this center. I'm already a bit lazy... I don't know... then you have to look there for information about what is happening and where. I like to go together with other folks and teachers, so I don't have to plan anything myself, it's convenient.

#### Depending on others

As examples illustrate, participants found it difficult to articulate why exactly they do not attend events and other public places in the community, but it seems that the reason might be that these young adults need someone to participate in activities with, someone to organize the activity and in general their position in organizing their free time is rather passive. Only one participant-Elza-said that she attends events completely independently. Thus, whether young adults will spend their free time engaging in the community rather than limiting their participation to attending formal programs depends largely on the people who are in their circle. This is vividly illustrated by the experience of Jana, who was the only participant in the study who actively visited different public places in the community during her free time. When asked how this happened, she said that she became so active after meeting her boyfriend (who does not have an intellectual disability).

Jana: I used to spend my weekends and holidays just sitting at home, but now every weekend I do something, go somewhere, it is so much more interesting! <...> When I go to Riga to see him, we walk around the city, and we go to museums. <...> I also like to dance at parties; I like to dance with my boyfriend. Here in town, there are outdoor parties in the summer. Me and my boyfriend go then. I have been many times, also in other cities.

Andris's experience also shows that whether and how he visits public places in his free time depends largely on the initiative of others.

Andris: Well, I go to concerts in the cultural center from time to time, and they are different ones. I like to listen to music.

<u>Ieva:</u> Do you go yourself...or how does it go?

Andris: Well... No, I don't go alone. My grandmother's friend calls me from time to time and asks if I want to go to a concert with her. Well, I usually say - why not? And then she tells me the date and time of the concert. And then we go together. She also buys tickets if necessary. <..> Well, I like it, yes, it's

very interesting for me. We've been going to cultural events with my grandmother and her friend regularly lately."

## 4.2.3. Consumption

Questions related to the experience of access to goods and services were difficult for almost all participants, so several specific prompts were given during the interview to help participants understand the question. Despite the fact that the young adults found the question difficult, two themes clearly emerged that characterised their experiences.

#### Life being managed by someone else

8 out of 10 participants, when asked to share their experience regarding accessing various goods and services, clearly stated that when it comes to visits to doctors, contacting social services, etc., they do not organize any of that themselves and mostly seemed to be oblivious to such matters in general. It was the family that was managing their lives.

Amanda: Mum usually handles all that; she calls whoever she needs to - finds out what and how, and we go together to the appointments. <..> It's comfortable to have Mum deal with these issues. I don't even know who to call or what questions to ask.

#### Attempts to engage

Several participants referred to their ability to shop independently, to use public transport, and to do other simple everyday things related to the consumption category of community participation. Their narratives often reflected pride in their ability to do these things and a desire to be even more autonomous in their daily lives.

Ojārs: I would love to go, but I can't go alone...I wouldn't manage...but nobody takes me to events... I can't go alone without my parents.<...>, But I would like to learn to do things on my own. For example, I would like to learn to ride the bus on my own. <...> When I go to my grandmother's house, they give me money, then I go to the shop by myself and buy what my grandmother asks me to buy, like sweets and lemonade. I really like to go to the shop by myself when I'm in the country with my grandmother, but here in town my brother goes, and I don't go. I'd like to go by myself, but I can't...It's too complex."

Organizing results into themes has allowed us to build a detailed picture of young adults' daily life experience in the community and the importance participants attach to it. From the data analysis, several points of interest must be discussed that characterize the structure and involvement level of community participation as well as the subjective meaning of significance that participants attributed to various activities.

Looking at these results in the light of the Theoretical framework, first, when it comes to the structure-community participation of young adults with intellectual disabilities mostly took place only in segregated settings, namely formal programs and the family; at best, it included some community presence through attending events in public places with family. This community participation structure is consistent with previous research indicating that living in the community and receiving community-based services does not in itself ensure community participation for people with intellectual disabilities outside of segregated contexts (Merrell et al., 2019).

The second point of interest refers to the question of what community participation is perceived as meaningful. As described in the Theoretical Framework, it is a crucial aspect of understanding social inclusion as a subjective phenomenon. In order to experience meaningful participation, people with intellectual disabilities need to be in a permissive environment where opportunities for participation are given (Byhlin & Käcker, 2018) and for participants of this study, as also previously documented by S. Hall (2017) formal programs provided with such opportunities. The themes that emerged from participants' narratives show that attendance of formal programs was, in a way, a separate sheltered world where young adults felt comfortable and wanted to participate actively rather than simply a place of productive community participation. It is important to emphasize that young adults saw participation in formal programs as a positive and suitable arrangement for their lives. These observations are in line with Bredewold & van der Weele's (2022) findings on sheltered institutions, showing that if well organised, they are able to lead towards Social Inclusion of persons with ID through being tailored to people's needs. Unlike mainstream settings, sheltered environments can better embed values important for people with ID- in her study, defined as 'shelter,' 'rhythm,' 'encounter,' and 'contribution,' and allow them to view dependence on others as a normal necessity of life. At the same time, even though formal programs provide ways for all participants to be involved in various activities, these programs cannot serve as a complete replacements for a broader community – formal programs cannot always meet the diverse interests and needs of clients. Instead of focusing on offering increasingly diverse activities in formal programs, according to Hall (2017), there is a need to increase support in generic activities that would allow more people with intellectual disability to get involved and enhance their social roles.

As previous studies have already reported (Hall, 2017, Merrell et al., 2019), community participation of people with ID outside formal programs was very fragmented and limited. When it comes to hobbies and leisure activities, this research shows that a great majority of the participants do them alone and at home. This, to a large extent, reflects earlier studies (Garolera et al., 2021). However, young adults who had a chance to participate in the community beyond formal settings and family contexts valued such opportunities and attributed high importance to such experiences. Places of memberships such as theatre groups and churches present opportunities for repeated encounters (Bigby & Wiesel, 2019) that lead to

meaningful participation of those young adults who regularly attend those places. The way how individuals described their participation in church and theatre groups were in line with a study done by Robinson et al. (2020), stating that in order to become embedded in a particular community, it is important for young people to feel accepted and included beyond their disability. The fact that only a minority of participants were able to find such an environment in a society also shows that current policy efforts fail to create in practice prerequisites for people with intellectual disabilities to ensure their active involvement in the wider community, beyond the formal programs.

