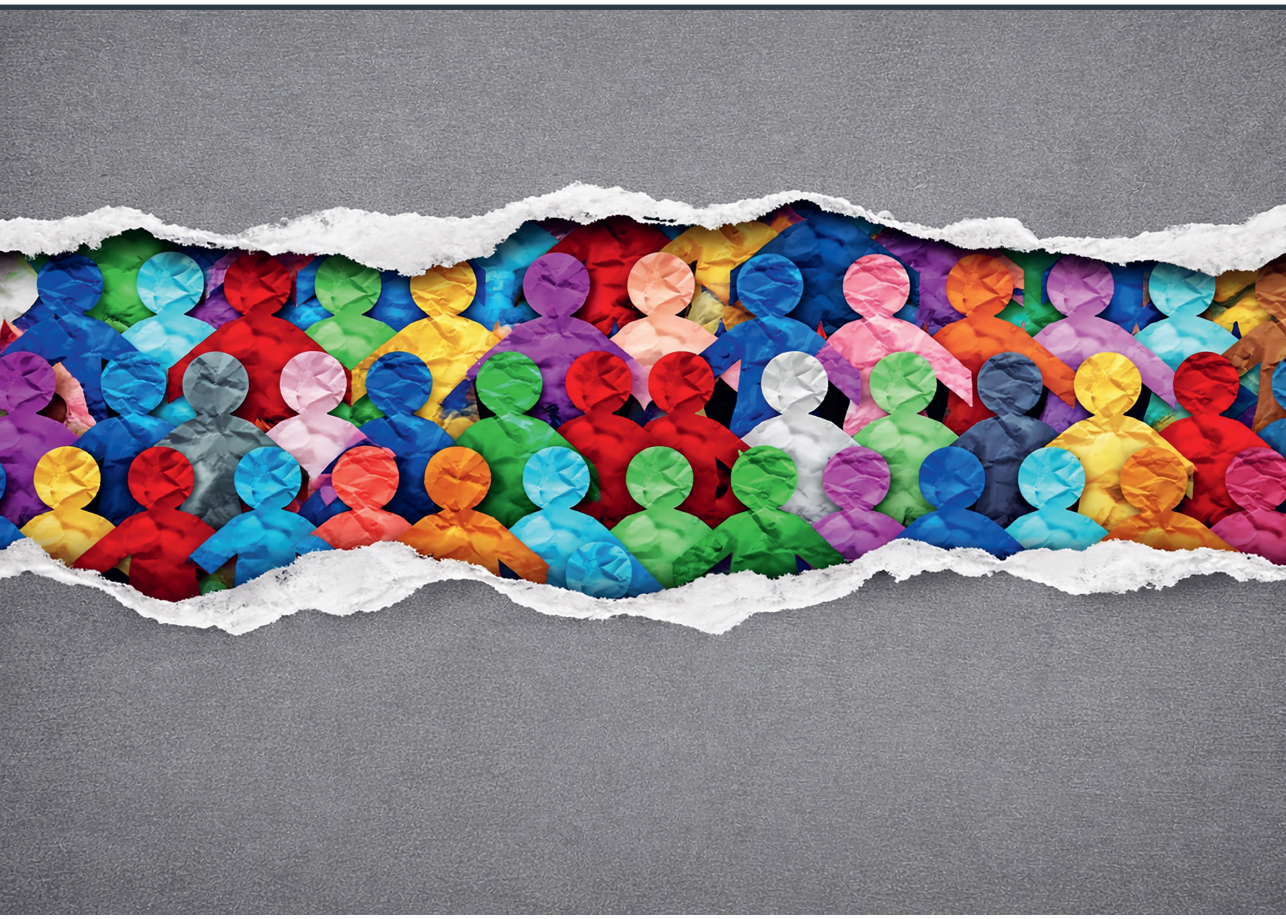
RIGA TECHNICAL UNIVERSITY

Simone Zorzi

QUALITY OF LIFE AND SOCIAL INCLUSION FACTORS IN SERVICES FOR PERSONS WITH INTELLECTUAL DISABILITY

Doctoral Thesis



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RIGA TECHNICAL UNIVERSITY

Rezekne Academy Center of Education, Languages and
Social Technologies

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Doctoral Student in the Study Programme "Educational Sciences"

QUALITY OF LIFE AND SOCIAL INCLUSION FACTORS IN SERVICES FOR PERSONS WITH INTELLECTUAL DISABILITY

Doctoral Thesis

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ABBREVIATIONS

AAIDD	American Association on Intellectual and Developmental Disabilities
ADL	Activities of Daily Living
BISS	Baltic Institutions Social Science
CRPD	Convention on the Rights of Persons with Disabilities
EU	European Union
FVG	Friuli Venezia Giulia
IT	Italy
IADL	Instrumental Activities of Daily Living
ID	Intellectual disability
LV	Latvia
LC	Living conditions
PwD	Persons with disability
QoL	Quality of Life
Q-VAD	Questionnaire for evaluating the living conditions of adult persons with disability
RA	Rasch analysis
SI	Social inclusion
UN	United Nations
WHO	World Health Organization

ABSTRACT

Simone Zorzi's doctoral thesis, titled *Social Inclusion and Quality of Life Factors in Services for Persons with Intellectual Disabilities*, was developed in the field of educational sciences, within the subfield of disciplinary pedagogy (special pedagogy), at Rezekne Academy of Riga Technical University. The work was supervised by Professor Dr. Paed. Velta Ļubkina, leading researcher Olga Vindača, and leading researcher Inga Jēkabsone. The total volume of the thesis is 158 pages, with 13 figures and 32 tables in the main text, as well as a list of references with 270 titles and 3 appendices, bringing the total to 233 pages. This research analyzes the living conditions of individuals with intellectual disabilities using the assessment tool for evaluating the living conditions of adult persons with disability (Q-VAD). This assessment tool was developed by the researcher of this study based on the conceptual framework regarding the living conditions of people with disabilities, which was constructed through an analysis of quality of life and social inclusion models for people with disabilities found in the literature.

The research was motivated by the lack of effective assessment tools to measure living conditions related to social inclusion and quality of life, despite the well-established understanding that increased participation enhances these aspects. The study was initially conducted in the Friuli Venezia Giulia Region (Italy), and following its psychometric validation, the tool was then applied in Latvia to adapt and implement it in the Latvian context. The study explores the relationship between social inclusion, quality of life, and the types of services offered in residential and day-care settings. It aims to identify factors that facilitate or hinder social inclusion and quality of life, directs the creation of strategies for analyzing these indicators, as well as evaluates service effectiveness in promoting social inclusion and quality of life for individuals with intellectual disabilities. Chapter I presents a literature review on theoretical and scientific models in intellectual disability and social inclusion. Chapter II outlines the design and development of the Q-VAD assessment tool, which aims to provide a nuanced understanding of living conditions, incorporating the following dimensions: quality of life, support needs for individual functioning, and Opportunities. Then it focuses on evaluating living conditions and identifying barriers and enablers of social inclusion and quality of life. Finally, Chapter III discusses the adaptation of the Q-VAD for Latvian perspectives through a pilot study based on the policy framework.

ANOTĀCIJA

Simone Zorzi doktora disertācija ar nosaukumu *Sociālās iekļaušanas un dzīves kvalitātes faktori pakalpojumos personām ar intelektuālās attīstības traucējumiem* tika izstrādāta pedagoģijas zinātnes jomā, specializējoties speciālajā pedagoģijā, Rezeknes akadēmijā Rīgas Tehniskās universitātes ietvaros. Darbu vadīja profesore Dr. paed. Velta Ļubkina, vadošās pētnieces Olga Vindača un Inga Jēkabsone. Disertācija sastāv no 157 lappusēm ar 13 attēliem un 32 tabulām galvenajā tekstā, kā arī atsauču saraksta ar 270 avotiem un 3 pielikumiem, kopumā sasniedzot 233 lappuses.

Šajā pētījumā tiek analizēti dzīves apstākļi personām ar intelektuālās attīstības traucējumiem, izmantojot pētnieka izstrādātu novērtēšanas rīku Q-VAD (Novērtēšanas rīks pieaugušo personu ar invaliditāti dzīves apstākļu novērtēšanai). Šis instruments tika izveidots, balstoties uz konceptuālu ietvaru, kas veidots, analizējot dzīves kvalitātes un sociālās iekļaušanas modeļus personām ar invaliditāti zinātniskajā literatūrā.

Pētījumu rosināja efektīvu novērtēšanas rīku trūkums, kas spētu mērīt dzīves apstākļus saistībā ar sociālo iekļaušanu un dzīves kvalitāti, neskatoties uz to, ka jau ir plaši apstiprināts, ka līdzdalības palielināšana uzlabo šos aspektus. Sākotnēji pētījums tika veikts Friuli-Venēcijas Džūlijas reģionā Itālijā, un pēc psihometriskās validācijas novērtēšanas rīks tika pielāgots un ieviests Latvijā. Pētījumā tiek analizēta sociālās iekļaušanas, dzīves kvalitātes un piedāvāto pakalpojumu veidu saistība dzīvesvietas un dienas aprūpes kontekstos. Tas mērķē uz faktoru identificēšanu, kas veicina vai kavē sociālo iekļaušanu un dzīves kvalitāti, stratēģiju izveidi šo rādītāju analīzei, kā arī pakalpojumu efektivitātes novērtēšanu šo aspektu veicināšanā.

I nodaļā tiek sniegts literatūras apskats par teorētiskajiem un zinātniskajiem modeļiem intelektuālās attīstības traucējumu un sociālās iekļaušanas jomā. II nodaļā izklāstīta Q-VAD novērtēšanas rīka izstrāde, kas sniedz padziļinātu ieskatu dzīves apstākļos, ietverot šādus aspektus: dzīves kvalitāte, atbalsta vajadzības individuālai funkcionēšanai un dzīves iespējas. Tā koncentrējas uz dzīves apstākļu izvērtēšanu un sociālās iekļaušanas un dzīves kvalitātes šķēršļu un veicinātāju identificēšanu. III nodaļā tiek apskatīta Q-VAD pielāgošana Latvijas kontekstam, izmantojot pilotpētījumu, kas balstās uz politikas ietvaru.

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INTRODUCTION

Over the last decades, a new view of persons with disability has emerged, followed by new approaches in planning and implementing services. There is an increased cultural and scientific debate, especially about neurodevelopmental disorders, intellectual disability, and autism spectrum disorders.

Currently, the rights of the person with disabilities (United Nations, 2006) are a crucial issue that concerns the following main points:

- deinstitutionalization processes and development of community and social participation;
- person-centered approaches to promoting independent living, social inclusion, and self-determination outcomes (Wehmeyer, 2020; Shogren, 2015);
- evidence-based practices in services and interventions to promote these outcomes.

The above themes are connected to the paradigm of quality of life, which in the last two decades has definitely become the scientifically validated framework to program and implement policies, services, and practices for people with intellectual disability (Renwick and Brown, 1996; Buntnix and Schalock, 2010). Quality of life has become the reference construct at the scientific level to plan practices and interventions, and, at the same time, the criterion for their verification. Individual quality of life consists of a multidimensional phenomenon composed of core domains influenced by personal characteristics and environmental factors. These core domains are the same for all people, although they may vary individually in relative value and importance. Evaluation of quality of life domains is based on sensitive indicators (Schalock et al., 2010). Domains that are seen as key to conceptualizing and measuring quality of life have been developed and examined critically, and have been described in detail elsewhere for individuals (Cummins,1996; 2000; Felce & Perry, 1995; Renwick, Brown, & Raphael, 2000; Schalock & Verdugo, 2002;) and for families (Turnbull, Brown, & Turnbull, 2004; Verdugo er al. 2005). Additionally, the subjective evaluation of quality of life plays a critical role in inclusive education and social participation, as it encompasses not only objective well-being indicators but also personal perceptions of health, self-esteem, social relationships, and overall life satisfaction (Mocevicieve, 2016). Quality of life cannot be fully understood without considering an individual's psychological and social context, highlighting the importance of person-centered approaches in disability services.

Some work has also been accomplished in identifying specific quality of life indicators within domains for individuals and families (Jenaro et al., 2005; Schalock et al., 2005; Summers et al., 2005), although it is recognized that specific indicators are highly variable from person to person, result from individual perception and choice, and change over the lifespan (Brown & Brown, 2003; 2005).

The model is multidimensional and assumes that quality of life is holistic in nature. Renwick and Brown's definition of quality of life is: "The degree to which a person enjoys the important possibilities of his/her life" (Raphael et al., 1994). Possibilities result from the opportunities and

The limitations each person has in his/her life reflect the interaction of personal and environmental factors. Three major life domains are identified: Being, Belonging, and Becoming. Although people value the same general aspects of life across and within cultures, quite narrow aspects of life can be of great importance to individuals (Brown & Brown, 2003). Thus, individuals respond both to their cultural environments and to their interests and personalities by developing their unique accents to the more generally valued aspects of life.

Promoting quality of life is both the ultimate goal of service systems for individuals with disabilities and the reference model for designing person-centered support programs. It serves as the conceptual foundation for policy-makers and social workers to develop inclusive policies and tailored interventions that enhance well-being and social participation. Currently, there are models and tools able to measure it validly and reliably (Van Loon et al., 2009; Verdugo et al., 2014).

One of the most important constructs closely connected to the quality of life is social inclusion. It is a core domain of quality of life (McIntyre et al. 2004; Schalock, 2004) and is essential for human functioning (Verdonschot et al. 2009). It means "to require valued participation, with valued people in valued activities that take place in valued settings" (Wolfensberger, 1998). Important aspects of social inclusion include holding or obtaining a valued role and participation in society, developing relationships, and having a sense of belonging (Thomas & Wolfensberger, 1999).

It is unique, complex, and personal, being influenced by several individual factors including skills, expectations, preferences, wishes, and resources (Brown & Brown, 2003; Martin & Cobigo, 2011). At the same time, social inclusion does not concern only the characteristics of people or context, but the process of interaction between them, which allows people with disabilities or other differences to feel recognized and valued like any other member of the community to which they belong (Meininger, 2010). Cobigo et al. (2012) have defined social inclusion as a series of complex interactions between environmental factors and personal characteristics that provide: opportunities to access public goods and services; valued and expected social roles of one's choosing based on his/her age, gender and culture; recognition as a competent individual and trusted person to perform social roles in the community; opportunities to belong to a social network within which one receives and contributes support.

These needs for social inclusion are the same for people with and without disability (MacNeil & Anderson, 1999). For people with intellectual disability, social inclusion outcomes depend particularly on policies, attitudes, and opportunities available and provided by social contexts (Duvdevany & Arar, 2004).

The Convention on the Rights of Persons with disability (United Nations, 2006) reinforces inclusion in the community and to live independently as a fundamental right. For these reasons, in the last years the process of deinstitutionalization, which has occurred at different times and different speeds since the 1960s, is strongly supported by the scientific and cultural community in the field of disability. There is an agreement across quantitative and qualitative studies that a move from any type of institutional setting to community living is associated with a quality-of-life improvement (McCarron et al. 2019). Participation in community leisure activities enhances

People's well-being and quality of life (McIntyre et al., 2004), positive attitudes, and social interactions (Siperstein et al., 2009). It is essential for human functioning (Verdonschot et al., 2009; Simplician et al., 2015).

However, while deinstitutionalization and community living have been shown to enhance quality of life, the mere availability of opportunities for participation does not guarantee meaningful engagement. Many individuals with intellectual disability struggle to internalize these experiences, which highlights the need for pedagogical approaches that actively foster inclusion and personal involvement.

The limited internalization of suggested activities by individuals with intellectual disabilities highlights the need for pedagogical approaches that prioritise interaction and relational engagement. In this regard, Žogla (2018) states that learning is fundamentally a relational process, shaped by meaningful connections between the learner, the educator, and the environment. This perspective suggests that enhancing relational dynamics may be key to fostering deeper understanding and more autonomous participation. Pedagogy is not simply the transmission of knowledge, but a dynamic process of exchanging values and constructing meaning among the learner, the educator, and the educational environment (Žogla, 2017).

In the context of social inclusion, this perspective underscores the importance of personalized, co-constructed learning experiences that actively involve individuals with disabilities in their developmental process.

From a capability perspective, particularly within the framework of personalized planning, individuals with intellectual disability—despite their impairments—must be recognized as rights holders by the United Nations Convention on the Rights of Persons with disability. This means that their choices, preferences, and lived experiences must shape the interventions and inclusion strategies designed for them. Wehmeyer's approach to self-determination in special education supports this, highlighting that individuals with disabilities must be active participants in their life projects, rather than passive recipients of externally imposed solutions. As MacNeil & Anderson (1999) suggest, the need for social inclusion is universal, applying equally to people with and without disabilities. However, for individuals with intellectual disability, the outcomes of social inclusion depend largely on the policies, societal attitudes, and opportunities available within their environment (Duvdevany & Arar, 2004; MacNeil & Anderson, 1999). From this perspective, learning and development occur through relational and contextual interactions—thus, meaningful inclusion cannot be achieved through one-size-fits-all solutions imposed from the outside. Instead, it requires adaptive, responsive, and co-constructed planning that acknowledges the individual as a full agent in their own life.

Thus, effective personalized planning for individuals with intellectual disability must go beyond service provision and structural improvements. It must be capability-oriented, ensuring that interventions:

- respect the person's autonomy and self-determination (Wehmeyer, 1998);
- are rooted in human rights and the Conventions of Rights of Persons with disability

framework;

- recognize the necessity of social contexts, attitudes, and policies in enabling inclusion (MacNeil & Anderson, 1999; Duvdevany & Arar, 2004);
- ensure that learning and participation are not externally imposed but co-created and meaningful to the individual (Zogla, 2018).

By integrating these perspectives, we can shift from external, institutionalized planning to empowering, participatory approaches where individuals with intellectual disability actively shape their inclusion pathways in ways that are personally meaningful and sustainable.

Over the last decades, many signals have indicated that disability service systems are changing. Several innovative policies and programs for social inclusion have been introduced (Merrells et al. 2017). These experiences confirm the achievement of important outcomes for quality of life.

However, changes seem to be proceeding rather slowly: obsolete organizational forms, together with professional practices that do not enhance the rights of people with disabilities, are still quite widespread.

Although the cited studies demonstrate that transitioning from institutional settings to community living significantly enhances quality of life, the risks of re-institutionalization and barriers to inclusion and the rights enshrined in the United Nations Convention remain markedly persistent, particularly among individuals with intellectual disability (McCarron et al., 2019). Despite the recognized right to participate in meaningful activities (Dusseljee et al., 2011), community involvement opportunities remain limited for individuals with intellectual disability. They engage less frequently in recreational and community programs than individuals without disability. Moreover, the scientific literature still lacks studies that genuinely aim to investigate the actual *living conditions* of persons with disabilities, particularly in relation to social inclusion outcomes and the connection between these outcomes and the types of services or interventions received.

The concept of living conditions is used to distinguish it from the dominant approach that focuses solely on care or assistance needs as the primary reference for guiding programming and funding decisions. It reflects the dynamic interplay between individual functioning, available supports, life context, and concrete opportunities. This interaction profoundly influences both social inclusion and overall quality of life, underscoring the importance of integrated and personalized approaches that promote autonomy, participation, and equity (Felce & Perry, 1995; Schalock & Verdugo, 2002; Carlsson & Adolfsson, 2022).

This research is driven by the need to develop a reliable data processing system for person-centered social-healthcare planning concerning the living conditions of adults with disabilities. Conducting a comprehensive analysis, review, and transformation of the service system requires effective monitoring of service quality, outcome assessment, and support for planning activities. Achieving this depends on having the most current knowledge about the living conditions of individuals with disabilities.

Recent scientific literature has emphasized the limitations of relying exclusively on the care-needs approach for defining tariff systems, direct payments, or individualized budgets (Schalock &

Verdugo, 2002). When analysing the full life cycle of individuals—from childhood to adolescence, adulthood, and into old age—it becomes evident that focusing only on care needs restricts the life perspective to a narrow and diminished view, centred on dependency rather than development. This assistance-based paradigm reflects a medical model that places individuals in a passive role, failing to promote autonomy, inclusion, and participation. Conversely, Quality of life frameworks highlight the importance of assessing personal outcomes, Opportunities, and support needs as part of a holistic, person-centred service model (Schalock et al., 2012). In alignment with the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006), this perspective shifts the focus from care to citizenship, empowerment, and social inclusion.

It is increasingly recognized, including at the legal level, that this perspective must evolve. The "UN Convention on the Rights of PwD" (ONU, 2006) symbolizes this shift in perspective. The fundamental framework for individuals with disabilities, including those with significant support needs, should be centered on equality and social inclusion. The integrated social-healthcare system is essential in implementing measures and interventions that bring this perspective to life. Several notable examples of population surveys from the international literature provide valuable insights and set significant precedents in the field. While this list is not exhaustive, it includes some key studies that have led to important research and findings.

The work employs triangulation from three perspectives: it adopts a triangulated approach, integrating international, European, and national perspectives, with a specific focus on the Italian and Latvian contexts where the study was implemented.

From an international perspective, the case of the United States was examined. Its ongoing political and scientific discourse on job placement and the evaluation of social inclusion outcomes for individuals with intellectual disabilities is supported by a comprehensive national database.

This database encompasses the entire national network of "vocational rehabilitation" services (Butterworth, Hiersteiner, Engler, Bershadsky, & Bradley, 2015). Annual surveys have been instrumental in estimating the proportion of Americans with intellectual disability engaged in job search activities. Despite significant changes over the past decade, the percentage of individuals with Intellectual disability involved in job search has remained stable at approximately 20% of the total population served. This stagnation contrasts with the more than doubling of individuals utilizing semi-residential services during the same period. Additionally, these surveys reveal considerable variations in service availability, organizational models, and outcomes across different states.

From the perspective of the European Union, there is a notable lack of comprehensive data and population-level research that sheds light on the life experiences of individuals with intellectual disabilities. This includes information on their post-school activities, employment status, home living arrangements, development opportunities, overall health, and the specific services and support they utilize. The comparison with international and national experiences has not yet yielded a survey tool that meets the needs of regional administrations.

In Ireland, since 1995, the establishment of the National Database on Intellectual disability has aimed to provide up-to-date information for the planning and programming of support systems for individuals with Intellectual disability and their families. This database includes comprehensive data on all individuals with Intellectual disability receiving support services. Each record reflects the most current information available, updated whenever there are changes in an individual's circumstances, and reviewed annually. The annual report offers a current snapshot of the situation. As of 2017, the database registered 28,388 individuals, with 16,768 males and 11,620 females. The growing body of research based on this data continues to generate significant studies and insights (National Intellectual Disability Database Committee, 2017).

In the United Kingdom, a sophisticated system for collecting statistical data, incorporating information from various routine sources, is being refined to provide a comprehensive overview of the living conditions of individuals with Intellectual disability across a broad spectrum of personal and social dimensions. This system, developed by the Learning Disability Observatory since 2010, aims to enhance the understanding of these conditions. The most recent report highlights a concerning trend: there has been no significant improvement in labor market access for individuals with Intellectual disability. Data from 2016 indicate a decline, with only 6% of individuals with Intellectual disability participating in the workforce (Hatton, Glover, Emerson, & Brown, 2016).

Italy has demonstrated its commitment to the rights of persons with disabilities by aligning national policies with international standards, following the ratification of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006). In this context, various legislative efforts have been developed to promote autonomy, inclusion, and active participation in community life, with specific attention to the needs of individuals with intellectual and severe disabilities (Italian Parliament, 2009; Ministry of Labour and Social Policies, 2017).

Despite these legal advancements, Italy still lacks a coherent and centralized national system for collecting and analyzing data on the living conditions of individuals with intellectual disabilities. Responsibilities in this area are divided among the State, Regions, and Municipalities, resulting in uneven implementation of public policies and significant disparities in terms of access to services, the quality of interventions, opportunities for school, work, and social inclusion, as well as adequate housing solutions.

In recent years, some initiatives have emerged, such as the establishment of the National Observatory on the Condition of Persons with Disabilities and various regional observatories, but data collection remains sporadic and lacks coordinated oversight. There are still a few large-scale or longitudinal studies capable of providing a comprehensive overview. Shared national tools to evaluate the impact of policies and services on the quality of life of persons with disabilities are still lacking. In this context, the National Recovery and Resilience Plan, which includes a dedicated mission on inclusion and social cohesion, represents a significant opportunity to develop more integrated and community-oriented services.

In Latvia, significant efforts have been made to align disability policies with the principles of the Convention on the Rights of Persons with disabilities, ratified in 2010. However, challenges remain

in achieving full social inclusion and providing adequate services. The prevalence of disability has increased significantly, reaching approximately 10% of the population in 2018, partly due to demographic aging and better diagnostic practices. Despite this, Latvia still relies heavily on institutional care, with limited community-based services and persistent disparities in service accessibility and quality. The deinstitutionalization process initiated in 2015 has encountered significant obstacles, including uneven distribution of resources and insufficient coordination among municipalities, often exacerbated by the phase-out of European Union funding. These factors underscore the pressing need for more inclusive, sustainable service systems and long-term planning, particularly for individuals with intellectual and neurodevelopmental disabilities (Baltic Institute of Social Science, 2020; Ministry of Welfare, Republic of Latvia, 2022).

However, despite these international efforts, Latvia continues to face significant challenges in fostering full social inclusion for individuals with disabilities, particularly in the integration of individuals with Intellectual disability into community life and education. A major barrier remains the persistent stigma surrounding Intellectual disability, which limits participation opportunities and reinforces exclusion (Mikelsteins & Ryan, 2018). Despite the start of deinstitutionalization, the progress has been sluggish, and the efficacy of inclusive policy is still influenced by social attitudes. As a result, policy-making, planning, and the evaluation of service efficacy and outcomes often proceed without robust factual references, relying instead on evidence from limited or selectively chosen groups. This research was launched to reduce this gap by developing a specific tool to assess key aspects of the living conditions of people with disabilities.

Accordingly, **the research problem** can be stated as follows**:** Despite existing data suggest that increased social inclusion enhances the quality of life for individuals with intellectual disabilities, two critical areas remain underexplored:

- the lack of availability of assessment tools for measuring the living conditions of persons with Intellectual disability regarding social inclusion and quality of life indicators in the services provided to these persons;
- models and systems of services designed to promote social inclusion and the quality of life of people with neurodevelopmental disorders.

The research object: the living conditions related to social inclusion and quality of life of individuals with intellectual disability in residential and day care services.

The subject of the study: the relationship between social inclusion, quality of life, and the type of services provided to individuals with intellectual disability.

The aim of the research: to explore the living conditions of persons with intellectual disabilities enrolled in day care and residential services, to identify the hindering and facilitating factors affecting quality of life and social inclusion within the socio-educational context of service provision.

The questions of the research:

- What are the theoretical and methodological foundations for assessing the living conditions related to social inclusion and quality of life of individuals with intellectual disabilities

within the framework of special education?

- What are the relevant pedagogically related factors that hinder and facilitate the social inclusion and quality of life of individuals with intellectual disabilities in these settings?
- What are the key findings and challenges in adapting and piloting the Q-VAD questionnaire in Latvia?

Research tasks:

1. To analyze the theoretical and methodological foundations for assessing the living conditions of individuals with intellectual disabilities, with particular emphasis on the factors influencing quality of life and social inclusion within the context of special pedagogy, to develop a comprehensive and coherent assessment framework.
2. To design and validate an assessment tool for evaluating the living conditions of persons with intellectual disability within a network of services in Italy.
3. To identify criteria and indicators of the factors that hinder and facilitate social inclusion for individuals with intellectual disabilities.
4. To implement the Q-VAD assessment tool in the Latvian context and to conduct a pilot study with individuals with intellectual disabilities in Latvian services.
5. To develop recommendations for introducing Q-VAD as a tool for evaluating the living conditions of persons with intellectual disabilities from the perspective of the Latvian socio-educational context.

The bases of methodological research:

The foundation of methodological research aimed at exploring the living conditions of individuals with disabilities stems from the need to consider theoretical models and dimensions that effectively describe individual functioning and quality of life.

- *Intellectual disability framework and conceptualizations* (Luckasson et a., 2002; Obi et al., 2011; Segawa, 2005; Cascella & Muzio, 2015; Li et al., 2016; Huang et al., 2016; Biellik & Orenstein, 2018; Gray & Wilkins-Haug, 2018; Milne et al., 2013; Bayat et al., 2015; Blau, 2016; Schalock, Luckasson & Tassé, 2021; Leonard et al., 2022; Mattie et al., 2023; Vincente et al., 2023; Boluarte Carbajal et al., 2024; McKinney et al., 2024);
- *Quality of life models in Intellectual disability field* (Felce & Perry, 1995; Cummins, 1996; Renwick, Brown, & Raphael, 2000; Schalock & Verdugo, 2002; Schalock et al. 2003; Gómez Sánchez, Schalock & Verdugo Alonso, 2021; Brown et al. 2022; Morán et al. 2023; Ijezie et al. 2023; Verdugo & Schalock, 2024; Gómez et al. 2024);
- Multidimensional *model of human functioning in Intellectual disability* (Luckasson et al. 2002; Bunthnix & Schalock, 2010; Luckasson et al. 2013; Schalock et al. 2021);
- *Support needs model* (Thompson et al. 2021; Luckasson & Schalock, 2020; Luckasson, Tassé, & Schalock 2022);
- *Social inclusion framework for support persons with Intellectual disability* (Bigby, 2008; Milner & Kelly, 2009; Burns, 2009; Buntinx & Schalock, 2010; Cobigo et al., 2012; Quinn

& Doyle, 2012; Simplican, 2015; Stancliffe & Hall, 2023; Chandan, H. C., 2024; Bredewold & van der Weele, 2023);

- Independence *of persons with Intellectual disability* (Wehmeyer & Schwartz, 1998; Trent et al., 2002; Sigafoos et al., 2005; Mansell et al., 2007; Kozma et al., 2009; Vorhaus, 2007; Aldridge, 2010; Dusseljee et al., 2011; Dollar et al., 2012; Ramdoss et al., 2012; Hamraie, 2013; Haigh et al., 2013; Di Gennaro Reed et al., 2014; Mittler, 2015; Smith et al., 2015; Trip et al., 2016; Kuijken et al., 2016; Sandjojo et al., 2019; Vilaseca et al., 2019; Šiška & Beadle-Brown, 2020; Ioanna, 2020; Wehmeyer, 2020; Bennett et al., 2018; Carter, 2023);
- *Self*-determination *opportunity and supports for persons with Intellectual disability* (Wehmeyer, Kelchner, & Richards, 1996; Wehmeyer & Schwartz, 1998; Wehmeyer et al., 2012; Shogren et al., 2015; Meral et al., 2023; Kuld et al., 2023; Burke et al., 2024; Mumbardó-Adam, Vicente, & Balboni, 2024; Shogren, Long, Hicks, & Ferreira, 2024).

Research limitations

The research is situated within theoretical boundaries defined by the integration of the dimensions of quality of life and individual functioning for people with disabilities, as outlined above. These dimensions, integrated into a theoretical framework, form the basis for the development of an assessment tool aimed at assessing the living conditions and factors that facilitate or hinder social inclusion and quality of life. Within this framework, crucial concepts such as self-determination and independence are also considered, as they influence social participation and access to educational, employment, and community Opportunities. Therefore, the theoretical boundaries of the research exclude other dimensions of disability that may not directly pertain to social inclusion or quality of life, such as clinical traits or specific medical conditions, focusing instead on the social and functional aspects that shape the daily experience of individuals with disabilities. The construction of the assessment tool and the exploratory study are carried out within these boundaries, seeking to collect information that can enhance the understanding of factors influencing well-being and participation in community life. In this sense, the research goes beyond merely measuring living conditions, exploring also the dynamic aspects of support and opportunities for inclusion, in order to provide concrete recommendations to improve social integration and support policies.

Research methodology

The research methodology employed in this study is grounded in a mixed-methods approach, integrating both theoretical and empirical strategies to investigate the living conditions, quality of life, and social inclusion of individuals with intellectual disabilities. The aim is to ensure a comprehensive, evidence-based understanding of the multifaceted realities faced by this population, while simultaneously validating and applying a structured assessment tool (Q-VAD) across different service contexts.

Theoretical methods:

- Scientific Literature Review and Overview: A comprehensive analysis of existing academic and scientific publications to create the theoretical framework, identify research gaps, and contextualize the study within the broader scientific discourse.
- Conventional research: Examination and interpretation of normative documents, legal frameworks, and policy guidelines relevant to the research topic to explore their implications for disability services and social inclusion.

Empirical methods:

Survey: the use of a structured assessment tool (Q-VAD) to collect data on the living conditions of individuals with Intellectual disability.

Data collection methods

An assessment tool (Q-VAD) to investigate the living conditions of adults with Intellectual disability across various types of services will be implemented.

Data processing methods in SPSS:

- reliability and validity analysis: ensures the Q-VAD consistently and accurately measures constructs like living conditions, quality of life, and social inclusion, assessing internal consistency, test-retest reliability, and content validity.
- Rasch analysis: evaluates the Q-VAD items to ensure they fit a probabilistic model, verifying that the assessment tool consistently measures the constructs across diverse populations.
- descriptive statistical mean: summarizes trends in responses collected through the Q-VAD, highlighting key patterns in quality of life and social inclusion.
- Factor analysis: Validates the dimensional structure of the Q-VAD, confirming that items group into meaningful domains like quality of life and support needs.

This Thesis represents the result of a research process within the field of disability and intervention systems, addressed from both the Italian and the Latvian perspectives.
The composition of the content and the development of the tools were initially designed in the languages of origin to ensure fidelity and authenticity to their respective institutional contexts. To enhance readability, accuracy, and stylistic propriety, the written document was further refined and edited for clarity in the English language. Specifically, the introductory, theoretical- methodological, and concluding chapters underwent a language editing process with the support of digital writing tools, including DeepL Write and Grammarly. These tools were used solely for

the reason of precision, clarity, coherence, and formal correctness of the text. In this way, the Thesis represents the originality and authenticity of the research, whilst achieving compliance with the linguistic and stylistic conventions expected in an international academic setting.

Approbation in the educational process includes

- In Italy, Q-VAD was validated, and an exploratory study was conducted involving a sample of 1688 adults with intellectual disabilities. The research examined and discussed the characteristics and factors across different types of services that influence the social inclusion and quality of life of individuals with intellectual disabilities.
- In Latvia, a pilot study involving disability experts and educators was conducted to translate, adapt, and implement Q-VAD. This process included administering the tool to 30 individuals with Intellectual disability to evaluate its suitability and effectiveness.
- List of student Scopus and Web of Science publications:
  1. Zorzi, S., Marzano, G. (2020). Parent training to support parents of children with autism spectrum disorders. Society, Integration, Education. Proceedings of the International Scientific Conference. Volume IV, May 22nd -23rd, 2020. 177-186
  2. Zorzi, S., Strods, G. (2020). Overcoming social inclusion barriers for people with intellectual disability. Society, Integration, Education. Proceedings of the International Scientific Conference. Volume IV, May 22nd -23rd, 2020. 187-195.
  3. Marzano, G. Zorzi, S. (2020). Communication skills for a mentor in social business. Society, Integration, Education. Proceedings of the International Scientific Conference. Volume V, May 22nd -23rd, 2020. 213-220.
  4. Marzano, G., Zorzi, S., Tambato, V. (2021). Improving social communication skills in autism spectrum disorders using programmable toy robots. Society, integration, education. Proceedings of the International Scientific Conference. 3. 173-184.
  5. Zorzi, S. (2021). The impact of the COVID-19 pandemic on services for persons with neurodevelopmental disorders: an Italian case. Society, integration, education. Proceedings of the International Scientific Conference. 5. 280-291.
  6. Marzano, G., Zorzi, S. (2022). Autism and creativity: A social robotics application. Society, Integration, Education. Proceedings of the International Scientific Conference. 1. 685-696.
  7. Zorzi, S, Marangone, E., & Giorgeschi, F. Berteotti, L. (2022). Promoting Choice Using Switches in People with Severe Disabilities. SAGE Open.
  8. Bertelli M.O., Zorzi S., Buonaguro, E.F., Bianco, A., Armellini, M., Scattoni, M.L. (2022). Teleassistance and telerehabilitation: epidemic situations and prospects. In Bertelli, M.O., Deb, S., Munir, K., Hassiotis, A., Salvador-Carulla, L. (Eds.) Textbook of Psychiatry for Intellectual Disability and Autism Spectrum Disorder. Springer Nature, Switzerland AG.
  9. Francescutti, C., Diminutto, M., Zorzi, S. (2022). Work and occupation of people

with neurodevelopment disorders. In Bertelli, M.O., Deb, S., Munir, K., Hassiotis, A., Salvador-Carulla, L. (Eds.) Textbook of Psychiatry for Intellectual Disability and Autism Spectrum Disorder. Springer Nature, Switzerland AG.

10. Zorzi, S., Dalmonego, C., De Vreese, L. P., & Gomiero, T. (2023). Adult Independence Living Measurement Scale: Psychometric validation of a scale to estimate personal skills for independent living in people with intellectual and developmental disabilities. Journal of intellectual disability research: JIDR, 67(6), 560–572.
11. Zorzi, S., & Berteotti, L. (2025). Independent Living for Persons with Neurodevelopmental Disorders. IntechOpen.

Under review

12. Zorzi, S. Berteotti, L. Jekabsone, I. (in press). The effect of digital technology in promoting communication skills of persons with neurodevelopmental disorders: a scoping review. Journal of Research in Developmental Disabilities.
13. Zorzi, S., Berteotti, L., Tambato, V. (in press) Promoting adaptive and social communication skills in young adults with autism spectrum disorder using Programmable Toy Robots with social story, a pilot study. Disability and Rehabilitation: Assistive Technology.

Participation in international conferences:

1. Zorzi, S., Marzano, G. (2020). Parent training to support parents of children with autism spectrum disorders. Society, Integration, Education. Proceedings of the International Scientific Conference. Volume IV, May 22nd -23rd, 2020. 177-186
2. Zorzi, S., Strods, G. (2020). Overcoming social inclusion barriers for people with intellectual disability. Society, Integration, Education. Proceedings of the International Scientific Conference. Volume IV, May 22nd -23rd, 2020. 187-195.
3. Marzano, G., Zorzi, S. (2022). Autism and creativity: A social robotics application. Society, Integration, Education. Proceedings of the International Scientific Conference. 1. 685-696
4. Zorzi, 2023. A perspective on Integrated care for people with disabilities and for older people with long-term care needs. EURECO Forum 2023: Supporting older persons with long-term care needs and persons with disabilities. 15 March 2023, Brussels, Belgium.
5. Zorzi, S. Berteotti, L. Jekabsone, I. (2024). The effect of digital technology in promoting communication skills of persons with neurodevelopmental disorders. Society Open Innovation Conference, July 9-12, 2024, Riga Technical University, Riga, Latvia.

Structure of the PhD thesis

The total volume of the thesis is 148 pages, with 13 figures and 32 tables in the main text, as well as a list of references with 266 titles and 3 appendices, bringing the total to 224 pages. The thesis is composed of three main chapters, each addressing a distinct aspect of the research and contributing to a comprehensive understanding of the living conditions, support needs, and social inclusion of individuals with intellectual disabilities.

Chapter I presents a thorough review of the scientific literature on intellectual disability, focusing on the development of theoretical models and the main concepts that guide educational and social practices. This chapter defines the core terminology used throughout the study and analyzes various models of pedagogical competence, illustrating how conceptual evolutions have influenced inclusive approaches and the recognition of the rights and potential of people with disabilities.

Chapter II is devoted to the design, development, and theoretical foundation of the Q-VAD assessment tool, developed to examine and assess the living conditions of adults with intellectual disabilities in a range of service settings. The tool integrates multiple dimensions of daily life, including quality of life, support needs related to individual functioning, and Opportunities. The chapter also addresses the implementation of the tool in real contexts, with the aim of identifying both barriers and enabling factors that affect autonomy, participation, and inclusion.

Chapter III focuses on the adaptation and implementation of the Q-VAD tool from a Latvian perspective. Through a pilot study involving Latvian disability practitioners, educators, and individuals with intellectual disabilities, the chapter explores the practical application of the tool within the Latvian service and educational context. Particular attention is given to the linguistic and methodological adjustments required to ensure cultural relevance, as well as to the tool's effectiveness in capturing meaningful data on living conditions and social inclusion. This chapter contributes to assessing the feasibility of the tool for evaluation and planning in disability services, offering insights into its potential integration within national systems.

Research stages

Stages	Research methods	Descriptions
Preparatory stage	Theoretical and document analysis	This stage involves the theoretical analysis and study of the relevance of quality of life and social inclusion for people with Intellectual disability. Multiple sources, including scientific literature, normative documents, and expert opinions, are examined to establish a solid theoretical foundation for the research. A key aspect of this phase is interpreting the Learning-Centered theoretical approach from a central planning perspective, ensuring the framework addresses systemic, structural, and service-related factors influencing quality of life and social inclusion. This approach bridges theory and practice to develop a model that effectively supports individuals with Intellectual disability in service systems.
Ascertaining stage	Literature review, and development of a conceptual framework and assessment tool	During this stage, the research framework is developed, including the formulation of research categories and structure. A comprehensive overview of scientific literature is conducted, defining the research object, aim, issues, key tasks, and the overall design and methods. An assessment tool is created to assess the living conditions of individuals with Intellectual disability.
Formational stage	Data collection by using a survey and descriptive statistical analysis	This stage includes the administration of Q-VAD to a sample of individuals with Intellectual disability, followed by data analysis. It also involves the development of a system to enhance social inclusion and quality of life for people with Intellectual disability. The results are enriched by integrating feedback from participants and stakeholders, as well as aligning them with theoretical models. The development of a system to enhance social inclusion and quality of life is informed by both theoretical insights and practical observations. It reflects the interconnected nature of service provisions that influence opportunities for participation, autonomy, and overall well-being for individuals with Intellectual disability.

