

Towards Deinstitutionalization: Housing For the Intellectually Disabled

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This document presents the research plan for the graduation studio Designing for Health and Care: Towards an Inclusive Living Environment. Its purpose lies on the formation of a problem statement followed by research questions that will stir the proposal of a design solution. The plan is divided in several sections, namely:

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1. Introduction

1.1 Problem Statement: Towards Deinstitutionalization

Until the mid-20th century, intellectually disabled (ID)*¹ individuals were treated as mentally ill and were excluded from society. The vast majority was marginalized, either living with their families, yet hidden from the 'outside' world, or in institutional settings such as primarily psychiatric establishments (Matheis, 2019). In the onset of the 21st century, a better scientific understanding of intellectual disabilities and the human rights movement were the advocates towards the deinstitutionalization* of ID people.

In December 2006, the United Nations adopted the Convention on the Rights of Persons with Disabilities and officially acknowledged the rights of disabled individuals to be equal members of the society (United Nations, 2006). Article 19 of this convention stresses their right to self-determination, including independent living* and social inclusion*. Thereafter, many countries worldwide, including the European Union, initiated a process of deinstitutionalizing intellectually disabled people and encouraging independent and individualized models of housing for them (European Union Agency for Fundamental Rights [FRA], 2017). Thus, in the recent decades, **the need for care and support, including housing, for the intellectually disabled rose significantly** (Roebuck, 2021); in the Netherlands, for instance, the **current annual growth rate of this demand is around 7%** (Woittiez et al., 2018).

This commitment to respect the rights of ID people and their inclusion in society gave room to the emergence of new housing typologies, such as supported living group homes*, village communities*, or shared apartments*, to foster their needs (Roebuck, 2021). The choice of the appropriate housing option is very important to the overall quality of life (QoL)* of ID persons ((Buntinx & Schalock, 2010, Bigby & Beadle-Brown, 2018). **Unfortunately, studies over the last two decades have indicated that the QoL of ID individuals is lower, compared to individuals without disabilities** (Bigby & Beadle-Brown, 2018).

Thus, one of the challenges of our society is to focus on this vulnerable minority; professionals from various disciplines -psychologist, social workers, health practitioners, to name a few, work along with ID people to improve their quality of life. Undoubtedly, architects, as mediators between humans and the built environment, are accountable for the formation of an environment catering their well-being. Biophilic design, is a tool that can be employed; its essence lies on the understanding that there could be specific constructed stimuli that have an immediate effect on the human psychological response (Woodward, 2022a). Furthermore, data from the field of healing architecture and evidence-based design suggest that there are designing methods that can improve the QoL of patients in medical facilities and ID housing settings (Valera Sosa, 2019, Möhn et al, 2022).

¹The definition of words with an asterisk * is given in Appendices

1.2 Research Goal

The aim of this research is to reformulate the supported living environment for people with intellectual disabilities. Taking into consideration their right to independent living, social interaction and well-being, the goal of this research is to propose a new housing model towards ameliorating their quality of life.

1.3 Research Questions

The current status of the living environment of ID people and my personal incentives stirred the establishment of the main research question as follows. Additionally, several sub-questions arise that will further guide the process:

How could **biophilic design** be implemented to improve the **quality of life** of young adults with **intellectual disabilities** who live in **supported living environments**?

Sub-questions:

1. How is the quality of life (QoL) defined for people with intellectual disabilities (ID) and what is its relevance when it comes to the built environment?
2. What cognitive and adaptive challenges do ID individuals who live in supported living housing face on a daily basis?
3. What types of supported living housing are currently accessible to ID adults to accommodate their right to a QoL in terms of the built environment?
4. What principles of biophilic design could be used as tools to propose a new model of supported living housing for ID people?