Similarly as in Overmars-Marx et al. (2019) Study participants showed a willingness to engage in micro-level community participation, such as shopping, and paid little to no interest in access to various other services. Even though participants in this study were not reporting it directly, there is a lot of evidence that limited control over one's own community participation negatively affects the sense of adult social status and control of life. (Carlsson & Adolfsson, 2022). In accordance with previous findings (Pallisera et al., 2022) Results showed that community participation of young adults with ID was, to a great extent, dependent on and shaped by others: staff and family. When they did not receive support, i.e., during their free time, it often resulted in young adults feeling bored and not being able to participate in activities that they found interesting.

# 4.3. Interpersonal relationships

The second specific objective of the present study is to investigate the structure, function, meaning, and significance of interpersonal relationships among young adults with intellectual disabilities in regard to their inclusion experience.

In the theoretical framework, three categories of important interpersonal relationships were identified as relevant to this study: friendships, relationships with family, and relationships with staff. accordingly, in the interview, participants were invited to share about all three of these categories of relationships. Within these categories, their structure, meaning, and significance were explored. Accordingly, several themes characterising the experience of interpersonal relationships were identified. Results are followed by discussion.

Dimension of Social Inclusion explored	Type of Interpersonal Relationships	Emerging themes capturing lived experience through structure, function, and subjective meaning and significance attributed towards the type of relationships
Interpersonal Relationships	Friends	Regular casual encounters

	Seeking emotional bond and reciprocity in friends  Struggling with loneliness
Family	Having somebody to spend time with  Reliance  The most important and stable relationships
Staff	Like at school  People that care  Between closeness and professionality

Table 3: Emerging themes of Interpersonal Relationships

## 4.3.1. Friendships

For the study participants, forming and maintaining friendships was an important aspect of their lives. Nevertheless, their social circles were very limited.

Several participants referred to everyone in formal programs, church, and theatre as friends, but their narratives lacked the personal aspect, and these relationships were only sustained in the context of the particular place/activity. When it comes to personal friendships, only four young adults had friends with whom they would meet individually. Jana was the only one who had a friend without Intellectual disability. She talked about her cousin and her friend with whom she grew up as her friends. Others have met their friends in segregated settings. Andris and Leons had a few friends in a formal program with whom they met and communicated beyond the context of formal programs. Also, Andris and Kristīne were still in touch with their former classmate from the Special school.

#### Regular casual encounters

When asked to share their experiences of friendship, young people highlighted that spending time together is a key part of such relationships. When it comes to the frequency of interactions, it was not clear from the accounts of participants how often exactly they were meeting. However, many emphasized that meetings need to be regular. Leons also pointed out that friendships are relationships that you are in control of and do not depend on others to maintain them.

<u>Ieva</u>: How often do you get together with friends?

<u>Leons</u>: Well, often- once a week, once a month, whatever! When they suggest that we should get together, I always say-yes! They usually suggest that we meet, and then I plan when and where we'll meet.

<u>Ieva</u>: How do you usually organize your free time?

<u>Leons</u>: I ALWAYS, ALWAYS do it myself! I call friends- we discuss, where are we going today?

For all participants, spending time with friends took the form of regular chatting, just hanging around, walking together, having conversations, etc.

Andris: On Saturdays and Sundays, if the weather is good.... Well, then I call my friends, if any of them want to, I invite them to go to the stadium with me. We get together: someone has a bike, someone has a scooter... so we meet and ride around the stadium, around the city.

## Seeking emotional bond and reciprocity in friends

Another structural element vividly present in the friendships participants had is reciprocity. It was important to the young adults that the relationship was a two-way street in which both parties were interested in maintaining it. Reciprocity was expressed in the way communication between friends was not always initiated by one party; the participants shared that friendship is based on knowing that each other can be counted on in times of need, and it was important to them that the emotional connection is reciprocal.

<u>Ilmārs</u>: Sometimes they ask me for advice, and sometimes I need their help.

<u>Leons</u>: "So, how do you say it...friendship...friendship is when there is mutual love.

When it comes to the functions of friendships as perceived among interviewed young adults, they were mostly emotional. Beyond casual interactions and spending time together, it was very important for the participants to experience trust and reliance towards their friends.

*Ilmārs: The best friend is the person you can tell everything to.* 

The necessity of trust to sustain friendship was also revealed in Jana's experience of losing a friendship.

Jana: Friendship is when you have someone you can talk to properly, when you have someone you can confide your problems and worries to, and the other person listens, and then it gets better. There have been times when I tell a supposedly real friend a sensitive thing, but then I regret having done it. I have had that experience... unfortunately."

#### Struggling with loneliness

In order to get better understanding of emotional needs in friendships among young adults with Intellectual disability, it is also important to pay attention to another theme-loneliness that was with varying intensity present in the lives of six participants. Young adults were longing for close friendships beyond

their immediate family. However, not everybody was able to form them, and that led to a strong sense of loneliness and isolation.

<u>Edijs:</u> "I used to go to a special school, and I used to get teased and bullied a lot there. I CAN'T MAKE FRIENDS. It is very painful for me; I cannot find friends.

Amanda: I have to be honest with you... I miss all this in my life.

## **4.3.2.** Family

The participants in this study were young adults living in a family or, as in the case of Ilmārs, who had just moved into a group home. Eight young adults lived with their parents or both parents, and one lived with his brother. Some had siblings who lived either with them or independently. All but Elza had no experience living independently. Some had siblings who lived either with them or independently; however, when talking about family, participants mostly referred to their parents and made it clear that they did not have strong ties with their siblings. Similarly, participants did not really mention people beyond immediate family, which also suggests that relationships with them, if any, are not as personally meaningful.

#### Having somebody to spend time with

Given that the young adults lived with their parents, as expected, they spent a lot of time with their parents on a daily basis. Most of their contact is at home through everyday things, shared hobbies and going on trips together. The way participants describe being with their family shows their desire for relationship and involvement. However, given that participants' social circle and participation in the community was very limited, contact with family, apart from formal programs, was almost the only way to satisfy this desire. The quote below similarly show that, although less pronounced, reciprocity in daily affairs is a present component of the relationship and is clearly reciprocal.