Control stage	Psychometric validation and assessment tool implementation, and data triangulation of the research results.	In Italy (Friuli Venezia Giulia), the validation of Q-VAD was conducted through exploratory research on a sample of 1688 adults with neurodevelopmental disorders. This process included quantitative analysis of the responses and qualitative feedback from professionals and participants to refine the assessment tool and assess its applicability within the Italian context. These combined methods ensured a comprehensive evaluation of the tool. In Latvia, a pilot study was carried out involving three disability experts and educators to translate, adapt, and implement Q-VAD. The adaptation process involved multiple steps, including the alignment of the tool with local contexts and qualitative feedback from experts, which complemented the insights gathered through initial quantitative data collection. Each dataset provided distinct but complementary insights, supporting the relevance of the Q-VAD across different settings.

Scientific novelty of the research

Development of Q-VAD assessment tool: The Q-VAD is an innovative tool designed to assess the living conditions of individuals with intellectual disability. Unlike existing tools, the Q-VAD integrates dimensions such as quality of life, support needs, and opportunities for personal growth, providing a holistic and nuanced evaluation framework.

1. Methodological contribution: A novel methodology for evaluating living conditions in residential and day care services was developed. This methodology integrates data obtained through the Q-VAD and provides a replicable framework for continuous improvement in service delivery.
2. Empirical analysis of social inclusion and quality of life: The research explores and establishes relationships between social inclusion, quality of life, and various types of disability services, including residential and day care settings, from an Italian perspective. This contributes to a deeper understanding of how different service models influence these outcomes.
3. Identification of key service factors and indicators: The study identifies factors within disability services that either promote or hinder quality of life and social inclusion. This insight provides a foundational framework for designing more inclusive and effective service models.
4. Implementation of Q-VAD assessment tool for the Latvian perspective: The Q-VAD was adapted to address practices in the Latvian environment. This tool represents the first application of a comprehensive assessment of the living conditions of a person with disability for services from the Latvian perspective, bridging gaps in existing methodologies.

Practical significance of the research

1 The research developed and validated a practical assessment tool—the Q-VAD to evaluate the living conditions of individuals with intellectual disabilities, focusing on quality of life and social inclusion. Tested within the Italian context, it integrates environmental and support factors, offering a data-driven framework to improve service delivery and promote inclusion.
2 Recommendations for disability service providers: the study provides a replicable methodology for monitoring and assessing living conditions, identifying barriers and enablers to social inclusion, and guiding the implementation of personalized supports. It highlights key indicators and service factors that influence quality of life, offering a framework for evaluating and improving residential and day care programs in alignment with individual needs.
3 Implementation in the Latvian perspective: through a pilot study, the Q-VAD was translated and adapted for the Latvian context, enabling its use by disability service providers to evaluate and improve services for individuals with intellectual disabilities.

Defense arguments

1. The assessment of the living conditions related to social inclusion and quality of life of individuals with intellectual disabilities requires a multidimensional pedagogical modelling, integrating the dimensions of individual functioning, quality of life, and social inclusion into a unified person-centered theoretical approach and step-by-step support, using structured and holistic assessment of individuals within the framework of special education.
2. The relevant pedagogically related factors influencing the effectiveness of services in promoting quality of life and social inclusion covers the types of services provided, support needs, problem behavior, age, and gender, focusing on the available Opportunities, (including the opportunity to do, to learn, to communicate, the opportunity of well-being and self-realization) while using the Q-VAD tool developed from the proposed theoretical framework, that is a valid and reliable for assessing living conditions, it is possible to identify barriers and enablers of social inclusion and quality of life, supporting data-driven improvements in disability services.
3. The pilot implementation of the Q-VAD assessment tool, basically developed from the Italian perspective, in the Latvian context confirmed its comprehensibility and usability by educators, producing meaningful differentiation in user profiles and supporting its feasibility for cross-national application in different service systems, demonstrating effective practices that can be pedagogically adopted from Latvian perspective on a regular basis.

1 THEORETICAL AND SCIENTIFIC FRAMEWORK FOR QUALITY OF LIFE AND SOCIAL INCLUSION OF PEOPLE WITH INTELLECTUAL DISABILITY

In recent decades, a new paradigm has progressively been established in the way programs are set up in favor of people with ID, involving the overcoming of the institutionalizing approach (Mansell et al., 2007) that has characterized care procedures in the last century. Instead, the focus is on promoting SI (Buntinx & Schalock, 2010; Giangreco, 2017) through community-based programs (Mansell et al., 2007; Kozma, Mansell, & Beadle-Brown, 2009; Šiška & Beadle-Brown, 2020), oriented towards increasing independence and self-determination (Wehmeyer and Schwartz, 1998; Stancliffe, 2001). Emerging paradigms such as neurodiversity, mad studies, and global disability studies, recently broadened the scope of disability studies and challenge traditional notions of normalcy and ability (Goodley, 2017).

In this regard, the Convention on the Rights of Persons with disabilities (United Nations, 2006) has stated that these individuals should be enabled to live in society as independently as possible and should have the right to choose where and with whom to live. To follow these directives, effective and adequate measures should be put into practice to facilitate this process. The directives of the European Union have also moved in this direction: during the 2007-2013 programming period, regulations for the European Structural and Investment Funds (referred to as "ESI Funds") included, for the first time, the "transition from institutional to community-based care" as an investment priority, placing the provision of de-institutionalization strategies as a precondition for the use of the ESI Funds. The European Disability Strategy 2021-2030 (European Commission, 2021) also envisaged support strategies for Member States to move away from large segregated institutions and stressed the importance of facilitating access for people with disabilities to live independently in the community by limiting the granting of ESI funds to those initiatives that supported the transition from institutional to community-based care as one of its priority areas.

However, the implementation of these policies aimed at giving people with ID greater control over their lives, particularly regarding lifestyle choices, has been progressing rather slowly internationally (Mittler, 2015). The objective of the present chapter is to illustrate the theoretical and scientific models that underpin the promotion of the rights of persons with ID as outlined in the Convention on the Rights of Persons with disabilities, with a particular focus on the constructs of QoL and SI.

A theoretical overview was carried out. It adopts a structured methodological approach inspired by the PRISMA 2020 guidelines (Page et al., 2020), which have been adapted to suit the purpose of synthesizing theoretical models and evidence. While PRISMA is traditionally used for systematic reviews evaluating intervention effects, its principles of systematic reporting, transparency, and rigor have been utilized here to ensure a comprehensive and credible process. The primary objective of this overview is to explore the constructs of independence, self-determination, individual functioning, support needs, SI, QoL, and LC in the context of promoting the rights of individuals with ID.

The first step of the study involved formulating a strategy for identifying and selecting relevant literature. A conceptual mapping process was employed to identify key terms and constructs related to the theme of intellectual disability. These terms were selected based on their prevalence in the literature and their capacity to encompass both the theoretical and practical dimensions of the topic. The selection was grounded in an in-depth review of interdisciplinary sources, including psychology, disability studies, and research on social inclusion. This process aimed to establish a thematic framework that synthesizes key definitions in line with the most recent theoretical developments and empirical findings.

The following terms were identified as central to the conceptual foundation of the study and are presented below, along with their definitions.

- "QoL" addresses the holistic well-being of individuals, encompassing both subjective and objective dimensions. Subjective aspects include personal satisfaction, emotional well-being, and perceived fulfillment, while objective dimensions involve access to healthcare, education, employment, and social participation (Schalock et al. 2010).
- "SI" refers to the process and outcome of integrating individuals with disabilities into mainstream society, ensuring their full participation and equal access to opportunities, resources, and relationships (Cobigo et al. 2012).
- "Individual functioning" refers to the cognitive, emotional, social, and adaptive abilities of individuals and their implications for day-to-day living and participation in society. This term encompasses how individuals navigate their environments and interact with others, highlighting their strengths and areas where support may be needed (Schalock, Luckasson & Tassé, 2021).
- "Support needs" reflects the specific assistance required by individuals to achieve independence, self-determination, and inclusion. This includes both formal supports, such as professional services, and informal supports, such as assistance from family and peers (Moran et al., 2023).
- "Self-determination" captures the capacity of individuals to take control of their lives, make personal choices, set goals, and take steps to achieve them. It is closely linked to concepts of autonomy and empowerment and is a critical component of QoL for individuals with disabilities (Wehmeyer & Schwartz, 1998).
- "Independence" refers to the ability of individuals with ID to live autonomously, make decisions about their own lives, and participate actively in their communities. It represents a fundamental human right and a key outcome of policies and programs aimed at SI (Ionanna, 2020).

These keywords formed the basis for the search strategy, ensuring the identification of literature relevant to these constructs. Boolean operators were used to combine and refine these terms, guiding the search across major academic databases, including PubMed, Scopus, Web of Science, and PsycINFO. Policy documents from international organizations, such as the United Nations (e.g., the Convention on the Rights of Persons with disabilities) and the European

Union, were also included to incorporate normative frameworks and practical directives, alongside foundational texts in disability studies to provide a broader theoretical perspective.

The identified sources were screened to ensure their relevance and quality. The screening process followed a systematic and rigorous approach:

1. Title and abstract review: Titles and abstracts were initially reviewed to assess their alignment with the predefined keywords and themes. This step helped eliminate sources that were tangential or unrelated to the topic.
2. Full-text review: articles that passed the initial screening underwent a detailed review to confirm their relevance and methodological soundness. Specific criteria were applied:
    - inclusion criteria:
        - studies directly addressing the constructs of independence, self-determination, and SI in the context of ID;
        - publications after 2006, reflecting the adoption of the Convention on the Rights of Persons with disabilities, with exceptions made for foundational works that provide historical or theoretical context;
        - peer-reviewed articles, policy reports, and books that contribute substantial theoretical or empirical insights;
    - exclusion criteria:
        - studies focused on unrelated populations or theoretical frameworks outside the scope of the keywords;
        - sources with insufficient methodological transparency or inaccessible full texts.
        - duplicates retrieved from multiple databases.

The selected sources were then systematically cataloged, with relevant data extracted to facilitate the synthesis and thematic organization of findings.

The final set of sources was analyzed and organized into thematic categories, ensuring a coherent integration of diverse perspectives. The key topic included:

1. theoretical foundations: this category explored the conceptual models underlying quality of life, individual functioning, independence, self-determination, and social inclusion in intellectual disability.
2. policy frameworks: international and regional policies, such as the Convention on the Rights of Persons with disabilities and European Union directives, were analyzed to highlight their impact on transitioning from institutional to community-based living.
3. implementation challenges: barriers to implementing inclusive policies and practices, including systemic obstacles and gaps in support systems, were critically examined.

This thematic synthesis allowed for a structured and critical exploration of the constructs, highlighting both progress and gaps in the literature and practice.

This process outlines the progression of source selection, from identification to inclusion, providing a clear overview of the systematic process employed in constructing this theoretical overview.

Before delving into the theoretical models, the chapter provides a concise overview of the prevalence of disability within the EU, offering essential context for the focus on intellectual disability in the following section.

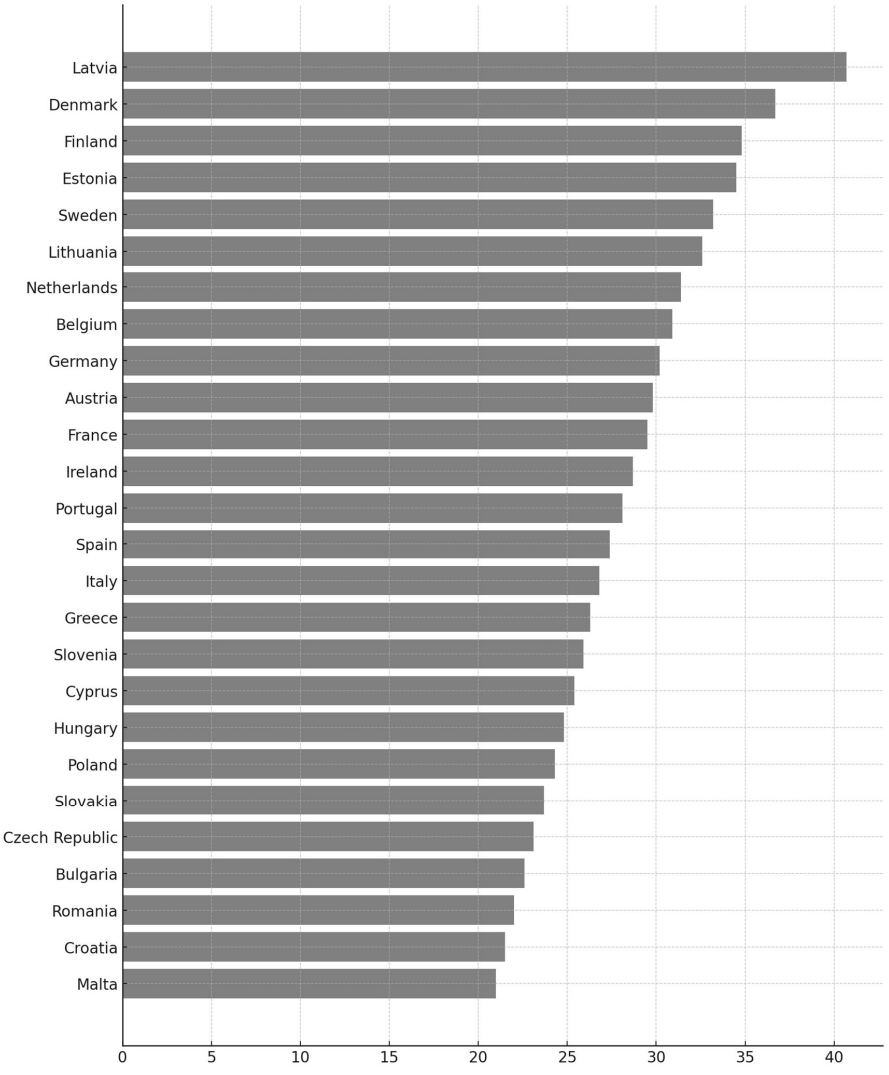
1.1 The Condition of Intellectual Disability: A Growing Phenomenon in Society and the Educational Context

In the EU, people with disabilities continue to encounter substantial barriers that limit their access to essential services such as healthcare, education, and employment. Moreover, they often face restrictions in participating fully in social and political life. Despite the EU's commitment to fostering inclusivity and equal opportunity, nearly half of the EU population perceives that discrimination based on disability remains pervasive in their country. In 2023, around 27% of EU residents over the age of 16 reported having a form of disability. According to Eurostat estimates, this equates to approximately 101 million people, or roughly one in every four adults in the EU, reflecting the urgency for inclusive policies that protect the rights of people with disabilities and promote their full participation in society. The information provided here draws on data reported by the European Council, which sheds light on disability prevalence and the challenges faced by people with disabilities in EU countries (European Council, 2023).

Disability prevalence varies significantly from country to country across the EU. Latvia recorded the highest rate of disability in 2023, with 40.7% of its population affected, closely followed by Denmark at 36.7% and Finland at 34.8%. The varying prevalence rates suggest that some EU countries may face unique challenges or socio-environmental factors that contribute to higher disability rates. This variation can be seen in Table 1.1, which provides a clear comparison of disability prevalence among EU member states. Understanding these differences is crucial for tailoring interventions and resources to the needs of each country.

Table 1.1

Percentages of Disability per European Country (European Council, 2023).



LV's high disability rate, which surpasses the EU average by a substantial margin, may be influenced by a combination of socio-economic factors, healthcare accessibility issues, and demographic trends, including an aging population and higher rates of chronic health conditions. Age and gender further influence disability rates, with older individuals more likely to report disabilities. This trend emphasizes the need for age-sensitive approaches in health and social policies to address the unique needs of an aging population with disabilities. Additionally, disability rates are consistently higher among women compared to men across all EU member states. In 2023, data showed that 29.2% of the EU's female population had a disability, compared to 24.3% of the male population. Notably, countries like LV, Romania, and Portugal show the largest gender disparity in disability rates, with LV experiencing a 9.4 percentage point difference between men and women. These insights underscore the intersectional nature of disability and the necessity of addressing gender-specific challenges in policy initiatives.

The condition of disability is increasingly recognized as a central and growing phenomenon in the field of education, requiring inclusive approaches and evidence-based frameworks. The focus has gradually shifted from a purely medical understanding of disability to a more dynamic, ecological model that considers the interaction between individual functioning and contextual supports. This perspective underscores the importance of designing educational environments that promote participation, autonomy, and quality of life for individuals with intellectual and developmental disabilities. As educational systems evolve, the implementation of such models becomes essential for fostering inclusive learning and social development (Schalock et al., 2010). The educational context is therefore not only a domain of individual development but also a powerful platform for reducing social exclusion and inequality. Inclusive and responsive education systems catalyze improving life outcomes and ensuring equitable access to services and opportunities throughout the life course.

People with disabilities face many challenges beyond access to services, including social exclusion, poverty, and discrimination. According to a Eurobarometer survey, 52% of individuals with disabilities in the EU reported feeling discriminated against, highlighting the persistence of social stigma and prejudice. Discrimination is not the only hurdle; people with disabilities are also disproportionately affected by unemployment. In 2020, 17.7% of people with disabilities aged 20-26 were unemployed, a rate significantly higher than the 8.6% unemployment rate for their non-disabled counterparts. This disparity in employment not only affects economic independence but also restricts SI and access to opportunities for people with disabilities. In addition to employment challenges, poverty remains a critical issue. In 2023, 28.8% of people with disabilities in the EU were at risk of poverty or social exclusion, in stark contrast to 18% of people without disabilities. The higher poverty risk for people with disabilities is closely tied to their limited access to stable employment and education. People with disabilities are more likely to leave school early, partly due to the limited availability of accessible educational facilities and resources. They also face obstacles in higher education; only 29% of people with disabilities obtain a tertiary degree compared to 44% of people without disabilities. These educational disparities underscore the need

for greater inclusivity and accessibility in educational systems to improve outcomes for students with disabilities.

Healthcare access is another critical area where people with disabilities encounter significant inequalities. Despite universal rights to preventive healthcare and treatment, people with disabilities are four times more likely to have unmet healthcare needs. These needs often remain unmet due to high costs, long distances to healthcare facilities, and extended wait times, which create barriers to necessary medical services. Furthermore, people with disabilities are at an increased risk of violence, particularly women, the elderly, and children. 17% of people with disabilities report being victims of violence, a rate more than double that of individuals without disabilities, who experience violence at a rate of 8%. These finding calls attention to the urgent need for protective measures and support systems to safeguard the well-being of vulnerable individuals in this community.

These challenges reveal that, despite advancements, significant work remains to achieve full social and economic inclusion for people with disabilities in the EU. Addressing these issues requires coordinated policies that tackle both the systemic barriers and the unique needs of people with disabilities, ensuring that they can participate equally in all areas of life.

1.1.1 Intellectual Disability in Europe: Prevalence and Support Services

ID is a condition affecting approximately 1-3% of the world population, and is marked by significant limitations in both intellectual functioning and adaptive skills, impacting areas such as communication, self-care, and social abilities (World Health Organization (WHO), 2019). ID typically manifests before the age of 18 and is often attributed to a combination of genetic, biological, and environmental factors, which vary in prevalence and impact depending on socio- economic contexts (AAIDD, 2020). Prevalence rates of ID differ significantly based on the availability of resources, early diagnostic services, and health policies adopted in each country.

In high-income countries with greater access to healthcare and diagnostic services, ID is more likely to be identified early and managed through structured support services, including educational and employment integration. In contrast, limited access to services and diagnostics in low- and middle-income countries often leads to inadequate management of ID, contributing to increased social isolation and stigmatization (WHO, 2019). Given its global implications, ID requires coordinated attention to improve the QoL of affected individuals and ensure their fundamental rights.

The prevalence of ID in the EU varies across countries, reflecting differences not only in diagnostic criteria but also in healthcare access and support programs (Gulliford et al., 2019). For instance, in Nordic and some Western European countries, where welfare systems and social support are well-developed, ID is more systematically diagnosed, resulting in higher detection rates compared to countries with less advanced infrastructure (European Union Statistics on Income and Living Conditions (EU-SILC), Eurostat, 2020). These variations also reflect socio-economic disparities,

as countries with more resources are better able to invest in early diagnostic systems and support programs, promoting recognition and management of ID from early developmental stages

According to the European Association of Service Providers for PwD (EASPD, 2020), individuals with ID in the EU primarily access three categories of support services: residential care, day centers, and supported employment programs.

- *Residential Services:* Approximately 50% of individuals with ID in the EU reside in residential services (or Residential facilities), such as group homes or institutions. These facilities offer continuous support, with dedicated staff assisting with daily activities and healthcare needs. In best practices, residential services are based on a person-centered approach, aiming to promote autonomy, well-being, and social participation among individuals with ID (EASPD, 2020). This approach respects individual preferences and encourages active involvement in daily decision-making. However, not all residential facilities adopt this person-centered model. Some are highly institutionalized, with rigid routines that restrict choices and social interaction opportunities. In such settings, the risk of institutionalization is high, often leading to isolation and dependency. Individuals with ID in these facilities may lack opportunities for active community participation and the development of personal and social skills (EASPD, 2020). Daily life in these environments, often regulated by institutional rules, limits access to external social experiences, contributing to lower QoL compared to more inclusive settings (European Disability Forum, 2020).
- *Day Care Centers:* Day care centers are critical services for many individuals with ID, providing a safe and supportive environment for daily, social, and recreational activities. These centers are designed to promote social interaction, autonomy, and personal skill development. Activities offered at day centers vary and may include self-sufficiency training programs, recreational activities such as art and music, and initiatives to enhance social and communication skills (EASPD, 2020). The EASPD (2020) report underscores the potential of day centers for improving the QoL of people with ID and to support families and caregivers, who benefit from temporary relief from care responsibilities. However, access to day centers varies widely across regions, and service quality can be inconsistent. Some facilities offer effective socialization experiences and pathways to community integration, while others, due to resource or staff limitations, may struggle to maintain adequate standards of quality. These disparities create significant differences in the experiences and benefits that day centers can provide to individuals with ID (European Commission, 2021).
- *Support to Employment*: Employment inclusion remains particularly challenging for individuals with ID, with only 25-30% having access to supported or sheltered employment programs (EASPD, 2020). Such programs aim to offer opportunities for economic independence and social integration by creating work pathways adapted to the individual abilities of persons with ID. Supported or sheltered employment presents opportunities for

learning and personal growth in a professional context, allowing individuals to develop useful skills for the job market and economic self-sufficiency. Despite these benefits, the employment inclusion of individuals with ID is hindered by numerous structural, social, and cultural barriers. Many employers are hesitant to hire people with ID due to biases, additional training costs, or a lack of state incentives. Furthermore, the shortage of targeted support programs and limited access to inclusive technologies and facilities reduce opportunities for individuals with ID to obtain meaningful employment. This lack of employment inclusion not only limits their economic independence but also reduces opportunities for socialization and community integration, increasing their economic and social vulnerability (Eurostat, 2020).

Institutionalization poses a significant risk for individuals with ID, profoundly impacting their QoL and overall well-being. In many European countries, individuals with ID live in highly structured institutions that aim to provide essential support for daily needs, safety, and healthcare. However, these settings often restrict personal freedom and autonomy, creating an environment where residents are subject to rigid routines that limit their ability to make independent choices or participate actively in decisions affecting their lives. This issue can extend to residential services and day care centers, which, if not professionally structured with a strong focus on rights, SI, and QoL, can unintentionally mirror conditions of institutionalization. Even settings designed to support individuals with ID can become overly restrictive when they lack these inclusive principles, thereby limiting autonomy and reducing opportunities for personal choice and meaningful community involvement. In such settings, individuals with ID may experience a diminished sense of agency and control, both crucial for personal development and mental well-being. This restricted autonomy often leads to dependency, as individuals have few opportunities to practice decision- making skills or engage in activities that foster self-reliance. Additionally, highly structured environments can restrict social interactions, both within and outside of the institution, leading to long-term social isolation and stunted development of essential social skills (European Disability Forum, 2020).

The risk of institutionalization is further compounded by the scarcity of alternative care models, such as family-based residences or independent living support services. These alternatives can provide a less restrictive environment where individuals experience greater autonomy and SI. Family-based care, for example, offers a supportive setting with a familial structure that enhances opportunities for personal choice and individualized care (Inclusion EU, 2019). Similarly, independent living services empower individuals by offering tailored support that allows them to live in their own homes or small, community-integrated residences. However, the limited availability of these options in many regions often results in continued reliance on traditional institutional models as the primary means of care.

The European Strategy for the Rights of PwD 2021-2030 addresses these challenges by advocating for deinstitutionalization and promoting the expansion of community-based support services. This strategy promotes a shift from institutional settings to more inclusive, community-integrated care,

enabling people with ID to live in environments that respect their rights to dignity, autonomy, and social participation (European Commission, 2021). By expanding these community services, the initiative seeks to ensure that individuals with ID have access to settings that foster self-determination, support the building of meaningful relationships, and encourage active involvement in society.

Research underscores the benefits of community-based living over institutionalization. Studies show that individuals with ID in community settings report higher levels of satisfaction, dignity, and social engagement compared to those in institutional care. Community living fosters social relationships and allows individuals to engage in daily activities that support personal growth and meaningful interactions (EASPD, 2020). These settings encourage independence, social integration, and self-fulfillment qualities that are often restricted in institutionalized environments. Given that the majority of individuals with ID currently reside in residential or day care services, this study focuses on examining the LC within these environments. The aim is to develop monitoring systems that evaluate QoL and safeguard the rights of individuals with ID. By systematically analyzing these LC, this study seeks to establish benchmarks and propose recommendations for improved care models that foster autonomy, inclusion, and overall well-being in residential and day care settings.

1.1.2 Intellectual Disability: Clinical Characteristics and Lifelong Support Perspectives

ID is a complex neurodevelopmental disorder characterized by significant limitations in both intellectual functioning and adaptive behavior. Typically diagnosed in infancy or early childhood, ID affects a broad range of cognitive abilities and daily life skills, emerging before the age of 22 (Obi et al., 2011; Schalock, Luckasson & Tassé, 2021). ID is often co-morbid with ID, such as autism spectrum disorder and attention-deficit/hyperactivity disorder, as well as with mental health challenges like anxiety and depression, neurological disorders, including cerebral palsy, and various medical conditions such as meningitis. The scope of ID is expansive, impacting the individual's personal, educational, and social development. This paragraph delves into the critical aspects of ID, from intellectual and adaptive functioning to the various genetic and environmental factors underlying this condition, as well as evaluating strategies and current diagnostic tools.

A comprehensive understanding of ID requires an exploration of both cognitive capacities and adaptive skills, as these components together influence the individual's daily functioning and QoL (Mattie et al. 2023).

- *Intellectual Functioning* - The cognitive dimension of ID, commonly known as intellectual functioning or intelligence, encompasses a variety of mental capabilities, including logical reasoning, problem-solving, learning capacity, and verbal skills. Intellectual functioning is frequently assessed through intelligence quotient (IQ) tests, which provide standardized scores as a metric of cognitive ability. An IQ score of 70 or below, which falls two standard deviations below the median score of 100, is widely used as a threshold to identify intellectual limitations indicative of ID (Maulik et al., 2011). However, while IQ scores

provide valuable data, they represent only one facet of an individual's cognitive profile and should be interpreted alongside adaptive behavior evaluations to achieve a comprehensive understanding.

- *Adaptive Behavior Functioning* - In addition, deficits in adaptive behavior are a defining component of ID, manifesting as challenges in three primary domains: social, conceptual, and practical skills. Social skills encompass interpersonal interactions, self-esteem, and social responsibility, while conceptual skills include abilities related to language, literacy, and financial management. Practical skills refer to essential tasks for independent living, such as personal care, occupational responsibilities, and the use of everyday tools. These adaptive skills are dynamic, developing, and evolving throughout the individual's lifetime to meet social and cultural expectations. Adaptive behavior evaluations are integral to identifying the levels of support and intervention needed to enhance the individual's QoL (Milne et al., 2013; Obi et al., 2011; Boluarte Carbajal et al., 2024).

The etiology of ID can be categorized into genetic and environmental factors (Leonard et al. 2022).

- *Genetic Causes of ID* - A range of genetic syndromes are implicated in ID (Oliveira et al. 2020). Phenylketonuria, an autosomal recessive metabolic disorder, is one such example. It prevents the metabolism of phenylalanine due to a deficiency in the enzyme phenylalanine hydroxylase, leading to a build-up of toxic metabolites in the body that can cause ID if untreated (Bayat et al., 2015; Blau, 2016). Another common genetic cause is Fragile X syndrome, resulting from an expansion of CGG repeats in the FMR1 gene, which causes significant cognitive and behavioral impairments (Jacquemont et al., 2014). Rett syndrome, an X-linked genetic disorder primarily affecting females, is associated with mutations in the MeCP2 gene, leading to progressive intellectual decline and motor dysfunction (Segawa, 2005). Additionally, neurodevelopmental conditions such as DiGeorge syndrome often present as a gradual cognitive decline rather than an immediate onset ID, highlighting the diversity in genetic etiologies (Cascella & Muzio, 2015).
- *Environmental Factors* - Environmental exposure is a significant contributor to ID, particularly when such exposures occur during pregnancy. Infections such as rubella are also associated with ID when contracted by the mother during pregnancy, with a higher incidence in cases where infection occurs during the first trimester (Biellik & Orenstein, 2018). Other maternal health conditions, including hypertension, diabetes, and various infections, can significantly increase the risk of ID in the child, especially if these conditions are poorly managed during pregnancy (Li et al., 2016; Huang et al., 2016). Furthermore, social-environmental and cultural factors may explain many interindividual differences in IQ (McKinney et al. 2024). Vincente et al. (2023) highlighted that, together with cognitive severity, occupational and psychoeducational support, as well as support for autonomy and independent living, were also predictors of the level of self-determination. The study emphasizes the role of contextual variables in the development of self-determination in

people with ID, placing the focus of intervention on social opportunities.

Evaluating and diagnosing ID requires a thorough evaluation of both intellectual functioning and adaptive behavior, with the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5, 2013) providing specific criteria for these evaluations. The DSM-5 outlines that ID diagnoses should be based on evidence of deficits in cognitive abilities and adaptive behavior, with the onset of symptoms occurring before the age of 22. A wide range of diagnostic tools is available, from genetic screening to advanced neuroimaging techniques. Chromosomal analysis, including methods such as fluorescent in situ hybridization, enables the detection of chromosomal deletions or mutations responsible for ID (Gray & Wilkins-Haug, 2018). Blood and urine tests also help in identifying inborn metabolic errors, such as those found in PKU and galactosemia, through biochemical analysis (Bayat et al., 2015).

Neuroimaging methods, such as magnetic resonance imaging and computerized tomography, offer valuable insights into brain structure and can identify physical anomalies, such as microcephaly and cerebral developmental delays, that may be associated with ID (Erbetta et al., 2015). Emerging imaging techniques, including functional MRI and diffusion tensor imaging, are currently used in research to explore neural connectivity and abnormalities in specific brain circuits implicated in ID. The complexities surrounding ID require a multidimensional approach to both evaluation and intervention. While advancements in genetic testing, prenatal screening, and neuroimaging have enhanced diagnostic accuracy, these tools also highlight the need for personalized support strategies. Early intervention, focusing on cognitive, behavioral, and adaptive skill development, remains essential for optimizing developmental outcomes. As research progresses, particularly in the realms of gene therapy and neuromodulation, there is potential for novel therapeutic approaches that could improve the QoL for individuals with ID and provide their families with expanded support options. Understanding the varied etiology and spectrum of ID is vital for developing inclusive educational, social, and healthcare policies that address the unique needs of this population.

Lifelong care for individuals with ID requires a holistic, multidisciplinary approach that goes beyond basic health care, involving consistent support and tailored planning throughout the person's life. Unlike other populations, individuals with ID benefit from lifelong support essential for ensuring optimal QoL and promoting self-determination, SI, and physical and mental well- being (Schalock et al., 2010). Care is, therefore, not merely a health intervention but a continuous commitment that integrates health services, education, employment, and SI (Bigby & Douglas, 2020). Early and thorough evaluation is fundamental for creating an Individual Plan, which is tailored to each person's unique needs and provides flexible, targeted interventions. This approach enables timely interventions with lifelong positive effects for the individual. Individual plan relies on participatory planning, including family and caregivers, and are continually updated to reflect the individual's developmental needs (Mansell & Beadle-Brown, 2012). Personalized individual plan supports the individual through age-related changes, fostering autonomy and social

engagement. Adult services play a central role in ensuring that the dignity and QoL of individuals with ID. In many cases, QoL is significantly influenced by the environment and resources available within residential or support services, which should actively promote participation, independence, and emotional and social well-being (Bigby & Douglas, 2020). Studies indicate that the quality of support facilities and the professionalism of staff are closely linked to positive outcomes for individuals with ID, both in terms of physical health and SI (Mansell & Beadle-Brown, 2012). Services need to adopt support practices that go beyond physical assistance, promoting independence and providing opportunities for choice and engagement. The transition from child to adult services marks a critical phase in the life of a person with an ID. Transition planning is a vital component of lifelong care, ensuring continuity in care and support, and facilitating integration into living and working environments that enhance autonomy and active participation (Henninger & Taylor, 2014). This transition requires collaboration among health, social, and educational services, working together to provide uninterrupted care and personalized support throughout adulthood. SI is a key component of lifelong care to enable individuals with ID to live fully within the community. Experiences in inclusive life, work, and social settings contribute not only to psychological well-being but also to the individual's sense of belonging and self-esteem (Verdonschot et al., 2009). Services play a crucial role in promoting this process, offering programs that support work and SI to overcome stigmatizing barriers and enable genuine integration. Finally, legal and financial planning is essential to ensure long-term stability for individuals with ID. Establishing stable financial support through tools like trusts and special funds, alongside legal protections such as guardianship and decision-making assistance, protects the individual's rights and allows them to live with greater financial security and legal protection (Wehman, 2013). Families are encouraged to seek specialized consultancy, guiding them toward secure, long-term management solutions. In conclusion, lifelong care for individuals with ID requires personalized, adaptive planning that addresses each individual's changing needs. QoL, inclusion, and personal security are achievable only through effective support services, targeted health interventions, and appropriate legal and financial planning. The goal of services should be to facilitate an independent and dignified life for individuals with ID, promoting participation and active contribution to society.

1.2 Quality of Life Models in the Intellectual Disability Field

QoL is a multidimensional construct that reflects an individual's well-being through various domains, deeply influenced by both personal characteristics and environmental factors. It is inherently subjective, with its expression and significance varying from person to person, yet it comprises universal dimensions applicable to all individuals. According to Schalock et al. (2010), "Individual QoL is a multidimensional phenomenon composed of core domains influenced by personal characteristics and environmental factors. These core domains are the same for all people,

although they may vary individually in relative value and importance. Evaluation of QoL domains is based on culturally sensitive indicators" (p. 21). This highlights the interaction between the universal and individualistic aspects of QoL, where shared dimensions are shaped by personal experiences and cultural contexts. Renwick and Brown's model further enriches this understanding by defining QoL as "the degree to which a person enjoys the important possibilities of his/her life" (Raphael et al., 1996). This definition emphasizes the individual's ability to seize life's opportunities, which are molded by both personal abilities and external conditions. Their model identifies three primary life domains: Being, Belonging, and Becoming. 'Being' refers to one's identity, encompassing physical, psychological, and spiritual aspects; 'Belonging' pertains to social connections and one's relationship with the environment; and 'Becoming' relates to personal growth and self-actualization through meaningful activities. These domains, while universal, manifest differently based on individual preferences and circumstances.

Although the fundamental aspects of life—such as health, emotional well-being, and social relationships—are valued globally, research demonstrates that how these domains are prioritized varies across cultures and individuals (Verdugo et al., 2005; Morán et al., 2023). For instance, while Western cultures may emphasize material success, other societies might prioritize communal living and social integration. Brown and Brown (2003) illustrate how individual personalities also play a role in shaping what people consider vital to their QoL, leading to personal interpretations and "accents" on generally valued aspects of life.

Thus, while the concept of QoL is universally relevant, it is ultimately shaped by a dynamic interplay of personal aspirations, environmental contexts, and cultural influences. This makes QoL a shared yet deeply individualized phenomenon, with its multidimensional nature accommodating both universal core domains and the unique experiences of each person. A central element in recent scientific reflection on QOL is the union with the support paradigm. Providing personalized support is essential to improve the QOL of people with neurodevelopment disabilities, constituting the indispensable element to encourage full social participation, independence, and promote general well-being. In this sense, the union of the two paradigms to form the QoL support model is significant. This model provides a valuable framework for developing policies, providing support, transforming organizations, implementing systemic changes, and evaluating outcomes (Gomez et la, 2021; Morán et al., 2023).

Independence and self-determination play a fundamental role in promoting individual functioning, QoL, and SI, particularly for individuals with ID. These two factors are not only essential components of the QoL construct but also key goals to pursue for its improvement and maintenance. Self-determination, which encompasses autonomy and competence, is vital for achieving independence, as it enables individuals to tackle personal and societal challenges, thus significantly enhancing their QoL (Ellenkamp et al., 2016; Mumbardò-Adam et al., 2024). Greater self-determination in individuals with ID has important effects on the person's life. As highlighted by Kuld and collaborators (2023), higher levels are related to improved adaptive behaviors, lower

rates of problem behaviors, better opportunities for community participation, and greater motivation to learn.

Independence, understood as the ability to manage daily tasks autonomously, build social relationships, and participate in work life, contributes greatly to increased self-esteem and SI (Wehmeyer & Bolding, 2001). When individuals are empowered to make decisions and take charge of their own lives, significant improvements in self-confidence and personal fulfillment are observed (Schalock & Verdugo-Alonso, 2002).

While self-determination and independence are closely linked, they have distinct implications. Self-determination refers to the ability to set goals, make choices, and take control of one's life (Wehmeyer & Palmer, 2003), promoting the exercise of both individual and social rights. Independence, on the other hand, pertains to living without excessive reliance on others, allowing individuals to make decisions and live life on their terms (O'Leary, 2017).

Promoting and facilitating independence and self-determination not only enhances the QoL but also enables individuals with disabilities to fully exercise their individual and social rights. By providing them with the necessary tools and opportunities to actively participate in society, we foster the creation of a more inclusive community, one that values the contributions and recognizes the full potential of every individual.

Domains essential to understanding and measuring QoL have been the subject of extensive research, evolving to reflect the complexity and diversity of human experience. A comprehensive approach to QoL evaluation must account for the interplay between subjective perceptions of well- being and objective conditions in which individuals live. Several key models have shaped our understanding of QoL, each highlighting core domains of life that contribute to overall well-being. In order to deepen the understanding of how quality of life can be conceptualized and operationalized, the following sections present a selection of key theoretical models that have been widely acknowledged in academic research and applied practice.

1.2.1 Schalock and Verdugo-Alonso Quality of Life Model

One of the most influential models in the field is that of Schalock and Verdugo Alonso (2002), which outlines eight key domains that offer a comprehensive view of QoL. These domains include physical well-being, emotional well-being, interpersonal relations, self-esteem, personal development, material well-being, self-determination, and rights. What distinguishes this model is its integrative approach, combining objective factors like material conditions and social rights with subjective aspects such as emotional fulfillment and autonomy.

Developed to be relevant across various populations, including individuals with intellectual and developmental disabilities, the model is also broad enough to apply to the general population. It is founded on the principle that every person, regardless of ability or circumstances, deserves a high QoL. By structuring QoL into these eight domains, Schalock and Verdugo Alonso offer a well-rounded perspective that balances both subjective experiences and objective measures of well- being. The model is composed of the following domains (Figure 1.1):

- *Physical Well-being*: This domain focuses on the physical health and safety of an individual, including aspects like general health, access to medical care, nutrition, and exercise. It also includes the absence of pain or discomfort, factors critical for leading a fulfilling life.
- *Emotional Well-being*: Emotional health encompasses feelings of happiness, satisfaction, and emotional stability. Schalock and Verdugo Alonso emphasize that emotional well- being is central to an individual's perception of QoL, influencing how they experience all other life domains.
- *Interpersonal Relations*: This domain highlights the importance of personal relationships, including those with family, friends, and partners. Social support, emotional connections, and a sense of belonging within these relationships are crucial for fostering well-being.
- *Social inclusion*: SI focuses on the degree to which individuals are integrated into their communities and have access to social networks and opportunities. For those with disabilities, SI is particularly significant, as it emphasizes overcoming barriers to participation and ensuring equal access to community resources.
- *Personal Development*: The ability to learn, grow, and achieve personal goals defines this domain. Personal development includes opportunities for education, skill acquisition, and self-fulfillment, allowing individuals to reach their potential.
- *Material Well-being*: This domain reflects the importance of financial security, adequate housing, and access to resources. Material well-being is often considered an objective measure of QoL, but it interacts with subjective perceptions, as individuals' satisfaction with their economic situation varies.
- *Self-determination*: One of the core pillars of the Schalock-Verdugo Alonso model, self-determination refers to an individual's ability to make choices and exercise control over their own life. Autonomy and personal agency are essential for individuals to feel empowered and responsible for their destiny.
- *Rights* encompass both civil and human rights, such as the right to privacy, freedom of expression, and protection from discrimination. Ensuring that individuals' rights are upheld is critical for promoting dignity and respect, which are foundational for QoL.