2. Theoretical Framework

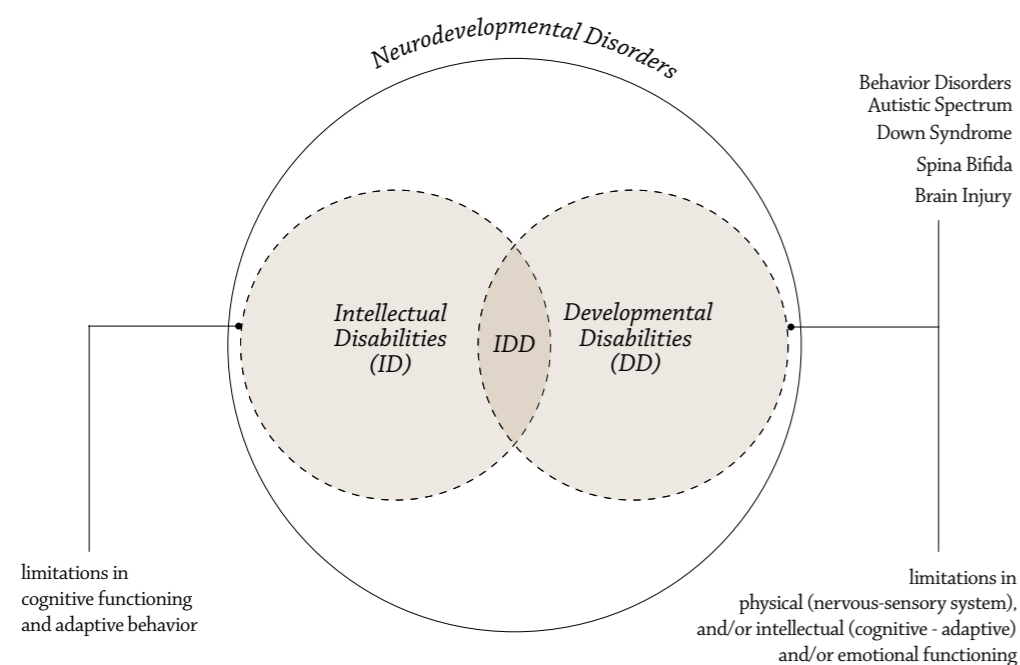
The theoretical framework is rooted on academic literature in regards to four major areas: a. persons with intellectual disabilities and their rights to social inclusion and independent living. b. supported living typologies c. quality of life, and finally d. architectural principles.

a. Persons with intellectual disabilities and their rights to social inclusion and independent living

Intellectual disability (ID), formerly known as mental retardation, is a neurodevelopmental condition (Figure 1), causing deficits in the intellectual and adaptive functioning of an individual before the age of 22² (American Association on Intellectual and Developmental Disabilities [AAIDD], n.d). This type of disability affects the cognitive functioning, especially in the areas of learning, problem solving, judgement and the adaptive behavior, mainly connected with practical skills needed in everyday life. The severity of intellectual disability is classified as mild, moderate, severe or profound (AAIDD, n.d, American Psychiatric Association [APA], 2013).

Before the term ‘mental retardation’ was altered to ‘intellectual disability’ in 2013, the diagnosis was based primarily on the cognitive factors and the IQ of the individuals; nowadays IQ testing is a complimentary diagnostic tool, with the adaptive functioning being the main one (Cervantes et al., 2019). The 5th edition of the Diagnostic and Statistical Manual of Mental Disorders presents the areas of adaptive functioning affected as:

² Giving a functional definition for intellectual disability is not an easy task. In European Union, for example, not all Member States have a legal framework on disability, in general and particularly in intellectual disability. Thus, in EU there isn't a definition on intellectual disabilities unanimously accepted (Lecerf, 2021). Yet, all State Members have signed the United Nations convention on the Rights of Persons with Disabilities (United Nations, 2006). The Dutch policy uses the definition mentioned in the theoretical framework (Woittiez et al., 2018).



Own diagram based on data provided by AAIDD (2021) APA (2013), Matson (2019), NICHD (n.d.)

Figure 1. Diagram showing the most common neurodevelopmental disorders.

Conceptual – language, reading, writing, math, reasoning, knowledge, memory.

Social – empathy, social judgment, communication skills, the ability to follow rules and the ability to make and keep friendships.

Practical – independence in areas such as personal care, job responsibilities, managing money, recreation, and organizing school and work tasks” (APA, 2013).

This shift in understanding of intellectual disability is greatly associated with the ability of the ID person to live a more or less autonomous life. The diagnosis of severity level based on adaptive functioning emphasizes the environmental and social aspects of the disability and has a more practical value for assessing and providing the level of support ID individuals need (Cervantes et al., 2019). It also underlines the ability of ID people to learn the skills needed in everyday life (Matheis 2019). Social inclusion and independent living are feasible, as the UN Convention suggests (United Nations, 2006).

Matheis (2019) explains how the philosophy of care of ID individuals has changed: in the past, social inclusion was perceived as a normalization process of social integration and as an extension ID disabled should adapt their skills to the way non disabled people live. On the contrary, nowadays, social inclusion refers to creating an inclusive environment where ID people’s rights are respected and supported.

In this context, the rights of ID individuals deriving from the UN Convention to freely decide where, with whom and how to live seems a feasible goal, provided that their strengths, challenges and needs will be taken into account. The European Network for Independent Living (ENIL) makes clear that living independently does not exclude receiving care and support; it is “about having choice and control over your life and having the same range of opportunities as a non-disabled person” (European Network on Independent Living & Inclusion Europe [ENIL], 2018, 1).