<u>Kristīne</u>: "We are together all the time. We are together on all holidays. We help each other every day."

#### Reliance

Relationships with family and parents, in particular, had several functions in the lives of young adults. As already underlined in the analysis of the participants' community participation experiences, parents are key people when it comes to access to different services - they are the actual managers of their children's lives, and participants also indicated that they expect and receive considerable help, knowing that in the current situation, it is impossible for them to live independently from their parents. Those relationships had strong informational and instrumental functions.

<u>Leons</u>: Ugh...to be honest, it depends. They are important to me, of course, but there are also arguments and conflicts. It happens... How to put it better... But it would be very difficult to live without a

family - you have to buy your own food, buy your own clothes. But when you live with your family, they help you."

#### The most important and stable relationships

All participants who talked about their relationship with their family gave it great importance, saying that it was their most central and important relationship.

*Edijs*: The most important people in my life are my mum, dad, brother, and grandma.

<u>Viola:</u> Mum is just... I have no words to describe how much good, how much support she has given me. How much she has done. Her role in my life is just invaluable. I don't know what I would have done if I hadn't had her. There is no other person like her, and there will never be. Thanks to her, I can live my life to the best of my ability. We have a loving relationship; I like it. I am independent- but she is always there for me.

It was also clear from the narratives of several workers that building relationships was necessary to avoid loneliness, with family replacing absent friends.

Amanda: It's good to have them...at least you don't have to be all alone.

#### 4.3.3. Staff

As all the participants attended the day center daily, contact with the staff was part of their daily routine. However, participants often found it difficult to describe their experiences and relationships with staff and the role they gave them in their lives. All ten participants described their relationships as positive. However, the importance that they attributed to them varied significantly. Three themes emerged from the participants' narratives, reflecting how young adults experience interpersonal relationships with the staff members in the formal programs.

#### Like at school

Several participants, when asked to share about their relationships with staff members in the formal program, talked about them as teachers, emphasizing that their interactions replicate the school environment. The interactions were strictly within the formal program, and the participants were aware that the staff had a specific role - to support and supervise the workshops and activities. This is probably why reciprocity as a structural element of relationships did not appear in the participants' narratives.

<u>Kristīne:</u> We work together in the workshops; we sew. They teach me everything. <...> They're the ones who come to me and ask about different topics. <...> They are good. They teach me everything. Well, they are my teachers, like at school.

#### People that care

Another theme that emerged in several participants' narratives regarding their relationship with staff was related to how they expressed support- they saw staff as people who cared about them. Young people

stressed not only that employees are important to them as support providers, but they also appreciated that these are people who care about them and their well-being. Elza emphasized that staff are the people she can trust completely. Meanwhile, Leons emphasized that staff are attentive to the individual needs of each person.

<u>Leons</u>: They take care of me, they pay attention to whether there is something interesting for me to do, how I feel. They notice everything I do and say kind words to me, even if it's just watering the flowers. Well, we work here. If I need help, they always help me. They offer all sorts of interesting activities; they try to make sure that everybody has a good time here.

#### Almost friends

As mentioned above, participants recognized that staff is professionals whose job is to provide support. However, through the participants' narratives, it was possible to observe a nuanced view of their relationship with staff. As can be seen in the quotes below, Amanda and Ilmārs point to the fact that staff can take on the role of a friend while remaining professional and aware of the boundaries of the relationship. They described it as an opportunity to communicate informally and feel comfortable and relaxed in their presence.

<u>Ilmārs:</u> We talk about work things and also about private things. Because if I need help with a private matter, they can help with good advice. So it's both a professional and a friendly relationship. <...> I have never had any problems with the staff. It's good. They are friends and teachers. Two roles. I am aware of that. So when we have a workshop, they are teachers, so we must not disturb them. But in the breaks, then we can talk, joke with each other, and ask for help. You have to be aware of the boundaries; there is a line that you must not cross. If they are leading the lesson, then you have to obey them, but in your free time, you can be more relaxed. You have to be able to read a room-sometimes you are a student, sometimes you are a friend. You must not mix them. Otherwise, it's no good."

The themes identified from the narratives of participants confirm previous research (Hurd et al., 2018; Sullivan et al., 2016) on that close interpersonal relationships are valued and desired by young adults with intellectual disabilities. Feeling included in the social community through having close relationships is very important for the person's well-being (Strnadová et al., 2018).

When it comes to structured- relationships, participants reflected on the segregated nature of their lives. As the community participation for most participants was very limited, so was their circle of people with whom they had personal close relationships. Even though community participation does not automatically lead to the development of close relationships, it is a fundamental prerequisite to making new social connections possible (Garolera et al., 2021).

It is well documented that people with intellectual disabilities usually have less amount of close relationships than their peers without a disability (Umb Carlson, 2022; van Asselt-Goverts et al., 2015), and their social networks are quite restricted (Pallisera et al., 2022). Nevertheless, as previously reported (Kelly & Wagstaff, 2022) Participants still had a range of different close relationships in their lives. Participants' had a close relationships with family members with whom they lived, staff and other clients of social services.

The study confirmed that most of the people with ID do not have close relationships with people without ID beyond their family and paid staff. Only two of the study participants had maintained relationships with school friends (who were not attending their formal program); this could confirm what has been described in the literature that young people transitioning to adulthood are often unable to maintain existing relationships when they leave school (Small et al., 2013).

Many studies have reported that people with Intellectual disabilities often form close relationships with the staff (Giesbers et al., 2019). This was also expressed by some of the participants of this study; at the same time, they seemed to be aware that they are professionals and can only take a certain *role* of a friend or family member as part of their work. Therefore, it does not fully support previous findings that staff is perceived as friends and those relationships are seen similarly as peer friendships (Pallisera et al., 2022). In their interactions with staff at the day center, young adults highlighted that they appreciate staff who take an interest in their lives beyond the narrow context of the program, listen and listen to what they have to say, and those with whom they can also have fun and joke around. Similar results can be found in the literature(Bigby & Beadle-Brown, 2016). Professionals need to support people with intellectual disabilities rather than take care of all aspects of life where they face challenges (Pallisera et al., 2018). This supportive function of staff was clearly evident in participants' narratives, with several participants referring to staff as teachers, meaning people who teach and who help people achieve certain goals.