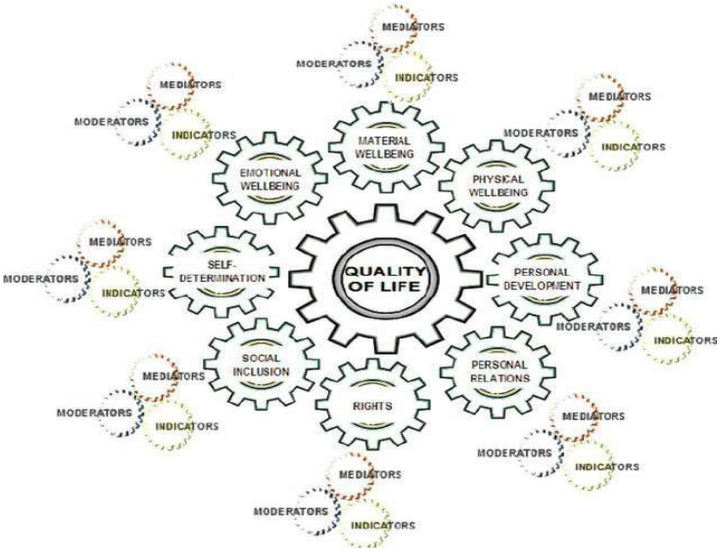


Figure 1.1 **Quality of Life Conceptual and Measurement Framework**

(Adopted from Schalock et al. 2010).

In each domain of QoL, both subjective and objective indicators of individual well-being are identified and considered for measurement across different stages of evaluation and outcomes for individuals with disabilities.

This model is particularly powerful because it is both comprehensive and dynamic. It acknowledges that the relative importance of each domain may change over time and across different life stages. For example, material well-being may be a priority for young adults seeking financial stability, whereas emotional well-being and interpersonal relationships may become more central later in life, when individuals seek meaning and satisfaction in their social and emotional lives. Moreover, the model emphasizes that these domains are interdependent, meaning that a deficiency in one area can affect others. For instance, poor physical health may negatively impact emotional well-being, SI, and personal development. Schalock and Verdugo Alonso's framework is widely used in both research and practice, particularly in assessing the QoL of vulnerable populations, including people with disabilities. Its multi-dimensional structure allows for a nuanced evaluation of how various life circumstances contribute to or detract from an individual's overall well-being. By offering a flexible yet comprehensive structure, the model provides a powerful tool for policymakers, healthcare professionals, and social workers aiming to enhance the QoL across different populations. Advances in the conceptualization and theory of QOL, supported by an extensive body of recent research, have now placed focus on the role of person-centered supports, contextual factors, and the exercise of rights in the community. The measurement tools of the

construct allow for orienting practice towards improving self-determination, social participation, and shared citizenship of people with ID (Verdugo & Schalock, 2024).

1.2.2 "3B" Quality of Life Model

The QoL model developed by Renwick & Brown (1996), known as the 3B model, identifies three core domains of QoL: Being, Belonging, and Becoming. This model integrates additional dimensions and emphasizes the dynamic and subjective nature of QoL, underscoring that the enjoyment of life is influenced by both the individual's internal state and their relationship with the external environment.

- *Being* refers to the individual's self-identity, encompassing physical, psychological, and spiritual aspects. Physical being includes aspects such as physical health, appearance, and personal hygiene, while psychological being involves mental health, cognitive capacities, and emotional states. Spiritual being reflects personal beliefs, values, and aspirations, which may or may not be tied to religious practices.
- *Belonging* focuses on social connections and the individual's relationship with their environment. It includes social belonging (relationships with family, friends, and community), physical belonging (having a place in the world, such as a home or neighborhood), and community belonging (feeling integrated into society and contributing to its well-being).
- *Becoming* pertains to personal growth and development, which involves the pursuit of goals, aspirations, and self-actualization. It emphasizes the importance of purposeful activities and the ability to shape one's future, aligning with concepts of autonomy and self- determination found in Schalock and Verdugo Alonso's model.

The 3B model is particularly useful in capturing the subjective *experiences* of individuals and how they navigate through life's opportunities and challenges. It recognizes that QoL is not static, but rather a fluid state that evolves as individuals engage with their environment and pursue personal goals (Brown, Raphael & Renwick, 1997; Renwick, Brown, & Raphael, 2000). The measurement and evaluation of QoL cannot fail to consider the lived experience of people with disabilities or families that include disabilities. Looking through this lens allows us to take into consideration the fact that human beings typically find and express positive states of well-being, satisfaction, and QoL even in conditions that others might judge to be lacking in quality (Brown et al., 2022).

Renwick and Brown's emphasis on *personal agency* and the *interaction with external conditions* complements the more structured and objective domains of Schalock and Verdugo Alonso's model. Together, these models offer a comprehensive understanding of QoL that integrates personal perceptions with societal and environmental factors (Brown & Brown, 2003). Although the domains identified by both Schalock and Verdugo Alonso and Renwick & Brown models provide a broad framework, research shows that the experience of QoL varies significantly across cultures and individuals shaping the prioritization of QoL domains. For example, Western cultures often emphasize self-determination and material well-being, while more collectivist cultures may place

a greater emphasis on SI and interpersonal relations. Additionally, personal traits and life experiences play a critical role in shaping how individuals perceive their QoL. Brown and Brown (2003) argue that personality factors significantly influence what individuals consider important for their well-being. For instance, a person with a high need for social interaction may place more importance on interpersonal relations, while another individual might prioritize personal development and autonomy.

These models underscore the complexity of QoL as both a *universal* and *individualized* phenomenon. While certain domains like health, emotional well-being, and social relationships are universally valued, the ways in which individuals experience and prioritize these aspects differ greatly. The integration of both subjective and objective elements in models like those of Schalock and Verdugo Alonso and Renwick and Brown provide a robust framework for understanding the diverse and dynamic nature of QoL across different populations and contexts.

The comprehensive QoL models developed by Schalock and Verdugo Alonso, as well as Renwick and Brown, offer a multidimensional approach to assessing well-being. By integrating objective factors like material well-being and rights with subjective experiences of emotional well-being and personal growth, these models provide a holistic understanding of QoL. They are adaptable across cultures and individual circumstances, making them essential tools for research, policy-making, and clinical practice aimed at enhancing the QoL for diverse populations. subjective importance can vary significantly across individuals. Furthermore, Brown and Brown (2003) note that specific indicators within each domain may shift throughout the lifespan and are often contingent on personal choice and perception. For example, material well-being may hold higher value during early adulthood, while emotional well-being might become more significant later in life.

1.2.3 Supports Needs Model in Enhancing Quality of Life

In addition to personal and environmental factors, the concept of "supports needs" is fundamental in fostering QoL (Moran et al., 2023). Schalock et al. (2010) describe supports as "resources and strategies that aim to promote the development, education, interests, and personal well-being of an individual and that enhance human functioning" (p. 175). This perspective emphasizes that achieving a good QoL requires not only personal agency but also access to external resources and support systems. Over time, the understanding of supports has expanded to include a "systems of supports" approach. As explained by Shogren & Wehmeyer (2015), this involves the planned and integrated use of individualized strategies and resources across multiple life settings, ensuring the enhancement of human performance in a holistic manner. Such a system encompasses various elements, including natural supports like family and community, assistive technology, prosthetics, educational interventions, environmental accommodations, personal strengths, and professional services. These elements combine to create an ecosystem that facilitates well-being, emphasizing the interdependent and cumulative nature of support systems. For supports to be effective in improving QoL, they must adhere to certain principles. Schalock et al. (2018) argue that interventions and supports should be relevant, appropriate, timely, consistent, person-centered,

respectful, evidence-based, and effective. These characteristics ensure that support systems are both comprehensive and individualized, catering to the specific needs of individuals within their particular environments. For example, technology may significantly enhance autonomy for one person, while social support from family members may be the most critical factor for another. Furthermore, the concept of person-centered support highlights the importance of tailoring interventions to individual needs rather than adopting a one-size-fits-all approach. This includes respect for the individual's preferences, values, and cultural context, which are central to enhancing personal well-being. Person-centered supports also emphasize the dynamic nature of QoL, recognizing that individual needs and preferences evolve over time.

However, the conceptualization of supports must be located within a holistic approach to understanding the life and human functioning of people with ID. This is an approach that places a strong emphasis on understanding the multidimensional properties of the context, responsibility, and performance management and calls for greater vigilance in professional responsibility (Schalock et al., 2021).

Using biomedical, psychoeducational, sociocultural, and justice perspectives in combination provides the basis for a holistic approach to intellectual and developmental disabilities (Luckasson & Schalock, 2020). Each perspective is grounded in its philosophy, providing a unique look at human life and barriers, jointly building the framework for interventions and supports. These perspectives together organize information to improve understanding and enable more accurate decision-making and recommendations (Luckasson et al., 2022). Integrating these four perspectives into a holistic approach to ID has important implications including: (a) a focus on human functioning and the many factors that influence it; (b) the interaction between the person and the context with its risk factors, as ID is not exclusively internal to the individual; (c) a structured framework of specific support strategies towards barriers and risk factors, providing individualized support systems aimed at improving functioning; and (d) a strong emphasis on human and legal rights given by the integration of the justice perspective.

1.2.4 Individual Functioning Model

The functionality approach in ID represents a comprehensive and systematic perspective aimed at understanding human functioning within this population. This approach incorporates multiple dimensions, acknowledging the complexity and interactivity of various factors that influence outcomes. As defined by Luckasson & Schalock (2013), it is "a systems perspective towards understanding human functioning in ID that includes human functioning dimensions, interactive systems of supports and human functioning outcomes" (p. 658). The approach emphasizes a holistic view of individuals with ID, considering not just their cognitive abilities but also their adaptive behaviors, health, participation, and the broader contexts in which they live. The functionality approach to ID was formally introduced by the American Association on Intellectual and Developmental Disabilities (AAIDD), formerly the American Association on Mental Retardation (AAMR), in the 1992 manual (Luckasson et al., 1992). This model was revolutionary

at the time because it moved away from a sole focus on deficits or impairments, broadening the understanding of ID to include environmental and contextual factors. Over time, the model has been refined, with significant updates in the 2002 and 2010 AAIDD manuals (Luckasson et al., 2002; Schalock et al., 2010), and most recently in the 2021 11th edition (Schalock et al., 2021). The updated edition further reinforces the multidimensional and person-centered approach, emphasizing supports, functioning, and context. The AAIDD model provides a comprehensive framework that is consistent with the International Classification of Diseases (ICD) model, which also adopts a multidimensional understanding of disability (Buntinx, 2006). This compatibility enhances the model's utility across both clinical and policy settings, ensuring a global approach to understanding and supporting individuals with ID.

The functionality approach in ID represents a significant shift from traditional deficit-based models to a more holistic, multidimensional understanding of human functioning. By incorporating dimensions such as intelligence, adaptive behavior, health, participation, and context, this approach provides a comprehensive framework for assessing and supporting individuals with ID.

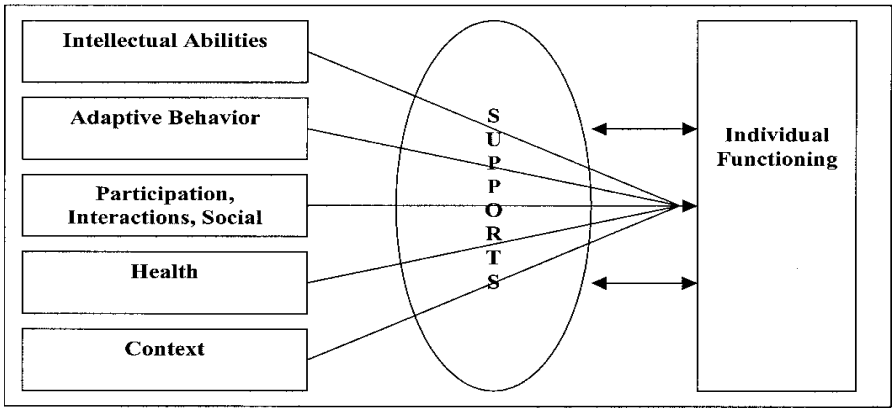


Figure 1.2: **AAIDD Functioning Model of Persons with Intellectual Disability**

(Adopted from Luckasson & Schalock, 2012; Schalock et al., 2021).

Moreover, the emphasis on interactive systems of support highlights the importance of individualized, person-centered interventions that are designed to promote positive outcomes across the lifespan. The functionality approach not only improves understanding of ID but also enhances the QoL for individuals by fostering greater independence, participation, and well-being. The multidimensional model proposed by AAIDD outlines five key dimensions that are critical to understanding human functioning in ID. These dimensions are interconnected and interact with

one another to influence outcomes in various life domains. Each dimension provides a unique lens through which the functioning of individuals with ID can be assessed and supported (Figure 1.2).

- *Intelligence* is a fundamental dimension of human functioning, defined as general mental ability. According to the AAIDD, intelligence encompasses a wide range of cognitive processes, including reasoning, problem-solving, planning, abstract thinking, and learning from experience (Schalock et al., 2010). Individuals with ID often have significant limitations in intellectual functioning, which can affect their ability to navigate complex tasks, solve problems, and adapt to new situations. However, intelligence alone does not define an individual's potential for success or fulfillment. This is why a broader understanding of functionality, beyond just cognitive ability, is critical for individuals with ID (Schalock et al., 2010).
- *Adaptive behavior* refers to the practical, conceptual, and social skills that individuals acquire and use in their daily lives. These include skills related to communication, self-care, social interaction, and the management of everyday responsibilities (Luckasson & Schalock, 2013). For individuals with ID, limitations in adaptive behavior can significantly impact their ability to function independently and interact effectively within their social environments. Understanding adaptive behavior is essential for designing effective support systems and interventions that enhance the individual's ability to perform daily tasks and engage in meaningful social roles.
- *Health* within the AAIDD model is defined as a state of complete physical, mental, and social well-being (Luckasson et al., 2002). The physical and mental health of individuals with ID plays a crucial role in their overall functioning and QoL. Many individuals with ID experience co-occurring physical or mental health conditions, which can further complicate their care and support needs (Schalock et al., 2010). Thus, maintaining and improving health is a key dimension in the functionality approach, as good health enables greater participation in social and occupational activities and supports overall well-being.
- *Participation* refers to the involvement of individuals in everyday activities across various domains of social life. It encompasses the performance of roles and tasks within family, work, and community settings (Schalock et al., 2010). For individuals with ID, participation is often limited by societal barriers, such as lack of access to appropriate services, social stigma, and physical or environmental constraints. Promoting participation is a central goal of the functionality approach, as greater engagement in social and community life is associated with better outcomes, including improved QoL and enhanced SI (Buntinx, 2006). Successful participation requires both individual capacity and supportive environments that enable individuals to function optimally within their communities.
- *Context* considers the various environmental and social conditions that shape the lives of individuals with ID. This dimension reflects an ecological perspective, which considers how different levels of context—micro, meso, and macro systems—affect individual functioning (Schalock et al., 2010). The microsystem includes the individual, their family,

and close associates who directly influence daily life. The mesosystem involves the organizations and communities that provide services and support to individuals, while the macrosystem refers to the broader social, cultural, and political contexts that impact the overall service delivery system and societal attitudes toward disability (Luckasson et al., 2013). The context dimension underscores the importance of recognizing that individuals do not function in isolation; their outcomes are shaped by the environments in which they live, work, and interact. Different support strategies are required at each contextual level to enhance individual functioning and outcomes.

The update of this model was proposed in the 12th edition of the AAIDD manual, based on the aforementioned multidimensional model, integrating the fundamental advances in the field since 2010, offering a comprehensive approach to ID. The proposed approach is an integrative, cohesive, and holistic approach to the conceptualization of ID (Schalock et al., 2021). To date, the sector literature has integrated different perspectives and placed a strong emphasis on the use of systematic evaluation for intellectual functioning and adaptive behavior. The updated model also reflects a particular focus on the human and legal rights of people with disabilities, emphasizing skills and supports for self-defense and empowerment. The integration of perspectives from the capabilities approach, together with the support paradigm, has increased the emphasis on the need for community-based alternatives and inclusive environments. In continuity with the previous conceptual models, constant commitment is emphasized in applying evidence-based practices, in the definition and achievement of outcomes that can improve the QOL of people with ID. Using an integrative approach to ID is central to having a complete representation of human functioning within practices that use precise terminology, evidence-based practices, standards of clinical judgment, and a shared vision of valuable outcomes (Schalock et al., 2021).

The concept of support needs is central to understanding the functioning of individuals with ID. Support needs refer to the array of assistance, interventions, and accommodations required by a person to perform daily activities, participate in social life, and achieve a satisfactory QoL (Thompson et al., 2009). These needs are dynamic and vary significantly across individuals, contexts, and over time. They are not merely determined by the severity of the disability but also by environmental, personal, and contextual factors (Schalock et al., 2010). The systematic evaluation and provision of appropriate supports are crucial to promoting both the functioning and inclusion of individuals with ID within their communities. The literature defines support needs as a critical component in facilitating the participation and functioning of individuals with ID in various domains of life, including education, employment, and social integration (Thompson et al., 2009).

Support systems consist of resources and strategies that are provided to enhance personal development and interests. At the same time, the latter influences the functioning and consequently the levels of well-being of an individual (Schalock et al., 2021).

Unlike traditional deficit-based models that focus solely on limitations, the support needs model views disability through the lens of the individual's interaction with their environment and the

resources available to them (Schalock & Luckasson, 2015). This approach aligns with the International Classification of Functioning, Disability, and Health (ICF) framework, which views disability as a dynamic interaction between health conditions and contextual factors, both personal and environmental (World Health Organization, 2001). Supports are often categorized into different types: natural supports (such as family, friends, or community members), formal supports (including services provided by professionals or organizations), and technology-based supports (such as assistive devices and technologies) (Shogren & Wehmeier, 2015). Together, these supports play a fundamental role in reducing the impact of functional limitations and enhancing participation in daily life.

To be defined as support, they must meet some defining characteristics. First, they must be individual-centered, holistic, coordinated and results-focused; secondly, they must find their foundation on the values of the person and their context and support relationships; an important element is the fact that they must consider choice, autonomy and inclusion in contexts; ultimately, they form the bridge that connects and aligns personal goals, support needs and desired outcomes (Schalock et al., 2021). Together, these supports play a fundamental role in reducing the impact of functional limitations and enhancing participation in daily life.

Several models have been developed to assess and address support needs in individuals with ID. One of the most widely referenced is the Supports Intensity Scale (SIS) developed by Thompson and colleagues (2004), which measures the intensity of support needed across various domains of life, including home living, community living, lifelong learning, employment, health and safety, and social activities. The SIS represents a paradigm shift by emphasizing the level of support required rather than focusing on the person's deficits or impairments.

Other models, such as the Personal Outcome Measures (POM) developed by the Council on quality and Leadership (Gardner & Carran, 2005), integrate the concept of support needs with personal goals and outcomes, recognizing that the success of support interventions should ultimately be evaluated based on the individual's perceived QoL and personal satisfaction. These models highlight the importance of individualization in support planning, acknowledging that needs and preferences differ significantly from one person to another (Schalock et al., 2008).

The relationship between support needs and QoL has been extensively discussed in the literature. Research consistently shows that the provision of appropriate and individualized supports is directly correlated with enhanced QoL outcomes for individuals with ID (Schalock et al., 2002). QoL frameworks, such as those proposed by Schalock (2004), often include dimensions such as emotional well-being, SI, personal development, and self-determination, all of which are influenced by the adequacy of supports provided.

Supports must be adaptable and responsive to both personal changes (e.g., aging, health fluctuations) and contextual shifts (e.g., changes in living situations, community environments). Failure to address evolving support needs can lead to decreased participation, heightened social isolation, and reduced QoL, underlining the importance of continuous and flexible support systems (Shogren et al., 2017).

SI is another critical outcome influenced by the adequacy of support. Inadequate or inappropriate supports can impede individuals with ID from fully participating in society and enjoying their rights as equal citizens (Hall, 2010). Effective support systems not only enable individuals to participate in community activities but also foster meaningful relationships, civic participation, and access to social networks (Simplican et al., 2015). The extent of SI, however, is dependent on the type, intensity, and quality of the supports provided.

Research by Verdonschot et al. (2009) highlights that even when individuals are physically present in community settings, they may still experience exclusion or marginalization if the supports they receive do not address their specific social and emotional needs. This concept is reflected in the Ecological Model of SI (Overmars-Marx et al., 2014), which emphasizes the role of environmental factors, alongside individual and interpersonal supports, in shaping opportunities for social engagement.

Accurately assessing support needs is critical for developing effective service systems and individualized plans. A reliable measure of support needs allows service providers, policymakers, and caregivers to allocate resources efficiently, ensuring that individuals receive the appropriate level and type of support (Schalock & Verdugo, 2012). Furthermore, systematic evaluation can facilitate transitions between life stages or settings, ensuring continuity of care and preventing gaps in support that might otherwise occur (Luckasson & Schalock, 2013).

The identification of support needs also informs the development of person-centered planning approaches, where interventions and services are tailored to meet the unique needs and goals of each individual (Claes et al., 2010). This is particularly important in promoting self-determination and autonomy, as individuals with ID are empowered to make choices about their lives with the appropriate supports in place (Shogren et al., 2006).

A key component of the functionality approach is the integration of support systems that are tailored to meet the needs of individuals with ID. These systems of supports are multidimensional and consider both personal abilities and environmental factors that contribute to human functioning. As noted by Luckasson & Schalock (2013) and Schalock et al. (2021), supports can include natural supports (e.g., family and friends), professional services, and technological aids. The goal is to provide a comprehensive support system that addresses the various dimensions of functionality, enabling individuals to achieve meaningful outcomes in their lives.

The concept of interactive systems of supports reflects the recognition that supports must be individualized and flexible, adapting to the changing needs and circumstances of the individual over time. Schalock et al. (2010) emphasize that support systems should be person-centered, focusing on the individual's unique strengths, needs, and preferences. This approach is crucial in promoting independence, autonomy, and self-determination, which are essential for enhancing QoL in individuals with ID. The ultimate goal of the functionality approach is to achieve positive outcomes in human functioning. These outcomes include improvements in physical and mental health, increased independence in adaptive behavior, greater participation in social and community activities, and enhanced well-being. The authors highlight that outcomes should be assessed not

only in terms of the individual's abilities but also in relation to their QoL and personal satisfaction. Measuring outcomes requires a multidimensional approach that considers both individual progress and environmental factors. The use of person-centered evaluates, which focus on the individual's goals, preferences, and desired outcomes, is critical in evaluating the effectiveness of support systems and interventions (Schalock et al., 2010; Schalock et al., 2021). Additionally, the functionality approach emphasizes the importance of long-term outcomes, recognizing that ID is a lifelong condition that requires ongoing support and adaptation to changing circumstances.

1.2.5 Self-Determination Functional Model

In his essay "The Courage to Choose", Savater argues that humans are practical beings—agents driven by desires and the will to act upon them (Smith, 1998). In his interpretation, acting is not merely responding to instinctual impulses, but rather fulfilling a personal project: while humans have a basic biological programming as living beings, they are also called to self-program and self-determine as humans. Thus, the dignity of each person lies in their ability to guide their actions concerning a range of options.

This drive for self-determined action characterizes all individuals, regardless of their abilities and competencies, and is one of the fundamental conditions that underpin the QoL for everyone. The engine of human action, therefore, fundamentally resides in the possibility and capacity for choice, effectively integrating knowledge, imagination, and decision-making within the realm of what is possible.

One of the earliest definitions of self-determination as a specific concept within education was provided by Deci and Ryan, who identified it as "the ability to choose among various opportunities and to use those choices to determine one's actions. [...] Individuals have a natural inclination to develop psychologically, to strive to independently overcome the challenges of their environment, and to engage in self-determined behaviors" (Deci & Ryan, 1985, p. 38). Thus, self-determination, even before being a capacity, is a necessity that requires not only a set of personal skills but also a supportive context and social resources (Deci & Ryan, 1985; Ryan & Deci, 2000).

Ward (1992) argues that self-determination is a crucial goal for individuals, especially as they reach adulthood. He highlights that self-determination results from attitudes that enable individuals to define their own goals and the skills that allow them to achieve them. The foundational elements of this progressive construction include self-actualization, assertiveness, creativity, positive self-regard, and the ability to advocate for oneself.

In a similar vein, Hoffman and Field (1995, p. 136) define self-determination as "the personal ability to identify and attain goals, based on an understanding and appreciation of oneself." They further state that self-determination is "promoted or discouraged by certain factors under the individual's control (values, knowledge, skills) and by other context-related variables (opportunities to make choices, attitudes from others)" (Hoffman & Field, 1995, p. 140).

Therefore, self-determination should be understood as a multidimensional construct. Mithaug and colleagues (1998) describe it as characterized by a series of skills through which individuals:

- understand and express their interests, needs, and abilities;
- establish their expectations and goals to meet those interests and needs;
- choose, decide, and plan;
- act to carry out their plans;
- evaluate the consequences of their actions;
- Modify actions and plans to effectively achieve their goals.

It is immediately evident that individuals with ID, particularly those discussed in this work, are less prepared to face the various aspects of this process.

A significant contribution to the definition of the self-determination construct and its promotion as a central concept in the perspective of QoL for individuals with disabilities has been made by the group coordinated by Wehmeyer. In various contributions, these authors (Wehmeyer & Metzler, 1995; Wehmeyer, Kelchner & Richards, 1996; Wehmeyer & Schwartz, 1998; Wehmeyer, 1999; Wehmeyer & Garner, 2003) have stated that an individual possesses self-determination when acting as the primary causal agent of their own life and when their decisions regarding their well- being are free from undue influences or external pressures. The concept of causal agent is central to this theoretical perspective, referring to the fact that a person undertakes actions or has the strength and authority to do so to impact certain aspects of their life. In other words, a self- determined person acts as a causal agent with the intent of shaping their future and destiny.

Following numerous studies considering individuals of various ages, including those with typical development, learning disabilities, and ID, Wehmeyer and colleagues have attempted to operationally specify the construct of self-determination by proposing a specific framework. As illustrated in Figure 1.3, this model considers both the individual dimension—namely, the skills necessary for a person to engage in self-determined behaviors—and the environmental dimension, which encompasses the opportunities provided by the context to assume the role of causal agent in one's existence. From this framework, it becomes immediately evident how complex the situation is for individuals with disabilities, who often not only have a limited repertoire of skills that promote self-determined behaviors but also must relate to an environment oriented toward making decisions on their behalf, even regarding the most common aspects of daily life.

Another crucial aspect that the model highlights is the importance of support, emphasizing the educational dimension throughout a person's life cycle, especially for those in situations of disability. In other words, the components of self-determination should be integrated into educational and rehabilitative pathways at every age, not just during specific moments of life that seem most associated with decision-making processes (e.g., school-to-work transition, choice of living arrangements, etc.) (Figure 1.3).

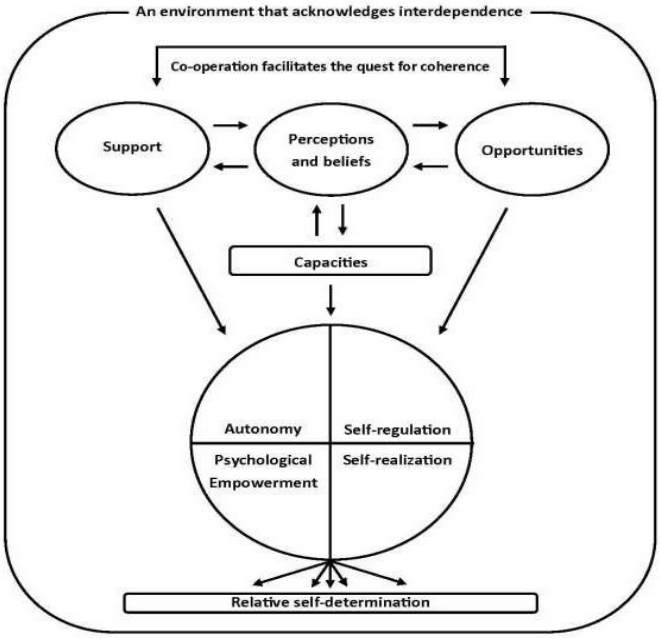


Figure 1.3: **The Functional Model of Self-Determination** (adopted from Wehmeyer, 1999).

Referring to this functional approach, the construct of self-determination is articulated into four fundamental components:

- *Autonomy*, which includes the level of independence and the person's ability to act based on their system of values and interests. Human development follows a progression from dependence on others for care to self-care and decision-making autonomy. The outcome of this progression is autonomous functioning, or behavioral autonomy.
- *Self-regulation*, which essentially encompasses self-management skills (self-instruction, self-monitoring, and self-reinforcement), goal setting, and problem-solving. Each of these strategies can enable a person to gain more adequate control over their life.
- *Psychological empowerment*, primarily manifested in an internal locus of control and adequate levels of self-efficacy. When a person possesses these competencies, they attribute the results of their actions to personal components and have confidence in their chances of success.
- *Self-actualization*, relating to the individual's level of self-awareness, including their strengths and limitations. This self-knowledge and understanding are shaped by experience and interpretation of their environment, influenced by the evaluations of significant others, reinforcements, and causal attributions of their behavior (Schalock & Verdugo Alonso, 2002).

These essential dimensions take shape in self-determined behavior, characterized by the following constitutive elements:

- Ability to choose;
- Ability to problem-solve;
- Ability to make decisions;
- Ability to set and achieve goals;
- Ability to self-manage;
- Ability to self-advocate;
- Perception of control and self-awareness.

In summary, the various definitions of self-determination emphasize particular, yet complementary, aspects of the construct. Generally, all converge on identifying the adaptive goal, which is the ability of individuals with disabilities to assume roles in the community typically associated with adulthood. Certainly, personal competencies and manifested deficits can affect this potential, but efforts must be made to ensure good levels of self-determination, which do not require, as a basic condition, the ability to perform all activities independently. Understanding the construct of self-determination benefited from numerous theoretical contributions in the early 1990s (Burke et al., 2024). Starting from the functional model described by Wehmeyer, where self- determination is defined as the ability to act as a primary causal agent. The construct has recently been reconceptualized by Shogren and colleagues and redefined as Causal Agency Theory by incorporating advances in the field of disability and international research (Schogren et al., 2015). The innovative aspect of the theory of causal action lies in the fact that it pays attention not only to behavior but more generally to the self-determined action at the foundation of causal action. Volitional action, agentic action, and action control beliefs are the fundamental characteristics of self-determined action. They can be simplified using common language such as "decide, act, and believe" (Burke et al., 2024). Highlights essential elements that promote self-determination, including decision making, expressing preferences, problem solving, goal setting and achievement, self-management, self-regulation, self-advocacy, and self-awareness (Schogren et al., 2024). Identifying the processes that lead to self-determined action, causal agency theory allows us to recognize tools and interventions, approaches that are culturally relevant (Meral et al., 2023). Finally, the development of this conceptual framework has allowed us to go beyond a common misunderstanding of Wehmeyer's model, according to which self-determination implies complete independence. In this perspective, however, greater emphasis is placed on interdependence and support systems that promote both individual and shared goals and values (Burke et al., 2024).

This interpretation of the self-determination construct highlights the educational dimension aimed at fostering both the acquisition of specific skills and the provision of adequate supports. Moreover, the self-determination prospects of individuals with disabilities are inevitably linked to the experiences provided to them for learning, practicing, and refining specific skills, whether in family, school, or social contexts. Efforts to support self-determination must be accompanied by frequent, intentional, and well-structured opportunities for individuals to acquire, demonstrate,

practice, and develop, even partially, appropriate skills and behaviors. This educational orientation must not diminish in the face of very complex situations such as severe ID or autism; rather, it should intensify. This interpretation of the self-determination construct highlights the educational dimension aimed at fostering both the acquisition of specific skills and the provision of adequate supports. Moreover, the self-determination prospects of individuals with disabilities are inevitably linked to the experiences provided to them for learning, practicing, and refining specific skills, whether in family, school, or social contexts. The role of context and Opportunities is crucial, serving as a powerful promoter of self-determination by creating an environment that encourages and facilitates meaningful choices. Efforts to support self-determination must be accompanied by frequent, intentional, and well-structured opportunities for individuals to acquire, demonstrate, practice, and develop, even partially, appropriate skills and behaviors. This educational orientation must not diminish in the face of very complex situations such as severe ID or autism; rather, it should intensify.

1.2.6 Independence Concept in Quality of Life Models

The models presented in the previous sections offer distinct yet complementary perspectives on how the construct of QoL can be understood and measured, particularly in the context of individuals with intellectual disabilities. Although each framework emphasizes different domains, a fundamental and cross-cutting element is independence. Independence is consistently regarded both as a desirable outcome and as a foundational condition for promoting self-determination, social inclusion, and overall well-being. The present paragraph illustrates the role of independence in the promotion of QoL and SI, highlighting its function both as a central objective of interventions and as a necessary condition for achieving personal well-being and active societal participation.

Independence is a fundamental concept in the philosophy of independent living, particularly for individuals with disabilities. It represents the ability to make choices, control one's environment, and participate in society without unnecessary reliance on others (Ioanna, 2020). Independence exists on a continuum, ranging from full dependence to complete autonomy. While total independence is ideal, all individuals experience varying degrees of dependence and interdependence throughout their lives (Aldridge, 2010; Hamraie, 2013). This continuum underscores that independence is not an absolute state but one that adapts to personal capabilities, available supports, and environmental factors (Vorhaus, 2007). Independence is closely tied to self- determination, encompassing skills that enable individuals to manage daily tasks, make informed decisions, and engage in meaningful activities, such as employment and social participation. In the realm of disability studies, independence extends beyond physical autonomy; it includes the ability to exert control over one's life and live according to personal values and preferences (Ioanna, 2020). This perspective challenges traditional deficit-focused models of disability, advocating instead for removing societal barriers and providing the supports necessary for independence (Mansell et al., 2007).

Historically, the independent living movement emerged in response to the institutionalization practices of the 20th century. Disability activists advocated for the right to live in the community and control their own lives, leading to the creation of the first Center for Independent Living in Berkeley, California, in 1972, and the passage of the Americans with Disabilities Act in 1990 (Wehmeyer & Schwartz, 1998). It enshrined the principles of independence and inclusion into law, while the CPRPD further solidified the right to independent living globally, emphasizing equal opportunities and the necessary supports to enable autonomy (United Nations, 2006). This shift from institutional care to community-based living continues to influence policies that encourage independence while recognizing the need for support systems that evolve with individuals' needs (Šiška & Beadle-Brown, 2020).

Support systems are crucial for achieving independence, including personal assistance services, adaptive technologies, and environmental modifications, which enable individuals to manage their lives and participate in the community (Kozma et al., 2009). Independence is often interdependent, as all individuals rely on others at times. Recognizing this interdependence helps frame independence as a process that maximizes autonomy while acknowledging the role of supports (Bennett et al., 2018).

Independence is also closely linked to SI, both of which enhance QoL. It allows individuals to make decisions based on their values and participate in meaningful activities, which is essential for psychological well-being (Wehmeyer & Schwartz, 1998). SI breaks down barriers of isolation, ensuring that individuals with disabilities have equal opportunities to contribute to their communities (Carter et al., 2024). The reciprocal relationship between independence and inclusion fosters a higher QoL, as accessible public spaces and inclusive workplaces allow individuals to fully exercise their independence (Šiška & Beadle-Brown, 2020).

The term "independence" is often used as an umbrella term encompassing a wide range of behavioral repertoires that individuals enact to carry out daily activities and self-care. This implies the ability to rely on one’s resources in the absence of support from others (Sandjojo et al., 2019). Most individuals with ID face challenges in independently managing daily life activities (Sigafoos et al., 2005; Ramdoss et al., 2012), which is why they often depend on support from family members, paid caregivers, or other reference figures (Vilaseca et al., 2019). These difficulties may relate to personal care, household tasks, community participation, and employment (Dusseljee et al., 2011; Ramdoss et al., 2012). Despite these challenges, independence is regarded as a significant goal by individuals with ID (Kuijken et al., 2016). Higher levels of independence are associated with increased indicators of happiness and personal satisfaction and, overall, a better QoL (Dollar et al., 2012; Ramdoss et al., 2012).

The United Nations Convention on the Rights of PwD (Convention on the Rights of Persons with disabilities, 2006) states that individuals should be able to live in society as independently as possible and have the right to choose where and with whom they live. Effective measures must be implemented to facilitate this process.

European directives have also moved in this direction; during the 2007-2013 programming period, the regulations for Structural and Investment Funds (the so-called “ESI Funds”) prioritized the “transition from institutional to community-based care,” placing the provision of deinstitutionalization strategies as a prerequisite for accessing ESI funds. The European Disability Strategy 2010-2020 also included support strategies to encourage member states to move away from large, segregated institutions, emphasizing the importance and right of individuals with disabilities to live independently in the community while limiting ESI funding to initiatives that support this transition.

However, the implementation of these policies aimed at granting individuals with ID greater control over their lives, particularly regarding lifestyle choices, has been relatively slow at the international level (Mittler, 2015). Considering the broad use of the term “independence” in the context of disability, it is important to specify that the concept should not be viewed in absolute terms, but as a continuum ranging from total dependence to complete independence (Aldridge, 2010). No one, regardless of the presence of ID, is completely independent in all areas of daily life throughout their life. Every human being is, in fact, interdependent on others for sustenance, care, community participation, and their emancipation process (Hamraie, 2013, 2017; Bennett et al., 2018). Areas of independence and dependence generally coexist within individuals, and dependence is often a necessary factor for achieving independence (Vorhaus, 2007). Therefore, the concept of 'independence' should not be considered as 'complete autonomy' because promoting 'independent living' requires awareness of barriers and the ability for individuals with disabilities to receive the appropriate support to live as they wish (Di Gennaro Reed et al., 2014).

It is indeed possible to provide adequate support and to teach and develop skills so that individuals with ID can be guided toward a higher level of independence, which is potentially achievable by each individual. To reach this goal, the main action involves transitioning from an aggregated housing service planning system to a system of personalized planning, interventions, and supports (Wehmeyer & Bolding, 2001; Schalock et al., 2007; Schalock et al., 2010; Wehmeyer, 2020) to promote independent living.

The chapter explored the theoretical underpinnings of independence as a fundamental component of quality of life. Rather than being seen as complete autonomy, independence is understood as a dynamic process supported by individualized planning, adequate support, and skill development. In different models, independence is closely linked to self-determination—the ability to make personal choices—and individual functioning, which refers to the cognitive and adaptive skills needed for daily living and participation. Together, these elements contribute directly to a significant and measurable improvement in quality of life. Building on this foundation, the next section addresses social inclusion, a related concept that emphasizes connection, contribution, and recognition within the community as essential aspects of well-being.

1.3 The Concept of Social Inclusion for Individuals with Intellectual Disability

Cobigo et al. (2012) provided a comprehensive definition of SI, emphasizing three key aspects: (1) an individual's sense of belonging within a social network where they both receive and contribute support, (2) their experience of holding a valued social role, and (3) the community's trust in their ability to fulfill that role. The varied interpretations of SI highlight its conceptual complexity, which extends beyond personal concerns to encompass civil rights, equality, and economic factors (Simplican et al., 2015). It is also a critical factor in the well-being of individuals with intellectual and developmental disabilities (Buntinx & Schalock, 2010) and a core element of the United Nations Convention on the Rights of PwD (Quinn & Doyle, 2012). Despite this, people with intellectual and developmental disabilities often face significant social isolation (Bigby, 2008; Forrester-Jones et al., 2006; Milner & Kelly, 2009), with their social networks largely consisting of family and professionals (Lippold & Burns, 2009). A major challenge in achieving SI for these individuals is the lack of clarity surrounding the concept itself (Amado et al., 2013; Bigby, 2012). The multitude of definitions often conflates SI with related concepts such as social integration, social networks, community participation, and social capital. This variation complicates effective service delivery and intervention, resulting in insufficient data on its practical application (Duggan & Linehan, 2013; Martin & Cobigo, 2011). Additionally, the ambiguity surrounding SI impedes communication among key stakeholders—individuals with disabilities, family members, service providers, researchers, and policymakers—who may have differing views on its meaning and objectives (Clement & Bigby, 2010).

Nevertheless, SI remains a vital component of well-being for individuals with intellectual and developmental disabilities (Buntinx & Schalock, 2010) and continues to be a fundamental aspect of the United Nations Convention on the Rights of PwD (Quinn & Doyle, 2012).

1.3.1 Social inclusion model for enhancing community participation and relationships

In an attempt to clarify the concept, Simplican et al. (2015) proposed a SI Model consisting of two core domains: interpersonal relationships and community participation (Figure 1.4).

These domains capture the structural and functional components that contribute to SI. Interpersonal relationships and community participation are consistently highlighted in the literature as essential elements of SI (van Asselt-Goverts et al., 2013; McConkey & Collins, 2010), and both are integral to an individual's QoL (Schalock, 2004). The model suggests that these two domains should not be seen in isolation but rather as mutually reinforcing, with greater community involvement enhancing social networks and vice versa.

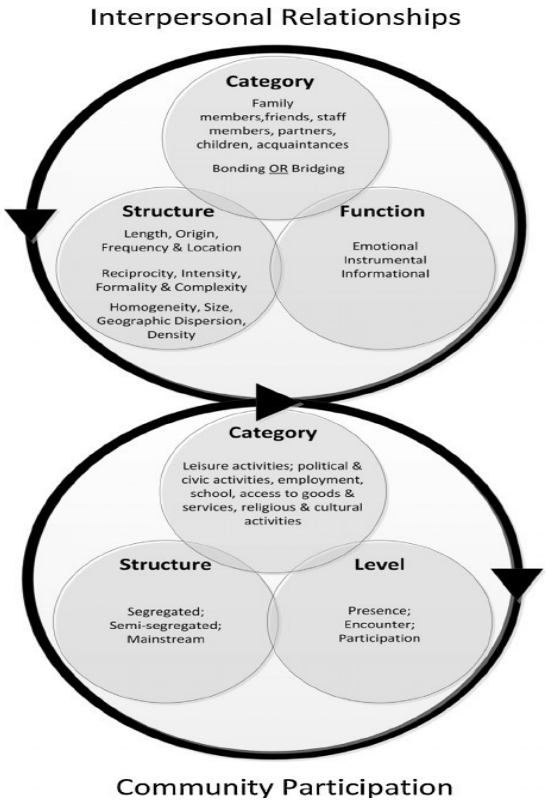


Figure 1.4: **The Social Inclusion Model** (Adopted from Simplican, Leader, Kosciulek, and Leahy, 2015).