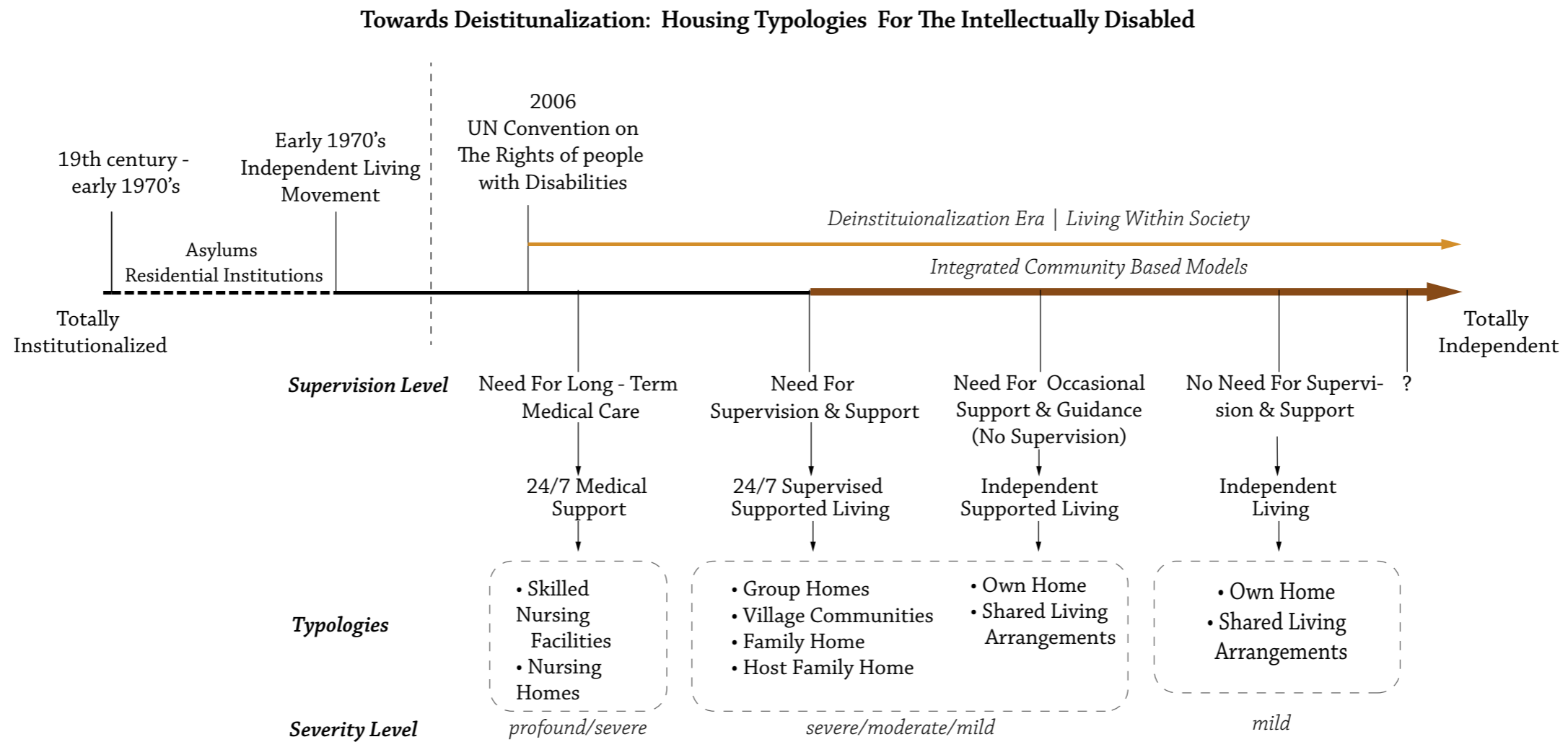
b. supported living typologies

Does independent living equals totally autonomous living for every intellectually disabled individual? The answer is negative. Not all ID individuals can live in totally independent home settings; in most cases, the severity of their condition in cognitive and adaptive functioning and other medical and personal factors determine the most suitable housing option, ranging from a skilled nursing type facility for the profound and severe cases, supported living arrangements for those needing supervised or occasional support, to the fully autonomous housing for those who feel confident living by themselves (Roebuck, 2021).