Relationships with family were very important for research participants. This has also been shown in the earlier studies (van Asselt-Goverts et al., 2015). In line with previous studies, young adults with ID had close relationships with family members based on trust and continuity (Umb Carlson, 2022). At the same time, having close relationships with the family seemed to serve as a replacement for friendships, and that possibly can lead to further unintended segregation (Merrells et al., 2019).

When it comes to the way how young people described their friendships, unlike the Merrells et al. (2019) study, the results of this research did not show that young adults form relationships in a child-like way and did not include elements of play. Instead, close interpersonal relationships were sustained through diverse ways of reciprocity, regular casual encounters, and conversations that all helped to create strong emotional bonds based on trust and a sense of reliance. Reciprocity was a strong structural component in friendships- it indicates that the person in the relationship feels equal and on the same level as the other

party (Callus, 2017). Similarly, as observed by Garolera et al. (2020), when it comes to the importance of friendships for participants, for them, it is important to know that they can rely on their friends in any circumstances in which they may need them.

Overall, the results indicate that close relationships involve a combination of emotional, instrumental, and informational functions. As previously reported in the literature (Callus, 2017; Fulford & Cobigo, 2018; Sullivan et al., 2016) for people with intellectual disabilities, close relationships with other people were important, as they allowed them to not spend time alone and to engage in social activities, and were necessary to receive support and help. The inability to form relationships with peers contributed to the feeling of loneliness and isolation from others. According to Wigfield et al. (2020), a lack of meaningful interactions is the main cause of social isolation and loneliness.

# 4.4.Belonging

The third specific of this study was to correlate and categorize ways of belonging in regards to the Social Inclusion of young adults with Intellectual Disability.

A sense of belonging is highly subjective, expressed through feelings towards people, places, and activities. Unlike relationships and even more community participation, it is a much more abstract and, therefore, more difficult to articulate dimension of social inclusion. In general, the research participants found questions related to the experience of belonging, i.e., how they feel in particular places and relationships, more difficult and were often unable to describe their experience in detail. Nevertheless, in their narratives about important relationships in their lives and in sharing the ways in which community participation happens for them, a sense of belonging was present as an equally important dimension of Social Inclusion, even if it was not always clearly articulated. Experience of belonging occurred and was experienced in places of meaningful participation as well as in family.

Dimension of Social Inclusion explored	Object of belonging	Emerging themes regarding having a sense of belonging
-	Towards locations Towards activities	Community of belonging: formal program
Sense of belonging	Towards people	Community of belonging: integrated settings  Belonging towards family

Table 4: Emerging themes of belonging

#### Community of belonging: formal program

Eight out of ten participants had a strong sense of belonging to the formal program they attended. Several of the sense of belonging indicators defined in the theoretical framework were present in the participants' experiences with varying degrees of intensity. A sense of belonging among participants was experienced through being comfortable and respected and feeling "at home." For example, Jana emphasized that attending a formal program would allow her to feel like a part of a community.

<u>Jana:</u> We are in a community. We can help each other: if I need help, I know I can ask for help, and if someone needs my help, I help. <...> How to describe it? We are all like brothers and sisters here. Like one big family.

Analysing the participants' narratives, it became evident that the strong sense of belonging felt by the young people was largely due to the supportive and welcoming environment created by the staff.

<u>Ilmārs:</u> "You are supported here; help if you need it. If you need advice, you can ask.<..>And yes, the most important thing is that you will never be refused help here. That is why it is worth coming here. <...>Everyone here has an individual approach. Everyone can do to the best of their ability; no one will be blamed if she or he is not able to do something."

Elza, Ilmārs, and Kristīne referred to everybody in a formal program as friends but did not single out individual people and their relationships with them. Such a perception indicates a collective fellowship among the formal program's clients. The emphasis on engaging with everyone points to a sense of inclusivity and mutual support among participants, contributing to their overall sense of belonging.

<u>Ilmārs:</u> <..> There are different topics of conversation, different interests. But in general, I have quite similar friendships with everybody. I try to talk to everybody; it's important to me, and it seems to work."

#### Community of belonging: integrated settings

As previously discussed, for some of the participants in the study, an important part of life was participation in communities in integrated settings within society. In particular, it is about attending theatre groups and church. According to the participants' descriptions, these places primarily served as communities in which young adults could experience a strong sense of belonging. In general, the factors that shaped these feelings were similar to those in the formal programs: these were places where participants felt important, comfortable, and respected. However, nobody expressed feeling "like at home". Interestingly, Edijs, who stressed the importance of the theatre group in his life, which was also expressed as a strong need for belonging, was one of the few who did not talk about the feeling of belonging in the

formal programs. Overall, it was not an important part of his life, although the experience was clearly positive.

<u>Edijs:</u> it's a place that I'm very familiar with; it's a place where I feel comfortable, <..> When I am there, I can say with certainty-Yes, that's an example of social inclusion in practice!

<u>Kristīne:</u> I feel better immediately when I go there, its such a peaceful and good place to be in. Everybody prays a lot there. People talk about Jesus there. I have a lot of friends there too.

The sense of belonging to a community was also strongly reflected in how interviewees talked about people in that community. They did not meet beyond particular settings and were only referred to as a group by young adults. However, participants called everyone in the community friends or 'just like friends.' As with the formal programs, this indicates a strong sense of belonging to the community.

<u>Kristīne</u>: It's important because you can talk to them about God, about the Bible. You can pray with them. If something bad happens to me, I tell them, and we can pray together in that intention. If I have something on my heart, I can tell them. I can trust them, I am not afraid to tell them my problems because they listen.

<u>Edijs:</u> Well, I don't know....no, they are not friends. It's complicated. I think they are my colleagues? I think... the closest to having a friendship... I have is with people in the amateur theatre. They are good acquaintances of mine, and it's a place that I'm very familiar with; it's a place where I feel comfortable. <...> I've made friends with people there, and I feel good there. So it's important to me, that's why I go there.