Unlike broader definitions of SI, Simplican et al. (2015) focus specifically on the components that underlie interpersonal relationships and community participation. By doing so, their model distinguishes SI from the processes that might facilitate it (such as social skills training or policy changes) and from the subjective feelings of belonging that may result from inclusion.

Interpersonal Relationships - Interpersonal relationships are fundamental to achieving meaningful SI for individuals with intellectual disability. Interpersonal relationships are essential to human life, having an important impact on experiences at home and in the community. Relationships encompass different contexts, taking place at the family level, at work, in recreational activities, and in online communities. This is a crucial area for understanding SI given the difficulties that people with ID often experience such as problems related to social isolation, the availability of less emotional support, belonging to smaller social networks, so that they often report higher levels

higher levels of loneliness than those without disabilities (Stancliffe & Hall, 2023). In their comprehensive model of SI, Simplican et al. (2015) emphasize the importance of interpersonal relationships, which they conceptualize in terms of three distinct components: category, structure, and function. Each of these components contributes to the quality and depth of the social connections that individuals with ID form, and together, they form the bedrock for social belonging and participation.

- The *category* component refers to the types of people who make up the social networks of individuals with ID. These networks typically include family members, friends, acquaintances, paid staff, professionals, and intimate partners. For individuals with ID, relationships with paid caregivers or staff and other individuals with disabilities are often particularly important. McVilly et al. (2006) found that people with disabilities often value relationships with other disabled individuals because they share common experiences and perspectives, which can foster a sense of mutual understanding and belonging. McVilly et al. (2006) further elaborated that people with ID derive significant emotional and psychological benefits from these relationships, as they help meet various social and emotional needs. The diversity in relationships, ranging from family and staff to peers and acquaintances, helps individuals feel connected to different social groups, contributing to their sense of community and inclusion.
- *The structure* of interpersonal relationships refers to the formal and informal characteristics that define how these relationships function and develop over time. Van Asselt-Goverts et al. (2013) describe several structural factors, including the duration of relationships, how and where they began, the frequency of contact, and the initiators of contact. These elements significantly shape the strength and quality of relationships. For example, long-lasting relationships that involve regular, reciprocal interactions are likely to provide greater emotional stability and support. The location of social interactions also plays a role, as relationships that are maintained both within the home and in community spaces (e.g., at social events or public venues) expose individuals to a broader range of experiences and social opportunities. As more individuals engage in both physical and digital environments, online interactions are also becoming a crucial element of these relationships, allowing for new forms of communication and participation in broader social networks (van Asselt-Goverts et al., 2013).
- *The function* of interpersonal relationships refers to the roles that these relationships play in providing various types of support, which Simplican et al. (2015) categorize into emotional, instrumental, and informational support. Emotional support encompasses feelings of love, care, and trust, which are essential for fostering personal well-being and a sense of belonging. Instrumental support involves tangible forms of assistance, such as help with daily activities, transportation, or financial aid (Heaney & Israel, 2008). Informational support, on the other hand, includes advice, guidance, and the sharing of knowledge, which can be vital for navigating social systems, making decisions, and resolving problems.

Research indicates that individuals with ID require all three types of support to thrive and achieve SI. Abbott & McConkey (2006) and Dodevska and Vassos (2013) highlight that emotional, instrumental, and informational supports are critical for these individuals to overcome barriers in their social environments and improve their QoL. Without this multidimensional support, individuals with ID are at risk of social isolation and marginalization.

Community Participation - In addition to interpersonal relationships, community participation is the second key domain in Simplican et al.'s (2015) model of SI. Participation within community contexts offers people the opportunity to build relationships and improve SI. The presence of people with disabilities in neighborhood events, recreational and religious activities, online communities, education, and employment allows them to become valued members of their communities. This cascade allows you to promote a greater sense of belonging and improve central aspects of the QoL (Stancliffe & Hall, 2023). Similar to interpersonal relationships, community participation can be conceptualized in terms of category, structure, and level of involvement. Participation in community life is not only about being physically present but also about engaging meaningfully in activities that help individuals form social roles and contribute to their communities.

- *Category*. Community activities for individuals with ID can be categorized into a range of types, including leisure activities such as sports and hobbies, political and civic engagement, productive activities like employment and education, access to goods and services (consumption), and participation in religious or cultural activities (Verdonschot et al., 2009). These activities provide individuals with opportunities to build social roles, engage with others, and find a sense of purpose. For instance, participating in employment or educational settings allows individuals to contribute economically and socially, while leisure and civic activities offer avenues for building friendships and community ties. For individuals with ID, the ability to engage in such varied activities is crucial for their broader SI, as these roles help them develop a sense of belonging and identity within their communities.
- *The structure* of community participation refers to the different types of settings where these activities occur. Simplican et al. (2015) categorize these settings as segregated, semi-segregated, and integrated. Segregated settings typically involve individuals with ID and their caregivers and take place in specialized environments, such as group homes, sheltered workshops, or disability-specific programs. While these settings offer some benefits, such as a supportive environment tailored to the needs of individuals with ID, they often limit exposure to the broader community. Semi-segregated settings may involve both individuals with disabilities and community members, but still maintain a level of separation from mainstream activities. Examples include community programs or volunteer-led initiatives where individuals with disabilities participate alongside others but within a structured, supportive environment (Hall, 2010). Integrated settings, by contrast, are mainstream

environments where individuals with ID participate alongside the general population, such as in public parks, workplaces, or community centers. Integrated participation is seen as the ideal for promoting SI, as it provides opportunities for individuals with ID to engage with a broader range of people and contribute to community life. However, societal barriers and discriminatory attitudes often make it challenging for individuals with ID to fully participate in integrated settings (Hall, 2010).

- *The level of Involvement* can be understood as a continuum ranging from mere presence to encounter and full participation. Community presence refers to being physically present in a community space without engaging in meaningful interactions with others (O'Brien & Lyle, 1987). Some theorists have dismissed the idea of mere presence as insufficient for true SI, arguing that it does not lead to meaningful community engagement (Clement & Bigby, 2010). However, Simplican et al. (2015) suggest that presence may be an important precursor to more active forms of participation, particularly for individuals with ID who may face barriers to deeper community involvement. Community encounters, on the other hand, involve brief, often superficial interactions with strangers in community settings, such as casual conversations with neighbors or service providers. Although encounters may not lead to lasting relationships, they still provide individuals with a sense of being part of the social fabric of their communities (Bigby & Wiesel, 2011). Full participation, the highest level of community involvement, entails active engagement in meaningful activities and the development of interpersonal relationships within the community. This level of involvement allows individuals to take on valued social roles and build lasting connections with others.

The two domains of interpersonal relationships and community participation are deeply interconnected. Strong interpersonal relationships can facilitate greater community involvement, and participation in community activities can, in turn, lead to the development of new social connections. However, for many individuals with ID, both domains are often underdeveloped, leading to a vicious cycle of social isolation and limited opportunities for inclusion (Duggan & Linehan, 2013). Breaking this cycle requires intentional efforts to enhance both interpersonal relationships and community participation simultaneously, ensuring that individuals with ID are not only present in their communities but also actively engaged and valued members of society.

In the adult life course, companions for community activities of various ages, the impact of age-related mobility limitations on inclusive participation, retirement, and end-of-life considerations should be considered. Examining strategies to promote SI also means addressing challenges such as loneliness and the need for security (Stancliffe & Hall, 2023).

This interconnectedness between interpersonal relationships and community participation underscores the relevance of an ecological approach to SI, as discussed in the following chapter. By examining how various environmental layers influence these domains, it becomes evident that fostering strong social connections and encouraging active participation are not isolated efforts but rather essential components of a broader strategy. The subsequent chapter will explore how

addressing these ecological dimensions can effectively promote meaningful engagement for individuals with ID, ultimately contributing to their overall well-being and inclusion in society.

1.3.2 Ecological Approach to Social Inclusion

An ecological approach to SI considers the complex interplay between individuals and their broader social, cultural, and environmental contexts. Rather than focusing solely on the individual, this perspective emphasizes how multiple layers of an individual's environment—ranging from personal relationships to societal structures—affect their ability to be socially included. At its core, this approach is grounded in Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1994), which outlines how different environmental layers interact to influence human development. These layers include:

- *Microsystem*: This is the immediate environment surrounding the individual, such as family, friends, and close social networks. In terms of SI, it focuses on how meaningful relationships and daily interactions foster a sense of belonging and participation.
- Mesosystem: The mesosystem involves the interconnections between different elements of the microsystem, such as how family relationships intersect with professional or community involvement. A strong mesosystem enhances SI by creating cohesive support networks.
- *Ecosystem*: This refers to broader social structures that impact the individual indirectly, such as local government policies, community organizations, and the availability of resources. Access to inclusive services, public transportation, and education programs can greatly affect an individual's social participation.
- *Macrosystem*: The macrosystem encompasses the broader cultural, legal, and economic context. SI in this layer deals with overarching societal values, laws, and norms that shape attitudes toward diversity, disability, and inclusion. For example, civil rights legislation and national social policies play a critical role in fostering or hindering SI.
- *Chronosystem*: This dimension involves the element of time and how changes over time—whether in an individual's life or society—impact SI. Shifts in public policy, societal attitudes, or personal circumstances (e.g., aging, employment) influence the degree to which individuals are included in society.

An ecological approach highlights that achieving SI requires interventions and strategies at multiple levels. Effective inclusion efforts must address not only personal relationships but also systemic barriers—such as discriminatory policies, economic inequalities, and social stigma—that impact an individual's ability to participate fully in society. By adopting this broader perspective, policymakers, service providers, and communities can create environments that promote inclusive opportunities across all areas of life.

Building on this perspective, the Ecological SI Model proposed by Simplican et al. (2015) (Figure 1.5) emphasizes the need to consider multiple environmental layers—such as the individual,

interpersonal, organizational, community, and policy levels—in promoting SI for individuals with intellectual and neurodevelopmental disabilities.

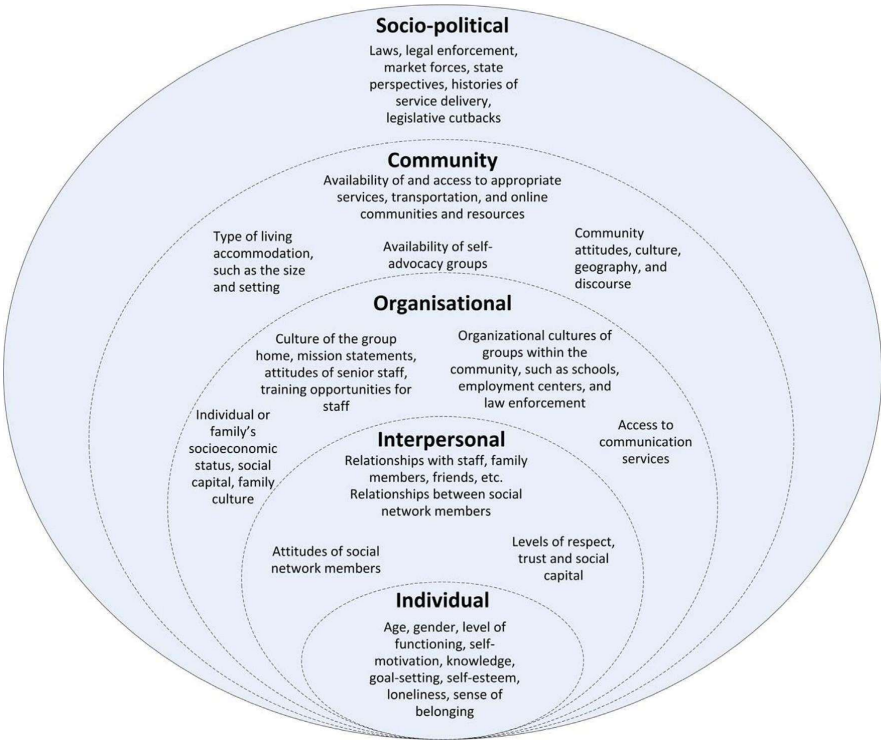


Figure 1.5: **Ecological Social Inclusion Model** (Adopted from Simplician et al. 2015).

An ecological approach to disability systems, policies, and intervention planning highlights the importance of addressing barriers at various levels of society to ensure meaningful participation. According to this model, successful SI is not solely dependent on individual abilities or motivation but is shaped by a range of factors, including family and peer support, the accessibility of community resources, the inclusivity of organizational practices, and broader societal attitudes and policies. By targeting these interconnected layers, the Ecological SI Model offers a comprehensive framework for fostering genuine inclusion in community life for individuals with ID. Ecological conditions can either facilitate or hinder SI, functioning as both enabling and disabling factors. Additionally, it is recognized that the outcomes of SI may vary, resulting in either positive or negative effects. While examples of these ecological conditions and their outcomes are not exhaustive, they suggest potential areas for future research using an ecological approach to SI. This framework can be further understood through the following dimensions:

- *Individual*. Individual enabling and disabling conditions encompass various personal factors that influence SI for individuals with ID. Key variables include a person's level of functioning, self-motivation, confidence, and familiarity with relevant activities and environments, as well as the effective use of goal-setting strategies (Abbott & McConkey, 2006; McConkey & Collins, 2010). Positive individual outcomes of SI often manifest as increased happiness, enhanced self-esteem, and a profound sense of belonging within a community (Cobigo et al., 2012). However, it is crucial to recognize that SI can also lead to adverse outcomes, such as heightened feelings of loneliness and disconnection, particularly if individuals find themselves in settings where they feel marginalized or unsupported. For example, a person may engage in community activities but still experience isolation if meaningful connections do not develop.
- *Interpersonal.* Interpersonal enabling and disabling conditions pertain to the nature of relationships individuals maintain with staff, family members, and peers. Positive relationships with staff can foster an inclusive atmosphere, while negative staff attitudes can severely hinder participation (Hermsen et al., 2014; McConkey & Collins, 2010). Family attitudes also play a critical role in shaping the social experiences of individuals with ID; supportive families can empower individuals to engage more fully in community life (Clement & Bigby, 2009). Furthermore, the dynamics between families and staff, as well as interactions among families, significantly affect SI. Positive interpersonal outcomes may manifest as increased trust and respect among peers, resulting in enhanced social capital. Conversely, negative experiences, such as discrimination in employment or abuse from intimate partners or caregivers, can diminish self-esteem and social capital (Hall & Wilton, 2011; Ward, Bosek, & Trimble, 2010; Beadle-Brown et al., 2010). Thus, the interplay of these interpersonal conditions is vital to understanding the SI experience.
- *Organizational* conditions exist within both informal networks, such as family structures, and formal settings, including workplaces and group homes. For families, relevant organizational conditions encompass socioeconomic status, social capital, and family culture (Chenoweth & Stehlik, 2004). Within group homes, factors such as the organizational culture, mission statements, and the attitudes of management can greatly influence SI (Bigby et al., 2012; Dodevska & Vassos, 2013). Self-advocacy organizations can also vary in their group culture, impacting individuals' self-efficacy and self-determination (Walmsley & The Central England People First History Project Team, 2014). Changes in organizational culture can lead to more affirming practices, whereas hostile or ambivalent environments can undermine enabling conditions at both the individual and interpersonal levels. Thus, the interconnectedness of organizational conditions with other levels is crucial for fostering SI.
- *Community-level* conditions encompass factors such as the type of living arrangements, availability of services, and community attitudes towards individuals with disabilities.

The characteristics of living accommodations—such as size, setting, and access to transportation—play a significant role in SI (Duvdevaney & Arar, 2004; McConkey & Collins, 2010). Moreover, community attitudes, culture, and geography can significantly influence how individuals with ID are perceived and treated. Research indicates that contact with people with disabilities can foster more positive attitudes within the community (Sharma et al., 2006), but the quality of that contact is essential; negative interactions can reinforce stereotypes. Further investigation is needed to understand the nuanced effects of SI on public attitudes and the broader community conditions that contribute to inclusive environments (Amado et al., 2013).

- *Political* conditions involve the influence of laws, legal enforcement, market dynamics, and historical perspectives on service delivery (Quinn & Doyle, 2012; Vanhala, 2015). While little research has focused on how SI affects political change, it is often observed that political mobilization—driven by groups including parents, professionals, and self-advocates—can lead to significant shifts in policy (Vanhala, 2015). The interplay between SI and political conditions is critical, as legislative decisions, such as budget cutbacks, can impose additional pressures on families and negatively impact organizational cultures and staff behaviors (Hermsen et al., 2014). Thus, understanding the broader political landscape is essential for creating conditions that support SI for individuals with ID.

Overall, the ecological approach and model of SI are crucial for understanding the multifaceted barriers and enablers that individuals with intellectual and developmental disabilities face, providing a comprehensive framework to promote meaningful participation and enhance their QoL across all environments. Building on this ecological understanding and the theoretical models previously discussed, the following paragraph proposes a theoretical framework aimed at assessing how these interconnected factors shape the LC of individuals with intellectual disabilities.

1.4 Theoretical Framework for Assessing the Living Conditions of Individuals with Intellectual Disability

The demand for a comprehensive framework and precise evaluation tools to evaluate the LC of individuals with ID has grown increasingly urgent, largely due to the complex array of factors that affect their QoL (Morán et al., 2023; Ijezie et al., 2023; Gómez et al., 2024). Research has demonstrated that the QoL experienced by individuals with ID is intricately influenced by multiple dimensions, including levels of SI, specific support needs, and the broader contextual or environmental factors that impact daily life. Together, these factors form the foundational elements necessary for understanding and improving the QoL for this population (Verdugo & Schalock, 2024; Brown et al., 2022). Therefore, an integrated approach is essential to comprehensively evaluate outcomes, inform evidence-based policies, and shape targeted interventions that address the unique needs of individuals with ID (Gómez Sánchez, Schalock & Verdugo Alonso, 2021).

To monitor outcomes effectively and to devise meaningful strategies for policy and intervention, it is necessary to construct a framework that includes key constructs related to QoL, personal functioning, support needs, and SI. Such an approach ensures that no single factor is examined in isolation, allowing for a more holistic understanding of how these factors interact to influence the lives of individuals with ID. For instance, support needs are not only about aiding with daily activities but also about promoting autonomy and personal growth through community and social engagement (Schalock, Luckasson, & Tassé, 2021; Luckasson & Schalock, 2020; Luckasson, Tassé, & Schalock, 2022).

Synthesizing these interconnected elements enables researchers and practitioners to gain a more comprehensive view of the multifaceted challenges faced by individuals with ID and their families. This perspective is supported by studies demonstrating that inclusive environments, which foster social integration and community participation, can significantly enhance QoL for individuals with ID (Stancliffe & Hall, 2023; Chandan, 2024). By facilitating greater access to social networks, community programs, and public spaces, inclusive environments promote a sense of belonging and purpose, leading to improvements in mental health, emotional well-being, and overall life satisfaction. This highlights the critical need for social settings that facilitate meaningful interactions and are accessible to people of varying abilities (Morán et al., 2023; Bredewold & van der Weele, 2023).

Moreover, a holistic perspective not only increases the accuracy and relevance of data collection but also informs the development of targeted interventions that address the specific needs of this population. By adopting a multifaceted framework, stakeholders can design interventions that consider various dimensions of well-being, such as physical health, emotional support, social relationships, and opportunities for personal development. This approach ensures that interventions are not only responsive to the immediate needs of individuals with ID but are also adaptable to their evolving needs over time (Gómez Sánchez, Schalock, & Verdugo Alonso, 2021; Verdugo & Schalock, 2024).

An essential component of this comprehensive approach is the integration of diverse theoretical models, such as the ecological model of disability, which offers a more inclusive understanding of the numerous factors that impact individuals with ID. This model recognizes that the experiences of individuals with ID are shaped by interactions between personal characteristics—such as their unique abilities, interests, and health—and external societal factors, including community support, social attitudes, and access to resources. By emphasizing these interactions, the ecological model of disability provides valuable insights into how the broader social and physical environments can either enable or restrict the participation of individuals with ID in everyday life (Simplican et al., 2015).

The findings of this overview underscore several essential principles that guide the development of a comprehensive framework for assessing the LC of individuals with ID. These key points provide a solid foundation for the construction of a framework for evaluating the LC of PwD.

- Integrated Framework: An integrated approach is essential to capture the complexity of factors influencing the QoL for individuals with ID. This includes SI, support needs, and environmental influences as interdependent dimensions.
- Holistic Understanding: Addressing QoL requires a comprehensive understanding of personal functioning, autonomy, and community engagement rather than isolating specific factors.
- Role of Inclusive Environments: Inclusive environments that foster meaningful participation, provide access to social networks, and facilitate community integration significantly enhance well-being and life satisfaction.
- Adaptable Interventions: Frameworks must allow for interventions that are both responsive to immediate needs and adaptable to the evolving circumstances of individuals with ID.
- Theoretical Models: The ecological model of disability provides a robust foundation for understanding the interactions between personal and societal factors, guiding more effective policy and intervention design.
- Reliable Tools: The development of reliable evaluation tools grounded in this framework is critical for accurately reflecting lived realities and generating actionable insights for improvements in policy and practice.
- Broader Vision: This framework and its applications aspire to contribute to an inclusive and equitable society where individuals with ID are empowered to lead fulfilling and independent lives.

Building on these theoretical foundations, the present study does not merely adopt existing models of quality of life, social inclusion, and support needs, but contributes to their development by integrating them into a unified analytical framework focused on living conditions. While established theories have traditionally addressed these constructs as related but distinct domains, this research advances the field by operationalizing their interaction within service contexts, highlighting how organizational arrangements, educational practices, and support structures concretely shape opportunities for participation, autonomy, and well-being. In this sense, the study extends ecological and quality of life models by translating them into an evaluative framework capable of capturing the dynamic relationship between individual functioning and service environments, thereby offering a pedagogically grounded perspective on social inclusion and quality of life for individuals with intellectual disability.

The goals of this research study are therefore twofold: first, to establish a well-founded framework that captures the multiple dimensions impacting the lives of individuals with ID; and second, to develop reliable and effective evaluation tools that support this framework. These tools will be instrumental in ongoing efforts to enhance QoL and support meaningful participation in society for individuals with ID. By grounding these tools in a multifaceted framework, practitioners can ensure that evaluations accurately reflect the lived realities of this population and generate actionable insights for improvements in policy and practice.

The subsequent chapters of this study will delve into the research methodology, objectives, and findings across each phase of the project. These sections will provide a detailed exploration of how each component—ranging from data collection and analysis to the development of evaluation

instruments—aligns with the overarching aim of improving LC and QoL for individuals with ID. This extended, comprehensive approach not only addresses immediate concerns related to QoL but also supports the broader vision of fostering a society that is inclusive, supportive, and responsive to the diverse needs of all individuals. By doing so, the study aspires to contribute to the creation of a society in which individuals with ID have equitable opportunities to live fulfilling, independent lives in supportive and inclusive communities.

2 METHODOLOGY FOR EVALUATING LIVING CONDITIONS OF PERSONS WITH INTELLECTUAL DISABILITY

In this chapter, the design and development process of the assessment tool aimed at evaluating the life conditions of individuals with ID are presented. This assessment tool (*Questionnaire for the evaluation of life conditions of PwD – Q-VAD*) is crafted to provide a comprehensive and nuanced understanding of their LC, extending beyond conventional measures to include various dimensions such as QoL, support needs, and opportunities for personal growth and SI.
The integration of these constructs reflects the theoretical framework introduced in Chapter 1, which emerged from a detailed analysis and synthesis of contemporary QoL models. This chapter also describes the methodology adopted for the tool's development, outlining the key phases of its design, validation, and theoretical alignment.

2.1 Strategy and Context of Research Environment

The research project was coordinated by the researcher of the study in his role as Director of Social-Health Services for PwD at the Central Directorate of Health, Social Policies, and Disability of the Friuli Venezia Giulia Region (IT), with the support of a group of six experts in the disability field. The student led the process of developing, implementing, and validating the assessment tool, engaging and training staff from the various services involved.
The research setting was chosen due to the student's professional role as Director, which enabled access to a broad network of services for individuals with ID. This context is particularly relevant considering the study's focus, outlined in Chapter 1, on enhancing QoL and SI among individuals with ID. The diversity in service types (Residential and Day Care Centers) aligns with the multidimensional framework discussed earlier, offering a representative sample in terms of adaptive functioning and clinical complexity. Moreover, this setting facilitated the direct application and validation of the tools developed within the theoretical model presented in Chapter 1.
The survey encompassed the entire system of services for adult disability within the Friuli Venezia Giulia Region. The Friuli Venezia Giulia region is located in the northeast of Italy, bordered by Austria to the north, Slovenia to the east, Veneto to the west, and the Adriatic Sea to the south. It has a population of approximately 1.2 million people, distributed across four main provinces: Trieste, Udine, Gorizia, and Pordenone. Friuli Venezia Giulia has adopted an integrated approach to support and services for people with disabilities. The region has developed various programs to promote SI for individuals with disabilities. These initiatives include school integration programs, vocational training, and employment support activities designed to foster economic independence and community integration.
For adults with ID who do not qualify for employment support programs and are unable to live fully independently, the region offers residential services and day care centers. These facilities are

designed to provide continuous assistance, enabling people with disabilities to live in a safe and inclusive environment.

These services are coordinated and managed by various administrative bodies established on behalf of the municipalities, following legal provisions. These provisions allow for different management structures: individual municipalities, consortia of municipalities, or delegation of functions to the Health Authority. Over time, the choice of institutional arrangements has led to diverse forms of management and local organization across different territories, contributing to a complex landscape for planning and governance.

Despite this heterogeneity in management, the regional system of services exhibits a degree of homogeneity, primarily characterized by the following types of service units:

- Semi-Residential Services (Day care centers): These are commonly referred to as "socio-educational centers for the disabled." They provide daytime care (typically from 8:30/9:00 AM to 3:30/4:00 PM) for approximately 220 days a year.
- Residential Services: This category includes various types of housing services, organized into protected residential settings.

2.1.1 Q-VAD Development Process

Q-VAD was designed and created to establish a validated tool that could be used regionally by educators, social workers, healthcare professionals, and, where feasible, by individuals with disabilities themselves. The aim was to systematically explore areas of study that, according to current scientific literature, are essential for analyzing and designing interventions to improve the most significant aspects of a person's LC.

The first step taken by the working group was to review and analyze the scientific literature on disability. Recent advancements have underscored the importance of integrating the constructs of Functioning and Support (Luckasson et al., 2012; Schalock et al., 2021) and QoL (Renwick & Brown, 1996; Schalock & Verdugo-Alonso, 2002) as foundational frameworks for designing service systems and interventions. These models demonstrate that understanding people's outcomes, developmental trajectories, and LC requires considering both individual factors (such as clinical, functional, and health conditions) and contextual factors (including the characteristics of environments, Opportunities, and available supports). Additionally, it is crucial to integrate these with subjective dimensions, particularly the satisfaction individuals feel with their lives.

Given the objectives outlined, the assessment tool was developed with the following key features:

- Rooted in Established Scientific Models: The tool is based on leading scientific models and constructs designed to accurately represent and describe operating conditions and needs.
- Comprehensive in Scope: It addresses a broad range of personal, social, and family dimensions, QoL, and the overall existential condition of the individual. This approach avoids a narrow focus on limitations in functioning (Buntinx & Schalock, 2010; Bertelli, Bianco, Piva, Merli, & Salvador-Carulla, 2015).

- Detailed Evaluation of Health Conditions: it delves into specific aspects of physical and psychological health, including problem behaviors (Emerson et al., 2016; Coli, Scuticchio & Bertelli, 2017; Bertelli, Cooper & Salvador-Carulla, 2018).
- Contextual Information Collection: It gathers and analyzes information about the life context, particularly focusing on the opportunities provided by various services.
- Support Intensity Description: It describes the intensity of existing supports, serving as a foundation for personalized support planning and the adoption of flexible financing models (Slasberg, Beresford & Schofield, 2012).
- Modular Design: The instrument features a modular structure, facilitating completion by professionals with the appropriate expertise and knowledge of the individual.
- Focused on Synthesis: It is designed to identify predictive indicators of certain operating conditions while allowing for detailed analysis and further insights using existing tools in the literature.
- Operational Language: Q-VAD uses clear, operationalized language to minimize ambiguity and reduce learning time for operators.
- First-Person Formulation: It is largely formulated in the first person to enable, where possible, self-completion by individuals with disabilities.
- Data Compatibility: It produces data that is comparable and aggregable, aiding in the analysis, planning, and orientation of programming systems, policies, services, and related financing.
- Open Access: It is freely available, avoiding the use of instruments covered by copyright or registered trademarks.

Q-VAD (provided in Appendix 1) is organized into the following sections, as summarized in Table 2.1:

- *Section 1: Socio-Personal Data and General Information* - This section collects both traditional data (e.g., personal, certifying, and social information, as well as aids) and additional indicators reflecting the individual's LC. It includes information on "the use of tools and technologies" and "leisure activities," offering a comprehensive view of the person's environment and daily life.
- *Section 2: Support Needs for Individual Functioning* - This section includes 19 items designed to assess the adaptive strategies and associated supports necessary for key areas of daily living. It evaluates the most representative option reflecting the individual's functional condition. The scale is influenced by general evaluation tools such as the HoNOS-LD: "Health of the Nation Outcome Scales for People with Learning Disabilities" (Wing et al. 1998), with added specific subscales for identifying residual skills in individuals with more significant impairments (Tesio et al. 2002).
- *Section 3: QoL* - This section assesses essential indicators of QoL domains, as detailed by Renwick & Brown (1996) and Schalock & Verdugo Alonso (2002). Respondents rate their perceived satisfaction on a Likert scale from 1 to 5 for each of the 21 items, covering

physical, material, and emotional well-being, interpersonal relationships, SI, personal development, and self-determination.

- *Section 4: Opportunities* - This section focuses on the opportunities and supports available in various life contexts for performing daily activities. It features 14 items derived from the operational model and the concept of support needs (Luckasson et al., 2002). Each opportunity is rated on a Likert scale from 1 to 5 based on its frequency of availability, with records of the actual, partial, or non-use of each opportunity by the individual.
- *Section 5: Behavioral Disorders* - This section examines behavioral problems that, according to the literature, have high incidence rates among individuals with ID. It consists of 9 items where respondents indicate the most representative option concerning the frequency and intensity of these problems.
- *Section 6: Health* - Dedicated to the health condition and necessary interventions for individuals with disabilities, this section applies the Cumulative Illness Rating Scale (*CIRS*) (Conwell et al. 1993) to evaluate health status and related interventions.

Table 2.1

Summary of Sections of Q-VAD (created by researcher).

Q-VAD	**Item number**
1. Socio-Personal Data and General Information	32 items
2. Support Needs for Individual Functioning	17 items
3. QoL	20 items
4. Opportunities	14 items
5. Behavioural disorders	9 items
6. Health	23 items
TOTAL	**105 items**

Sections 2, 3, and 4 were developed as potential measurement scales, for which a specific psychometric study has been conducted and is detailed below. Q-VAD comprises a total of 92 items. When fully operational, it typically requires about 1 hour to complete. As previously noted, it is designed to be administered by one or more professionals who have been involved with the individual for at least 6 months, and, where feasible, partially completed by the individual with disabilities themselves. It is important to note that the health section is solely the responsibility of healthcare professionals who possess the relevant clinical documentation.
The survey involved all the regional territories, covering a total of 108 day care services and 58 residential services. Table 2.2 shows the gender distribution of the 1,688 subjects assessed in the survey. Males are the majority, representing 54.6% of the sample, compared to 45.4% females.

Table 2.2

Participants Involved in the Study (created by researcher).

Gender	N	%
Females	766	45,4
Males	922	54,6
Total	1688	100,0

Table 2.2 reports the age distribution of the surveyed population, which ranges from 11 to 74 years. Daycare services typically serve a younger population, with an average age of 39.9 years and 47.3% of individuals under 40. In contrast, residential services cater to an older population, with an average age of 46.4 years and only 25.2% of individuals under 40.

Table 2.3

Participants Distribution by Residential, Day Care Services, and by Age Group

(created by the researcher).

	N	%	Residential %	Day Care %
Up to 19 years	49	2,9	3,5	2,5
20-24 years	129	7,6	5,0	9,2
25-29 years	164	9,7	4,7	12,6
30-34 years	150	8,9	5,0	11,1
35-39 years	169	10,0	6,9	11,8
40-44 years	223	13,2	10,3	14,9
45-49 years	239	14,2	16,0	13,1
50-54 years	251	14,9	19,4	12,3
55-59 years	193	11,4	15,8	8,9
Over 60 years	121	7,2	13,4	3,6
Total	1688	100,0	100,0	100,0

Although the research was designed to have minimal impact on participants, corresponding in many cases to activities ordinarily conducted within the services during evaluation and intervention planning phases, informed consent was still obtained from all participants. A specific procedure was implemented for minors, and all ethical aspects were reviewed and approved by the Ethics Committee of the Central Health Directorate of the Friuli Venezia Giulia Region. Participation was voluntary, and data were collected anonymously and processed exclusively in aggregated form, in accordance with ethical principles for research involving persons with intellectual disability and with reference to the Convention on the Rights of Persons with Disabilities (United Nations, 2006). Given the characteristics of the target population, consent was obtained through legal representatives when required, while attention was paid to involving individuals with intellectual disability in an accessible and respectful manner, consistent with a person-centred pedagogical approach. The Q-VAD was completed by trained professionals within residential and day care services, acting as mediators between the assessment tool and the participants' living contexts.

Fifty-one percent of users have managed residential and semi-residential services for at least 10 years, 23% have been in charge for at least 20 years, and 11% have managed the services for at least 30 years. In contrast, approximately 23% of the surveyed users have held their management roles for less than 5 years. The average duration of management across all users is 14.3 years (Table 2.3).

Table 2.4

Population of Residential and Semi-Residential Services of the Participants by Classes of Duration of their Program (created by the researcher).

Years of case management	**% of clients**
less than 1 year	4
from 1 to 5 years	19
from 5 to 10 years	19
from 10 to 20 years	28
from 20 to 30 years	12
over 30 years	11
ND	5
Total	100,0

2.1.2 Psychometric Validation of Q-VAD

The implementation of Q-VAD involved several critical steps to ensure its effectiveness and reliability. This process was carefully structured to address the unique needs of the target population and to guarantee comprehensive and accurate data collection. Below, the key phases of the implementation are outlined:

The first phase focused on gathering detailed personal data for all individuals within the semi-residential and residential services network in the Friuli Venezia Giulia (FVG) region. A comprehensive reference database was developed, ensuring that all individuals in the target population were accurately identified and included. This database provided a solid and reliable foundation for the survey.

The Q-VAD detection modules were seamlessly integrated into a dedicated web application. This system included advanced error prevention mechanisms to minimize data entry mistakes. Additionally, the application required the mandatory completion of all forms, ensuring that no data was omitted. These features significantly enhanced the quality and completeness of the collected data.

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Service operators tasked with administering the assessment tool participated in an extensive training program conducted by the regional technical team. This program comprised eight modules, each lasting four hours, for a total of 32 hours. The training covered key areas, such as the objectives of the research project, theoretical and methodological foundations, and practical guidelines for administering Q-VAD. Approximately 250 operators from public services and third- sector organizations completed the training, ensuring standardized and efficient application of the tool across the region.

To further ensure the efficiency of the data collection process, the responsibility for administering the tool was assigned to the heads of each service unit. These individuals were tasked with overseeing the timely and accurate completion of the questionnaires, ensuring that they were finalized within a period of 60 days from the activation date of the research.

Additionally, to protect the privacy of participants, all questionnaires were anonymized through the use of specific alphanumeric codes. This approach ensured that individual responses could not be directly linked to personal identities, adhering to strict confidentiality and data protection standards.

To ensure a smooth survey process, a two-tier helpdesk system was established. The first level of support addressed general queries related to the content and interpretation of the assessment tool items. For more complex issues and specific instrument applications, a second-level support system was staffed by the regional technical team. This structure provided prompt and effective assistance, minimizing potential disruptions during the survey period. To ensure a smooth survey process, a two-tier helpdesk system was established. The first level of support addressed general queries related to the content and interpretation of the tool items. For more complex issues and specific instrument applications, a second-level support system was staffed by the regional technical team. This structure provided prompt and effective assistance, minimizing potential disruptions during the survey period.

The acquisition of comprehensive socio-personal and health information was subjected to rigorous review, following a random sampling plan that covered 10% of the total questionnaires submitted. The control systems embedded in the computer application, along with the help desk activities,

ensured that this segment of data was complete and free from distortions due to misinterpretation of the questions.

In contrast, the evaluation of the reliability of items related to Supports, QoL, and Opportunities involved detailed psychometric analyses. These analyses aimed to develop summative and factorial indicators and enhance the discriminative power of the measurement items.

The psychometric properties of the scales were assessed through exploratory factor analysis (EFA), reliability testing, and validity analysis, following established guidelines for scale development (Hinkin, 1998; Furr & Bacharach, 2013) and specific protocols for exploratory factor analysis (Fabrigar et al. 1999; Costello & Osborne, 2005). EFA was selected because the items in the Q-VAD batteries were initially derived from factors and sub-factors identified in empirical studies (Williams, Onsman, & Brown, 2010). To identify theoretically relevant factors, a common factor model using principal axis factoring (PAF) was employed (Costello & Osborne, 2005). An oblique rotation (direct oblimin) was applied, anticipating significant correlations between factors (Fabrigar et al., 1999). Model adequacy was evaluated through inter-item correlation inspection, applying a criterion of $r > .3$ for inclusion, and by utilizing the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and Bartlett's Test of Sphericity (BTS) (Tabachnick & Fidell, 2013). The Kaiser criterion (eigenvalues > 1) was used to determine the number of factors to retain, and the relevance of the factors was assessed by examining factor loadings, with a preference for values > 0.6 (Field, 2013). A qualitative judgment was also applied to evaluate the adequacy of the factor structure. For item evaluation, the factor loading matrix was analyzed, including items with loadings > .3 on a single factor and minimal cross-loadings (> .3) on other factors (Tabachnick Fidell, 2013). Items with cross-loadings were accepted if their loading on the primary factor was at least 0.4 and twice as high as on any secondary factors. Internal consistency (i.e., reliability) of the items assigned to each factor was measured using Cronbach's alpha, with .7 considered the minimum acceptable level. Factor relationships were explored by correlating indices based on the mean of all factors.

Additionally, RA (da Rocha et al. 2013) was conducted using Winsteps v. 4 software to refine the linguistic formulation of items and enhance their ordinal scalability. The results of the factor analyses for each individual section are presented below.

- *Section 2- Support Needs for Individual Functioning*. Out of the 17 items analyzed, item 17 was excluded due to its item-to-total correlation falling below the predefined acceptance threshold. The results of the factor analysis are detailed in Table 2.5.

Table 2.5

Criteria and Factors for the Item Battery on the Intensity of Supports, Mean, Standard Deviation, Cronbach Alpha, and Factorial Indicators (created by the researcher).

Factors and items of the sub-scales	**Mean**	**DS**	**Alpha Cronbach**	**F1**	**F2**
Support for relationships	*16,15*	*7,891*	*.939*		
1. Recognize the living environments, places, and paths to reach spaces, objects, activities, and people of interest	2,57	1,294			,648
2. Can you predict your day's commitments and activities	2,02	1,412			,691
3. When you need to perform an important task/activity of your day	2,02	1,343			,671
4. When people turn to you...	2,95	1,161			,980
5. When you speak...	2,03	1,393			,695
6. When you need or desire to express something...	2,35	1,240			,896
7. When you find yourself interacting with other people ...	2,21	1,362			,843
Supports for ADL and IADL	*16,41*	*10,697*	*.955*		
8. You can move around your living environment	2,64	1,392		,600	
9. When you need to wash...	1,83	1,452		,879	
10. You can get dressed and undressed	2,25	1,524		,820	
11. When you need to eat...	2,71	1,361		,539	
12. When you need to go to the bathroom...	2,40	1,497		,731	
13. When you prepare your own meals...	,78	1,134		,846	
14. To keep your living spaces tidy and clean...	1,19	1,308		,902	
15. When you move to your country city...	1,39	1,445		,888	
16. When you need to make purchases...	1,22	1,324		,697	

The factor analysis reveals two well-defined factors. The first factor is predominantly associated with support for communication and relationships, while the second factor groups items that are specifically categorized in the literature as activities of daily living (ADLs) and instrumental activities of daily living (IADLs). No cross-loadings were identified, and all factor loadings exceed the minimum threshold of .3, with the lowest value being .539. The Cronbach's alpha for the two subscales is .939 for the first factor and .955 for the second, indicating excellent internal consistency. As anticipated, the two factors are strongly correlated (r = .749). Additionally, the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy is .960, and Bartlett's test of sphericity is significant (p < .0001), confirming the adequacy of the factor model.

- *Section 3 - QoL.* The QoL subscale initially comprised 21 items. Item 3, "You happen to have physical pain," was removed due to its item-total correlation falling below the established acceptance threshold in the reliability analysis. Additionally, three other items were excluded from the factor analysis due to their complex interaction with the factorial structures and their contribution to interpretative challenges. The excluded items are: *"Are you are satisfied with the spaces reserved for you to stay alone (when needed) and/or to protect your privacy?"; "Are your living environments are adapted to your needs and preferences?"; and "Meet the services, opportunities, or recreational places in your neighborhood/territory meet your needs, interests, and desires?"*

  Semantically, these items did not align well with the final two factors, as they overlapped with the evaluated life dimensions and presented broad interpretative margins. Furthermore, from a syntactic perspective, these items were more complex. The results of the final analysis are detailed in Table 2.6.

Table 2.6

Criteria and Factors for the Item Battery on the QoL, Mean, Standard Deviation, Cronbach Alpha and Factorial Indicators. (created by the researcher).