The names of the housing typologies for ID individuals vary, depending on the legal terms and social security system of each country. Figure 2 demonstrates an overview of the evolution of their living environments, from the time they were totally institutionalized to the most typical

independent models that are available nowadays; it is based on the related literature review found in Bowers, 2019, Connery, 2016, ENIL, 2018, Larson et al., 2021, Martin et al., 2019 and Roebuck, 2021. Appendix II gives a definition for each one of terms.

Which of these housing options offer, according to research, an optimal quality of life to intellectually disabled, in terms of independent living, social interaction and well-being? The review of literature indicates that not all ID individuals with the same diagnosis have the same strengths and challenges and, consequently, the same housing needs (Connery, 2016, Roebuck, 2021.) As a rule of thumb, we may say that when independent living is embraced within the housing environment it is more beneficial for the residents. The architectural challenge, however, comes when QoL is taken into consideration while designing.



Own diagram based on data provided by Bowers (2019), Connery (2016), ENIL (2018), Larson et al. (2021), Martin et al. (2019), Roebuck (2021).

Figure 2. Housing typologies available for ID people.

c. Quality of Life

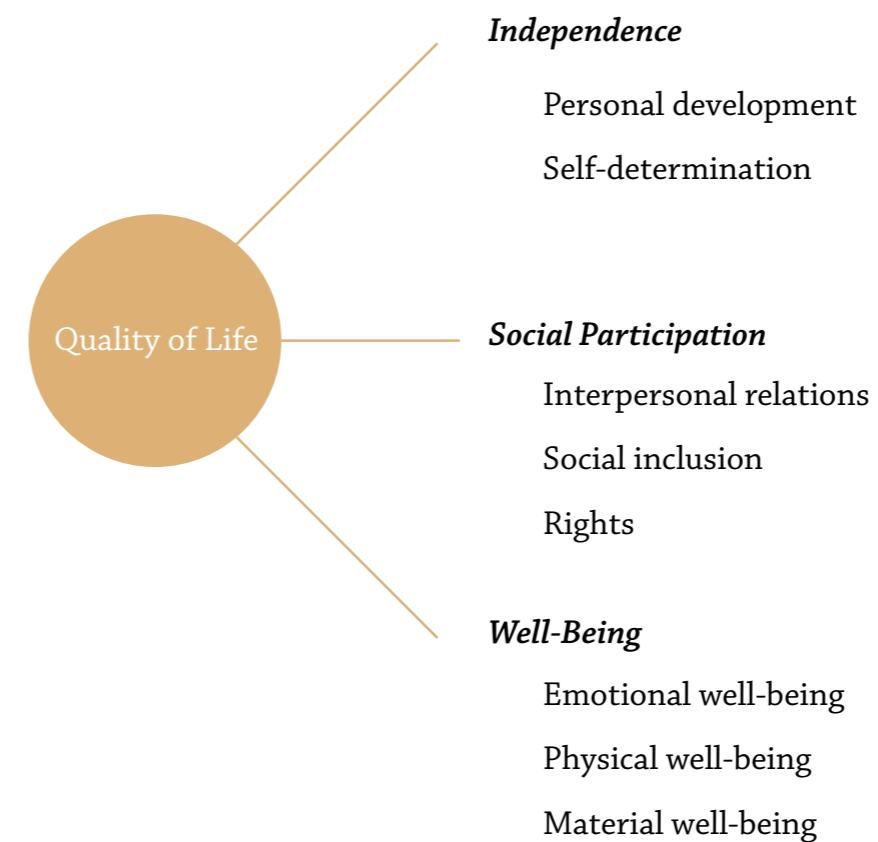
Quality of life is a multidimensional construct and essential component of human rights. One fundamental question researchers of ID have been aiming to answer is focused on its definition and whether the QoL criteria are the same to all people, disabled or not.

Until now, there isn't a universally agreed definition of the quality of life, yet there are two that are most widely accepted. The first, defined by the World Health Organization (WHO), is based on more subjective indicators: each individual perceives the notion of the quality of his/hers life on the areas of physical and psychological health, social relationships, and environment (WHO, 2012). The second, which is widely employed in studies regarding ID individuals, focuses on the social dimensions of functioning, rather on the subjective perception, and covers three main domains: independence, social participation and well-being (Memisevic & Djordjevic, 2019).

For the last 30 years, Schalock has studied and researched extensively the QoL of ID individuals; his pioneer work consolidated their human rights and led to the conclusion that quality of life consists of the same factors for all people and has subjective and objective components. These factors (Figure 3) are grouped in eight areas: (1) emotional well-being, (2) interpersonal relations, (3) material well-being, (4) personal development, (5) physical well-being, (6) self-determination, (7) social inclusion, and (8) rights (Schalock, 2004, Schalock et al. 2011, Verdugo et al, 2012). Schalock's theory makes QoL measurable for the ID people and also correlates it with the built environment.