#### Belonging towards family

The ways in which the family strongly influences and shapes the community participation experiences of the participants have already been described, especially when it comes to engaging with the world outside formal programs and how close and meaningful personal relationships are built with family members, especially when young people lack such opportunities in other contexts. Seven out of ten young people experienced a strong sense of belonging to family. Young adults were extremely attached to their families, and it was important for them to identify with family.

Jana: My family is my world.

<u>Leons:</u> Family listens to me and listens to what I say. <...> I don't hide anything from my family; I don't have any secrets from them."

Belonging is a dimension of Social Inclusion that is hard to capture due to its highly subjective nature; however, in the light of the proposed Theoretical framework, it is crucial as it allows us to see Social Inclusion as a personal and informal experience.

As outlined in the theoretical framework, it refers to the subjective experience of feeling needed, important, valued, comfortable, respected, and "at home" towards other people, locations, or activities (Hall, 2010; Reeves et al., 2023). Results indicate few points of interest for a discussion.

Findings of this study show that participants experienced belonging in environments where they were able to engage in meaningful participation and form positive relationships. This is in line with a study done by Renwick et al. (2019), describing belonging as a process experienced through having social relationships, interacting with people who are similar, and negotiating meaningful roles in the community (Renwick et al., 2019) it also in line with findings by Hall (2017) that the more included and involved are people with intellectual disabilities in various activities, the stronger their sense of belonging is.

This research shows that a sense of belonging most vividly is experienced towards specific communities, meaning belonging towards place, activities, and people are intertwined. Similarly, as in previous research, it was evident that a sense of belonging among young adults with intellectual disability was underpinned by a supportive moral culture (Reeves et al. 2023). Belonging was experienced both in segregated settings where the environment and program are specially tailored to meet the needs of people with disabilities, as well as in integrated settings in the community, and those experiences are somehow similar. In line with previous research (Robinson & Idle, 2022) It was attitudes towards them that were central to experiencing belonging. It is well-documented that individuals with intellectual disabilities require acceptance and comfort to foster a sense of belonging (E. Hall, 2010; Robinson et al., 2020), a finding corroborated by this study.

The second point of interest concerns belonging to the family. In line with previous studies (Robinson et al. 2018), participants felt a strong sense of belonging to their families. Even though belonging is an important dimension of the Social Inclusion experience and is also highly valued by participants, such a strong notion of belongingness towards family might present challenges as it might limit Inclusion in other contexts. This is because the family environment while providing a supportive and comfortable setting, may not adequately facilitate the adult's participation and social interactions in the broader community (Grung et al., 2023). A strong sense of belonging to the family may contribute to a sense of dependency on family members for decision-making, problem-solving, and daily tasks; this can lead to social isolation and difficulty in forming connections with peers and community members (Merrells et al., 2019)As explored previously, this study also shows that parents are in charge of many aspects of their adult children's lives and their main social connections.

# **CONCLUSIONS**

This research aimed to explore how young adults with Intellectual disabilities live in the community and attend daycare centers or specialized workshop experience and make sense of their Social Inclusion based on their individual and lived perspectives in Latvia. The research was based on the definition of Social Inclusion as a largely relative and subjective phenomenon that occurs as an interaction and evolving process between spending time in activities that create meaningful participation, having meaningful interpersonal relationships, and a sense of belonging. In order to achieve the general objective, the experiences of ten young adults with ID living in the community and attending formal services in six different towns in Latvia were captured. Through semi-structured interviews analyzed applying IPA methodology, young adults with intellectual disability were given a chance to have their voices heard. By listening and understanding the unique experiences of people with intellectual disabilities, professionals and policymakers can develop support mechanisms that are more person-centred and consider the perspectives of this often-marginalised group, promoting Social Inclusion on their terms.

The first specific objective of this research was to investigate the structure and involvement level of community participation among young adults with intellectual disabilities and explore the subjective meaning of significance they derive from various activities in diverse settings shaping their Social Inclusion experience. Results showed a great difference in that attending a formal program brought to the community participation experience of young adults with ID that otherwise was very limited. Participants experienced diverse and meaningful participation through involvement in formal programs: it provided opportunities to engage in specially tailored activities that replaced work in mainstream settings, provided diverse opportunities for leisure and self-improvement that included attending different places and events in mainstream settings, and served as a platform for socialization. Outside these programs, their community participation was very limited and fragmented, depending to a large extent on their parents' initiative, both in terms of leisure time and the use of various services. Only three participants were independently involved in regular community activities. Without opportunities and support that would help them to engage in the activities in the wider community, the young adults spent most of their time at home, experienced boredom, and were highly dependent on their parents.

The second specific objective of this research was to investigate, among young adults with intellectual disabilities, the structure, function, meaning, and significance of interpersonal relationships concerning their inclusion experience. Results showed that important interpersonal relationships participants had reflected the segregated nature of their lives and were strongly related to the places of participation-social circles of research participants were small and predominantly composed of people with whom they met daily: staff in the formal programs, family members, and other people with ID in the formal

programs. A strong attachment to family replaced the lack of significant friendships with peers, yet loneliness was still a present theme in several participants' narratives. The way in which young adults developed and sustained close relationships presented a multifaceted picture in which the need for emotional closeness, trust, and reciprocity stood out, and the different functions and expressions of relationships with family, employees, and professionals were clear to the participants.

The third specific objective of this study was to correlate and categorize ways of belonging in regard to the Social Inclusion of young adults with Intellectual Disability. In brief, while the theoretical framework proposed to distinguish experiences of belonging between places, people, and activities, the results clearly showed that young adults' sense of belonging is more focused on specific communities and contexts as a whole rather than on individual elements within them. Participants' narratives made it clear that a sense of belonging in their lives is linked to environments where they can meaningfully engage in activities, build close relationships with people, and be supported in these processes. Thus, speaking specifically in the context of the participants' lives in this study, a strong experience of belonging was felt towards formal programs, the church community, and theatre groups in a mainstream community. It is important to note that the sense of belonging was expressed in similar ways in segregated and integrated contexts, with and without the presence of formal support. Participants felt a strong sense of belonging to their family, which could possibly be related to the inability to engage and build relationships and receive support in other contexts.