Factors and items of the sub-scales	Mean	DS	Alpha Cronbach	F1	F2
Physical and relational well-being	19,99	6,043	.881		
1. You feel energetic and vital	2,21	1,038		,566	
2. Do you rest and relax properly?	2,42	1,058		,616	
4. Do you feel comfortable in the places where you live?	2,70	0,949		,846	
5. Are there things (people, activities, events) that make you happy?	2,88	0,929		,701	
6. Are you satisfied with the things you do and how you spend time in your day?	2,35	0,974		,775	
7. Are you satisfied with the personal belongings and/or possessions you own and how you can dispose of them?	2,40	1,086		,661	
8. Are your living environments adapted to your needs, requirements and preferences?	2,61	0,974		,610	
9. Do you feel satisfied with the relationship you have with your family?	2,42	1,157		,642	
Self-realization and self-determination	12,85	7,914	.888		
10. Are you gratified by the activities you can carry out together with other people in the neighborhood/territory?	1,21	1,218			,547
11. Do you have close friends with whom you can maintain constant relationships	0,9	1,172			,560

(excluding family members, staff and volunteers of the facilities)?					
12. Do you have the opportunity to carry out activities that are rewarding for you together with other people?	1,8	1,26			,588
13. Do you have the opportunity to put into practice what you know how to do in your life?	1,29	1,295			,753
14. Have you learned any new skills and/or knowledge?	1,02	1,193			,730
15. Have you had access to new roles and/or Opportunities?	0,53	1,011			,649
16. Do you have the opportunity to express to someone your preferences, do you wish?	2,38	1,269			,558
17. Do you have the opportunity to make choices about your activities during your day?	2,12	1,227			,660
18. Do you have the opportunity to decide who to be with, who to meet who to attend, with whom to carry out certain activities?	1,6	1,234			,705

The two factors appear to be well identified. The first factor seems to best represent the aspects related to the expression of a general, physical and relational well-being. The second groups the items that probe the sense of self-determination and self-realization of the person. No items with cross loadings emerge and all factorial weights exceed the value of .3 (minimum value .547). The Cronbach Alpha for the two sub-scales is .881 for the first factor and .888 for the second, respectively. As expected, the two factors are moderately correlated (.516). Finally, theKMO sample adequacy test (Keiser Meyer Olkin) is .925 and the Bartlett sphericity test is significant <.0001. Table 2.7 shows the correlations between the 6 new variables calculated through factor scores.

Table 2.7

Pearson Correlation Matrix Between the Six Variables Obtained Through the Calculation of Factor Scores for the Batteries of Items Related to Opportunities, Quality of Life, and Intensity of Supports (created by the researcher).

	Opportu-nity-Doing	**Opportunity-Learning**	**Physical and relational well-being**	**Self-determination**	**Supports for ADL and IADL**	**Support for Communication and Relations**
Opportunities-Doing	1					
Opportunities-Learning	,601**	1				
Physical and relational well-being	,457**	,301**	1			
Self-determination	,690**	,571**	,585**			
Supports for ADL and IADL	-,556**	-,483**	-,345**	-,624**	1	
Support for Communication and Relationships	-,562**	-,410**	-,443**	-,628**	,788**	1

**. The correlation is significant at the 0.01 (2-code) level.

All sub-scales exhibit significant correlations, consistent with theoretical expectations and the significance attributed to the different factors. For instance, opportunities for engagement and learning have a notably high and significant impact on the dimension of self-realization and self-determination within the QoL scale. Conversely, a high need for support negatively impacts opportunities and has a particularly pronounced effect on self-realization and self- determination. Additionally, the two factors derived from the Support to Operation scale are strongly positively correlated with each other.

- *Section 4 – Opportunities.* The Opportunities subscale comprises 14 items. Items 11 and 12, which pertain to job placement opportunities, were removed from the analysis due to their item-total correlations falling below the established acceptance threshold in the reliability analysis. The results of the factor analysis for the remaining items are presented in Table 2.8.

Table 2.8

Criteria and Factors for the Item Battery On Opportunities, Mean, Standard Deviation, Cronbach Alpha, and Factor Weights (created by the researcher).

Factors and items of the sub-scales	**Mean**	**DS**	**Alpha di Cronbach**	**F1**	**F2**
Opportunities to do	*20,34*	*9,51*	*.888*		
1. Have you carried out/received support for your personal care activities?	3,13	1,384		,620	
2. Have you carried out/received support for the care of living environments?	2,48	1,628		,606	
3. Have you used appliances and technologies?	1,82	1,723		,487	
4. Have you had/received opportunities to move around the territory?	2,66	1,384		,826	
5. Have you had/received opportunities to use community services?	2,16	1,338		,812	
6. Have you had/received opportunities to participate in significant community activities?	1,68	1,208		,622	
7. Have you had/received opportunities to be engaged in roles, tasks and activities that are useful to the people you live with, who live close to or frequent?	1,81	1,610		,509	

8. Have you had/received opportunities to socialize/meet the people who are important to you?	2,37	1,436		,738	
9. Have you had/received opportunities to participate in recreational and/or socializing activities that are meaningful to you?	2,23	1,310		,750	
Opportunities to learn	*2,99*	*3,48*	*.817*		
10. Have you had/received opportunities to learn skills for the autonomous management of your person?	1,21	1,475			,744
11. Have you had/received opportunities to learn cognitive, scholastic, technological skills?	,98	1,347			,753
12. Have you had/received opportunities to learn skills for external autonomy?	,80	1,237			,793

The factor analysis reveals two relatively well-defined factors. No cross-loadings are observed, and all factor loadings exceed the minimum threshold of .3, with the lowest value being .487. The first factor is primarily associated with opportunities for engagement (opportunities to do), while the second factor groups items specifically related to opportunities for new learning (opportunities to learn). The Cronbach's alpha for the two sub-scales is .888 for the first factor and .817 for the second, indicating robust internal consistency. As anticipated, the two factors are significantly correlated ($r = .55$). The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy is .876, and Bartlett's test of sphericity is significant ($p < .0001$).

Furthermore, to examine latent variables within the items of the analyzed assessment tool, the RA, a component of Item Response Theory, is employed. We illustrate the utility of RA by applying it to the Section on Support for Functioning, which aligns well with the characteristics of this psychometric approach. RA's model is predicated on two probabilistic rankings:

- Item Difficulty: The challenge level of each item within the measurement instrument.

- Subject Abilities: The skill levels of the individuals being evaluated.

By evaluating these rankings, RA calculates a series of indicators that help assess the quality of both the collected data and the measurement tool. Specifically, this method enables the extraction of a minimal set of items that provides a highly reliable indicator for measuring the latent variable under investigation. Additionally, RA facilitates a thorough analysis of data quality and permits revisions and improvements to the item structure. A key feature of RA is its ability to adapt responses based on the intrinsic meaning of answers, rather than assuming equal distances between response options. For the type of items analyzed, we utilized RA with multilevel variables using the Partial Credit Model (Masters, 1982). This approach allows for individual weighting of each response option for every item. Table 2.9 presents the items ordered by increasing difficulty, along with the corresponding scores identified by the model.

Table 2.9

Criteria of Supports in the Area of ADL and IADL Subjected to Rasch Analysis: Sorted by Difficulty Gradient and Outfit Indicators (created by the researcher).

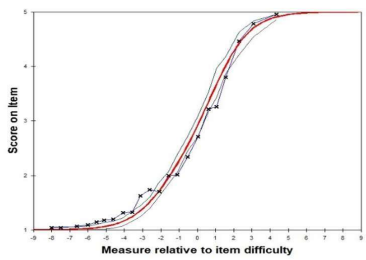
	Score	**Outfit**	**Zstd**
When you need to eat ...	-2,24	1,07	0,90
You can move around your environment of life	-2,04	1,50	5,90
When you need to go to the bathroom ...	-1,41	0,81	-3,40
You can get dressed and undressed	-1,02	,063	-8,10
When you need to wash ...	0,03	0,68	-7,30
When you move to your country city ...	1,04	1,11	1,70
When you have to make purchases ...	1,45	1,74	8,10
When you prepare your meals ...	1,54	0,78	-2,90
To keep your living spaces tidy and clean ...	2,70	1,05	0,50

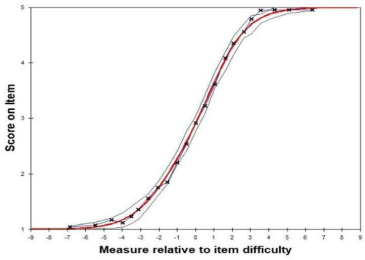
To identify a minimal set of items that reliably measures the latent variable defined by the Supports for ADL and IADL factor, we analyzed the data presented in Table 2.9. Initial analysis revealed that some items (highlighted in pairs) were redundant, contributing duplicative to the overall measure score (from the perspective of Rasch analysis, this is akin to counting the same response multiple times). To refine the indicator and avoid redundancy, as well as floor and ceiling effects, we employed an iterative "trial and error" approach guided by Rasch analysis suggestions.

We prioritized retaining items with ZSTD (Standardized Fit Statistic) values closest to zero, as these items better support the null hypothesis (H0). Upon removing an item, we re-evaluated the distribution and score variations to determine if the removal was justified. Based on these evaluations, the most significant items for constructing a reliable indicator were:

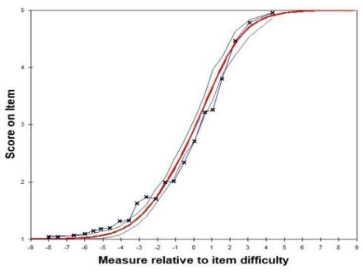
When you need to eat...When you need to go to the bathroom...When you need to wash...When you prepare your meals...; To keep your living spaces tidy and clean...

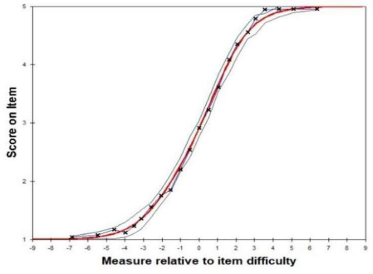
Below, a graphical representation of the response deviations relative to the Rasch model is provided. The deviations are considered satisfactory, particularly given the sample size of 1688 cases and the diverse pool of several hundred operators involved in the survey.

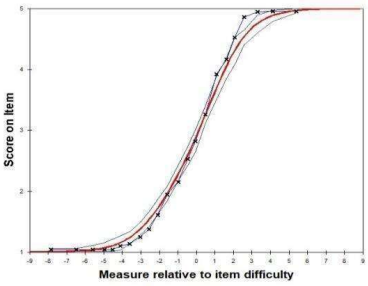


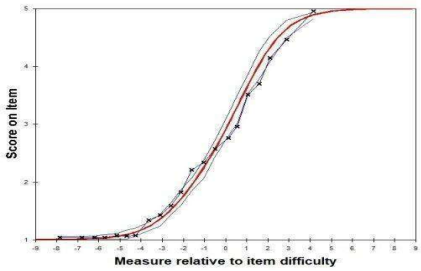


Can you move around living environments when you need to wash ...

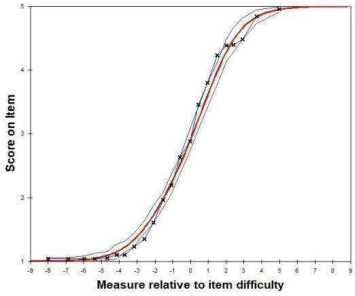




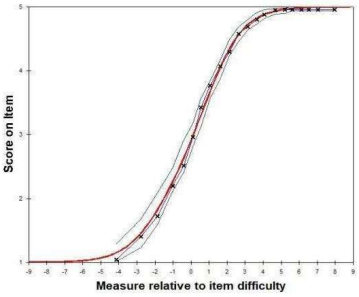




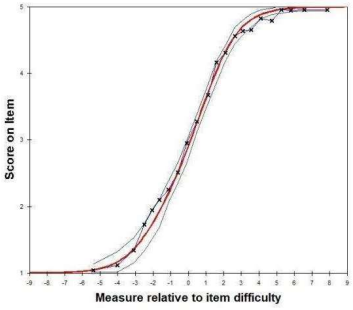
To keep your living spaces tidy and clean, when you move to your country city…



When you need to go to the bathroom ...



When you prepare your meals ...



When you have to make purchases ...

The classification of cases according to the extent of deviation from the theoretical model is particularly noteworthy. Tables 2.10 and 2.13 provide a detailed account of the most significant deviations observed. This analysis is crucial for addressing any ambiguities or issues in the Q-VAD responses, establishing a hierarchy of response quality across different services, and guiding

training and informational efforts aimed at enhancing the survey's quality and refining the items. Table 2.10 displays the 10 cases with the most pronounced deviations from the expected values, highlighting instances where observed responses significantly diverge from theoretical expectations. This information is instrumental for targeted interventions to improve the accuracy and reliability of the survey data.

Table 2.10

List of the 10 Subjects with Observed Scores More Divergent from those predicted by the Rasch Model (created by the researcher).

Subject n.	Score	E.S. model	Outfig Msnq	Oufit Zstd
4	3,42	,60	9,90	5,7
9	3,42	,60	9,90	5,7
94	5,13	1,05	9,90	5,5
109	1,07	0,46	9,90	7,7
433	1,98	0,49	9,90	6,8
1553	5,13	1,05	9,90	3,1
25	3,42	,60	8,29	2,9
1364	2,49	,52	8,18	4,0
201	-4,57	,84	8,14	2,6
531	-4,57	,84	8,14	2,6

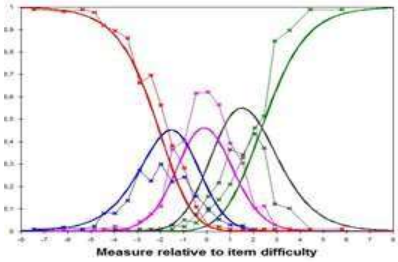
Table 2.11 shows the answers that have obtained values that most deviate from the expected.

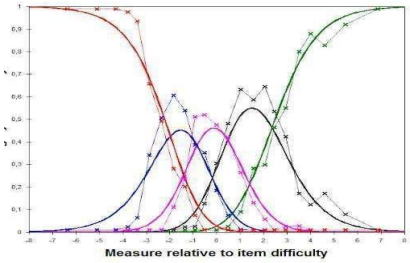
Table 2.11

List of the 10 Individual Response Scores that most Diverged from those Predicted by the Rasch model (created by the researcher).

Item	Observed value	Expected value	Residue	Standardized residue	Subject n.
6	4	5	-1	-18,58	94
9	1	4,95	-3,95	-17,11	9
9	1	4,95	-3,95	-17,11	4
6	1	4,84	-3,84	-9,96	109
9	4	4,99	-0,99	-9,92	1553
9	1	4,78	-3,78	-9,5	433
9	3	4,95	-1,95	-8,44	25
1	2	1,01	0,99	8,34	531
1	2	1,01	0,99	8,34	201
9	2	4,87	-2,87	-8,06	1364

Finally, two examples illustrate items for which a more precise formulation of the response options was deemed necessary.





Considering the item, "When you move to your country city...". The continuous lines in the graph represent the theoretical distribution of responses (encoding A: Green, B: Black, C: Pink, D: Blue, E: Red), while the "X" markers connected by straight lines depict the actual distribution of responses. Ideally, each response should be identifiable, which requires the absence of overlapping "peaks" in the graphical representation. In this example, responses B and D are not distinguished, as they overlap with responses A and E. This graphical evidence indicates a "lack of clarity in distinguishing between responses," suggesting that respondents find it difficult to differentiate among the options. Table 2.12 provides a comparison between the original version of the item and the revisions made following the Rasch analysis.

Table 2.12

List of Comparison between the Original Version of Item and the Revisions Made (created by the researcher).

Original version	**Modified version**
a) I move alone and independently	a) I move alone and independently
b) I reach the places of interest with some indication before leaving, or occasional supervision	b) I reach the places of interest with some indication before leaving
c) I reach different places, but I need constant supervision and directions as I move	c) I reach different places, but I need constant supervision and directions
d) I reach some places, but I have to be guided Physically, most of the time	d) I reach some places, but I have to be physically guided
e) are unable to reach any place	e) are unable to reach any place

The graph related to the item "When you need to wash ..." has a distribution that is free of overlap between the different answers. The potential of AR in the verification of any need for reformulation of the semantics of items is therefore evident.

Q-VAD was designed to incorporate a wide array of indicators that cover aspects of functioning, context, health status, and personal perceptions, to support population-level surveys of individuals with disabilities straightforwardly and reliably. It was implemented following a brief training period for staff, and its proper use was maintained with the support of remote assistance during the data collection process. This ensured that the tool was applied consistently and effectively across the participating services.

A high level of engagement was observed from the service coordinators involved in the data collection process. While formal feedback on their participation was not systematically gathered, their active involvement played a crucial role in ensuring that the survey data was completed on time and with the required level of accuracy. The entire process was carried out over a two-month period, which was sufficient to ensure comprehensive data collection across all services involved, both day and residential.

The Q-VAD assessment tool has demonstrated robust psychometric properties, particularly regarding its scales addressing Functioning Support, Opportunities, and QoL. The psychometric evaluation, utilizing methods such as exploratory factor analysis and Rasch modeling, has provided essential insights into the item selection process, ensuring that the items chosen most accurately represent the targeted dimensions of the tool. These analyses have also been instrumental in refining the semantic clarity of the assessment tool's components, thereby enhancing its overall precision and applicability. The ongoing repetition of the survey is expected to facilitate confirmatory analyses, offering a more detailed evaluation of any changes introduced into the instrument and further validating its use across various contexts.

The results of the psychometric analyses underscore the Q-VAD's reliability and suitability as a tool for evaluating key areas of support and service delivery. Furthermore, the practical implementation of the tool confirmed its validity in real-world conditions. The integration of Q- VAD data not only provided valuable insights into environmental factors (LC and assistance) affecting SI but also established a replicable framework for continuous improvement in service delivery. By ensuring a structured and data-driven approach, the methodology enables service providers to refine their interventions and adapt support strategies to better meet the evolving needs of individuals with disabilities. Specifically:

- Supports of individual functioning: This subscale identifies two distinct but interrelated factors—support for communication and relationships, and support for activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Both factors exhibit excellent internal consistency, with Cronbach's alpha values of .939 and .955, respectively, and significant correlation ($r = .749$). The Kaiser-Meyer-Olkin (KMO) value of .960 and significant Bartlett's test ($p < .0001$) confirm the adequacy of the factor model.

- Opportunities: Two strongly correlated factors are evident—opportunities for engagement ("to do") and learning opportunities. Both demonstrate robust reliability (Cronbach's alpha of .888 and .817) and effectively capture meaningful personal development and social engagement dimensions. The KMO value of .876 and significant Bartlett's test ($p < .0001$) further affirm the adequacy of this subscale.
- QoL: This subscale is structured around two well-defined factors—physical and relational well-being, and self-realization and self-determination. These factors exhibit strong reliability (Cronbach's alpha values of .881 and .888) and moderate correlation ($r = .516$). The KMO value of .925 and significant Bartlett's test ($p < .0001$) indicate the model's suitability for capturing key quality-of-life dimensions.

Rasch analysis provided a detailed examination of the latent variables within the Q-VAD items, particularly for the Functioning Support scale. The adequacy of the Rasch model was confirmed through a high degree of consistency between observed and expected values, satisfactory deviation levels across the items, and significant improvements in scale structure. This approach:

- identified redundant items contributing to duplicative measurement scores, refining the scales for clarity and efficiency.
- highlighted a minimal set of high-quality items that reliably measure key support areas.
- ensured better alignment between observed responses and theoretical models, validating the internal consistency of the scale.
- highlighted the importance of periodic refinements to maintain the instrument's validity and ensure its responsiveness to real-world conditions.

As a result of the initial survey, Q-VAD has been formally adopted through a decree from the Regional Administration, solidifying its role as a standardized assessment tool for the systematic collection of data on the LC of individuals with disabilities across various regional services. The decision to formalize the use of Q-VAD reflects its suitability for monitoring the delivery of services and ensuring a more structured approach to understanding the needs and experiences of individuals with disabilities in day and residential settings.

The integrated version of Q-VAD, updated following the analysis of the first round of data collection, is now accessible through the regional web platform at: disabilita.regione.fvg.it/it/schede/biblioteca/biblioteca.html.

This updated version incorporates the initial modifications made based on empirical data, ensuring that the tool remains effective for ongoing evaluations of disability services. The future rounds of data collection using Q-VAD are expected to provide further insights, allowing for continuous refinement of the assessment tool and ensuring that it meets the evolving needs of both service providers and individuals with disabilities.

Q-VAD was developed and validated to assess the life conditions of individuals with ID, with a focus on functioning support, QoL, and opportunities. The process involved reviewing scientific literature, defining key dimensions, and designing a structured tool capable of capturing a comprehensive range of factors related to individual well-being and SI. The assessment tool

underwent psychometric validation, including exploratory factor analysis and Rasch modeling, to refine its structure, ensure internal consistency, and confirm its ability to measure the intended constructs reliably. This led to adjustments in item formulation, removal of redundancies, and optimization of response options to improve clarity and applicability. Q-VAD was implemented across various disability services, with professionals trained to administer it. Data collection was supported by a dedicated web platform and a structured helpdesk system to ensure accuracy and completeness. The results of the first data collection phase contributed to further refinements, and the assessment tool was officially adopted as a standardized tool for assessing and monitoring the LC of individuals with disabilities. The updated version, incorporating initial modifications, is now available for continued use and further validation in future evaluations.

2.2 Key Outcomes from the Q-VAD Tool Implementation Regarding Social Inclusion and Quality of Life

Despite the significant advances in understanding disability issues at both national and international levels in recent decades, our knowledge about the LC of individuals with ID remains limited. Much of the current understanding is derived from local reports, requests from family members or advocacy groups, and perspectives from professionals and service providers. Scientific literature often focuses on small samples, specific intervention procedures, or particular themes, which means it fails to provide a comprehensive view of the existential conditions faced by these individuals. There is a notable lack of large-scale studies correlating indicators of functioning and QoL with contextual factors in the scientific literature.

This gap in comprehensive data presents a significant challenge in supporting institutional systems to effectively plan and implement policies, support mechanisms, and interventions for individuals with disabilities. To address this, there is a need for administrative systems to establish a routine process grounded in a specialized data system that combines broad dimensions of investigation, psychometric rigor, and practical considerations for data collection and training.

Q-VAD was developed to fill this gap by analyzing a range of dimensions and indicators, providing detailed data on factors crucial for describing the functioning and QoL of individuals with disabilities (Edwards & Luckasson, 2002; Renwick & Brown, 1996; Schalock & Verdugo-Alonso, 2002; Buntinx & Schalock, 2010; Bertelli et al., 2015).

In the validation process, the tool was deployed among adults in the residential and day care services network for living and SI in the FVG Region.

For the analysis of outcomes related to SI and QoL, the same sample of 1,688 individuals from the validation phase was used.

Although the Q-VAD tool offers broad possibilities for psychometric analysis, the focus here is on selected subscales—Support for Functioning, Opportunities, quality of life, Behavioral Distinctiveness, and Health—as well as on factor analysis results and the associations between Q-VAD dimensions and different types of disability services.

2.2.1 Socio-Demographic Data Analysis

First of all, Q-VAD provides important information of a socio-demographic, diagnostic, and general nature concerning the individual's life condition. Table 2.13 presents key socio- demographic data and a general overview of the population classification.

Table 2.13

Sociodemographic Data of the Population with Disabilities from the Q-VAD Survey (N=1,688) (created by the researcher).

Variables	**N**	**%**
Females	766	45,4
Males	922	54,6
<18	25	1,5
18-29	317	18,8
30-39	319	18,9
40-49	462	27,4
50-59	444	26,3
60>	121	7,2
Living facilities (residential services)	620	36,7
Services for SI (semi-residential services)	1068	36.3

Diagnostic information from medico-legal sources was available for 1,345 out of the 1,688 cases analyzed, representing approximately 80% of the total sample. The unencrypted diagnostic data reported in certifications has been recoded into broad categories. This process involves a degree of imprecision due to the variability in medical terminology used across different diagnoses. Despite this, the data provides valuable insights and offers a snapshot of the discrepancies between the health issues identified through the Cumulative Illness Rating Scale (CIRS) and those underlying the conditions of impairment and disability that justify the need for forensic evaluations and likely contributed to individuals' use of semi-residential or residential services.

Table 3.2 displays conditions with a prevalence exceeding 2%. The most prevalent condition is ID, directly cited for 75% of the population, and likely affecting most of the remaining 26.4%, who

have health conditions commonly associated with ID (e.g., Down syndrome, neonatal pathologies). Outcomes from congenital and neonatal pathologies follow at a considerable distance, with a prevalence of 22.7%. Autism is reported in only 4.1% of cases, which can be attributed to the average age of the population, as many had forensic evaluations during periods when autism was less frequently diagnosed.

Table 2.14

Prevalence of more than 2% of Macro Classes of Pathologies as Shown by Medical-Legal Certifications (created by the researcher).

Conditions of pathology from forensic medical certifications	Prevalence %
ID	73,6
Pathologies and conditions of psychiatric importance	15,3
Autism	4,1
Epilepsy	16,6
Congenital and neonatal pathologies	22,7
Paraplegia, tetraplegia, paraparesis, etc.	18,3
Sensory	11,8
Genetic	20,5
Traumatic posts	2,3
Osteoarticular	7,5
Neurodegenerative	2,8
Metabolic	2,6
Cardiovascular	4,0

Indeed, 85% of autism diagnoses pertain to individuals under the age of 39, and 61.5% are for those under 29 years old. The notably low prevalence of psychiatric and behavioral disorders in the diagnostic data contrasts sharply with the high prevalence observed in CIRS evaluations. One plausible explanation is that many psychiatric and behavioral issues emerged after the forensic

medical certification, which often occurred at a younger age and was seldom revisited, especially given the primary focus on ID. Consequently, the co-occurrence of ID and psychiatric disorders is reported at just 11.2%. Despite acknowledging the limitations of the data, cross-referencing the CIRS findings with medico-legal diagnostic data suggests that the true prevalence of this dual diagnosis might exceed 57% in the studied population.

Regarding the severity of diagnoses, the available data is qualitatively insufficient. For instance, among the 990 individuals diagnosed with ID, approximately 50% have severe or profound impairments, while 22% have moderate to mild impairments. No severity evaluate is available for the remainder. For psychiatric disorders, major psychiatric conditions (such as psychosis, depression, and bipolar disorders) are equally distributed among the 206 individuals identified, with other psychiatric issues also being noted. In cases of paresis, about 54% are diagnosed with tetraplegia, while the remaining 46% have other forms of paresis, including paraplegia.

The genetic pathology category predominantly includes Down Syndrome, which accounts for 81% of the cases reported. Overall, analysis of comorbidities from medico-legal evaluations reveals that 70% of the population has two or more major categories of pathology, with an average of 2.07 categories per individual across the entire group.

The first section of Q-VAD gathers important information on indicators that can be considered "proxies" for assessing the level of SI and participation in community life among individuals with disabilities. Table 2.15 highlights some of these indicators, focusing on leisure activities and interpersonal relationships, including friendships.

Table 2.15

Day Trips and Friendships of Population of Housing and Day Care Services

(created by the researcher).

Day trips and friendships	NO	%	YES	%
Do you go out in the course of your day to do the things you want?	785	46,5	903	53,5
Do you have friends who are not the companions of the day or residential center?	1.085	64,3	603	35,7
If yes, do you go out with your friends?	189	31,3	414	68,7

Half of the individuals report being able to go out later in the day to engage in activities of their choice, while nearly the other half experience a condition of "relative confinement." Only one in

three people indicate having friends outside of the service network, and of those, just two-thirds have the opportunity to spend time with them. This data closely aligns with findings from the international literature, which highlights a prevalent risk for many individuals with ID of leading "a sort of parallel life" compared to the general population (O'Brien, 1987; Clement & Bigby, 2010). The data on autonomous mobility further supports this picture of severe limitations in movement and participation in community life (Table 2.16). Just over one in ten individuals use public transportation or bicycles independently, and cases of individuals who operate motor vehicles are exceptionally rare.

Table 2.16

Autonomous Mobility of Population of Residential and Day Care Services

(created by the researcher).

Autonomous mobility	no	%	yes	%
Use the means of transport alone (e.g. train, bus, bus)?	1.463	86,7	225	13,3
Do you use a bicycle?	1.475	87,4	213	12,6
Do you use the moped/scooter?	1.678	99,4	10	0,6
Do you drive the car?	1.682	99,6	6	0,4

A broader utilization is observed for communication tools and web usage (Table 2.17). However, smartphone use is reported by less than one-quarter of the total population, and web-based communication tools are used by less than one in ten individuals. This is a critical issue, as international literature for over a decade has highlighted the potential of technological communication tools, particularly smartphones, as significant aids in various aspects of functioning and QoL for individuals with ID (Smith et al. 2020; Dratsiou et al. 2021)

Table 2.17

Communication Tools and Use of the Internet in Population of Housing and Day Care Services (created by the researcher).

Communication and use of the Internet	no	%	Yes	%
Do you have a mobile phone (smartphone)?	1.286	76,2	402	23,8
Do you own/use a PC freely?	1.354	80,2	334	19,7
Do you surf the internet?	85	25,5	249	74,5
Are you subscribed to a social network?	109	32,6	225	67,4

2.2.2 Analysis of Living Conditions Basing on Q-VAD Subscales

The following paragraph presents the psychometric analyses of the data obtained from the various subscales of the Q-VAD instrument. Although the items on the instrument were predominantly designed in the first person to accommodate potential self-evaluate use, all surveys conducted for this study were carried out using an evaluative approach by others. In this section the results for each subscale are presented.

- *Opportunities.* It is well-established that opportunities are intricately linked to outcomes related to personal development, independence, SI, and QoL for individuals with disabilities (Giangreco, 2017; Wilson et al., 2017). For the population at risk of "invisibility," as discussed in the previous section, what opportunities for life can they access? Q-VAD features a section with 14 questions specifically designed to explore this aspect of daily life. This section quantifies opportunities to engage in or receive support for essential daily activities. Through exploratory factor analysis, 12 of these items were selected to construct two latent dimensions: "Opportunity to Do" and "Opportunity to Learn." Table 3.6 presents the descriptive data collected from responses on an ordinal scale (Likert scale 0 - 4, where 0 = Never and 4 = Every day or almost every day) for each item. The table highlights items where more than 50% of responses fall into the "extreme" categories (0 - 1 or 3 - 4). Between 60% and 70% of respondents report either never (score 0) or rarely (score 1) having the opportunity to enhance their autonomy in personal care (item 7: 63.4%), acquire cognitive, educational, or technological skills (item 8: 68.2%), or

develop external autonomy in community life (item 9: 75.6%). Conversely, data from items 1 and 2 reveal a high likelihood (score 4 and score 5) of receiving support for self-care (76.5%) and the upkeep of daily living environments (61.7% The domain of work and employment shows the fewest opportunities: 91.8% of individuals have "never had opportunities to search for or engage in employment," and only 12.7% report regular opportunities to perform work-related tasks. Additionally, nearly one-third of respondents report never or rarely having opportunities to socialize with significant individuals in their lives or to participate in meaningful social or community events. These findings align with data from the socio-demographic section, indicating a significant variability in profiles, consistent with the diverse outcomes associated with ID. This variability underscores the meta-syndromic nature of these disorders, characterized by highly differentiated functioning and performance indicators in activities and SI. The analysis of opportunities reflects not only the general LC of individuals but also highlights the current focus of services. Despite some important areas of intervention with enabling and inclusive value, there remains a predominant emphasis on welfare and protective aspects.

Table 2.18

Opportunities to Carry Out Activities Offered to the Population of Services for Housing and Day Care Services (0 = Never / 4 = Every Day Or Almost Every Day)

(created by the researcher).

Opportunities	0	1	2	3	4
1. Have you carried out/received support for your personal care activities?	11,0%	6,0%	6,5%	12,4%	64,1%
2. Have you carried out/received support for the care of living environments?	24,3%	6,0%	7,9%	20,8%	40,9%
3. Have you used appliances and technologies?	40,7%	8,1%	7,8%	15,0%	28,4%
4. Have you had/received opportunities to move around the territory?	14,5%	6,4%	12,4%	32,2%	34,4%
5. Have you had/received opportunities to use community services?	18,6%	12,3%	18,2%	36,3%	14,7%
6. Have you had/received opportunities to participate in significant community activities?	20,9%	23,8%	29,9%	17,7%	7,8%

7. Have you had/received opportunities to learn skills for the autonomous management of your person?	52,5%	10,9%	10,6%	15,1%	11,0%
8. Have you had/received opportunities to learn cognitive, scholastic and technological skills?	58,3%	9,9%	9,9%	15,1%	5,7%
9. Have you had/received opportunities to learn skills for external autonomy?	64,7%	10,9%	8,2%	12,2%	3,9%
10. Have you had/received opportunities to be engaged in roles, tasks and activities that are useful to the people you live with, who live close to or frequent?	36,0%	10,4%	12,5%	18,7%	22,3%
11. Have you had/received opportunities to be engaged in activities and tasks related to a work assignment?	69,8%	3,1%	4,3%	10,1%	12,7%
12. Have you had/received opportunities to research and/or do a job?	91,8%	1,7%	1,4%	1,1%	4,1%
13. Have you had/received opportunities to socialize/meet the people who are important to you?	17,5%	10,6%	17,6%	26,0%	28,4%
14. Have you had/received opportunities to participate in recreational and/or socializing activities that are meaningful to you?	16,1%	11,4%	23,6%	31,5%	17,4%

- *Quality of life:* The section comprises 21 items, each corresponding to indicators across various domains of QoL: physical well-being, material conditions, emotional well-being, interpersonal relationships, SI, self-determination, and personal development. Table 2.19 presents the percentage of responses for each item on an ordinal scale (Likert Scale 0 - 4, where 0 = Not at all and 4 = Very much), based on the total sample of 1,688 individuals. The table highlights items where more than 50% of responses fall into the extreme categories (0 - 1 or 3 - 4).

Table 2.19

QoL of the Disability Population of Housing and Day Care Sevices (0 = Not at all / 4 = A lot)

(created by the researcher).

Quality of life	0	1	2	3	4
1. Do you feel energetic and vital?	5,5%	18,0%	37,4%	28,0%	11,1%
2. Do you rest and relax properly?	4,4%	14,6%	31,9%	33,1%	16,0%
3.Do you happen to have physical pain?	11,8%	29,6%	37,6%	17,9%	3,0%
4. Do you feel comfortable in the places where you live?	2,7%	6,8%	28,0%	42,8%	19,7%
5. Are there things (people, activities, events) that make you happy?	2,5%	4,6%	21,1%	46,2%	25,5%
6. Are you satisfied with the things you do and how you spend time in your day?	4,7%	11,6%	37,4%	36,1%	10,2%
7. Are you satisfied with the personal belongings or possessions you own and how you can dispose of them?	6,4%	13,3%	28,8%	37,1%	14,5%
8. Do the living environments you experience on a daily basis allow you to stay alone (when you need them) or protect your privacy?	12,9%	15,1%	22,7%	33,2%	16,2%
9. Are your living environments adapted to your needs, requirements and preferences?	2,7%	9,4%	29,7%	40,2%	17,9%
10. Do you relate to people living in your neighborhood/territory (even in the case of a person placed in residential service)?	22,6%	25,9%	23,4%	20,5%	7,6%
11. Do the services, opportunities or recreational places in your neighborhood/territory (e.g. shops, bars, church, parish, theatre, cinema...) meet your needs, interests, desires?	15,8%	19,4%	30,6%	24,8%	9,5%

12. Do you carry out/participate in significant activities in the territory/neighborhood where you live (recreational activities, sports, volunteering ...)?	38,7%	24,1%	19,0%	13,7%	4,4%
13. Do you feel satisfied with the relationship you have with your family or with the reference figures outside the context of assistance?	8,1%	11,8%	28,5%	32,9%	18,7%
14. Do you have friends with whom you can maintain constant relationships (excluding family members, staff and volunteers of the facilities)?	53,4%	20,6%	12,6%	9,7%	3,7%
15. Do you have the opportunity to carry out social activities that are rewarding for you (e.g. going out, going to parties)?	20,3%	21,0%	26,2%	23,1%	9,3%
16. Do you have the opportunity to put into practice what you know how to do in your life (e.g. going out alone, using means, using the PC, doing a job / activity ...)?	40,0%	18,5%	20,6%	14,6%	6,3%
17. Have you learned any new skills or knowledge? (autonomy skills, training courses...)?	48,7%	18,8%	18,1%	10,8%	3,6%
18. Have you had the opportunity to access new roles or new life opportunities (e.g. training, work, living)?	72,6%	11,7%	8,2%	4,9%	2,6%
19. Do you have the opportunity to express your preferences and wishes to someone?	13,6%	9,1%	21,1%	37,5%	18,7%
20. During your day do you have the opportunity to make choices related to your activities (e.g. what to eat, what to wear, what to do)?	15,0%	13,3%	28,1%	31,9%	11,7%
21. Do you have the possibility to decide who to be with, who to meet, who to attend, with whom to carry out certain activities?	24,2%	23,8%	27,4%	16,9%	7,7%

The respondents in the survey generally express satisfaction with key aspects related to their living environments (item 9) and their relationships with family members (item 13). The areas concerning external relations and the opportunity to visit external places (items 10 and 15) show a more balanced distribution between dissatisfaction and satisfaction. In contrast, areas associated with "agency"—such as friendships, a sense of purpose, the ability to see preferred individuals, and opportunities for personal growth—demonstrate lower scores and higher levels of dissatisfaction.

- *Support needs for individual functioning:* Seventeen items assess the level of personal support required across various dimensions of individual activity. These items address skills and needs related to personal care, activities of daily living (ADL) (McDowell, 2006), and the organization of daily and domestic life (Instrumental Activities of Daily Living – IADL) (Ahn et al., 2009). Responses are recorded on a 5-point scale, ranging from substantial absence of support to high levels of support. Table 2.20 displays data on the intensity of support needed for basic functioning among the 1,688 subjects involved in the study. The table highlights items where more than 50% of responses fall into the extreme categories (0 - 1 or 3 - 4). The percentage of individuals requiring intense personal support (values 0 and 1 on the scale) ranges from approximately 15% for item 4 ("When people turn to you...") to nearly 80% for item 12 ("When you prepare meals..."). For 6 out of the 17 items (primarily those related to instrumental activities of daily living and travel outside the service), the majority of respondents report needing high levels of support. Notably, 25.1% of individuals face significant communication challenges related to expressing needs and desires, and 36.7% struggle with planning daily commitments and activities. These findings highlight areas where enabling and compensatory interventions could be explored to reduce the need for personal support.

Table 2.20

Levels of Intensity of Support for the Basic Functioning of the Population of Residential and Day Care Services (4 = Maximum need for support / 0 = No support needed)

(created by the researcher).

Level of personal support in basic operations	0	1	2	3	4
1.Do you recognize the living environments, places and paths to reach spaces, objects, activities and people of interest?	26,1%	39,1%	12,3%	11,1%	11,4%
2.Can you predict your day's commitments and activities?	18,4%	23,5%	21,5%	14,8%	21,9%
3.When you need to perform an important task/activity of your day...	15,0%	25,1%	27,1%	12,0%	20,8%
4.When people turn to you...	40,1%	34,3%	10,8%	9,8%	5,0%
5.When you speak...	16,7%	27,5%	19,1%	15,6%	21,0%
6.When you need or desire to express something...	19,4%	31,6%	23,9%	14,6%	10,5%
7.Can you move around your living environment?	35,4%	29,5%	12,8%	8,5%	13,8%
8.When you need to wash...	15,8%	23,2%	17,1%	16,2%	27,7%
9.Can you get dressed and undressed?	28,5%	24,4%	12,4%	13,0%	21,7%
10.When you need to eat...	40,0%	22,5%	17,8%	8,6%	11,2%
11. When you need to go to the bathroom...	35,6%	17,1%	15,8%	14,9%	16,5%
12. When you prepare your own meals...	3,6%	7,8%	11,1%	18,4%	59,2%
13. To keep your living spaces tidy and clean...	5,7%	16,7%	12,2%	21,3%	44,1%

14. When you move to your country city...	13,3%	9,4%	23,0%	11,2%	43,1%
15. When you find yourself interacting with other people...	18,0%	34,8%	14,4%	16,0%	16,8%
16. When you need to make purchases...	6,9%	14,6%	16,1%	18,7%	43,7%
17. When you participate in some activity in your country or city...	11,5%	29,8%	15,5%	15,2%	28,0%

- *Behavioral disturbances:* Q-VAD addresses eight categories of behavioral disorders that are commonly observed with higher prevalence in individuals with ID and autism (Rattaz et al. 2018). Each behavioral issue is rated based on its impact on the individual's life using the following five levels.
    1. "No problems during the evaluation period";
    2. "Occasional appearance of the behavior in question";
    3. "The problems significantly affect the performance of the activities of the person and others";
    4. "The problems have an extremely significant impact on the performance of the activities of the person and others and require careful monitoring for management and prevention.";
    5. "The problems seriously affect the functioning and performance of most activities of daily life and require constant supervision or physical intervention for prevention".

  Table 2.21 presents the prevalence of responses across these eight items, categorized by the intensity of impact as outlined above.

  To estimate the point prevalence of problem behaviors, reports indicating intensity levels of the first and second categories were excluded. A single instance of maladaptive behavior at levels 3 through 5 was deemed sufficient to identify the presence of problem behaviors. Consequently, 47.4% of the subjects exhibit at least one problem behavior, while 29.5% exhibit two or more. Table 2.21 provides prevalence data for each type of problem behavior, categorized by gender, age group, and type of service

Table 2.21

Population of Residential and Day Care Services by Presence and Intensity of Problem Behaviors (created by the researcher).