Indeed, for the last 20 years, many researches have focused on the variables that associate QoL with the living environment of ID people. Simões & Santos (2017) analyzed the environmental characteristics that can affect or predict better QoL for ID individuals; they found that the type of residential setting and other living conditions that promote independent living affect positively their well-being. Towards this direction, Bigby & Beadle-Brown (2018) conducted a realist review of literature researching the factors that improve the QoL of ID individuals living in supported accommodations; small-scale community settings between 1-6 people with a home-like environment provide a higher QoL. Similar findings are reported by Bertelli et al., (2013) who also mention that, according to research evidence, the housing environment that is safe and pleasant has healing qualities as it minimizes stress and reactive behaviors.

All these findings support the idea that architecture can 'make a difference' in the living arrangements of ID persons. Nevertheless, J. Roos et al. (2022) have recently conducted a scoping review on the impact the built environment on the QoL of ID persons living in long term facilities, reporting that the research done on the design components is limited. Therefore, more action needs to be taken.



Own diagram based on data provided by Schalock, 2004, Schalock et al. 2011, Verdugo et al, 2012

Figure 3. Domains of quality of life.

d. Architectural Principles

For the architectural programming, the stage of design where research acts as a catalyst to establish goals, especially when it comes to health and care facilities, evidence-based design* is fundamental. This is because it is a tool that promotes a user-center approach to the design process (Menezes et al., 2022). According to Menezes et al. (2022), evidence-based design is instrumental to the development of the program, since the study of the site conditions, precedents and space needs are the foundation for the anatomy of the program. Valera Sosa (2019) also supports the effectiveness of evidence-based design as a tool of healing architecture. For him, healing in architecture is equivalent to ‘good architecture for health’, in other words an approach that sets architecture as a variable to enhance physical and mental wellbeing (Valera Sosa, 2019). The author lists several environmental factors that promote healing, including light, nature, acoustics, air quality and materials (Valera Sosa, 2019). Yet, the most important factor that makes the ‘architecture’, and as an extension the building, is the human activity. Therefore, the function of the building is meant to cater the needs of humans. Woodwarth (2022b) stresses the fact that experiencing nature can be healing, thus he presents recent research and evidence that human inclination to biophilia should stir the process of programming.

In regard to biophilic design, Zhong et al. (2021) point out that the essence of biophilic buildings is centered around three domains concerning the experience: nature in the space, nature analogues and nature of the space. Alternatively, Kellert (2018) suggests the basic elements of biophilic design comprise direct experience with nature, indirect experience with nature and experience of space and place. The application of biophilic design lies on the reconnection of people with nature as biological beings. Thus, this affinity with biophilic patterns enhances health, productivity and the well-being (Kellert 2018). Specifically, the positive impacts of biophilic design on health include reducing stress and negative emotions, relieving pain, contributing to illness recovery, amplifying positive emotions, reducing stress, relaxing the brain, and lowering blood pressure (Kellert, 2018, Zhong et al., 2021).

Usually, the incorporation of nature in a design leads to the integration of green spaces, healing gardens, plants and landscaping that would bring occupants closer to nature. Nevertheless, what is often overlooked is the presence of water, that could be beneficial to individuals with intellectual disabilities. As an integral part of biophilic design, seeing, hearing and touching the water reduces stress, increases the feeling of tranquility and lowers the heart rate and blood pressure (Zhong et al., 2021). Additionally, for people with intellectual disabilities, water-based interventions, such as hydrotherapy and swimming, can have a positive impact on their functional skills, as well as on their psychology (Naumann et al., 2021).

<i>Research Sub-Question</i>	<i>Research Method</i>
I. How is the quality of life (QoL) defined for people with intellectual disabilities (ID) and what is its relevance when it comes to the built environment?	- Literature Review
II. What cognitive and adaptive challenges do ID individuals who live in supported living housing face on a daily basis?	- Literature Review - Ethnographic Research tools: fieldwork observations, informal unstructured and semi-structured interviews with supportive staff, caregivers and residents - sketches, photographs, mapping.
III. What types of supported living housing are currently accessible to ID adults to accommodate their right to a QoL in terms of the built environment?	- Literature Review - Reference studies: Plan analysis to examine the existing housing options and what is offered programmatically. Additionally, how they foster independence, social interaction and the well-being of the individuals.
IV. What principles of biophilic design could be used as tools to propose a new model of supported living housing for ID people?	- Literature Review - Reference Studies: diagrammatic analysis of built examples in the field of healthcare, where the architects implement design concepts of healing architecture and biophilic design.