The results of this study can be more comprehensively understood through an ecological perspective as it shows how the interplay between individual characteristics, social environments, and societal structures influences the social inclusion of people with intellectual disabilities. The results confirmed the interconnectedness between meaningful community participation, interpersonal relationships, and belonging- these three dimensions intersect to create an experience of Social Inclusion. This study shows that despite living in the community and receiving specially tailored social services, young adults' lives remain largely disconnected from the rest of society, and specially designed segregated services and family environments are often the only places where social inclusion is experienced. Participants' narratives revealed that most of them lacked experience of Social Inclusion on the broader community, not primarily because they had experienced rejection or restrictions, but because they often lacked access to relevant opportunities and the related know-how to broaden their social world, the parents of participants and the staff who worked with them played a mediating role between them and the wider community, thus promoting a positive but narrow experience of Social Inclusion, but not creating enough opportunities and support mechanisms to encourage a more diverse and independent experience of Social Inclusion for young adults on the broader community.

The social model of disability highlights the societal obstacles that hinder the inclusion of people with disabilities in the community. While the results of this study revealed the importance of formal programs and demonstrated the narrow and limited social world of most of the young adults with ID, the results of the study also show that if people with intellectual disabilities are given the opportunity to engage in a mainstream community in a welcoming and supportive environments, even without formal support and specially adapted activities, it is possible to experience Social Inclusion: through meaningful participation, creation of interpersonal relationships and growing sense of belonging all that according to their individual needs and interests. Thus, it is clear that social inclusion in the wider community is possible and important for people with ID. These results demonstrate the importance of promoting a shift from a medical model to a social model of disability, thereby raising public awareness of disability and breaking down barriers to the inclusion of people with disabilities in society.

This study has some limitations that need to be taken into account when interpreting the results. It focused on a comparatively narrow population and the sample size was also rather small. When analysing the results it is important to note that they are not representative of, and do not apply to, the whole community of people with intellectual disabilities. The aim of this study was to explore people's unique experiences of Social Inclusion in more depth rather than make broad generalisations. Despite its limitations, this study is a valuable contribution to the understanding of a phenomenon of Social Inclusion among people with ID.

This study contributes to the fast-growing body of literature exploring the lives of people with intellectual disabilities through first-person accounts. Research on social inclusion of people with intellectual disabilities is a topic that has not received enough attention in Latvia; very little was known about whether and how young people with intellectual disabilities who meet the goals of the national deinstitutionalization plan—namely, living in the community and receiving community-based services—experience social inclusion in their lives. This study is important as it provides new knowledge in this field.

Although this study did not focus on policy evaluation as such and the quality of particular services, the results clearly show that the deinstitutionalization process in Latvia has had a strong impact on promoting the social inclusion of people with intellectual disabilities. As has already been described, Latvian legislation emphasises the equality of people with intellectual disabilities and the need for their inclusion in society with the help of the DI process. However, the results, which contrast the rich experience of social inclusion in a segregated environment with the absent or fragmented experience of inclusion in the mainstream community, raise concerns about whether the deinstitutionalization process's goal of living in the community for people with ID will be limited to their physical proximity to the mainstream society rather than real contact and meaningful experiences of inclusion. The findings of this study on the lives of

young adults with ID in Latvia, whose general situation is in line with the country's deinstitutionalisation goals, provide food for thought on the direction in which the country's support mechanisms and services should be heading. Formal programmes, that are one of the cornerstones of deinstitutionalisation, generally provide young adults with a rich experience of social inclusion replicating what usually is experienced in the wider society, and these programs are also highly valued by the people themselves. On the other hand, as this study shows, they do not really serve as a bridge to their inclusion in society as a whole. This is probably less about the quality of the particular service than about the failure of the wider support service system to create a framework that allows people to really engage with the wider community. Even though this study conceptualises Social Inclusion as a subjective and personal experience- a phenomenon to be lived based on an individual's personal preferences and perspectives, it would be wrong to state that the policy goal of Social Inclusion has been achieved only because people value formal programmes and feel good in their families or only because they physically are present in the mainstream society. If the aim of the state is really to include people in society on the basis of their individual needs and preferences, it would be important to provide people with more and better options to choose from and relevant support, because at the moment, as this study shows, people don't really have much to choose from when it comes to ways to be included in society. Such an approach would not be an imposition of normative standards of social inclusion; on the contrary, promoting ways for broader inclusion in society would enable people with ID to make informed choices about their lives that can result in Social Inclusion that really corresponds with the aspirations of the person.

In order to further increase knowledge and understanding of people with Intellectual disabilities and to contribute to the development of Social Work as an academic discipline, future research should seek to deepen and extend the insights gained from this work. First of all, this research focused on documenting subjective experiences of Social Inclusion, but to better understand the multifaceted phenomenon of Social Inclusion, the factors that promote or hinder social inclusion should also be addressed and analyzed in more detail. For example, this study shows that the support circle around the person plays an important role in the social inclusion experiences of young adults with ID, however, it also called into question whether this support is always helpful in broadening the social world of the person with ID- the results are raising the question of whether relying on other people could be compromising aspirations and needs of people with ID. Therefore, further research could delve into the problematics of autonomy as well as the dynamics of dependence and reliance among young adults with ID on their caregivers, particularly their families. Eventually that would help to develop more effective strategies for promoting Social Inclusion. Secondly, the results of the study showed that a few young adults experienced social inclusion in the mainstream community through various free time activities. However, this was only a very small proportion of participants and the communities to which they belonged were very diverse, so it was only possible to draw

general conclusions. To gain a more conclusive understanding of how this happens and how communities and groups in a mainstream society could be more inclusive would require more in-depth research, which was not possible in the present study. Finally, it also must be noted that this study focused on a relatively narrow group of people with ID; future research should also be carried out with people who, as a result of deinstitutionalization, have started living in group homes or on their own, as well as those who are not attending formal programs. The experience of social inclusion should also be further explored from the perspective of people with more severe intellectual disabilities. In order to promote a more comprehensive understanding of inclusion issues, in addition to exploring the experiences of people with ID themselves, attention should also be paid to proxy informants such as service providers, family members, etc. Similarly, in order to promote the development of meaningful and appropriate support systems, there is a need to indepth evaluate the effectiveness of national deinstitutionalization process with a focus on how those policy efforts affect individuals and their life experiences.