Type of problem behaviour	1	2	3	4	5
Self-directed aggression	74,2%	13,2%	8,1%	3,6%	1,0%
Hetero-direct aggression	52,7%	27,2%	10,5%	7,2%	2,4%
Aggression towards things	76,8%	14,8%	4,0%	3,1%	1,3%
Stereotypes	51,5%	19,9%	15,6%	8,8%	4,1%
Ingestion of inedible substances	93,3%	4,1%	1,1%	0,8%	0,7%
Marked oppositionality	44,3%	32,2%	12,0%	8,2%	3,3%
Inappropriate social behaviour	54,4%	26,1%	10,5%	6,0%	3,0%
Inappropriate sexual behaviour	86,8%	10,7%	1,4%	0,7%	0,4%

The prevalence of behavioral disorders, as reported in international literature, is challenging to assess due to the heterogeneity of populations, diagnostic frameworks, severity of intellectual and functional limitations, and measurement tools used (Banks & Bush, 2016; National Collaborating Centre for Mental Health, 2015). It is important to note that this study focuses on individuals within residential and semi-residential services, and therefore, does not represent the broader population of individuals with ID or autism. While the observed prevalence rates are high compared to general population estimates, they align with findings from studies on similar populations available in the literature. For comparative purposes, the final column of Table 2.22 includes data from a significant Canadian study (Crocker et al. 2006), which examines a population with partial correspondence in service types to those in the current sample.

Table 2.22

Prevalence of Problem Behaviors by Type (Values 3, 4, and 5) of the Ordinal Scale of Evaluation (created by the researcher)

		1	2	3	4	5	6	7	8	Total	Croker & al. 2006
Gender	Males	20,3 %	11,6 %	9,2%	30,6 %	2,6 %	22,8 %	20,0 %	3,3 %	47,9 %	51,4
	Females	19,8 %	14,0 %	7,4%	26,1 %	2,6 %	24,3 %	18,9 %	1,6 %	45,2 %	52,3
Age class	Up to 29 years	26,4 %	14,7 %	10,9 %	34,0 %	4,1 %	27,2 %	20,1 %	2,7 %	54,1 %	53,4**
	30-39 years	18,7 %	13,5 %	10,4 %	31,3 %	2,8 %	23,0 %	19,9 %	2,8 %	44,8 %	51,0
	40-49 years	16,9 %	12,9 %	6,5%	27,3 %	1,9 %	23,0 %	17,5 %	2,5 %	46,2 %	55,0
	50-59 years	20,2 %	10,8 %	8,0%	26,4 %	2,4 %	21,6 %	21,6 %	1,4 %	45,1 %	46,9
	60 and more years	15,6 %	8,9%	3,3%	13,3 %	1,1 %	21,1 %	15,6 %	5,6 %	38,0 %	48,1
Service Type	Protected residences	25,4 %	21,2 %	12,1 %	40,1 %	6,2 %	33,9 %	24,1 %	5,5 %	60,8 %	62,8**
	Residential services	25,7 %	11,1 %	6,3%	27,7 %	2,0 %	25,3 %	22,9 %	2,4 %	49,4 %	52,7
	Apartment community-based programs	18,3 %	6,7%	8,3%	26,7 %	0,0 %	21,7 %	16,7 %	1,7 %	46,9 %	50,5
	Semi-residential	17,6 %	11,4 %	8,0%	26,5 %	1,9 %	20,5 %	18,0 %	1,8 %	43,5 %	42,5
	Innovative semi-residential	12,7 %	3,6%	5,5%	9,1%	1,8 %	12,7 %	9,1%	0,0 %	29,1 %	n.r.

**Sign <0,01; (1 = heterodynes aggression; 2 = self-directed aggression and self-harm; 3 = aggression towards environments or things; 4 = ritual stereotypes and compulsive behaviors; 5 = ingestion of inedible substances; 6 = oppositionality; 7 = socially inappropriate behavior; 8 = sexually inappropriate behavior).

Considering the data from existing literature alongside the findings of this survey, it is crucial to emphasize that the high incidence of behavioral disorders among individuals with ID underscores the necessity of viewing these behaviors as an inherent component of ID or autism. In other words, problem behaviors are not extraneous issues but rather integral aspects of fragility, alongside other established compromises and vulnerabilities, which necessitate targeted interventions, services, and professional support.

Furthermore, while the data highlight the challenges faced by individuals with disabilities, they also prompt significant reflection on the role of environmental contexts. The elevated estimates of behavioral disorders in institutional settings align with established trends in the literature. The prevalence of oppositional behaviors, stereotypies, and inappropriate social behaviors, particularly within institutional environments, emphasizes the issue of "problematic environments" and highlights the difficulties associated with managing these behaviors in community settings or less restrictive environments.

- *Health conditions:* Epidemiological data on individuals with ID are notably sparse, although the international literature has long documented these issues. Research over the past two decades unequivocally shows that this group exhibits a higher prevalence of health conditions across all major systems compared to the general population, with some conditions occurring at particularly high rates. Comprehensive reviews of this issue can be found in the extensive international literature (Emerson et al. 2016; Straetmans et al. 2007; Emerson & Baines, 2010), which identifies key dimensions of the frailty experienced by individuals with ID. To assess the health condition, the Cumulative Illness Rating Scale (CIRS) was utilized (Conwell et al. 1993). Additionally, a "checklist" of health and rehabilitation interventions was used to represent the service commitment and care efforts. The evaluate of health conditions, conducted by the health districts of the Reference Health Care Companies and personnel from the "Subjects managing services of regional importance (SRR)" who participated in the survey, is an ongoing process. This process began with an initial sample of 430 individuals evaluated in 2017, extended to an additional 30% of the population in 2018, and aims to cover at least 70% by 2019 and 100% in subsequent years. The data presented here are thus partial, referring to the year 2019, but they already provide significant insights. Table 3.11 displays data for 1,137 individuals residing in protected residences, housing communities, and semi-residential services, representing 1,750 subjects, detailing the frequencies of health problems across the 14 dimensions considered by CIRS, as well as medication usage percentages. Table 2.23 summarizes these data, adjusted for gender, age class, and service type, onto the entire reference population, while the following two columns present data specific to the 1,137 evaluated subjects.

Table 2.23

Prevalence of Pathology Conditions in the 14 Evaluation Dimensions Provided by CIRS Scale (created by the researcher).

Pathology conditions	Frequency data collected %	% of those taking therapy	% of those who hire therapy among those who have the problem	Average severity (scale 0-4) For those who have the problem
Heart	9,67	5,28	54,55%	1,83
Hypertension	10,82	9,59	88,62%	1,66
Vascular system	5,89	3,96	67,16%	2,01
Respiratory system	5,72	3,78	66,15%	1,75
Eye, ear, nose, pharynx, larynx	28,50	8,62	30,25%	2,10
Upper gastric apparatus	10,99	8,09	73,60%	1,86
Lower gastric apparatus	10,29	8,53	82,91%	191
Liver	2,81	1,67	59,3.8%	1,66
Rene	2,37	1,14	48,15%	2,04
Urinary genie system	11,52	7,83	67,94%	1,85
Muscular apparatus	36,68	12,23	33,33%	2,33
Nervous system	59,45	,39,75	66,86%	2,75
Endocrine system	19,00	16,18	85,19%	1,82
Psychopathological/behavioural	68,25	49,60	72,68%	2,57

The data presented underscores the fragility of the health status within this population, corroborating findings from international surveys and particularly highlighting the high prevalence of psychiatric/behavioral issues and conditions affecting the nervous system. For these two dimensions assessed by the Cumulative Illness Rating Scale CIRS, the percentage of individuals with reported problems is 68.25% within the sample analyzed (consistent with data from 400 cases, which indicated a prevalence between 64.6% and 71.1%). Among those identified with psychiatric and behavioral problems, 72.68% are on medication. Both the nervous system and psychiatric areas continue to exhibit the highest severity of pathological conditions (severity index = 2.75).

The Q-VAD data offers numerous opportunities to explore correlations between various dimensions, such as opportunity, QoL, and service contexts for individuals with disabilities. To provide a nuanced understanding of these relationships, this analysis employs two main methodologies: cluster analysis and linear regression models. The previous discussion of LC was presented in a general context, not accounting for the specific service environments in which individuals reside. Recognizing that behavior, human activity, and life outcomes are influenced by both individual and contextual factors (World Health Organization, 2001; Luckasson et al., 2002), this study introduces a more detailed classification of service contexts to evaluate their impact on key indicators. The regional service nomenclature, which originally included three types of living services (protected residence, Residential services, and apartment-community-based program) and one type of day center, is expanded into five levels for this analysis. These levels are divided into three categories related to living arrangements—protected residences, housing communities, and low-threshold living solutions—and two categories related to SI—day care centers and community-based inclusion solutions. Protected residences encompass facilities that provide extensive care. Housing communities, or "group homes," offer small, supported living environments with 24-hour assistance. Low-threshold living solutions include both traditional apartment - community-based programs and independent living arrangements with varying levels of support. SI solutions are divided into day care centers, which offer various socio-recreational and educational activities, and community-based options that promote social engagement in non- specialized settings, such as sports associations and community spaces. Table 2.24 illustrates the different service types, including the total number of individuals served, average number per unit, and average age, thereby providing a comprehensive overview of how different service contexts influence the LC and QoL for individuals with disabilities.

Table 2.24

Classification of Services for Persons with Disability in the FVG Region

(created by the researcher).

Type of services	Total	n. medium components	Average age
Protected residences	307	27,9	45,32
Residential services	253	7,9	48,84
Housing solutions and low protection threshold, and community-based apartments	60	3,3	42,07
Day care centres	963	10,9	40,64
A day community-based program for inclusion	105	6,2	33,31
Total	1.688		

The three-item batteries were subjected to separate cluster analyses, excluding items identified as unreliable or unsuitable through reliability and exploratory factor analyses. The clustering process employed was the two-stage clustering algorithm available in SPSS version 26. This method, introduced by Chiu et al. (2001), is adept at handling both continuous and categorical data and involves two distinct phases. The first phase, known as "pre-clustering," generates a preliminary data matrix where pre-clusters serve as inputs for the subsequent phase. The second phase, "clustering," resembles hierarchical clustering but differs in that it employs a multivariate model: continuous variables within clusters are assumed to be normally distributed, while categorical variables follow a multinomial distribution. The algorithm automatically determines the number of clusters using Akaike's Information Criterion (Bacher, Wenzing, & Vogler, 2004). Across all three analyses, a clear distinction emerged with only two clusters in each case. This outcome was anticipated to some extent, given that the dimensions analyzed—Opportunity, QoL, and Support— were distinct yet strongly correlated. The validity of the cluster separation is supported by the silhouette measurement of cohesion and separation, which were 0.45 for Opportunity, 0.48 for QoL, and 0.55 for Support. These results allow for a meaningful interpretation of the clusters as

representing high and low levels of Opportunity, QoL, and Support. Table 2.25 displays the clusters generated from the analysis, illustrating these distinctions.

Table 2.25

Groups Emerged from the Analysis of Clusters and Their Number

(created by the researcher).

	Opportunity	**QoL**	**Supports**
Loud	980	1.048	807
Low	708	640	881
Total	1.688	1.688	1.688

The following three graphs illustrate the dispersion diagrams of the dimensions derived from the exploratory factor analysis, with individual points representing people classified according to their cluster membership. The graphs reveal that the cluster distinctions occur on a continuum, with no sharp demarcation between the two groups. Each graph further demonstrates that individuals within each cluster can occupy varying positions across the quadrants defined by the factor score averages. Despite this variation, the clustering algorithm has not delineated distinct groups, indicating a more nuanced distribution of data points across the identified clusters.

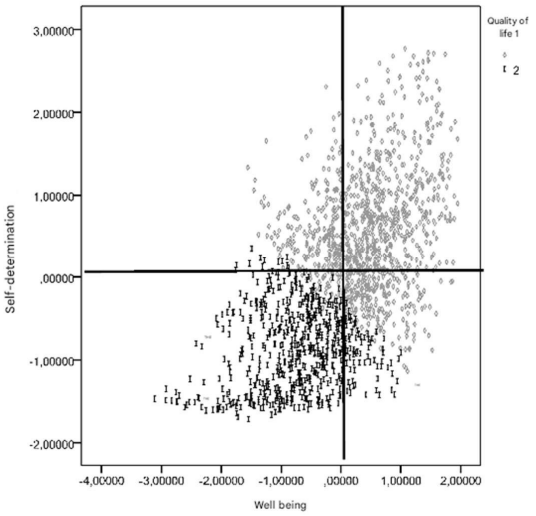


Figure 2.1: **Diagram of Factor Scores in the two Dimensions of Quality of Life. Points Identified by Membership in High (1) and low QoL Clusters (2)** (created by the researcher).

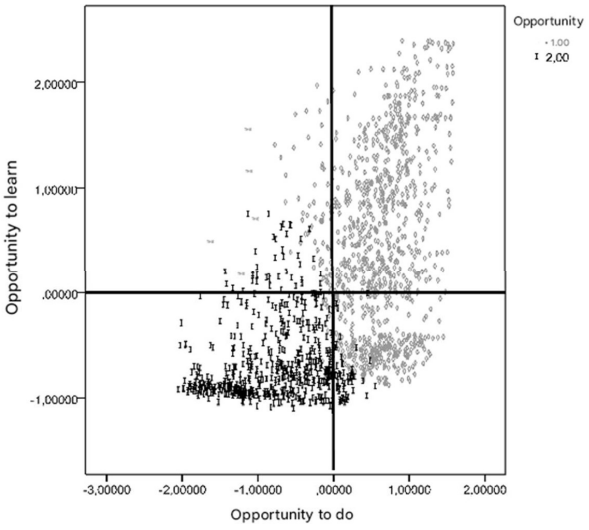


Figure 2.2: **Diagram of Factor Scores in the two Dimensions of Opportunity. Points Identified by Cluster Membership of High (1) and Low Opportunity (2)**
(created by the researcher).

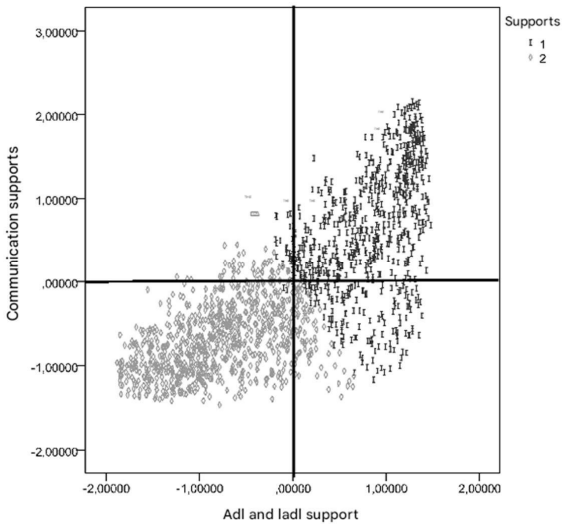


Figure 2.3:**Diagram of Factor Scores in the two Dimensions of Need for Support. Points Identified by Cluster Membership of High (2) and Low Support Needs (1)**

(created by researcher).

The clustering analysis enables a preliminary classification of LC, resulting in eight distinct combinations derived from the three identified groups. Table 2.26 presents these classifications, where, for instance, the first combination refers to individuals with high opportunities (+), high QoL (+), and low support needs (-). The second group includes those with high opportunities (+), high QoL (+), but also high support needs (+). The remaining categories follow this same logic.

Table 2.26

Classification of the Population of Housing and Day Care Services of the FVG Region by Levels of Opportunity, QoL, and Need for Support (created by the researcher).

Opportunities, QoL, and Supports for individual functioning	**N. almost**	**%**	**Group**
++-	632	37,4	1
+++	170	10,1	2
+--	80	4,7	3
+-+	98	5,8	4
-+-	99	5,9	5
-++	147	8,7	6
---	70	4,1	7
--+	392	23,2	8
Total	1.688	100,0	

The first and second groups, representing nearly 50% of the population, include individuals who exhibit varying levels of opportunity and QoL, independent of their support needs. Groups three through six are characterized by vulnerabilities in either opportunities or QoL, which may be associated with high support needs (groups 4 and 6) or, in some cases, low support needs (groups 3 and 5). The final two groups represent individuals with both low opportunities and QoL, either without significant support needs (group 7) or with high support needs (group 8). Table 2.27 illustrates how these groupings intersect with different types of services.

Table 2.27

Classification of the Population in Housing and Daycare Services Based on Opportunity Levels, QoL, and Support Needs: Percentage Distribution by Type of Service

(created by the researcher).

Opportunities, QoL and support for individual functioning	Protected residence	Residential services	Apartments	Semi-residential Services	Community-based program	Groups
++-	47	129	48	323	85	1
	15,3%	51,0%	80,0%	33,5%	81,0%	
+++	31	46	7	85	1	2
	10,1%	18,2%	11,7%	8,8%	1,0%	
+--	3	12	2	57	6	3
	1,0%	4,7%	3,3%	5,9%	5,7%	
+-+	28	15	0	53	2	4
	9,1%	5,9%	0,0%	5,5%	1,9%	
-+-	13	10	0	70	6	5
	4,2%	4,0%	0,0%	7,3%	5,7%	
-++	29	16	1	99	2	6
	9,4%	6,3%	1,7%	10,3%	1,9%	
---	14	1	0	52	3	7
	4,6%	,4%	0,0%	5,4%	2,9%	
--+	142	24	2	224	0	8
	46,3%	9,5%	3,3%	23,3%	0,0%	
Total	307	253	60	963	105	
	100,0%	100,0%	100,0%	100,0%	100,0%	

The majority of people in housing communities (69.2%), in apartment-community-based programs (91.7%), and in innovative semi-residential services (92.0%) score highly on indicators of

Opportunity and QoL, even in the presence of high support needs. Conversely, 46.3% of individuals in protected residences fall into a group characterized by low opportunities, poor QoL, and high support needs. However, there are also intermediate situations, including a group of 15.3% who have high opportunities, high QoL, and low support needs. The profile of semi-residential services is more varied, with some polarization in the highest (33.5%) and lowest (23.3%) categories, while 43% of users fall into the remaining six categories, with percentages ranging from 5.4% to 10.3%.
Despite the limitations of the classification algorithms, the table underscores the inadequacy of service categories characterized by higher levels of protection (based on both the number of clients and their institutionalizing care approach) in fully representing the complexity of user situations. This issue goes beyond mere nomenclature; current service classifications imply a relative uniformity in service contexts. In other words, the conditions of individuals influence the type of services chosen, but the reverse also holds: the nature of the services can impact the individuals' conditions. This topic, closely related to the appropriateness of services and interventions, will be explored further in the next section.

2.2.3 Factors and Indicators Influencing the Effectiveness of Services in Promoting Quality of Life and Social Inclusion

In this paragraph, two other critical aspects will be examined to deepen the understanding of service context appropriateness:
Impact of Service Types: The effect of different service types on key indicators used to represent the LC of individuals with disabilities will be analyzed.
Dimensions of Appropriateness: Aspects of "appropriateness" in service placement will be evaluated, focusing on the alignment between support needs and the level of protection offered by various service models.
Bivariate analyses, including one-way ANOVA, reveal statistically significant differences among indicators of QoL, OR needs, and support requirements across different service types. Table 2.28 presents the average factorial scores and the results of the variance analysis, with service type as the grouping factor.

Table 2.28

Opportunities, QoL and Support Needs for Individual Functioning in Housing and Day Care Services of the FVG Region: Averages of Factor Scores and ANOVA at One Way

(created by the researcher).

Factorial indicators	Protected residences	Residential services	Low threshold solutions	Day Centres	The day community-based program	Sign.
Opportunity-to-do	-,5776690	,4515424	,9361054	-,0589860	,6070600	0,000
Opportunities - learn	-,2025923	,1891983	,9267313	-,1088872	,6055538	0,000
Physical and relational well-being	-,3738313	,2194149	,6453113	-,0158926	,3413346	0,000
Self-realization and self-determination	-,4430305	,3410398	1,3735289	-,1212179	,8004613	0,000
Supports for ADL and IADL	,6435980	-,1597458	-1,0276308	,0199631	-1,0927188	0,000
Support for Communication and Relationships	,6374619	-,2534146	-,6714436	-,0194964	-,6907171	0,000

Protected residential programs are typically characterized by lower opportunities, diminished QoL, and higher levels of support needs. Conversely, individuals in less restrictive service settings

generally exhibit greater opportunities, better QoL, and lower support needs. Statistically significant differences in average scores across various types of services have been observed. This interpretation provides an additional perspective, complementing the insights gained from cluster analysis.

Table 2.29 presents four regression models that integrate the relationships among QoL, personal characteristics, and service type, while accounting for key population characteristics. Each service type is represented by a binary variable, with the effects of service type evaluated relative to protected residences. Additionally, the regression models incorporate an indicator of problem behaviors, calculated based on a count of behaviors that significantly impact daily life (with impact/intensity values ranging from 2 to 4 in the relevant evaluation items).

Table 2.29

Opportunities, QoL and Services: Linear Regression Models – Standardized Estimates and Statistical Significance (created by the researcher).

	Opportunities to do	**Opportunities to learn**	**Welfare physical and relational**	**Self-determination**	**Welfare physical and relational**	**Self-determination**
Age	.026 (.207)	-.083 (.000)	-.029 (.205)	-.025 (.176)	-.034 (.122)	-.019 (.241)
Gender	.023 (.225)	.026 (.220)	.014 (.506)	.018 (.306)	.010 (.631)	.006 (.700)
Opportunities to do					.324 (.000)	.356 (.000)
Opportunities to learn					.029 (280)	.162 (.000)
Supports for ADL and IADL	-.250 (.000)	-.366 (.000)	.049 (.182)	-.258 (.000)	.140 (.000)	-.109 (.000)
Support for communication	-.327 (.000)	-.134 (.000)	-.413 (.000)	-.378 (.000)	-.297 (.000)	-.242 (.000)
Problem behaviours	.093 (.000)	-.057 (.010)	-.128 (.000)	-.005 (.807)	-.173 (.000)	-.036 (.026)
Residential services	.212 (.000)	.015 (.590)	.093 (.001)	.099 (.000)	.029 (.289)	.022 (.268)

Low-threshold housing solutions	.144 (.000)	.081 (.001)	.101 (.000)	.180 (.000)	.059 (.012)	.117(.000)
Day Care Centres	.102 (.000)	-.116 (.000)	.036 (.230)	-.045 (.069)	.013 (.666)	-.060 (.006)
The day community-based program	.107 (.000)	.001 (.957)	.039 (.151)	.076 (.000)	.006 (.831)	.040 (.037)
	R^2 = .396	R^2 =.269	R^2 =.222	R^2 =.488	R^2 =.293	R^2 =.618

The relationship between opportunities and QoL is significantly influenced by the type of service, with variations observed across different models. This relationship remains statistically significant even after accounting for support needs, problem behaviors, age, and gender. All service types other than protected residences show better outcomes in terms of available opportunities. Specifically, "learning opportunities" are less effective in day care centers compared to sheltered residences, while low-threshold housing solutions yield the best results. In terms of QoL, day care centers are comparable to protected residences, whereas other service types exhibit a statistically significant positive effect.

The final two models incorporate the variables related to opportunities as independent predictors of the variability in QoL indicators. Generally, greater opportunities correlate with better QoL (with all effects being statistically significant, except for learning opportunities on physical and relational well-being). Nevertheless, some service types still exhibit a residual statistically significant effect. Notably, day care centers perform poorly concerning the second QoL indicator.

While further refinement and additional control variables could enhance the characterization of the "case-mix," the regression models reveal a consistent and coherent specific effect of service type on both opportunities and QoL. Protected structures and traditional day care centers appear to face greater challenges and criticalities in providing support without compromising other vital dimensions of life for individuals with disabilities. In contrast, innovative service models seem to better balance protection with relational and social development.

These findings do not permit definitive conclusions regarding service quality or ranking service types in terms of value. Nonetheless, they highlight the issue of appropriateness, emphasizing the need for a well-aligned combination of operational profiles and protection levels. Optimizing developmental opportunities and QoL requires services to be tailored and differentiated to meet the diverse needs of individuals with disabilities. While the Q-VAD survey provides valuable data, further insights into appropriateness will necessitate deeper exploration beyond its current informational potential. Figures 3.4 and 3.5 illustrate the intersection of support needs indicators

for different service types, with each individual plotted based on their support scores and service type affiliation, represented by distinct symbols.

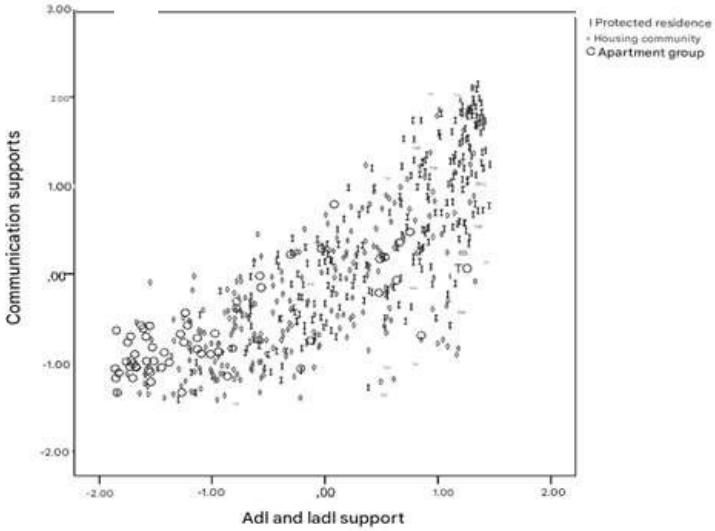


Figure 2.4: **Distributions of Support Needs by Type of Residential Program Service**

(created by the researcher).

The graph illustrates a considerable overlap in support needs across various service types. Notably, the profiles of individuals in housing communities (represented by gray rhombuses) and those in protected residences (indicated by black rods) are consistently superimposed across all levels of support needs. Additionally, there is a discernible overlap between the profiles of users in apartment-based community programs (denoted by black circles) and those in housing communities, with some overlap also observed with users in protected residences.

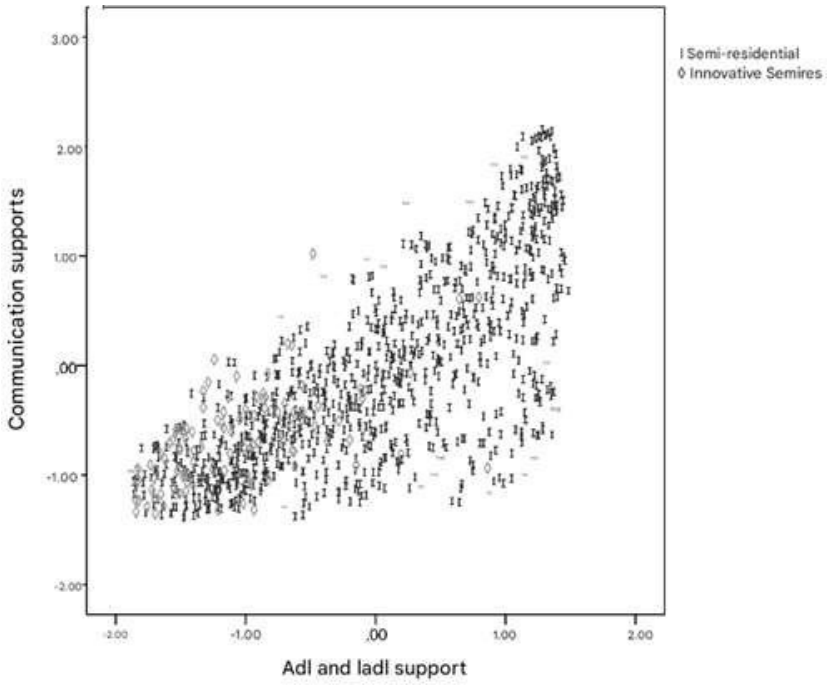


Figure 2.5: **Distributions of Support Needs by Type of Day Care Inclusion Program Service** (created by the researcher).

The support needs profile for inclusion services shows a more distinct differentiation. However, in the first quadrant, which represents individuals with below-average support needs for both ADL-IADL and communication, there is nearly complete overlap between the profiles for day care centers and day community-based programs. From a support needs perspective, a significant number of individuals might transition to day community-based programs. Table 2.30 presents the number of individuals who could potentially switch service types based on their support needs levels, with cases segmented according to the quadrants depicted.

Table 2.30

Classification of Support Levels by Type of Service (created by the researcher).

	Protected residences	Residential services	Low threshold solutions	Day Care Centres	The day community-based program	Total
Sost Adl >0 Sost With >0	199	73	6	356	2	636
Sost Adl >0 Sost Com<0	37	38	3	140	3	221
Sost Adl <0 Sost With >0	13	11	2	45	4	75
Sost Adl<0 Sost Com<0	58	131	49	422	96	756
Total	307	253	60	963	105	1.688

Based on a purely arithmetic evaluation, using the group with the lowest level of support as a reference, 189 individuals (33.8% of the total in protected residences) could transition to low-threshold services. Additionally, 422 individuals (48.8% of the total in day care centers) could shift from daytime services to day community-based programs.

The study has provided a detailed examination of various dimensions and indicators related to individual activity and QoL for people with ID within the network of housing and SI services. While the study is localized to a specific regional context, the extensive sample size and multidimensional approach have shed light on several significant aspects of the LC of individuals with ID that could have broader implications.

Initially, the presentation emphasized critical data regarding the social participation of individuals with disabilities, highlighting the significant invisibility of this adult population (Yalon- Chamovitz, 2009; Francescutti & Bertelli, 2019). Nearly 50% of these individuals primarily engage with their service or home environment, with minimal presence in social and community settings, often only participating when accompanied. Their engagement in social media activities such as tweeting or posting on Facebook is rare, and they are even less likely to organize or participate in advocacy or protest activities. This population is characterized by limited visibility and is often

overlooked, necessitating proactive efforts to "seek out" rather than expecting them to "come forward."

The data on health conditions underscore the pronounced fragility of this population, particularly in the psychiatric and behavioral domains, with an estimated prevalence of 64.6%. Among this group, over 80% are currently undergoing therapeutic interventions. This fragility extends beyond psychiatric issues to encompass various health systems, as established by existing literature.

A specific analysis of behavioral disorders reveals that nearly 50% of individuals exhibit at least one problematic behavior, with approximately 30% displaying two or more. It is evident that precarious health conditions and behavioral issues are prevalent across all types of services considered in this study. Given the cross-sectional nature of the investigation, it is apparent that the likelihood of developing additional physical and behavioral problems over the course of life is significant.

The discussion regarding the socio-educational versus health-focused nature of services for individuals with ID seems misplaced. Significant progress in adult life within the community cannot be achieved without a clinical perspective. Conversely, an exclusive focus on clinical aspects may obscure the potential for human development and social participation. Future services and welfare systems must better address this complexity and ensure that professionals working with adults with ID possess the necessary vision, culture, and skills to plan and implement appropriate interventions.

Although the survey highlights the social marginalization and underlying fragility of this population compared to the general population, it also reveals a highly varied landscape of opportunities and QoL. A significant portion of the population reports satisfaction with various life dimensions and the opportunities provided by the service network and families for engaging in activities, pursuing interests, and acquiring new skills. However, others face substantial issues with QoL and limited development opportunities. Generally, the data indicate a situation heavily skewed towards welfare functions and largely confined within the physical and social boundaries of service structures. This aligns with existing literature, which suggests that service inclusion promotes community presence but does not necessarily enhance genuine social participation (O'Brien, 1987; Clement et al., 2014).

Service contexts are pivotal and have the potential to make a significant difference, particularly in the future. Innovative services and low-threshold housing solutions, developed over the past two decades, may cater to individuals with fewer support needs. However, these services also facilitate the expression of functions that might remain latent in more protective organizational forms. Longitudinal studies are necessary to better understand these effects, and regular application of the Q-VAD survey will provide valuable insights into individuals' life trajectories.

Descriptive analyses and regression models indicate that individuals with limited support needs, residing in highly protective service settings (such as protected residences and traditional semi-residential services), face significant challenges in accessing developmental opportunities and achieving satisfactory QoL. The high prevalence of behavioral disorders, including oppositional

behaviors, self and hetero aggression, and inappropriate social behaviors, may not only result from individual predispositions related to ID but also from contextual factors within these "problem environments," which may exacerbate or hinder the management of these behaviors. International studies emphasize that untreated behavioral disorders can increase the risk of institutionalization, which, in turn, may exacerbate the likelihood of their onset, persistence, and escalation (Bodfish, 1992; Ayelet, Soffer & Rimmerman, 2016; National Collaborating Centre for Mental Health, 2015). The survey highlights a clear need and urgency to improve the appropriateness of service types and contexts to meet individuals' needs and expectations. Otherwise, there is a risk of limiting opportunities and QoL. Particular attention must be given to reassessing semi-residential services, which have long been considered "undifferentiated containers" for the adult destinies of individuals with ID. Our analysis suggests that more than half of the current occupants of these services could benefit from alternative support options. Significant improvements in appropriateness should also be pursued in other types of services. This involves two fundamental technical and professional challenges: the adoption of validated tools and procedures for the timely evaluation of the needs, preferences, and expectations of individuals with disabilities, and the implementation of models and practices for creating personalized projects through direct involvement of the individual.

Additionally, there is a pressing need to provide respectful support to families to balance their desire for protection and security with the rights of individuals with disabilities to self- determination, even in situations characterized by significant support needs and dependence.

The study provided a comprehensive evaluation of the LC, support needs, and QoL of individuals with ID using the Q-VAD tool. The data analysis highlighted significant disparities in SI, opportunities, and well-being, emphasizing the importance of individualized and appropriate socio-educational settings for these individuals.

Key findings include:

- Limited social participation: nearly half of the individuals primarily interact within service environments, with restricted access to community life and friendships outside of structured programs.
- Health and behavioral challenges: a high prevalence of psychiatric, behavioral, and physical health issues was observed, with nearly 50% of individuals displaying at least one problematic behavior.
- Variability in opportunities and QoL: while some individuals report positive experiences and engagement, others face barriers to autonomy and self-determination, particularly in more restrictive service settings.
- Impact of service types: more individualized, community-based, and flexible service models are associated with better outcomes in terms of opportunities and QoL, whereas traditional residential and semi-residential services tend to be linked to lower autonomy and participation.

Regression models confirmed the influence of service models on individual well-being, underscoring the need for more adaptive and enabling environments. The study also highlighted the necessity for personalized support planning, balancing protective care with autonomy- enhancing interventions.
The findings suggest that restructuring service models and improving the appropriateness of placements could significantly enhance QoL and SI. Regular longitudinal evaluations using Q- VAD will be crucial for monitoring these trends and refining support strategies over time.
An additional aim of the study was to explore the potential applicability of the Q-VAD tool beyond the national context in which it was developed. This opens the way for its use in other countries, supporting international comparisons and the development of inclusive service models aligned with QoL and social inclusion principles. In this regard, the next chapter focuses on evaluating the potential use of the tool within the Latvian context, examining its relevance, adaptability, and contribution to local disability policy and practice.

3 IMPLEMENTATION OF Q-VAD TOOL FROM A LATVIAN PERSPECTIVE

The Q-VAD tool has been recognized as an invaluable instrument for assessing the QoL among individuals with disabilities, leading to an exploratory pilot study aimed at translating and adapting it for use within LV's disability services framework. The objective of this adaptation is to evaluate how effectively the Q-VAD can be implemented within LV's diverse disability services, potentially expanding the assessment tool's impact and applicability.

This chapter begins by examining the normative policies, disability legislation, and service structures present in LV, providing critical context and justifying the relevance of the Q-VAD's application within the country's specific disability support system. This foundational section highlights LV's established services and policies aimed at supporting individuals with intellectual and neurodevelopmental disabilities, setting the stage for understanding how Q-VAD integration could support these initiatives.

The adaptation of Q-VAD to a new language and cultural context is a multifaceted process that involves careful attention to linguistic precision and cultural relevance, as well as adherence to psychometric standards (Mihailova & Kivite-Urtāne, 2017; Volgemute et al., 2025). Ensuring that the Latvian version retains the same meaning and measurement properties as the original requires a rigorous translation and validation process, including both forward and backward translation, expert reviews, and pre-testing with potential respondents to confirm clarity and relevance in the local context. In this pilot study, the translation and cultural adaptation of the Q-VAD into Latvian aims to achieve an assessment tool that is not only linguistically accurate but also meaningful within LV's cultural framework.

The successful adaptation of Q-VAD will establish a foundation for comprehensive research into the LC and well-being of individuals with disabilities in LV. It will also facilitate the identification of risk factors impacting particularly vulnerable groups, enabling systematic monitoring of quality- of-life outcomes. Ultimately, this pilot study seeks to provide insights that can inform and enhance disability services in LV, helping to guide policies that support well-being and SI for individuals with disabilities. This chapter will detail the full adaptation process, including preliminary results from testing the instrument's usability and applicability within Latvian disability services.

3.1 Policy Framework for Individuals with Intellectual Disability in Latvia

LV has undertaken significant efforts to build an inclusive and comprehensive support framework for individuals with ID, reflecting its commitment to international human rights standards. Central to this endeavor is its alignment with the principles of the UNCRPD, which Latvia ratified on 1 March 2010 (United Nations Treaty Collection, 2010). The Convention on the Rights of Persons with Disabilities promotes equality, autonomy, and accessibility as fundamental rights for individuals with disabilities—principles that Latvia has embedded into its legislative, educational, and social policy frameworks. In particular, the education sector has seen increased focus on

inclusive practices, aiming to ensure access to quality education for learners with intellectual disabilities in mainstream and specialized settings. These developments underscore Latvia's broader commitment to fostering full participation, social inclusion, and the reduction of systemic barriers across all life domains, including schooling, employment, and community living.

One of the most transformative shifts in LV's approach to disability has been the move from a traditional medical model to a human rights-based approach. This paradigm shift redefines disability not merely as a medical condition but as a social construct influenced by barriers that impede full participation in society. Consequently, LV has restructured its welfare and legislative systems to prioritize non-discrimination, equal rights, and social integration for individuals with disabilities. These changes signal a broader societal shift toward viewing individuals with ID as active participants in their communities rather than passive recipients of care.

LV's disability strategy prioritizes personalized interventions and inclusive practices, aiming to enhance individual well-being and facilitate meaningful SI. This strategy aligns with the overarching goals of the Convention on the Rights of Persons with disabilities by addressing the multifaceted needs of individuals with ID and ensuring their participation in society as equal citizens. These efforts have been complemented by legislative reforms, policy initiatives, and the development of community-based services designed to reduce reliance on institutional care. Together, these measures highlight LV's dedication to evolving its support systems in accordance with international standards, striving to create a society where individuals with disabilities can thrive as integral members of their communities.

LV's legislative framework for disability rights and support is anchored in several essential laws that together establish a comprehensive social welfare and healthcare system. These laws promote inclusion, protect rights, and guarantee non-discriminatory access to services, forming a legal foundation aligned with the United Nations Convention on the Rights of PwD (Convention on the Rights of Persons with disabilities), which LV ratified in 2010 (BISS, 2020). The Convention on the Rights of Persons with disabilities' principles of equality, autonomy, and accessibility have been embedded into LV's policies, reflecting the country's commitment to creating a robust support structure for individuals with disabilities. The principal components of this legislative framework include the Law on Social Security, the Disability Law, and provisions under the Medical Treatment Law and Health Care Financing Law. Each of these statutes provides specific protections and entitlements for individuals with disabilities, covering a range of social, medical, and financial supports. The Law on Social Security, enacted in 1995, forms the basis of LV's social welfare system by establishing key principles for equitable access to social services. Article 2(1) of this law mandates that all individuals should be able to access social support services without discrimination based on factors such as disability, race, ethnicity, age, or socioeconomic status. While the law does not create a separate classification for people with disabilities, it incorporates specific provisions that ensure they receive essential protections against discrimination in accessing social benefits. Key areas covered by this law include social insurance, healthcare, and

rehabilitation, which are foundational supports for individuals with disabilities (Saeima of the Republic of Latvia, 1995).

Chapter II of the Law on Social Security enumerates a broad set of social rights designed to enhance the well-being and integration of vulnerable populations. It includes provisions for educational support, employment assistance, healthcare rights, and family and housing support, reflecting LV's commitment to a comprehensive social welfare network. Articles 5 and 29 of this law explicitly address social insurance and access to medical care, thereby ensuring that individuals with disabilities have access to these essential resources, safeguarding both their physical and social welfare (Baltic Institute of Social Sciences, 2021). The Law on Social Security thereby establishes LV's approach to social support by setting clear rights and responsibilities within the social security network and by ensuring services are accessible and delivered in a non-discriminatory manner.

The Disability Law, implemented in 2011, serves as the cornerstone of LV's disability-specific legislation. It introduces a structured classification system for disabilities, distinguishing between "predictable disability" and "disability." Predictable disability is defined as a temporary impairment that may progress without intervention, while disability refers to a long-term condition that significantly affects a person's physical, mental, or functional abilities, limiting their capacity for self-care and social participation (Saeima of the Republic of Latvia, 2010).

Disability evaluations under this law are conducted by the State Medical Commission based on standards set by the Cabinet of Ministers. These evaluations form the foundation for determining eligibility for disability support and guide the development of individualized rehabilitation plans. The Disability Law mandates that people identified with either predictable or long-term disabilities are eligible for personalized rehabilitation plans, which may include medical services, social rehabilitation, and vocational training. By incorporating factors such as the severity and duration of the disability, work capacity, and personal care needs, these evaluations ensure that support is tailored to meet the diverse needs of individuals with disabilities (BISS, 2020; Podziņa, 2019).

The Disability Law further specifies that individuals with disabilities should receive prioritized access to healthcare and social services. Customized rehabilitation plans, developed and overseen by the SMC, allow for a targeted approach to support, promoting better health outcomes and greater independence. This tailored model helps individuals achieve a higher QoL while enhancing their ability to participate in society. This legislation, therefore, represents LV's commitment to a person-centered support system that aligns with international disability frameworks (BISS, 2021). The Medical Treatment Law, established in 1997, emphasizes the prioritization of healthcare access for individuals with predictable disabilities, specifying that such individuals should receive timely, state-funded medical services. Regulation No. 555, enacted under the Medical Treatment Law, requires that family doctor visits for individuals with Group I disabilities (those with the most severe impairments) and for children with disabilities are fully covered by state funding. This regulation is crucial for ensuring that those most in need receive essential primary healthcare without financial barriers, thereby supporting the health and well-being of vulnerable populations (Saeima of the Republic of Latvia, 1997).