Own diagram based on data provided by Kellert (2018) & Zhong et al. (2021).

Figure 4. Diagram showing principles of biophilic design.

3. Methodological Framework: A Human - Centered Approach

The main strategy to answer the research questions is qualitative research; it gives the opportunity for a better understanding of ID person’s real-life situation by using various methodological tools for empirical data gathering and their interpretation (Groat & Wang, 2013). In this research these tools will be literary reviews, architectural case studies analysis and ethnographic research (fieldwork, observations, interviews).

A study of the literary review related to each sub-question is one of the main tools to gain insight on the research that has already been conducted. Articles based on a scoping review methodology are also helpful, as they provide a synthesis of the existing knowledge on the field and directions for further research (Colquhoun et al., 2014).

Reference study analysis of supported living housing models will provide more empirical data, as “an architectural case study is an empirical inquiry that investigates a phenomenon or setting within its real-life context” (Groat& Wang, 2013, 418). The method of plan analysis will be employed for several existing case studies in order to create a catalogue of architectural principles that are currently implemented, as well as their programmatic applications.

A one-week fieldwork will be conducted at a supported living environment of ID individuals. My hands-on research activities will be based on the tools of ethnographic research, to better understand and interpret the strengths and challenges ID individuals face, their everyday practical and spatial needs, and how they interact with the built environment. For data collection during the fieldwork, I will use observations and note taking, interviews, sketches and photographs (Lucas, 2016).

Regarding the observations, both types of ethnographic observations will be used: non-participant, when I won’t interfere with the everyday routine of the residents, and active-participant in the event I wish to energetically participate in their everyday life practices (Groat& Wang, 2013, Lucas, 2016). Lastly, informal unstructured and semi-structured interviews with residents, supporting staff and caregivers will be my additional ethnographic tools. As Finesurrey (2018) mentions, informal unstructured interviews take the shape of an informal conversation, but they are helpful in gathering background information that will lead to a formal interview; semi-structured interviews have a prepared set of structured questions and a list of open-ended ones, or let the interviewee add personal comments and insights.

After the fieldwork is completed, an appropriate site will be chosen via mapping to identify the qualities that complement the body of my research.

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IV. What principles of biophilic design could be used as tools to propose a new model of supported living housing for ID people?	- Literature Review - Reference Studies: diagrammatic analysis of built examples in the field of healthcare, where the architects implement design concepts of healing architecture and biophilic design.

Figure 5. Research methods to explore the sub-questions.