Although this study did not focus on Social Work as a discipline, its findings on the Social Inclusion experiences of young adults with ID led to a number of recommendations for Social Work practice with people with intellectual disabilities and their relatives.

- First, formal programs: day-care centers and specialized workshops must recognize their immense potential to impact their clients' experience of Social Inclusion. It is important to keep improving the quality of services and the diversity of opportunities offered to people with ID. The deinstitutionalization process has made it possible to create a much-needed community-based service, and the needs and aspirations of clients must be heard in its implementation. It is important to consider a person's whole life experience when tailoring a service to their needs.
- Secondly, in order to create a broader, more diverse Social Inclusion experience for people with intellectual disabilities that is in line with their personal needs, social workers of people with ID need to find ways to help their clients engage in their local communities outside the context of formal programs according to their individual interests and capacities, providing not only opportunities for participation but also continuous support. Examples from other countries show that socialization support groups, mentoring support, and volunteering opportunities could be tools to promote the inclusion of people with Intellectual disability in a broader community.
- Thirdly, social work professionals who are working with young adults with ID should also pay special attention to the families of their clients, who are, as this study shows, the backbone of a non-formal support system and on whom their children's opportunities for

social inclusion to a large extend depend. Part of the process of becoming an adult is gaining independence and separating from one's family. Still, if the young adult has an intellectual disability, this process is not easy and straightforward, as they will often need continuous support throughout their lives. This study shows that parents are largely in charge of the lives of their children. Support mechanisms should be designed to relieve parents and promote the independence and skills of young adults with intellectual disabilities, which would allow them to experience inclusion into society on their own initiative rather than just being dependent on the choices of others.

• Finally, in order to promote the Social Inclusion of people with intellectual disabilities, social work professionals must also work with the community at large so that society would be able to let go of prejudices so that it grows to recognize people with intellectual disabilities as equal members of society, so that people, who encounter individuals with intellectual disabilities, be they service providers of some kind or hobby groups, religious organizations or others, to be knowledgeable and informed about how to foster positive contacts, create a welcoming environment and thus prepare the ground for a person with intellectual disabilities to feel socially included.

In summary, this study provides valuable insights into the so far under-researched topic of the experiences of people with intellectual disabilities. Only by recognizing and valuing the legitimacy of the voices and individual perspectives of people with ID is it possible to create the shift toward a more inclusive and equitable society. And that is one of the fundamental aims and missions of social work.

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## **APPENDIX A**

#### CONSENT TO PARTICIPATE IN THE RESEARCH

Interview with a young adult with intellectual disabilities about their lived experience of Social Inclusion

You have been invited to participate in the research. The information below will help you decide whether you would like to take part.

I am researching the Social Inclusion experiences of young adults with intellectual disabilities. Social Inclusion occurs when people participate in a variety of activities that are important to them, build relationships and feel valued and included.

I would like to interview you to find out about your experience of Social Inclusion. This means that I want to ask you questions about what you do in your daily life, about your relationships and whether you feel valued and included.

Any information obtained during the interview that could identify you will be confidential. I will not disclose your name and names of other that you will mention, but will use pseudonyms instead. The interview with you will be audio- recorded so that I can listen to it and analyse it afterwards. The recording will then be deleted. The information obtained will be included in my master thesis research.

If you have any questions, please feel free to ask at any time! You do not have to answer a question if you do not want to. You may stop the interview or take a break at any time.

By signing this form, I confirm that I agree to participate in the research.

Participant's name:	Signature:	Date:
Researcher's name:	Signature	Date:

# **APPENDIX B**

## Table of participant characteristics and interview details

Nr.	Pseudonym	Sex	Age	Attending specialised workshop or day care centre	Length of interview	Language
1	Amanda	F	29	Day care centre	30min	LV
2	Andris	M	25	Day care centre	27min	RU
3	Edijs	M	26	Day care centre	18min	LV
4	Elza	F	31	Specialised workshop	32min	RU
5	Ilmārs	M	31	Day care centre	43min	LV
6	Jana	F	28	Specialised workshop	36min	LV
7	Kristīne	F	35	Day care centre	49min	LV
8	Leons	M	31	Day care centre	30min	RU
9	Ojārs	M	27	Day care centre	27min	LV
10	Viola	F	29	Day care centre	49min	LV

# **APPENDIX C**

### Categories, dimensions, indicators, questions

Aim	Specific objective	Category	Dimension	Indicators	Question for interview guide
To explore how young adults with Intellectual Disability's living in community and attending day care centre or specialised workshop experience and make sense of their Social Inclusion based on their individual and lived perspective and lived experience.	To investigate the structure and involvement level of community participation among young adults with intellectual disabilities and explore the subjective meaning of significance they derive from various activities in diverse settings shaping their Social Inclusion experience	Community participation	Productive activities	Setting&Type of activity (Specialised workshops/Day care centre)  Amount of time that is spent in activity/frequency  Availability of opportunities/autonomy in choosing them  Involvement  Participation/encounters/mere presence	Please describe your normal day!  What do you do there (day care centre/specialised workshops)?  How would you describe your experience there?  What do you do there (day care centre/specialised workshops)?  -Can you describe your involvement there?  -How would you describe your experience there?  Can you please reflect on importance of attending day care centre/workshops for you?