The Medical Treatment Law also includes provisions that categorize individuals qualifying for expedited healthcare. These priority groups include people diagnosed with specific conditions, such as cancer and diabetes, as well as pregnant women and young children. Such prioritization is intended to reduce wait times and enhance healthcare accessibility for those facing severe health issues. Regulation No. 555, for instance, mandates that individuals with predictable disabilities should be able to access outpatient services within 15 working days, and surgeries within five months, helping to address conditions promptly and prevent complications due to service delays (World Bank, 2020).

Complementing the Medical Treatment Law, the Health Care Financing Law provides financial support for individuals with disabilities by exempting those with Group I disabilities from co-payment requirements. This exemption significantly reduces financial barriers to healthcare for individuals with severe disabilities, thus ensuring that they receive necessary services without undue financial strain. Recent amendments have further extended this exemption to include Group II individuals, broadening access to free healthcare for a larger segment of the disability community. This exemption policy applies to consultations with general practitioners, specialists, and certain treatments, underscoring LV's commitment to accessible healthcare for individuals with high support needs (Saeima of the Republic of Latvia, 2021).

LV's integration of social security, disability, and healthcare legislation exemplifies a comprehensive, multi-layered approach to disability support. By merging social rights with healthcare protections, LV's legislative framework creates a supportive environment that safeguards against discrimination and promotes equal access to social insurance, healthcare, and personalized support. This framework not only upholds the Convention on the Rights of Persons with disabilities' standards but also reflects LV's commitment to evolving its support systems to meet the changing needs of its population.

Looking ahead, LV's framework aims to continue refining its disability support services by balancing quality of care with fiscal sustainability. As LV's population ages and disability prevalence rises, proactive strategies, such as preventive healthcare, data-driven policy development, and streamlined access to resources, will be crucial in maintaining the inclusivity and effectiveness of its disability services (BISS, 2020; BISS, 2021).

Over recent years, LV has observed a notable rise in disability prevalence, influenced by both demographic changes and increased reporting of health limitations among its population. According to the State Medical Commission's administrative data, LV's disability rate reached approximately 10% of the population in 2018, representing a 50% increase since 2008 (Ministry of Welfare of the Republic of Latvia, 2023).

This significant rise highlights the growing demand for targeted disability services, particularly for intellectual and neurodevelopmental disabilities. Further emphasizing this trend, data from the European Union Statistics on Income and LC (EU-SILC) ranks LV as having the highest proportion of individuals over the age of 16 within the EU who report "long-standing limitations in usual activities due to health problems." In 2018, 40% of Latvian respondents indicated such limitations,

surpassing the EU-28 average of 24.7%, with 30.3% reporting "some" limitations and 9.7% indicating "severe" limitations.

Age, gender, and socioeconomic status significantly shape disability prevalence in LV. Older adults, particularly those over 65, and women report higher levels of disability. Chronic health conditions—including malignant neoplasms, cardiovascular diseases, musculoskeletal disorders, and neurodevelopmental disabilities—constitute some of the primary causes. Among these, intellectual and neurodevelopmental disabilities are increasingly recognized, both in diagnosis and support services. Studies indicate that neurodevelopmental conditions often remain undiagnosed until adulthood, suggesting that improved awareness and diagnostic tools have contributed to the observed increases in reporting and services required.

LV's demographic changes also drive the increased prevalence of disability. Between 2009 and 2019, the population aged 65 and over rose from 18% to 20.3%, while the working-age population (15–64) simultaneously declined. Projections for 2030 estimate that individuals aged 65 and above will account for 25% of the population, with an anticipated increase in the old-age dependency ratio to 46.4. This shift not only highlights the growing demand for disability services but also points to the need for long-term planning to meet the needs of an aging society, particularly for those with intellectual and neurodevelopmental disabilities who may require comprehensive, continuous support.

The prevalence of disabilities in LV has steadily increased in recent years, reaching 40.7%, which is among the highest rates in the European Union. In 2018, a significant number of people with disabilities, totaling 7,046 individuals, including 256 children, were in institutional care settings, reflecting a continued reliance on institutional support. Unfortunately, alternative community- based services remain limited, underscoring a pressing need for more inclusive care options within local communities. Mental disabilities in LV have also shown a concerning rise; in 2017, the prevalence of mental disorders reached 4,635 cases per 100,000 people, up from 3,753 cases in 2011. By the end of 2016, 88,319 individuals (approximately 4.5% of LV's population) were diagnosed with psychiatric or behavioral disorders (World Health Organization, 2019).

With these demographic and health trends, LV's social and healthcare policies face the dual challenge of expanding services and implementing preventive measures to support healthy aging and functional independence among older adults. LV's Disability Law and Social Security Law will need to evolve to accommodate the growing demand for community-based, long-term support, with a particular emphasis on intellectual and neurodevelopmental disabilities. Proactive strategies, such as targeted preventive healthcare programs and rehabilitation services, could mitigate the demand on institutional care, supporting a greater proportion of individuals within their communities. In response to these trends, some municipalities have piloted initiatives aimed at improving QoL and SI for people with ID. For example, the city of Riga has launched projects to enhance accessibility within public spaces and transportation networks, making these environments more conducive to independent living for individuals with disabilities. Similarly, regions like Vidzeme and Kurzeme have worked to implement community support programs that focus on day

care services and integration activities, fostering a sense of belonging and reducing the need for institutionalization in these populations. As LV moves forward, the importance of robust data collection and analysis is paramount to understanding the outcomes of these services and making data-driven adjustments to policies.

The deinstitutionalization process in LV, initiated in 2015, represents a substantial shift in the country's approach to supporting individuals with intellectual and neurodevelopmental disabilities by transitioning them from large-scale institutional care to more integrated, community-based settings. This approach aligns with international best practices for disability support and emphasizes the SI and empowerment of individuals through housing and services tailored to community life. The deinstitutionalization program, expected to conclude by 2023, specifically targets three main groups: adults residing in state or municipal social care facilities, minors in out- of-family care settings, and children with disabilities who live at home. Each group benefits from customized support systems designed to encourage independence while maintaining essential care structures (BISS, 2020). A crucial aspect of the deinstitutionalization initiative is fostering collaboration with local governments, which are expected to sustain and oversee community-based services once European Union (EU) funding is no longer available. However, financial sustainability and the availability of qualified personnel to provide specialized community care remain pressing concerns. Funding for deinstitutionalization projects in LV has predominantly been sourced through the EU's European Social Fund, with a focus on building community resources, housing modifications, and training programs for caregivers and social workers. According to BISS research, the transition's success heavily depends on whether municipalities can secure stable funding streams and maintain the necessary workforce to support individuals with ID in their new settings (BISS, 2020:130-131). NGOs in LV, such as the Latvian Movement for Independent Living, have voiced concerns that the deinstitutionalization process lacks a fully cohesive and comprehensive implementation strategy. This fragmentation has led to variations in service quality across different municipalities and limited awareness of the specific needs of service recipients. Municipalities often lack a unified plan, leading to inconsistencies in service delivery and, in some cases, resistance within traditional care institutions due to the complexities of managing decentralized services. One notable deinstitutionalization - related project is the "Stronger Together" initiative in Valmiera, a collaboration under the Central Baltic Sea Region Cross-Border Cooperation Program (2021-2027) aimed at fostering employment opportunities for people with intellectual and neurodevelopmental disabilities. This project, running from 2024 to 2027, focuses on bridging the employment gap by equipping employers with anti-discrimination training and developing targeted job readiness programs for individuals with ID. The project includes local Latvian municipalities, such as the Valmiera Development Agency, and partners from Sweden, enhancing cross-border collaboration to share best practices and create supportive employment environments for individuals with ID (Valmiera Development Agency, 2024). The deinstitutionalization framework also supports specialized residential solutions, such as group apartments and smaller housing units. These facilities enable individuals with ID to live semi-

independently while receiving tailored support to manage daily routines and social interactions. Municipal governments play a role in ensuring these housing solutions are accessible and equipped with the necessary resources, such as day care centers and vocational training opportunities. For instance, social enterprises in several municipalities are exploring ways to integrate individuals with ID into the labor market, often with financial support from the Latvian state, which subsidizes employers who adapt roles for individuals with disabilities. In response to these challenges, public awareness initiatives have been launched to educate Latvians about the principles of deinstitutionalization. Recent surveys reveal mixed public understanding of deinstitutionalization; while there is support for integrating individuals with ID into community life, about 14% of respondents fully understand the concept of DI, suggesting that continued public education is necessary for long-term success. These insights underscore the importance of ensuring that Latvian society is prepared to support and embrace the DI process, creating a fully inclusive environment for individuals with intellectual and neurodevelopmental disabilities (Ministry of Welfare of the Republic of Latvia, 2023).

LV has developed a range of services specifically tailored to support adults with intellectual disabilities, with a focus on fostering independence, enhancing social engagement, and improving overall QoL. These services are delivered through a structured framework that includes day care centers, assisted living programs, and residential care facilities, each designed to accommodate varying levels of need and support requirements. The service framework includes day care centers, assisted living programs, and residential care facilities, each serving different levels of need and support requirements.

- *Day care centers* are a crucial element of LV's disability services, accommodating about 40% of adults with intellectual and neurodevelopmental disabilities (BISS, 2020). These centers provide structured programs that focus on personal development, life skills, and social integration. Programs typically include life skills training, which helps participants manage essential daily activities like cooking, budgeting, and personal care. Occupational therapy sessions are also available, aimed at developing fine motor skills, coordination, and work-related abilities, which can facilitate vocational opportunities (World Bank, 2020). In addition to skills training, day care centers offer creative workshops, including handicrafts and art sessions, which provide therapeutic benefits and encourage self-expression. Social activities such as group discussions, games, and community outings foster interaction, teamwork, and communication skills, allowing participants to build supportive friendships and networks. Day care centers are also invaluable to families, offering reliable daytime care that gives caregivers a respite and the opportunity to pursue other responsibilities (BISS, 2021; Latvian Ministry of Welfare, 2022). To address accessibility, particularly in rural areas, the Ministry of Welfare has implemented mobile day-center units that bring services to remote communities. These mobile units deliver essential day-center activities like life skills training and social programs directly to underserved areas, thus ensuring wider accessibility. Many day care centers also incorporate specialized facilities such as

sensory-friendly rooms, which provide a calming environment for individuals with sensory processing needs. By offering customized programs and sensory support, day care centers foster inclusivity and allow individuals with a range of needs to thrive (BISS, 2020; World Bank, 2020).

- *Residential Services,* also known as residential care facilities, offer continuous, round-the-clock support for adults with intellectual and neurodevelopmental disabilities who have complex needs requiring a higher level of assistance. These facilities typically operate in smaller, family-style units that foster a home-like environment, creating a sense of community and stability. Individuals in residential care live in small group settings with consistent, specialized support from trained healthcare professionals, including social workers, nurses, and occupational therapists (Latvian Ministry of Welfare, 2022). Each resident in a residential care facility has a personalized care plan addressing their unique needs, which may include medical care, daily living support, and various therapeutic interventions. Activities such as physical therapy, cognitive rehabilitation, and art therapy are commonly integrated into daily routines to improve well-being and encourage personal development. Tailored to individual abilities, these therapeutic activities promote engagement, cognitive stimulation, and a sense of achievement. Socialization is also prioritized in residential care, with staff organizing group activities and facilitating interaction among residents. Although there is an ongoing shift towards community-based care, residential facilities remain essential for individuals with high support needs who may not be suited for more independent living arrangements. For these individuals, residential care provides a stable, supportive environment with comprehensive medical and emotional resources that are essential for maintaining their health and QoL (BISS, 2020; Podziņa, 2019).
- *Assisted Living Programs* provide semi-independent housing for individuals with intellectual and neurodevelopmental disabilities who need moderate support in their daily lives. These programs are typically situated in urban settings, allowing residents to participate in community activities and access essential services more readily. In assisted living, residents may live in shared or individual apartments, where they receive targeted support for tasks like financial management, meal preparation, and personal care. They are encouraged to be as independent as possible, making assisted living an empowering model of support (BISS, 2020). The integration of assisted living facilities within urban environments is a key feature, as it enables residents to access public amenities, employment opportunities, and social activities. EU funding has been instrumental in expanding these programs as part of LV's broader strategy to reduce institutional care reliance and enhance community integration. Assisted living residents are often involved in decision-making regarding their daily routines, fostering autonomy and self-confidence. Staff in these facilities also provide support in navigating social situations, seeking

employment, and participating in community events, thus enhancing the residents' social engagement and QoL (BISS, 2021; World Bank, 2020).

3.2 Implementation Process of Q-VAD Tool from Latvian Perspective

The Q-VAD framework align with LV's emphasis on data-driven policy development. Q-VAD's focus on quality-of-life domains directly aligns with the principles of the United Nations Convention on the Rights of PwD (Convention on the Rights of Persons with disabilities), particularly those related to autonomy, participation, and inclusion. By adopting the Q-VAD, LV can strengthen its compliance with these international standards, demonstrating its commitment to enhancing the well-being of individuals with disabilities. As part of the European Union, LV is committed to adopting evidence-based approaches to disability support. The Q-VAD aligns with EU strategies for deinstitutionalization, community-based care, and the promotion of SI, positioning it as a tool that complements LV's policy trajectory.

LV's ongoing deinstitutionalization efforts aim to transition individuals with ID from institutional settings to community-based living arrangements. The Q-VAD supports these priorities by:

- assessing transition success: the Q-VAD can evaluate the QoL of individuals before, during, and after their transition to community-based care, offering insights into the effectiveness of deinstitutionalization initiatives;
- guiding service development: data collected through the Q-VAD can inform the design of community-based services, ensuring they address the specific needs of individuals with ID, such as opportunities for social engagement, access to education, and vocational training;
- Promoting person-centered support: by emphasizing personalized quality-of-life evaluations, the Q-VAD aligns with LV's commitment to tailoring services to individual needs, a core principle of its disability framework.

Integrating Q-VAD could support ongoing quality-of-life monitoring, offering structured insights into how well services meet the needs of individuals with ID. By systematically collecting data across key life domains, service providers and policymakers could better understand program impact over time and make evidence-based improvements to enhance service delivery. The Q- VAD's potential application would allow LV to align disability services more closely with international quality standards, such as those outlined in the UN Convention on the Rights of PwD (convention on the rights of persons with disabilities) and supported by LV's Disability Law and Social Security Law (BISS, 2021; Ministry of Welfare of the Republic of Latvia, 2023).

To verify the compatibility of the Q-VAD with LV's current services, an exploratory study has been initiated. This study aims to assess how well the Q-VAD framework could integrate with local day care and residential services, focusing on the practicalities of adapting the assessment tool to the Latvian context. Results from this study would provide insight into the effectiveness of the tool in capturing quality-of-life improvements, thereby supporting data-driven and individualized care

planning. By enabling systematic outcome tracking across SI, autonomy, and interpersonal relationships, the Q-VAD could guide future policy and service adjustments, enhancing LV's ability to deliver inclusive, high-quality support that meets the evolving needs of its disability community (Podziņa, 2019).

In this context, the exploratory study on the Q-VAD's adaptation represents a valuable step toward establishing a standardized, outcome-focused evaluation method within LV's disability services. The information gathered through such evaluations could ensure that LV's policies and service offerings not only comply with international standards but also enhance QoL for individuals with ID, ensuring that their needs and rights are comprehensively addressed.

To ensure the reliability and validity of the adapted Q-VAD, a methodological approach was applied during the translation process, focusing on its validated sections. The pilot study included the most relevant validated subscales (2, 3, 4, and 5), which are key in detecting SI and QoL indicators.

This approach involves a detailed examination of the linguistic and cultural differences between the source and target languages, ensuring that the conceptual equivalence is maintained. Additionally, the translated version must be tested for coherence and comprehensibility through pilot tests and iterative revisions.

The translation and adaptation of the Questionnaire followed the following process (Beaton et al. 2000).

- *Direct translation*. The original English version of Q-VAD, including instructions, items, and response options, was fully translated into Latvian. This task was carried out independently by two native Latvian translators, both possessing C2-level proficiency in English and having backgrounds in rehabilitation and education.
- *The two translators (T1 and T2) convened to share and compare their translations*. They identified any discrepancies in terminology or expressions and discussed which version better captured the meaning of the original tool. This collaboration culminated in a single, unified Latvian version of Q-VAD.
- *Back-translation*. The newly translated Latvian version of Q-VAD was then back-translated into English by a separate English translator. This step was crucial for verifying that the back-translated text accurately reflected the source text, ensuring that no critical information was lost or altered in translation.
- *Approval by disability expert operators*. The assessment tool was then submitted to the attention of two disability expert operators in LV and IT to check the equivalence of the versions with reference to the semantic, idiomatic, conceptual, and experimental areas. For each item, it was examined whether the performance and the "target" concept had been correctly expressed, whether there were discrepancies, or whether consensus and alignment had been reached for each of them.
- *Testing of the translated version*. The Latvian version of Q-VAD was applied within Latvian disability services to evaluate its comprehensibility and the practical aspects of its

administration. The study involved administering the assessment tool to operators working in day care and residential services for individuals with ID within the municipal area of Rezekne. This testing phase aimed to assess whether the completion times fell within reasonable limits and to gather insights on the overall usability of the tool.

The study focused on adults with ID who were enrolled in day or residential services within the municipal area of Rezekne. A purposive sampling method was employed, selecting individuals from existing disability services networks. The opportunistic nature of the sample reflects the accessibility of participants and the practical constraints of the study setting, aiming to provide insights into this population's unique circumstances. While this approach limits generalizability, it offers a valuable exploration of service users' experiences in this specific geographic and social context. Participants who met one or more of the following conditions were excluded from the study:

- significant physical or psychopathological health issues in the six months before data collection. This included, for example, acute episodes of mental disorders, prolonged hospital stays, or medical conditions that significantly impacted their daily lives.
- Significant changes in care and functional levels in the last six months. These changes could involve relocations to new facilities, substantial modifications in care or assistance plans, or variations in personal autonomy.
- other conditions of personal or social instability, such as recent bereavements, family separations, or situations that significantly altered the participant's emotional and relational balance. These exclusion criteria were established to ensure that the data collection reflected stable conditions, allowing operators to respond to the Q-VAD items with greater reliability.

The study involved the compilation of the instrument for 31 adults with ID, aged between 18 and 54 (average age of 37), through interviews with their designated support operators. The selection of participants was facilitated by 11 operators who took part in the study. Inclusion criteria specified that participants must be aged between 18 and 65, possess a diagnosis of ID, be receiving services from either a day program or a residential facility, and have a support operator who had known them for at least six months, thereby ensuring the operator's ability to respond reliably to the assessment tool items. Exclusion criteria included any recent significant changes in LC (such as relocation or loss of family members) or in physical or mental health status.

Q-VAD, in its Latvian version, was implemented through a structured interview (following the structure of the tool item by item) conducted by the same person with pedagogical and rehabilitation training in disabilities, who formulated the questions and recorded the related answers. The time needed to complete the assessment tool was also measured. All recordings were transcribed, and a report was drawn up grouping the common elements. The interviewer has benefited from specific training in the use of the English language tool of n. 2 hours and remote support for any doubts and critical issues that emerged during the interview. The choice of operators to be involved was made considering a length of service of at least 3 years in the field of

disability, having a qualification as a care or educational operator, and the availability to collaborate in the study. After having gathered the availability of the participants and operators, the interviewer made a short presentation of the objective of the study, lasting approximately 30 minutes. Each interview was accompanied by a note from the interviewee regarding:

- the level of understanding of items for respondents: a Likert scale for each item (5 very clear – 1 difficult, needs detailed explanation) was applied;
- the level of items comprehension ("ability to get into the client's life") of the items for respondents: a Likert scale for each item (5 very easy – 1 very difficult) was applied.

Furthermore, the level of completeness of each single subscale dimension from the respondent's point of view was considered, and by all these indicators, the need or not to foresee changes was considered. The need to make changes to the translated assessment tool emerges as a consequence of the expression of difficulties by at least 15% of the operators involved in using the tool. As a result of the Direct Translation, two translations into Latvian of the Q-VAD assessment tool were obtained, accompanied by the respective indications in which each translator indicated any doubts about terms or phrases. The Reverse Translation resulted in two versions back translated into Latvian, accompanied by the respective reports regarding the terms or concepts that presented the greatest difficulties. The discrepancies presented were in any case minimal, confirming the fact that the operational construction of the items in the original language reduces the risk of interpretations and misunderstandings even following translations. Through cross-examination between translators, a single translation of the tool into Latvian was obtained, which indicated how each of the discrepancies had been resolved.

Finally, after analyzing the interview transcripts, the following information was drawn. The analysis of the collected data followed a structured approach combining both quantitative and qualitative methods. Quantitative analysis was conducted using descriptive statistics to summarize the data from the Q-VAD subscales, including means, standard deviations, and frequencies, providing a clear understanding of trends across the sample. Each subscale was evaluated independently to identify patterns in Supports needs, Opportunities, QoL, and Behavioral Disorders. The aggregated scores from these subscales were then compared to explore interrelations, such as the impact of support needs on Opportunities or the relationship between behavioral challenges and QoL indicators. Qualitative insights were derived from the feedback provided by operators during the interview process. Operators' comments on item clarity, comprehensibility, and respondent understanding were systematically reviewed and categorized to identify recurring themes or challenges. These insights were integrated with the quantitative findings to ensure a comprehensive interpretation of the data and to refine the assessment tool where necessary. This mixed-methods approach provided a robust framework for evaluating the effectiveness of the adapted Q-VAD tool, ensuring that both numerical trends and contextual nuances were considered in concluding. The levels of understanding and comprehension of the items for respondents are reported in Table 3.1. In this context, understanding refers to the

individual's capacity to interpret and make connections between concepts, events, and experiences across different situations, while comprehension indicates the ability to grasp the meaning or recognize the significance of specific information or tasks. This distinction allowed for a more nuanced evaluation of cognitive and functional engagement with each item.

Table 3.1

Levels of Understanding and Comprehension of the Items for Respondents

(created by the researcher).

Support needs for individual functioning.	**Understanding**	**Comprehension**
Do you recognize living environments, places, and paths to move within them?	5	5
Can you predict your daily schedule and activities?	5	5
When you have to perform an important task/activity of your day...	4	4
When people come to you...	5	5
When you talk...	5	5
When you need or desire to express something...	5	5
When you find yourself interacting with other people...	5	5
Can you move around in your living environment?	5	5
When you need to wash...	5	5
When do you take care of individual parts of your body (washing your hands, face, and teeth, combing your hair, shaving/makeup, cutting your nails)?	5	5
Can you get dressed and undressed?	5	5
When you have to eat...	5	5

When you need to go to the bathroom...	5	5
When you make your meals...	5	3
To keep your living space tidy and clean (clean house, tidy up your room, and keep your personal spaces tidy...)	5	5
When you move to your town/city...	5	5
When you're shopping...	5	5
When you take part in social activities (recreation, gatherings, parties...) in your town/town...	5	4
Quality of life	**Understanding**	**Comprehension**
Do you feel energetic and vital?	5	2
Do you rest and relax properly?	4	2
Do you feel comfortable where you live?	5	2
Are there things (people, activities, events) that make you happy?	4	3
Are you satisfied with the things you do and how you spend your time in your day?	5	4
Are you satisfied with the personal belongings or assets you have, and how you can dispose of them?	5	4
Do your daily living environments allow you to be alone (when you need to be) or protect your privacy?	5	5
Are your living environments adapted to your needs, needs and preferences?	5	3

Do you have relationships with people living in your neighborhood/territory (even if you are on residential service)?	5	5
Do the services, opportunities, or recreational places in your neighborhood/territory (e.g. shops, bars, church, parish, theatre, cinema...) meet your needs, interests, wishes?	5	4
Are you involved in significant activities in your neighborhood/territory (e.g., recreation, sports, volunteering...)?	5	5
Do you feel satisfied with the relationship you have with your family or with reference figures outside the care context?	5	2
Do you have friends with whom you are able to maintain constant relations (excluding family members, staff, and volunteers of the facilities)?	5	5
Do you have the possibility to carry out social activities that are rewarding for you (e.g., going out, going to parties...)?	5	5
Do you have the possibility to put into practice what you know how to do in your life (e.g., going out on your own, using means, using your computer, doing a job/activity...)?	5	3
Have you learned new skills or knowledge (autonomy skills, training courses...)?	5	5
Have you had the opportunity to access new roles or new Opportunities (e.g., training, work, living)?	4	4

Have you had the opportunity to express your preferences and wishes to someone?	5	5
During your day, do you have the possibility to make choices related to your activities (e.g., what to eat, what to wear, what to do)?	5	5
Do you have the possibility to decide who to stay with, who to meet, who to attend, and who to do certain activities with?	5	5
Opportunities	**Understanding**	**Comprehension**
Carrying out personal care activities?	5	5
Carrying out activities of care for the living environment?	5	5
Use household appliances or technology?	5	5
Moving around the territory?	5	5
Make use of community services (e.g., shops, offices, cinemas, gyms)?	5	5
Participate in significant community activities?	5	5
Learning skills for the autonomous management of one's person through targeted interventions/training?	5	3
Learning cognitive, scholastic, and technological skills (telephone, PC, etc.) through targeted interventions/training?	5	3
To be engaged in roles, tasks, and activities useful for the people you live with, who live near you, or who attend your life context?	3	3

Being engaged in activities and tasks related to a job with a working value (even unpaid)?	5	5
Looking for or performing a job?	5	5
Learning skills for external autonomy through targeted interventions/training?	5	5
Socializing/meeting people important to you?	5	5
Taking part in recreational or socializing activities that are important to the person?	5	5
Behavioural disorders	**Understanding**	**Comprehension**
Hetero-direct aggression	5	5
Self-directed aggression and self-harm	5	5
Aggressiveness towards environments or things	4	5
Ritual stereotypes and compulsive behaviors	4	5
Ingestion of non-edible substances	5	5
Oppositional behaviour	3	3
Socially inappropriate behaviour	4	5
Inappropriate sexual behaviour	5	5
Other behaviour disorders	5	5

While in the Supports needs, Opportunities and Behavioral disorders scales, we find a distribution of scores between “3” and “5”, similar to the evaluation of the level of understanding level (83.72% score "5", 11.62% score "4" and 65% score “3”) in the QoL scale, 65% of the items were rated "4" or "5", 15% with a score of "3" and 20% with a score of “2”. In other words, it seems that the QoL Scale presents greater difficulties for the interviewee in being able to consider the person's life condition. The items considered difficult were: “Do you feel energetic and vital?”, “Do you rest and relax properly?”, “Do you feel comfortable where you live?”, “Do you feel

satisfied with the relationship you have with your family or with reference figures outside the care context?". It can be noted that these are items that require a strong perspective taking action, which is inevitable in all processes of analysis of subjective well-being indicators involved in the evaluation of an individual's QoL. At the same time, for all of them, a high level of understanding was rated ("4" and "5").

The raw scores from the Q-VAD subscales (Supports needs, Opportunities, QoL, and Behavioral Disorders) were systematically aggregated and analyzed to identify patterns and trends in the data. With the aim of providing a demonstration of how the data provided by Q-VAD could be used, we consider in a purely opportunistic way the data obtained in an aggregate manner as if they referred to a group of subjects frequenting the same service. The application of the tool can allow the data to be analyzed in a composite way by considering the sum of the raw scores obtained in the individual subscales for the 31 subjects with ID evaluated. In the following graphs, the results obtained for the different subscales (Support needs, Opportunities, QoL, and Behavioral disorders) are indicated. Figure 3.1 indicates that support needs are greater for the areas of communication ("when you talk...", "when you need or desire…" …) and in predictive activity.

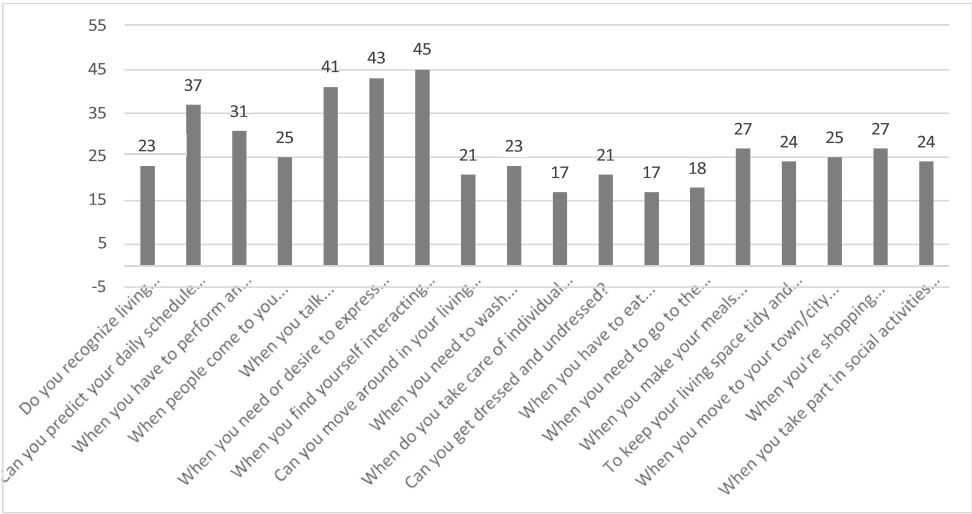


Figure 3.1: **Distribution of Aggregated Scores about Support needs Subscale**

(created by researcher).

Figure 3.2 shows the Opportunities indicators. The majority of subjects have high scores in the opportunities to receive help with self-care activities, socializing, and taking part in recreational activities. There are fewer opportunities for life activities in the SI community, for learning autonomy, and for personal development.

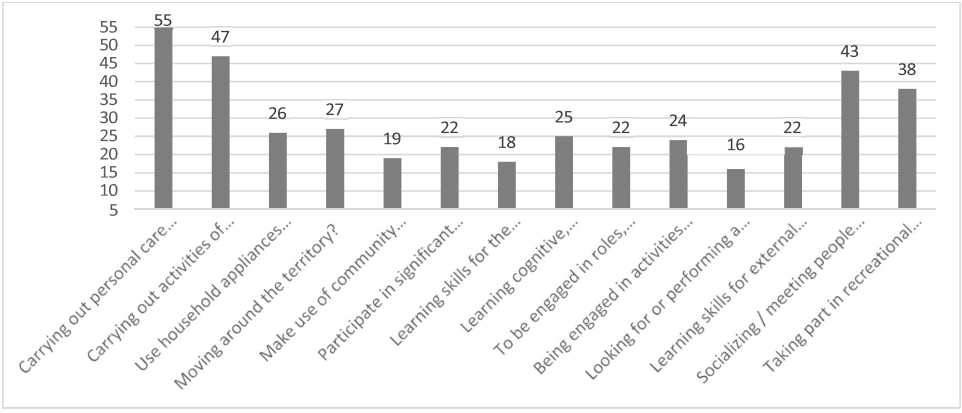


Figure 3.2: **Distribution of Aggregated Scores about Opportunities Subscale** (created by research).

These data are in relation to those of QoL indicators (Figure 3.3). Most levels of satisfaction are related con the indicators included in the personal well-being (emotional, physical, and material well-being). Lower levels of satisfaction for the SI, personal development, and self-determination are highlighted by the collected data.

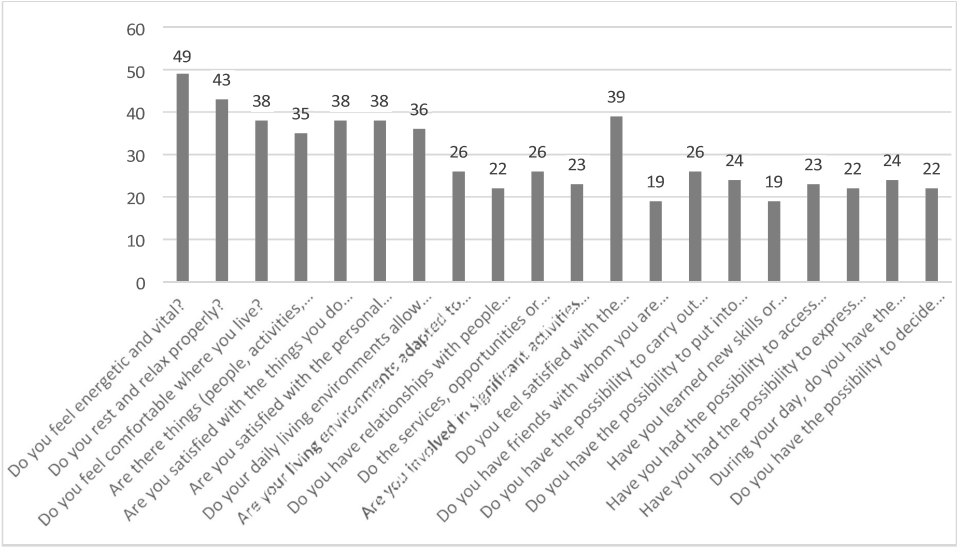


Figure 3.3: **Distribution of Composite Scores about QoL subscale** (created by research).

The scores for behavioral disorders reveal the presence of various types of behaviors, with external direct aggression and ritual stereotypic behaviors exhibiting a particularly high prevalence. This analysis offers a comprehensive view of the LC of this group, highlighting moderate support needs primarily related to communication challenges. Additionally, the data indicate low Opportunities and diminished satisfaction in QoL, particularly in the domains of SI and personal development.

These findings suggest critical considerations for intervention planning and service programming. For instance, one might question whether poor communication and relational skills are a cause or a consequence of the limited opportunities available to individuals for engaging with external life contexts and acquiring new skills. Furthermore, it raises the issue of whether the observed problematic behaviors stem from a lack of habilitative interventions and meaningful learning experiences. The presence of self-aggressive behaviors and stereotypies may indicate insufficient engagement in activities that hold significance for these individuals.

To address these challenges, it is essential that programming focuses on developing communication skills and creating opportunities for community involvement where these skills can be practiced. Engaging individuals in meaningful activities should also be a priority, as such involvement is likely to enhance their QoL and overall well-being. The data underscores the necessity for targeted interventions that not only address immediate behavioral concerns but also foster greater SI and personal growth.

In conclusion, the process of translating and adapting the Q-VAD assessment tool into Latvian entailed a meticulously structured and scientifically rigorous approach to ensure both linguistic precision and cultural relevance. The process encompassed several key phases, beginning with a direct translation of the original English version into Latvian. This phase involved careful linguistic adaptation to preserve the semantic integrity of the items. Subsequently, a comparative analysis of two independent translations was undertaken to identify and reconcile any discrepancies, ensuring linguistic consistency. The next phase involved back-translation, wherein the Latvian version was retranslated into English to evaluate its alignment with the original text, thus confirming its conceptual equivalence. Following this, disability experts evaluated the instrument for contextual appropriateness and conceptual fidelity, assessing whether the items were meaningful and relevant in the Latvian sociocultural context. The final phase of the adaptation process involved testing the translated version to evaluate its practicality, comprehensibility, and overall usability in real-world conditions.

The findings from the initial implementation yielded encouraging results. The participants demonstrated high levels of understanding and engagement with Q-VAD items, indicating that the linguistic adaptation process had been successful in maintaining clarity and accessibility. Minimal discrepancies in participant responses further underscored the reliability of the tool. However, some challenges were identified in the QoL scale, particularly in items requiring abstract reasoning or significant perspective-taking, which proved difficult for certain participants. Feedback from disability experts corroborated these findings, emphasizing the need to refine specific items and response formats to enhance their comprehensibility and cultural relevance.

Furthermore, the small sample size reflects the exploratory nature of this pilot study, which aimed to test the applicability of the adapted Q-VAD assessment tool and generate preliminary findings to guide future research. The reliance on operators introduces a potential for subjective bias, although their familiarity with participants also ensures informed responses and reliable data collection. Despite these limitations, the study offers a foundational understanding of the challenges and opportunities faced by this population, providing a basis for more extensive research and targeted interventions.

Despite these challenges, the Q-VAD demonstrated substantial utility as an evaluation instrument, effectively capturing critical dimensions of life quality and well-being among individuals with disabilities. The structured interview format, combined with standardized response methods, facilitated efficient data collection and ensured consistency in the administration process. Importantly, no major structural deficiencies were identified in the subscales, reinforcing the validity of the adapted tool.

Future research efforts should prioritize a systematic and comprehensive evaluation of the Q- VAD's psychometric properties to confirm its reliability and validity within the Latvian context. Large-scale validation studies are required to assess internal consistency, test-retest reliability, and construct validity across diverse demographic and diagnostic groups. Such studies will provide

robust evidence of the instrument's capacity to accurately measure the intended constructs and offer insights into its generalizability.

Longitudinal research is also critical for assessing the Q-VAD's sensitivity to temporal changes in participants' conditions. Such studies would elucidate the tool's ability to track shifts in QoL, behavioral patterns, and Opportunities, particularly in response to targeted interventions or systemic changes in disability services. This dynamic application would position the Q-VAD as a powerful tool for evaluating the efficacy of interventions and guiding evidence-based policy and program development.

Furthermore, comparative analyses with other internationally recognized quality-of-life evaluation instruments are essential for benchmarking the Q-VAD's performance. These studies will identify areas where the Latvian implementation excels and where further refinements may be needed, ensuring the tool adheres to the highest standards of validity and reliability. Findings from such comparative studies will also enhance the tool's credibility within the broader scientific community.

Another pivotal aspect of future research involves training and capacity-building for professionals tasked with administering the Q-VAD. Ensuring that personnel are well-versed in the theoretical foundations and practical nuances of the instrument will enhance the reliability of data collection and facilitate its integration into routine disability evaluations. Standardized training programs, combined with ongoing professional development, will strengthen the implementation process and amplify the impact of the tool.

In summary, the adaptation and validation of the Q-VAD assessment tool for use in LV represent a significant advancement in the assessment of QoL for individuals with disabilities. The ongoing refinement and multidimensional evaluation of the tool—including large-scale psychometric validation, longitudinal tracking, and comparative benchmarking—will solidify its role as a cornerstone for evidence-based disability services and policymaking. By addressing the evolving needs of individuals with disabilities, the Q-VAD has the potential to drive meaningful improvements in their QoL and overall well-being.

CONCLUSIONS AND PROPOSALS

As a result of the scientific literature research and empirical study, several conclusions were drawn that directly address and provide answers to the research questions posed in this Thesis. The following section summarizes the main findings related to the theoretical and methodological foundations for assessing LC, the development and validation of the Q-VAD assessment tool, the identification of SI and QoL-related factors, and the outcomes of its pilot adaptation in LV.
The study focused on the LC of individuals with ID in residential and day care settings, analysing the relationship between SI, QoL, and the types of services provided. Central to this work was the exploration of theoretical models within special education and their application to the socio-educational context of service provision. The research identified both hindering and facilitating factors influencing quality of life and social inclusion, highlighting the critical role of person-centred, inclusive practices. Boundaries of the current investigation are acknowledged, and directions for future research are proposed. Finally, recommendations are formulated at policy, institutional, and professional levels to guide the development of more responsive and equitable support systems for individuals with ID.

1. The first research question concerned the identification of theoretical and methodological foundations necessary to assess the LC of individuals with ID, particularly focusing on factors influencing their QoL and SI in educational and care settings. A structured literature review, conducted in line with PRISMA 2020 guidelines, allowed for the identification of core concepts relevant to the assessment of LC. Rather than focusing on intervention studies, the review was tailored to explore theoretical frameworks, resulting in the selection of key constructs such as QoL (Schalock et al., 2010), individual functioning (Schalock, Luckasson & Tassé, 2021), support needs (Moran et al., 2023), self-determination (Wehmeyer & Schwartz, 1998), independence (Ionanna, 2020), and SI (Cobigo et al., 2012). Through the integration of these models, a comprehensive conceptual framework was formulated. This framework underpinned the development of the Q-VAD instrument and offered a methodological foundation that aligns with inclusive pedagogy. It also reinforced the importance of assessing not only impairments or support needs, but also capacities, opportunities, and contextual influences on the lives of individuals with ID.

2. The second research question addressed the influence of pedagogical and service-related factors on the inclusion and QoL of individuals with ID. To empirically investigate this dimension, the Q-VAD tool was developed, tested, and validated through a large-scale study involving 1,688 individuals from day care and residential services in FVG (IT). The tool, grounded in validated models of functioning and QoL, was designed to capture a wide range of dimensions across six key sections: socio-personal data, support needs, QoL, opportunities, behavioral disorders, and health. The psychometric validation confirmed the reliability and robustness of the tool. High internal consistency values were found across the major sections, supported by strong construct

validity and inter-rater reliability measures. Each section revealed clear and interpretable factor structures: for support needs, two distinct domains emerged (social/communication support and support for daily living), while the QoL section reflected physical/relational well-being and self-determination. The "opportunities" dimension was also bifurcated into "opportunities to do" and "opportunities to learn", both essential for understanding participation and engagement.

These findings enabled a deeper analysis of how various service and pedagogical variables impact users' experiences. The data revealed substantial barriers to inclusion: a large proportion of participants experienced social isolation, with 64.3% having no friendships outside the service context. Autonomy was also limited—less than 15% of users could use transportation independently—and digital exclusion was widespread, with only 23.8% owning a smartphone. Most notably, over 90% of participants had never had access to paid employment, and learning opportunities to acquire independent living skills were often absent or insufficient.