4. Research Scheme

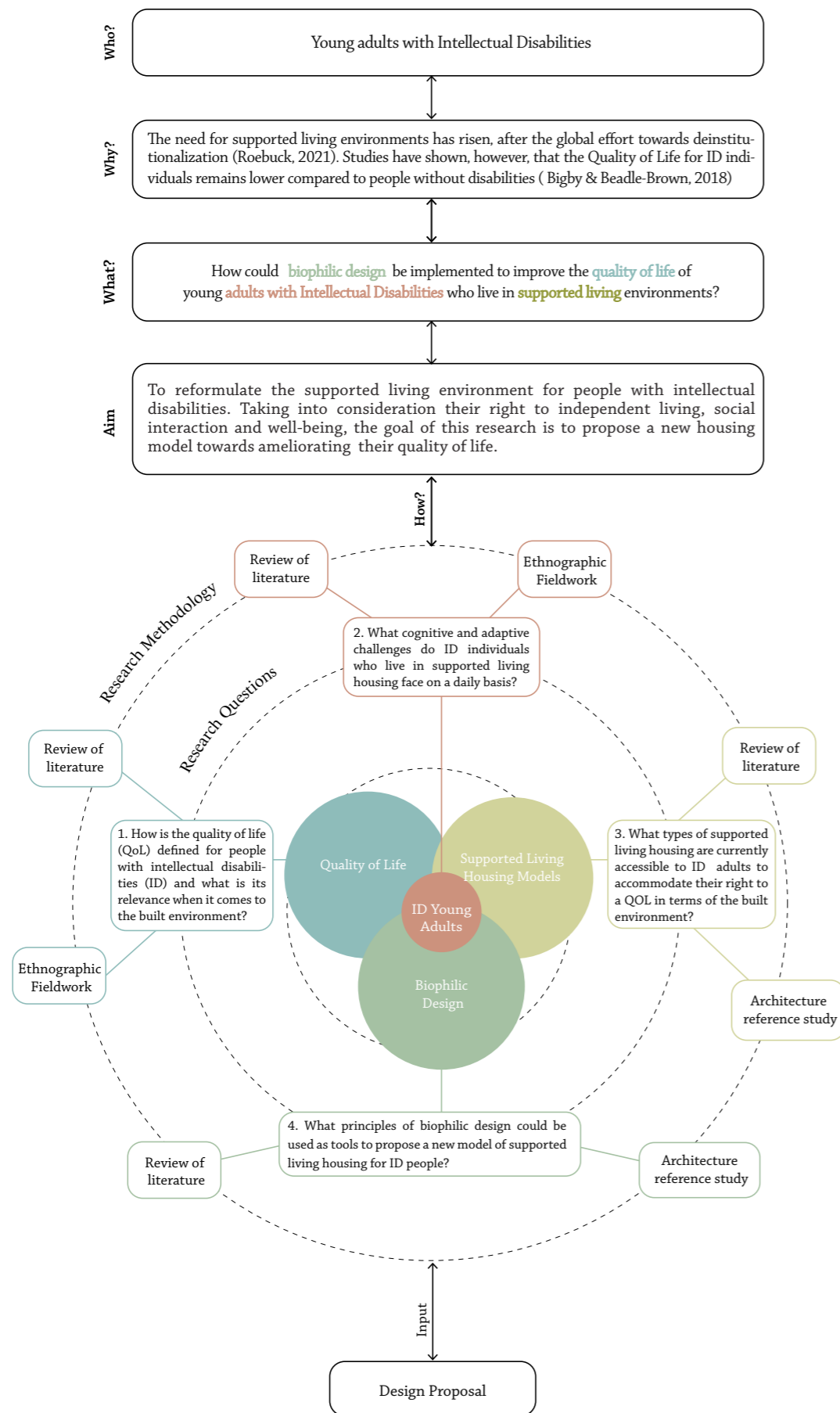


Figure 6. Research scheme

5. Workplan

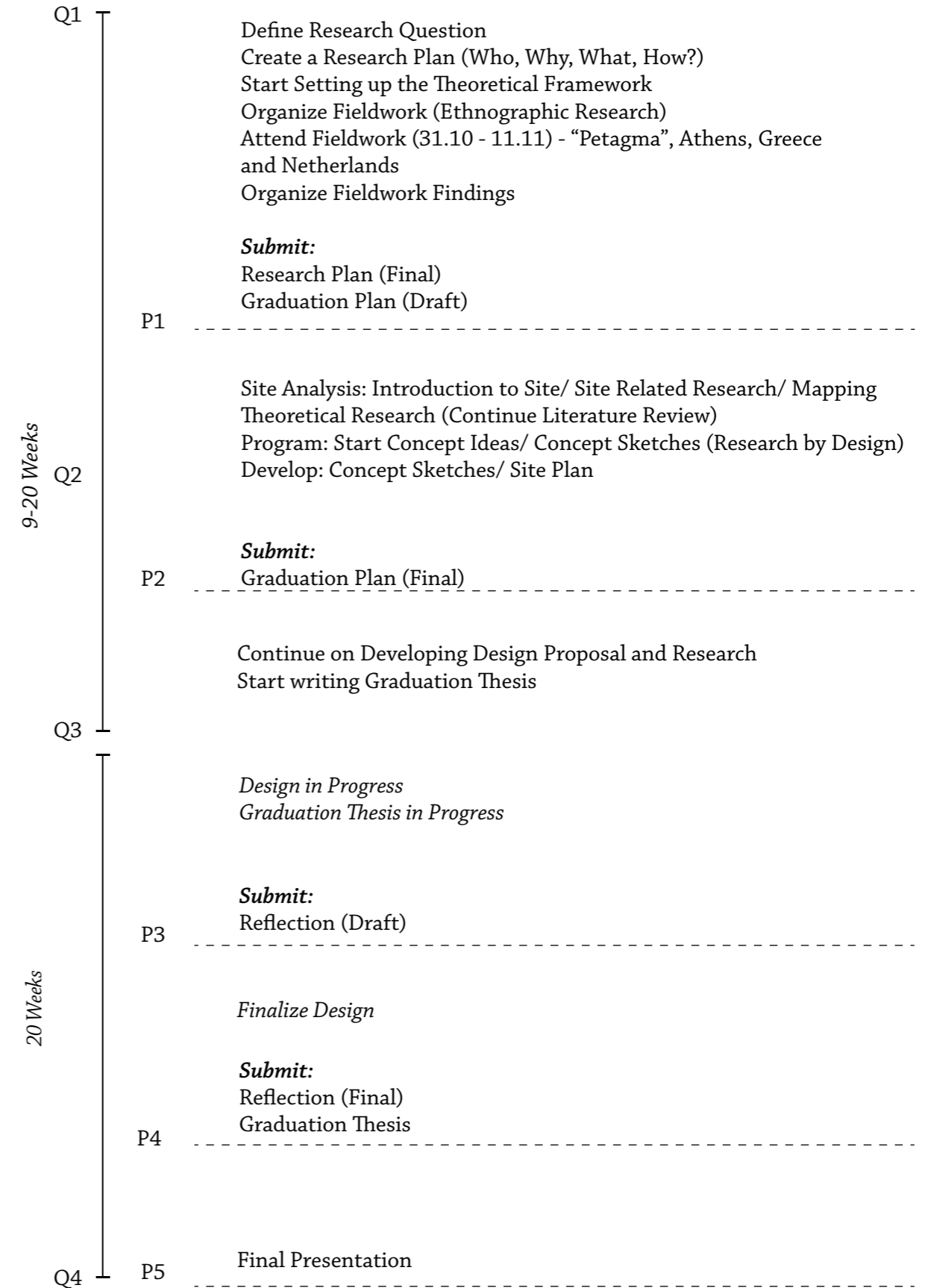


Figure 7. Workplan scheme

Appendix I

Intellectual Disability Definitions

Deinstitutionalization:	the transition from institutions to community-based housing environments (FRA, 2017).
Disabled individuals or People with disabilities:	individuals with physical, mental, intellectual or sensory impairments (United Nations, 2006, article 1).
Independent living:	having the freedom of choice and control to decide where, with whom and how to live. Supervision and support may or may not be provided (ENIL, 2022).
Intellectually disabled (ID) individuals:	individuals with limitations in the cognitive domain - mainly in learning, problem solving and judgement- and in adaptive functioning of everyday life - primarily in independent living, practical skills and social interaction (APA, 2013).
Quality of life (QoL):	a multidimensional construct, consisting of the same factors for all people and has subjective and objective components covering three main domains: independence, social participation and well-being (Memisevic & Djordjevic, 2019).
Social Inclusion:	participation in community-based and societal activities. Regarding ID individuals, social inclusion means creating an inclusive environment that ID people can be themselves and their rights are respected (Matheis, 2019).

Appendix II

Housing Typologies for ID Individuals Definitions

Family home:	a residence shared by a person with ID, and his or her related family members (Larson et al, 2021).
Group home:	the definition of group home varies from country to country since it can be managed by a public or private organization or by the individuals themselves. In this research the term is used in its broad meaning: A 24/7 supervised housing establishment where two or more people with disabilities live and receive support.
Host family home:	ID persons live with a family other than their biological and receive support (Martin et al. 2019).