		-How would you describe your experience there?
Recreation&	Structure	
Leisure	Type of activity Setting	Please tell me what you do in your free time?
	Amount of time spent in activity/frequency Availability of opportunities/autonomy in	For prompts:
	choosing them	hobbies/social/clubs/sports/books/chur ch/cinema/walking/coffee/shops/holida ys/trips/attendig events/spending time with friends/family.
		What exactly do you do in this activity and how often?
	Involvement	
	Participation/encounters/mere presence	What exactly do you do in this activity and how often?
		Can you describe your involvement there?
	Subjective meaning of significance	Why this activity is important to you?
Consumption	Structure	
	Type of activity	What is your experience regarding access to goods and services?
		For prompts
	Availability of opportunities/autonomy in choosing them	Shopping/ healthcare/hairdresser/public transport
	Involvement	

			Participation/encounters/mere presence	What is your experience regarding access to goods and services?  Can you describe your involvement there?  For prompts  Shopping/ healthcare/hairdresser/public transport
			Subjective meaning of significance	What is your experience regarding access to goods and services?  For prompts  Shopping/ healthcare/hairdresser/public transport
To investigate, among young adults with intellectual disabilities, the structure, function, meaning and significance of interpersonal relationships on	Interpersonal Relationships	Friends and close social connections	Structure  Amount of friendships and social connections  Frequency of interactions  Dynamic/longitude of relationships  Contexts in which contact is occurring  Diversity of people with whom relationships are formed	Please tell me about your friends!  What do you do together and how often do you meet?  How do you handle communication and activities with each other?
regards of their inclusion experience.			Function, meaning and significance  Emotional/instrumental/informational  Reciprocity	What is friendship for you? Why are they important to you?

				How do you handle communication and activities with each other?
		Family	Structure	
			Amount of family members that are present in the life of a person Frequency of interactions Context in what contacts are occurring	- Please describe what your family looks like! -What do you do together and how often? -Describe how do you handle communication and activities with each
			Function, meaning and significance	other?
		Emotional/instrumental/Informational Reciprocity	<ul><li>-What do you do together and how often?</li><li>-Describe how do you handle communication and activities with each other?</li></ul>	
				-In what ways are they involved in your life?
	Staff	Structure Contexts in which interaction is occurring Diversity of people with whom relationships are formed Amount of friendships and social connections	-Please tell me about staff members that are involved in your life! -What do you do together and how often?	
		Frequency of interactions  Dynamic/longitude of relationships	-Describe how do you handle communication and activities with each other?)	

			Contexts in which contact is occurring  Function, meaning and significance  Emotional/instrumental/Informational  Reciprocity	-Describe how do you handle communication and activities with each other?) -Describe their importance in your life!
To correlate and categorize ways of belonging on regards of the Social Inclusion of	Belonging	Towards people	Feeling needed  Feeling important  Feeling comfortable  Feeling respected  Feeling "at home"	-Describe how do you feel about being in specialised workshops/day care centre!  -Describe how do you feel when you are doing this (leisure&recreation) activity!
young adults with Intellectual Disability.		Towards locations	Feeling needed  Feeling important  Feeling comfortable  Feeling respected  Feeling "at home"	<ul> <li>Describe how do you feel when you are doing this (consumption) activity.</li> <li>Describe how do you feel about being friends with this person?</li> <li>Describe how your relationships with your family make you feel?</li> </ul>
		Towards activities	Feeling needed  Feeling important  Feeling comfortable  Feeling respected  Feeling "at home"	- Describe how your relationships with staff member make you feel?

### **APPENDIX D**

#### **INTERVIEW GUIDE**

I am researching Social Inclusion and what it means to young adults with intellectual disabilities. Social Inclusion is when a person can participate in different activities, build different relationships and experience sense of belonging.

I want to know what your experiences, feelings and thoughts about Social Inclusion are. This means I want to ask you questions about what you do in your daily life, your relationships with family, friends, acquaintances and whether you feel acknowledged and what is your experience of belonging.

If you have any questions, please feel free to ask! If you want to take a break or want to stop the conversation, please say.

### INTRODUCTORY QUESTION

Please, tell me a little bit about yourself!

### **PARTICIPATION**

One of the components of Social Inclusion is participation in various activities. This includes daily activities such as attending specialised workshop and day centre, school and work. These are also activities you do in your free time, your hobbies, interests and so on.

Please describe your normal day!

- A) Productive activities- day care centre/specialised workshops
- -What do you do there (day care centre/specialised workshops)?
- -Can you describe your involvement there?
- -How would you describe your experience there?
- -Can you please reflect on importance of attending day care centre/workshops for you?
- -Describe how do you feel about being there!
- B) Recreation and leisure activities

Please tell me what you do in your free time?

For prompts:

hobbies/social/clubs/sports/books/church/cinema/walking/coffee/shops/holidays/trips/attendig events/spending time with friends/family.

- -What exactly do you do in this activity and how often?
- -Can you describe your involvement there?

- -Why this activity is important to you?
- -Describe how do you feel when you are doing this activity!
- C) Consumption- access to goods and services
- -What is your experience regarding access to goods and services?
- -Can you describe your involvement there?
- -Describe how do you feel when you are doing this activity?

For prompts

Shopping/healthcare/hairdresser/public transport

### **RELATIONSHIPS**

Reciprocal relationships are also an important part of Social Inclusion. These include relationships with friends and acquaintances, with family, with staff and other people that are important to you.

D) Friends and close social connections

What is friendship for you?

Please tell me about your friends!

-What do you do together and how often do you meet?

(If necessary, follow up question: How do you handle communication and activities with each other?)

- -Why are they important to you?
- -Describe how do you feel about being friends with this person?
- E) Family
- Please describe what your family looks like!
- -What do you do together and how often?

(If necessary, follow up question: How do you handle communication and activities with each other?)

- -In what ways are they involved in your life?
- -Describe how your relationships with your family make you feel?
- F) Staff

Please tell me about staff members that are involved in your life!

-What do you do together and how often?

(If necessary, follow up question: How do you handle communication and activities with each other?)

- -Describe their importance in your life!
- -How your relationships with staff member make you feel?

# **APPENDIX E**

Non-plagiarism declaration: Submitted to the Erasmus Mundus Master's Programme in Social Work with Child and Youth:

- Has not been submitted to any other Institute/University/College
- Contains proper references and citations for other scholarly work
- Contains proper citation and references from my own prior scholarly work
- Has listed all citations in a list of references. I am aware that violation of this code of conduct is regarded as an attempt to plagiarize and will result in a failing grade in the programme.

Date (dd/mm/yyyy): 15/05/2024

Signature:

Name (in block letters): IEVA JOKSTE