Independent living:	ID persons live by themselves and receive no support.
Independent supported living:	ID individuals live in their own or with roommates, and receive occasional support according to their needs (Bigby & Beadle-Brown, 2018).
Institution:	A large public facility where many people with disabilities live together (Connery, 2016).
Nursing home:	Residential care facility for disabled individuals.
Shared living arrangement or shared apartments:	An ID person lives with a roommate who is paid to provide support. Often referred to as “adult foster care” or “paid roommates” (Connery, 2016)
Skilled nursing facility:	A residential care facility staffed with medical professionals.
Supervised supported living:	A 24/7 supervised living arrangement for ID persons.
Supported/assisted living housing or supported community living arrangements:	various types of housing where usually 2-8 ID individuals live and receive 24/7 supervision and support. (Bowers, 2019, 111).
Village community:	a type of clustered housing where the support is provided by volunteers who lived communally with ID people (Roebuck, 2021).

Appendix III

Architectural Principles and Design Definitions

- Biophilic design: the design process that lies on the inherent relationship of human beings with nature, thus contribute to their health and well-being (Bolten & Barbiero, 2020, Kellert 2018).
- Built environment: a “human-made space in which people live, work, and recreate on a day-to-day basis. It involves building design, interior and outdoor spaces, decoration, and the use of art” (Roos, J., et. al, 297).
- Healing architecture: the architectural practice that leads to the creation of an environment that promotes physical and psychological health and/or leads to a fast recovery (DuBose et al., 2016).
- Evidence-based design: a process of designing based on scientific research to create the best outcomes for the user of the built environment. In the health-care settings aims to improve the health outcomes and well-being (Menezes et al., 2022, Valera Sosa, 2019).

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