At the same time, several enabling factors were identified. Individuals who expressed satisfaction with their current LC tended to report higher QoL scores. Strong family ties and involvement in social or educational activities were positively associated with self-determination and personal well-being. Importantly, the type of service emerged as a determining factor in outcomes. Those in community-based or low-threshold services reported higher levels of QoL and more access to meaningful opportunities, even when their support needs were high. This suggests that service design plays a critical role in shaping life trajectories and that inclusive environments can buffer the effects of impairment and promote equity in outcomes.

A cluster analysis identified eight distinct user profiles. Nearly half of the participants belonged to clusters characterized by high opportunity and QoL scores. By contrast, the most vulnerable group—characterized by low autonomy, low QoL, and high support needs—was more frequently found in protected residential settings. Notably, satisfaction with Opportunities and QoL did not correlate directly with the intensity of support needs. This challenges deficit-oriented perspectives and reinforces the idea that inclusive pedagogical and environmental factors can significantly enhance personal outcomes, regardless of the severity of disability.

3. The third research question explored the findings and challenges that emerged from adapting and piloting the Q-VAD tool in Latvia, with the aim of evaluating its linguistic, conceptual, and operational feasibility in a different socio-educational context.

The tool was translated and culturally adapted using forward-backward translation, expert consultation, and a pilot test in the Rēzekne municipality. A total of 31 individuals with ID, supported by 11 professionals, participated in the pilot study. The adaptation process confirmed the instrument's high comprehensibility and relevance. The Q-VAD's language was described as clear and user-friendly, and its modular structure was appreciated for its applicability in both individual assessment and service monitoring. Some challenges emerged, particularly with items related to internal states—such as fatigue or emotional energy—which may require visual supports or alternative formulations for nonverbal individuals. Despite these minor limitations, the pilot

demonstrated that Q-VAD could be integrated into everyday service routines without major disruptions and without generating floor or ceiling effects. Professionals highlighted its potential for facilitating conversations about support, inclusion, and personal goals. Preliminary data collected in Latvia mirrored some patterns seen in the Italian study. Participants generally had access to care and leisure activities, but experienced limited opportunities for autonomy training, independent living, or employment, common constraints in center-based settings. Behavioral concerns were present and included manifestations such as aggression or ritualistic behavior. Higher support needs were again associated with reduced access to Opportunities and lower QoL scores. Importantly, the successful use of the tool in LV enabled comparative analysis between national systems. It revealed how cultural, institutional, and policy-related differences affect service outcomes. Despite its small scale, the pilot demonstrated that Q-VAD is both conceptually appropriate and methodologically feasible for use in Latvia, and that it can generate meaningful data for improving service quality, planning individualized interventions, and informing national policy in line with UNCRPD principles. The findings also highlight the tool's potential to contribute to LV's ongoing deinstitutionalization process by providing reliable, structured assessments that support transitions toward more inclusive service models.

4. Beyond the three research questions, the research yielded additional important findings that strengthen the scientific foundation for the Q-VAD tool and expand the understanding of how LC among individuals with ID can be systematically assessed and improved:

- The systematic literature review, conducted according to PRISMA 2020 guidelines, revealed a **lack of existing tools** specifically designed to assess the LC of individuals with ID, while highlighting key scientific criteria and dimensions for LC evaluation, forming the theoretical framework for the development of the Q-VAD assessment tool.
- Psychometric testing confirmed that the **Q-VAD tool is a valid and reliable instrument**, with strong internal consistency for all core sections (e.g., Support Needs $\alpha = .939$ and .955; QoL $\alpha = .881$ and .888; Opportunities $\alpha = .888$ and .817) and an excellent KMO value ($\geq .876$).
- Analysis of daily functioning revealed that more than half of the participants required high levels of support in instrumental tasks such as cooking (59.2%), maintaining hygiene in personal spaces (44.1%), shopping (43.7%), and mobility (43.1%), emphasizing **the need for targeted pedagogical interventions** aimed at developing practical skills and fostering autonomy.
- Despite satisfactory family ties, the levels of self-determination, personal development, and peer relationships were identified as low, highlighting the negative correlation between support needs and autonomy, emphasizing **the need for educational pathways** that prioritize agency and decision-making capacity.
- The presence of behavioral disorders (47.4% with at least one, 29.5% with two or more) and complex health needs (68.25% with medical comorbidities; 72% under

pharmacological treatment) reflected the clinical vulnerability of these individuals and pointed to **the need for integrated educational and healthcare strategies**.

- Functional profiling revealed that approximately 47.5% of users demonstrated high developmental potential but were not placed in appropriate service settings, indicating a misalignment between individual needs and service provision, which requires **more flexible and progressive inclusion pathways.**
- **Opportunities of life** for participation and learning **were found to be central to inclusion, but remain limited**: 91.8% of participants had never held a job, and one- third reported low or no social participation, reflecting a persistent culture of care over inclusion that hinders personal development.
- **The outcomes were influenced by service type** provided: institutional settings were associated with lower QoL and fewer opportunities, as well as higher support needs (46.3% of users in protected residences fell into the lowest functioning profile "---"), while community-based services yielded better outcomes, emphasizing the benefit from more inclusive environments.
- The adaptation of the Q-VAD from a Latvian perspective was completed through a rigorous forward-backward translation process and expert validation, resulting in **86% of the items being fully understood** by both users and professionals, while presenting a greater interpretive difficulty, especially with items requiring abstract reasoning (e.g., vitality, relaxation, emotional relationships), despite maintaining adequate linguistic clarity, influencing the conceptual accessibility of certain subjective well-being indicators.
- Despite the limited generalizability due to opportunistic sampling, the pilot study **confirmed the feasibility and practical relevance of using Q-VAD in LV** for monitoring service outcomes, planning individualized interventions, and informing national policies in line with the principles of the UNCRPD, supporting the country's ongoing deinstitutionalization process.

Based on the results obtained, the following recommendations could serve as a reference for the national and local governance system of disability-related policies and services in LC, supporting the introduction of the Q-VAD tool to assess the LC of persons with ID within the socio- educational context.

Policy level: for the Ministries and Government Bodies Responsible for Social Policy in LV

- *Expand national validation using a representative sample*. A national-level initiative should be launched to expand Q-VAD validation through a stratified sample across regions, service types, and support levels. This will confirm the tool's cross-context reliability and support its inclusion in national assessment frameworks.
- *Use Q-VAD to support deinstitutionalization monitoring*. Q-VAD should be integrated into national monitoring systems for tracking individual outcomes in transitions from

institutional to community-based services, focusing on qualitative indicators such as self-determination, autonomy, and participation.

- *Inform rights-based, inclusive policy development.* Aggregated Q-VAD data should be used to inform the development of inclusive and rights-oriented public policies in line with the UN CRPD, emphasizing empowerment, autonomy, and QoL in national disability strategies.

Institutional level: for Municipalities

- *Monitor differences in outcomes across service types.* Municipalities should analyse Q-VAD data to compare outcomes across various service models (institutional vs. community-based), and use this evidence to guide local-level planning that promotes more inclusive and person-centred services.
- *Target barriers to inclusion through data-informed actions*. Local authorities can use Q-VAD results to detect context-specific barriers to inclusion, such as lack of mobility, limited access to social networks, or digital exclusion, and coordinate targeted responses through social, environmental, and educational programs.

Pedagogical level: for Service Providers and Practitioners

- *Integrate Q-VAD into routine assessment processes*. Service providers should incorporate Q-VAD into regular assessment routines for care planning, service evaluation, and documentation, enabling structured and multidimensional insight into each service user's needs and experiences.
- *Use Q-VAD as a staff development and reflective tool*. Q-VAD should be integrated into professional development initiatives as a practical resource to promote team reflection, improve understanding of QoL and inclusion, and align daily practices with person-centred service models.
- *Apply Q-VAD profiles in individualized planning*. Practitioners should use Q-VAD-generated profiles to design tailored educational and support plans that promote autonomy, communication, participation, and learning, regardless of the person's support level.
- *Include Q-VAD in team-based planning processes.* Practitioners should integrate Q-VAD data into interdisciplinary planning meetings (educators, social workers, therapists), facilitating a shared understanding of needs and coordinated intervention strategies.
- *Use Q-VAD to support transition planning.* For young adults or individuals transitioning between services (e.g., school to adult services), Q-VAD can be a tool to assess readiness, identify gaps in skills or opportunities, and define next steps in a person's life project.

The defined boundaries of this PhD research provided a clear and focused framework for advancing knowledge within the field of special pedagogy. Through the development and implementation of the Q-VAD tool, the study established a structured and evidence-based model for evaluating key dimensions of inclusion and support within socio-educational services. These foundations offer a

valuable direction for future research, particularly regarding the pedagogical and professional competencies required of staff involved in disability services. Its broader approbation within higher education institutions is recommended to foster quality teaching and learning, while also strengthening the alignment between research, training, and the inclusive values promoted by special pedagogy. From a socio-educational perspective, the findings of the study highlight critical dimensions that directly affect the QoL and SI of individuals with intellectual disabilities within service environments.

- *Limited social participation*: Many individuals primarily engage within the boundaries of structured service settings, with minimal opportunities for interaction in the broader community. This suggests the need for educational strategies that extend beyond institutional settings and support the development of social skills and meaningful relationships in inclusive contexts.
- *Health and behavioral challenges*: The high prevalence of psychiatric, behavioral, and physical health issues points to the importance of interdisciplinary collaboration in educational and care settings. Educators and support staff must be equipped with the competencies to recognize and respond to complex needs, integrating therapeutic and pedagogical approaches.
- *Variability in opportunities and QoL*: the disparities in personal experiences reflect how restrictive environments can hinder the development of autonomy and self-determination. Socio-educational frameworks must therefore prioritize environments that promote choice, agency, and active engagement in learning and daily life.
- *Impact of service types*: The evidence indicates that more individualized, flexible, and community-integrated service models lead to better outcomes in terms of opportunities and QoL. This reinforces the educational imperative to design inclusive learning environments and support systems that adapt to individual needs and promote community-based participation.

In conclusion, the research objective and tasks of the current PhD thesis have been achieved, and the theoretical justification and empirical evidence in response to the defined research questions have been provided. The approbation allowed putting forward three theses for defence.

Based on the conducted PhD research, the following theses are put forward for defense:

1. The assessment of the LC related to SI and QoL of individuals with ID requires a multidimensional pedagogical modelling, integrating the dimensions of individual functioning, QoL, and SI into a unified person-centered theoretical approach and step-by-step support, using structured and holistic assessment of individuals within the framework of special education.

2. The relevant pedagogically related factors influencing the effectiveness of services in promoting QoL and SI covers the types of services provided, support needs, problem behavior, age, and gender, focusing on the available Opportunities, while using the Q- VAD tool developed from the proposed theoretical framework, that is a valid and reliable for assessing LC, it is possible to identify barriers and enablers of SI and QoL, supporting data-driven improvements in disability services.

3. The pilot implementation of the Q-VAD assessment tool, basically developed in the Italian perspective, in the Latvian context confirmed its comprehensibility and usability by educators, producing meaningful differentiation in user profiles and supporting its feasibility for cross-national application in different service systems, demonstrating effective practices that can be pedagogically adopted to Latvian perspective on regular basis.

Based on the conducted PhD research, the following theses are put forward for defense:

4. The assessment of the LC related to SI and QoL of individuals with ID requires a multidimensional pedagogical modelling, integrating the dimensions of individual functioning, QoL, and SI into a unified person-centered theoretical approach and step-by-step support, using structured and holistic assessment of individuals within the framework of special education.

5. The relevant pedagogically related factors influencing the effectiveness of services in promoting QoL and SI covers the types of services provided, support needs, problem behavior, age, and gender, focusing on the available Opportunities, while using the Q- VAD tool developed from the proposed theoretical framework, that is a valid and reliable for assessing LC, it is possible to identify barriers and enablers of SI and QoL, supporting data-driven improvements in disability services.

6. The pilot implementation of the Q-VAD assessment tool, basically developed in the Italian perspective, in the Latvian context confirmed its comprehensibility and usability by educators, producing meaningful differentiation in user profiles and supporting its feasibility for cross-national application in different service systems, demonstrating effective practices that can be pedagogically adopted to Latvian perspective on regular ba

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APPENDICES

Appendix 1

Q-VAD: Questionnaire for evaluating living conditions of adult persons with disability – English version

(created by researcher)

Q-VAD: Questionnarie for evaluating living conditions of adult persons with disability

English version

Client

Name _____ Surname _____ Birth Date ____/_____/ _____

Compiler Data

N.	Name	Surname	Position
1			
2			
3			
4			

Service – District – Service

Type and name of services where you are a guest _____

Reference management of the Service _____

Health District _____

1. Socio-Personal Data and General Information

1- Qualification

☐ None ☐ Elementary ☐ Middle school ☐ High school ☐ Bachelor's degree

2- School attendance certificates

☐ Yes ☐ No . If yes, specify _____

3- City of Residence _____

4- Does the domicile coincide with the residence?

☐ Yes ☐ No . If yes, specify _____

5- Doctor (*name and surname*) _____

6- Number of family members

☐ 1 (alone with no family) ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

7- Component bond 2

☐ cohabitant ☐ wife/husband ☐ mother ☐ father

☐ uncle/uncle ☐ cousin/uncle ☐ niece/nephew ☐ grandfather/grandmother

8- Component bond 3

☐ cohabitant ☐ wife/husband ☐ mother ☐ father

☐ uncle/uncle ☐ cousin/uncle ☐ niece/nephew ☐ grandfather/grandmother

9- Component bond 4

☐ cohabitant ☐ wife/husband ☐ mother ☐ father

☐ uncle/uncle ☐ cousin/uncle ☐ niece/nephew ☐ grandfather/grandmother

10- Component bond 5

☐ cohabitant ☐ wife/husband ☐ mother ☐ father

☐ uncle/uncle ☐ cousin/uncle ☐ niece/nephew ☐ grandfather/grandmother

11- Component bond 6

☐ cohabitant ☐ wife/husband ☐ mother ☐ father

☐ uncle/uncle ☐ cousin/uncle ☐ niece/nephew ☐ grandfather/grandmother

12- Component bond 7

☐ cohabitant ☐ wife/husband ☐ mother ☐ father

☐ uncle/uncle ☐ cousin/uncle ☐ niece/nephew ☐ grandfather/grandmother

13- Current adequacy of the family unit and/or informal network in responding to the needs of the person

☐ 0 – nothing ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 – maximum

14- Probability of the nucleus and/or family network to maintain current adequacy in responding to the person's needs

☐ 0 – nothing ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 - maximum

15- Presence of a contact person

☐ Yes ☐ No If Yes … ☐ cohabitant/spouse

☐ Mother

☐ Father

☐ brother/sister

☐ other _____

16- Presence of safeguard or protection measures

☐ Yes ☐ No If Yes … ☐ Curator

☐ Guardian/ person exercising parental and legal responsibility

☐ Individual support administrator

17- Certification of disability

☐ Yes ☐ No . If yes, diagnosis _____

_____

18- Assessment of the Disability Commission Law _____

19- Have job placement support programs been activated?

☐ Yes ☐ No

If yes, from _____to _____position _____

from _____to _____position _____

from _____to _____position _____

20- Aids & Prosthetics

☐ Yes ☐ No If yes ☐ Aids for personal health treatment

☐ Aids for the exercise of skills

☐ Orthosis and prosthetics

☐ Personal care and protection aids

☐ Personal mobility aids

☐ Home care aids

☐ Furniture and adaptations for the home or other rooms

☐ Communication and information aids

Digital Technology

21- Do you use a phone?

☐ Yes ☐ No If yes, ☐ Landline

☐ Mobile

☐ Smartphone

If so, how independent are you?

☐ I am independent

☐ I need some help

☐ I only use it to receive

22- Do you own/use a PC freely? ☐ Yes ☐ No

23- Do you use the Internet? ☐ Yes ☐ No

24- Are you subscribed to a social network (e.g., Facebook, Twitter, Pinterest, Linkedin, etc.)? ☐ Yes ☐ No

25- Do you use chat and other communication applications (e.g., WhatsApp, Telegram, Viber, etc.)? ☐ Yes ☐ No

Transports

26- Do you use transportation? ☐ Yes ☐ No

If yes ☐ Bicycle

☐ Motorine/Scooter

☐ Car

☐ Bus

☐ Train

☐ Taxi

If so, how independent are you?

☐ I am independent

☐ I need some help

☐ I need constant help

Relationships and Leisure

27- Do you go out in the course of your day to do the things you want? ☐ Yes ☐ No

If yes, how many times in the last month? _____

31 - Do you have any friends who are not classmates at the services?

☐ Yes ☐ No

If yes, do you go out with them?

☐ Yes ☐ No

If so, how many times in the last month? _____

32- What leisure activities do you do in your free time?

☐ Cinema

☐ Theatre

☐ Exhibitions

☐ Festival

☐ Concerts

☐ Participation in association activities

☐ Sporting practices/events

☐ Eating out

☐ Other _____

2. Support needs for individual functioning

Thinking about your life in the last 6 months, try to answer the following questions, indicating for the different activities the answer that best describes you. Choose the most representative option considering the different living environments. If you are unsure between two options, indicate the level of greatest support.

1 Do you recognize living environments, places, and paths to move within them?

A Yes, even in those, I've only been a few times.
B Yes, but in habitual environments, places, and paths
C I often need guidance to recognize and orient myself in living environments.
D No, I need physical guidance to recognize and orient myself in living environments.
E No, I need total assistance, and most of the time, I don't recognize the environment I'm in

2 Can you predict your daily schedule and activities?

A Yes, even activities that occur from time to time.
B Yes, only in certain particular situations can I need a little help...
C I need directions (verbal or visual) to orient me to the events of my day.
D I often need guidance to get my bearings on the events of my day.
E I need total assistance, and most of the time, I can't predict the events of my day.

3 When you have to perform an important task/activity of your day...

A I stay busy with the activity for as long as it takes
B I stay busy in the business under someone's supervision.
C I need someone to help me stay focused on the activity and orient me in the correct sequence of steps.
D I'm only busy for a short while, and then I need someone to finish it for me.
E Most of the time, I can't stay focused on the activity, and I need someone to do it for me.

4 When people come to you...

A I understand verbal language related to content, experiences, and personal needs (even if I need a little more time).
B I understand short sentences or simple verbal expressions...
C I recognize some words, signs, and gestures referring to basic needs or simple commands.
D I recognize when people try to communicate with me, but I don't understand the specific content.
E I don't recognize when people are trying to communicate with me...

5 When you talk...

A I can express myself in a clear and understandable way.
B I can express myself even if not fluent.
C I can produce simple sentences, but I need help to make myself understood...
D I can only pronounce a few words, and I have to be helped almost completely when I have to make myself understood...
E I don't express myself verbally.

6 When you need or desire to express something...

A I can express others' needs and experiences.
B I can express needs and experiences, but only with certain people.
C I can only express basic needs (hunger, thirst, bath...) or limited aspects of my everyday life.
D I can express the presence of a need, but I'm not able to specify it in a functional way (e.g.scream, hit myself, cry...).
E I can't express my needs.

7 When you find yourself interacting with other people...

A I can understand what kind of social context I am in and use the appropriate behaviors (e.g., greeting, smiling, looking into the eyes, waiting for the conversation turn).
B I recognize several social situations in which I find myself, but sometimes I need someone to remind me of the appropriate behavior (e.g., greeting, smiling, looking into the eyes, waiting for the conversation turn).
C I need constant guidance to understand the social contexts and behaviors to be held.
D I often do not understand the kind of social context in which I find myself, and I need constant help to regulate and control my behavior.
E I do not understand the context of the social relationship I live in, and the appropriate behavior to use on such occasions.

8 Are you able to move around your living environment?

A I always move alone.
B I move myself, but I need someone to supervise me in some situations.
C I move with constant supervision or physical assistance in some steps.
D I just do small commutes, and most of the time I have to be physically helped.
E I have to be fully helped in the journey.

9 When you need to wash yourself…

A I carry out the activity in complete autonomy.
B I do the activity alone and I only need some indication or supervision (e.g., transfers, water temperature control,...).
C I need constant guidance and help while I'm doing my work (e.g., moving, washing, and drying,...)
D I can only do a few small tasks and need physical help with most of the activity
E I must be helped completely

10 When do you take care of individual parts of your body (washing your hands, face, and teeth, combing your hair, shaving/putting on makeup, cutting your nails)?

A I do all the necessary activities myself.
B I do the work myself, but I need supervision or some guidance.
C I perform the simplest activities (e.g., washing my hands), but I need constant guidance and help in the most complex ones (e.g., shaving/makeup).
D I need physical help with most activities.
E I must be helped completely

11 Can you get dressed and undressed?

A I carry out the activity in complete autonomy (including shoes, corset, prosthesis,...)
B I carry out the activity alone, I only need some indication or supervision for tasks and fine manual skills (e.g. buttons, zippers, hooks,.)
C I do some of the work, and I need constant guidance and help
D I can only do a few small tasks and need physical help with most of the activity
E I must be helped completely

12 When you have to eat..

A I eat by myself using cutlery properly (e.g., cut, spread, open jars, pour water,...)
B I eat alone, using the cutlery, but sometimes I need a little help or supervision (no person is needed)
C I can eat using cutlery, but I need constant guidance or supervision (presence of a person required)
D I do some of the work, but I need physical help (e.g., holding the cutlery properly, loading the food...).
E I have to be helped completely/I'm fed artificially.

13 When you need to go to the bathroom...

A I use the toilet properly and clean myself independently.
B I'll do it myself, but I need supervision or some directions.
C I need help with some steps in using the toilet or cleaning tasks.
D I must be accompanied and physically assisted in the use of the toilet and cleaning tasks.
E I am not able to use the toilet properly and clean myself independently.

14 When you make your meals …

A I do it on my own, independently.
B I do the work myself, but I need some guidance or supervision...
C I need constant guidance and help while I'm doing my job.
D I can only do a few small parts of the activity, and I need help with everything else.
E I need someone to cook and prepare food for me.

15 When you need to tidy up and clean your living spaces (clean the house, tidy up the room, and keep your personal spaces tidy...)

A I do it on my own, independently.
B I need some verbal guidance or supervision.
C I need constant guidance and help while I'm doing my job.
D I can only do a few small parts of the activity, and I need help with everything else.
E I need someone to do it for me.

16 When you need to move around your village/town/city

A I do it on my own, independently.
B I reach the places of interest with some directions before leaving.
C I go to different places, but I need constant supervision and guidance.
D I reach some places, but I have to be physically guided.
E I'm unable to reach any place.

17 When you have to make purchases...

A I carry out the activity in complete autonomy (e.g., choice of shop, product, and payment)
B I do the activity alone, but I need some indication or supervision (e.g., to match the price to the object, count the rest)
C I need constant guidance and help while I'm doing my job.
D I can only do or collaborate in small parts of the activity, but I need help with everything else.
E I need someone to do the shopping for me.

18 When you participate in social activities (recreational moments, gatherings, parties...)

A I do the activity on my own
B I participate in the activity, but I need some guidance or supervision.
C I need constant guidance from someone.
D At several steps of the activity, I need someone to intervene in my place or to help me.
E I need someone to intervene in my place or to help me most of the time.

3. Quality of life

Thinking about your life in the last 6 months, try now to answer the following questions. Scores are given using Likert's scale
between 1 and 5, where 1 corresponds to "Not at all", while 5 on the opposite pole corresponds to "Very much".

	Items	Not at all (1)	(2)	(3)	(4)	Very much (5)
1	Do you feel energetic and vital?	☐	☐	☐	☐	☐
2	Do you rest and relax properly?	☐	☐	☐	☐	☐
3	Do you feel comfortable where you live?	☐	☐	☐	☐	☐
4	Are there things (people, activities, events) that make you happy?	☐	☐	☐	☐	☐
5	Are you satisfied with the things you do and how you spend your time in your day?	☐	☐	☐	☐	☐
6	Are you satisfied with the personal belongings or assets you have and how you can dispose of them?	☐	☐	☐	☐	☐
7	Do your daily living environments allow you to be alone (when you need to be) or protect your privacy?	☐	☐	☐	☐	☐
8	Are your living environments adapted to your needs, needs and preferences?	☐	☐	☐	☐	☐
9	Do you have relationships with people living in your neighborhood/territory (even if you are on residential service)?	☐	☐	☐	☐	☐
10	Do the services, opportunities, or recreational places in your neighborhood/territory (e.g. shops, bars, church, parish, theatre, cinema...) meet your needs, interests, wishes?	☐	☐	☐	☐	☐
11	Are you involved in significant activities in your neighborhood/territory (e.g., recreation, sports, volunteering...)?	☐	☐	☐	☐	☐
12	Do you feel satisfied with the relationship you have with your family or with reference figures outside the care context?	☐	☐	☐	☐	☐

13	Do you have friends with whom you are able to maintain constant relations (excluding family members, staff, and volunteers of the facilities)?	☐	☐	☐	☐	☐
14	Do you have the possibility to carry out social activities that are rewarding for you (e.g., going out, going to parties...)?	☐	☐	☐	☐	☐
15	Do you have the possibility to put into practice what you know how to do in your life (e.g., going out on your own, using means, using your computer, doing a job/activity...)?	☐	☐	☐	☐	☐
16	Have you learned new skills or knowledge (autonomy skills, training courses...)?	☐	☐	☐	☐	☐
17	Have you had the opportunity to access new roles or new Opportunities (e.g., training, work, living)?	☐	☐	☐	☐	☐
18	Have you had the opportunity to express your preferences and wishes to someone?	☐	☐	☐	☐	☐
19	During your day, do you have the possibility to make choices related to your activities (e.g., what to eat, what to wear, what to do)?	☐	☐	☐	☐	☐
20	Do you have the possibility to decide who to stay with, who to meet, who to attend, and who to do certain activities with?	☐	☐	☐	☐	☐

4. Opportunities

Referring to the last 6 months, try to think now if you've ever had the opportunity to...
Answer only by reference to the frequency of the opportunity, regardless of the skill you have and any help you receive.
Also, indicate whether you have taken advantage of the opportunity.

1. Never
2. Less than once a month
3. At least once a month, but not every week.
4. At least once a week
5. Every day or almost every day

Items	never (1)	Less than once a month (2)	At least once a month, but not every week (3)	At least once a week (4)	Every day or almost every day (5)	You took advantage of that opportunity. No	Not completely	Yes
1 Carrying out personal care activities?	☐	☐	☐	☐	☐	☐	☐	☐
2 Carrying out activities of care for the living environment?	☐	☐	☐	☐	☐	☐	☐	☐
3 Use household appliances or technology?	☐	☐	☐	☐	☐	☐	☐	☐
4 Moving around the territory?	☐	☐	☐	☐	☐	☐	☐	☐
5 Make use of community services (e.g., shops, offices, cinemas, gyms)?	☐	☐	☐	☐	☐	☐	☐	☐
6 Participate in significant community activities?	☐	☐	☐	☐	☐	☐	☐	☐
Learning skills for the autonomous management of	☐	☐	☐	☐	☐	☐	☐	☐

7	one's person through targeted interventions/training?								
8	Learning cognitive, scholastic, and technological skills (telephone, PC, etc.) through targeted interventions/training?	☐	☐	☐	☐	☐	☐	☐	☐
9	To be engaged in roles, tasks, and activities useful for the people you live with, who live near you, or who attend your life context?	☐	☐	☐	☐	☐	☐	☐	☐
10	Being engaged in activities and tasks related to a job with a working value (even unpaid)?	☐	☐	☐	☐	☐	☐	☐	☐
11	Looking for or performing a job?	☐	☐	☐	☐	☐	☐	☐	☐
12	Learning skills for external autonomy through targeted interventions/training?	☐	☐	☐	☐	☐	☐	☐	☐
13	Socializing/meeting people important to you?	☐	☐	☐	☐	☐	☐	☐	☐
14	Taking part in recreational or socializing activities that are important to the person?	☐	☐	☐	☐	☐	☐	☐	☐

5. Behavioural disturbs

Thinking about your life in the last 6 months, try to answer the following questions, indicating for the different activities the answer that best describes you.
Choose the most representative option considering the different living environments.

1 Hetero-direct aggression

A No direct behavior towards others during the period considered
B occasional irritation and some verbal assault
C frequent verbal aggression and occasional aggressive gestures
D onset of physical aggression resulting in minor injuries and risks to others that require careful monitoring for prevention
E onset of physical aggression with consequent injuries and important risks for others that require careful monitoring

2 Self-directed aggression and self-harm

A No self-harm behavior during the period considered
B occasional self-harm behavior (clapping on the forehead...)
C frequent self-harm without causing significant damage (e.g., redness, scratches, etc.).
D onset or risk of the appearance of self-inflicted behavior with consequent damage that is, in any case, reversible and without loss of function (e.g., cuts, bruises, hair loss, etc.).
E Onset or risk of the appearance of self-injurious behavior resulting in irreversible damage and permanent loss of function (impaired vision, permanent facial scars). Including suicide attempts

3 Aggressiveness towards environments or things

A No problems during the evaluation period
B Occasional occurrence of the behavior in question
C Issues have a significant influence on the performance of a person's and others' activities.
D Problems have an extremely significant influence on the performance of a person's and others' activities and require careful monitoring for management and prevention.
E Problems have a serious impact on the functioning and performance of most everyday activities and require constant supervision or physical intervention to prevent them.

4 Ritual stereotypes and compulsive behaviors

A No problems during the evaluation period
B occasional occurrence of the behavior in question
C issues have a significant influence on the performance of the person's and others' activities
D Problems have an extremely significant influence on the performance of a person's and others' activities and require careful monitoring for management and prevention.
E Problems have a serious impact on the functioning and performance of most everyday activities and require constant supervision or physical intervention to prevent them.

5 Ingestion of non-edible substances

A No problems during the evaluation period
B occasional occurrence of the behavior in question
C Issues have a significant influence on the performance of a person's and others' activities.
D Problems have an extremely significant influence on the performance of a person's and others' activities and require careful monitoring for management and prevention.
E Problems have a serious impact on the functioning and performance of most everyday activities and require constant supervision or physical intervention to prevent them.

6 Oppositivity

A No problems during the evaluation period
B occasional occurrence of the behavior in question
C Issues have a significant influence on the performance of a person's and others' activities.
D Problems have an extremely significant influence on the performance of a person's and others' activities and require careful monitoring for management and prevention.
E Problems have a serious impact on the functioning and performance of most everyday activities and require constant supervision or physical intervention to prevent them.

7 Socially inappropriate behaviour

A No problems during the evaluation period
B occasional occurrence of the behavior in question
C Issues have a significant influence on the performance of a person's and others' activities.
D Problems have an extremely significant influence on the performance of a person's and others' activities and require careful monitoring for management and prevention.
E Problems have a serious impact on the functioning and performance of most everyday activities and require constant supervision or physical intervention to prevent them.

8 Inappropriate sexual behaviour

A No problems during the evaluation period
B occasional occurrence of the behavior in question
C Issues have a significant influence on the performance of a person's and others' activities.
D Problems have an extremely significant influence on the performance of a person's and others' activities and require careful monitoring for management and prevention.
E Problems have a serious impact on the functioning and performance of most everyday activities and require constant supervision or physical intervention to prevent them.

9 Other behaviour disorders

A No problems during the evaluation period
B occasional occurrence of the behavior in question
C Issues have a significant influence on the performance of a person's and others' activities.
D Problems have an extremely significant influence on the performance of a person's and others' activities and require careful monitoring for management and prevention.
E Problems have a serious impact on the functioning and performance of most everyday activities and require constant supervision or physical intervention to prevent them.

6. Health

1 - Presence of disease conditions

Please indicate the presence of any illness in the different areas proposed. If so, indicate the level of severity of the problem from 1 to 4 (1: mild; 2: moderate; 3: severe; 4: very severe). Also indicate whether therapy is being taken and the level of autonomy by selecting from the different

alternatives proposed (A: no ‘therapy taken’; B: independent; C: receives help on some occasions or needs to be reminded; D: intensive care: receives help on all occasions; E: dependent).

Disease condition	Presence (If YES Check the box.	Level of severity of the problem (If the disease condition is present)				Presence of any ‘treatment intake’ and level of autonomy (If the disease condition is present)				
		1	2	3	4	A	B	C	D	E
Heart	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Hypertension	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Vascular	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Respiratory	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Eye, ear, nose, throat, and larynx	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Upper gastrointestinal	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Lower gastrointestinal	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Liver	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Kidney	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Genitourinary	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Skeletal muscle	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Nervous system	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Endocrine system	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Psychopathological/Behavioural	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

2 - Pain assessment

About health problems, how much pain do you feel at the moment?

☐ 0 (no pain) ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 (maximum pain)

If patients have important cognitive disorders or communication difficulties, explore the following 5 behavioral areas:

Breathing

2.01

0 Normal

1 Shortness of breath

2 Noisy and wheezy breathing, alternating periods of apnea and polypsnea

2.02 Vocalization
- 0 No problem
- 1 Occasional planting or grumbling
- 2 Repeated screaming or moaning

2.03 Facial expressions
- 0 Smiling or inexpressive
- 1 Sad or frowning eyelashes
- 2 Grimaces

2.04 Body language
- 0 Relaxed
- 1 Tense
- 2 Stiff with closed fists or attempting to strike

2.05 Consolation
- 0 No need to be consoled
- 1 Confused and seeking reassurance
- 2 Incapable of distraction and/or consolation

3 - Breathing assistance

☐ Yes ☐ No

If yes,

☐ Inhalation therapy or oxygen therapy
☐ Invasive mechanically assisted ventilation
☐ Continuous non-invasive mechanically assisted ventilation
☐ Postural drainage
☐ Physical therapy for drainage of chest secretions
☐ Bronchial and tracheal suctioning
☐ Tracheostomy care

4 - Breathing assistance

☐ Yes ☐ No

If yes,

☐ Oral cavity stimulation or jaw positioning
☐ Tube feeding (e.g., nasogastric)
☐ Parenteral feeding (e.g., intravenous)
☐ Illness diet
☐ Feeding

5 - Posture assistance for the prevention of pressure injuries

☐ Yes ☐ No

If yes,
☐ Rotation or positioning
☐ Pressure ulcer dressing

6 - Urinary continence problems
☐ Yes ☐ No
If yes,
☐ Independent use of internal/external urinary aids (condoms, diapers, etc.)
☐ Requires supervision for management of urinary aids
☐ Requires physical assistance in using aids (usually dry during the day, but not at night)
☐ Requires physical assistance in using aids (always)
☐ Uncooperative

7 - Gastrointestinal tract
☐ Yes ☐ No
If yes,
☐ Able to put on suppositories or do enemas
☐ Requires supervision for use of suppositories, enemas, and diapers
☐ Requires physical assistance in using devices
☐ Uncooperative

8 - Rehabilitation procedures
☐ Yes ☐ No
If yes,
☐ Specialist individual physiotherapy
☐ Specialist group physiotherapy
☐ Respiratory physiotherapy
☐ Specialist speech therapy
☐ Other forms of specialist rehabilitation (e.g., occupational therapy)

9 - Other types of health interventions
☐ Yes ☐ No
If yes,
☐ Prevention of infectious diseases
☐ Management of seizures
☐ Dressing of stomas
☐ Physiotherapy interventions
☐ Specialized therapeutic activities
☐ Pharmacological treatment with insulin

10 - Presence of other types of health interventions

☐ Yes ☐ No

Appendix 2

Q-VAD: Questionnaire for evaluating living conditions of adult persons with disability – Latvia version

(created by the researcher)

Q-VAD: Questionnarie for evaluating living conditions of adult persons with disability

Latvian version

Klients

Vārds _____ Uzvārds _____ Dzimšanas datums _____/_____/ _____

Kompilatora dati

N.	Vārds	Uzvārds	Pozīcija
1			
2			
3			
4			

Service – District – Service

Pakalpojuma veids un nosaukums, kurā esat viesis_____

Pakalpojuma uzziņu pārvaldība_____

Veselības rajons _____

1. Sociālie personas dati un vispārīga informācija

1- Kvalifikācija

☐ Nav ☐ Pamatskola ☐ Vidusskola ☐ Vidusskola ☐ Bakalaura grāds

2- Skolas apmeklējuma apliecības

☐ Jā ☐ Nē Ja jā, norādiet_____

3- Dzīvesvietas pilsēta_____

4- Vai dzīvesvieta sakrīt ar dzīvesvietu?

☐ Jā ☐ Nē Ja jā, norādiet

5- Ārsts (vārds un uzvārds)_____

6- Ģimenes locekļu skaits

☐ 1 (viena bez ģimenes) ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

7- Komponentu saite 2

☐ dzīvesbiedre ☐ sieva/vīrs ☐ māte ☐ tēvs

☐ onkulis/onkulis ☐ brālēns/onkulis ☐ māsasmeita/māsasdēls ☐ vectēvs/vecmāmiņa

8- Komponentu saite 3

☐ dzīvesbiedre ☐ sieva/vīrs ☐ māte ☐ tēvs

☐ onkulis/onkulis ☐ brālēns/onkulis ☐ māsasmeita/māsasdēls ☐ vectēvs/vecmāmiņa

9- Komponentu saite 4

☐ dzīvesbiedre ☐ sieva/vīrs ☐ māte ☐ tēvs

☐ onkulis/onkulis ☐ brālēns/onkulis ☐ māsasmeita/māsasdēls ☐ vectēvs/vecmāmiņa

10- Komponentu saite 5

☐ dzīvesbiedre ☐ sieva/vīrs ☐ māte ☐ tēvs

☐ onkulis/onkulis ☐ brālēns/onkulis ☐ māsasmeita/māsasdēls ☐ vectēvs/vecmāmiņa

11- Komponentu saite 6

☐ dzīvesbiedre ☐ sieva/vīrs ☐ māte ☐ tēvs

☐ onkulis/onkulis ☐ brālēns/onkulis ☐ māsasmeita/māsasdēls ☐ vectēvs/vecmāmiņa

12- Komponentu saite 7

☐ dzīvesbiedre ☐ sieva/vīrs ☐ māte ☐ tēvs

☐ onkulis/onkulis ☐ brālēns/onkulis ☐ māsasmeita/māsasdēls ☐ vectēvs/vecmāmiņa

13- Ģimenes vienības un/vai neformālā tīkla pašreizējā atbilstība personas vajadzībām

☐ 0 – nekas ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 – maksimums

14- Kodola un/vai ģimenes tīkla varbūtība saglabāt pašreizējo adekvātumu, reaģējot uz personas vajadzībām

☐ 0 – nekas ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 – maksimums

15- Kontaktpersonas klātbūtne

Jā ☐Nē Ja jā… ☐ dzīvesbiedrs/laulātais

☐ māte

☐ tēvs

☐ brālis/māsa

☐ cits_____

16- Aizsardzības vai aizsardzības pasākumu esamība

☐ Jā ☐Nē Ja jā ☐ Kurators

☐ Aizbildnis/persona

☐ Individuālā atbalsta administrators

17- - Invaliditātes apliecība

☐ Jā ☐ Nē Ja jā, diagnose _____

18- Invaliditātes komisijas likuma izvērtējums

_____

19- Vai ir aktivizētas darbā iekārtošanas atbalsta programmas?

☐ Jā ☐ Nē

Ja jā, no _____līdz _____vietai _____

no _____līdz _____vietai _____

no _____līdz _____vietai _____

20- palīglīdzekļi un protezēšana

☐ Jā ☐Nē

Ja jā ☐ Palīglīdzekļi personīgās veselības ārstēšanai

☐ Palīglīdzekļi prasmju attīstīšanai

☐ Ortoze un protezēšana

☐ Personīgās aprūpes un aizsardzības līdzekļi

☐ Personīgās pārvietošanās palīglīdzekļi

☐ Mājas aprūpes palīglīdzekļi

☐ Mēbeles un pielāgojumi mājai vai citām telpām

☐ Komunikācijas un informācijas palīglīdzekļi

Digitālās tehnoloģijas

21- Vai tu lieto telefonu?

☐ Jā ☐Nē

Ja jā,

☐ Stacionārais tālrunis

☐ Mobilais

☐ Viedtālrunis

Ja jā, cik neatkarīgs jūs esat?

☐ Esmu neatkarīga

☐ Man vajag kādu palīdzību

☐ Es to izmantoju tikai saņemšanai

22- Vai jums pieder/lietojat datoru brīvi? ☐Jā ☐Nē

23- Vai jūs izmantojat internetu? ☐Jā ☐Nē

24- Vai esat abonējis sociālo tīklu (Facebook, Twitter, Pinterest, Linkedin…)?

☐ Jā ☐Nē

25- Vai izmantojat tērzēšanas un citas saziņas lietojumprogrammas (piemēram, WhatsApp, Telegram, Viber utt.)?

☐ Jā ☐Nē

Transporti

26- Vai jūs izmantojat transportu?

Ja jā

☐ Velosipēds

☐ Motors/motorollers

☐ Automašīna

☐ Autobuss

☐ Vilciens

☐ Taksometrs

Ja jā, cik neatkarīgs jūs esat?

☐ Esmu neatkarīga
☐ Man vajag kādu palīdzību
☐ Man ir vajadzīga papildu palīdzība

Attiecības un atpūta

27- Vai jūs dienas laikā ejat ārā, lai darītu to, ko vēlaties? ☐Jā ☐Nē
Ja jā, cik reizes pēdējā mēneša laikā?_____

28- Vai jums ir kādi draugi, kas nav klasesbiedri no dienas centra vai dzīvojamo māju kopienas
☐ Jā ☐Nē
Ja jā, vai jūs ejat kopā ar viņiem? ☐Jā ☐Nē
Ja jā, cik reizes pēdējā mēneša laikā? _____

29- Kādas brīvā laika pavadīšanas aktivitātes jūs darāt brīvajā laikā?

☐ Kino
☐ Teātris
☐ Izstādes
☐ Festivāls
☐ Koncerti
☐ Dalība biedrības pasākumos
☐ Sporta treniņi/pasākumi
☐ Ēšana ārā
☐ Cits _____

2. Individuālas funkcionējošas atbalsta vajadzības

Domājot par savu dzīvi pēdējo 6 mēnešu laikā, tagad mēģini atbildēt uz šādiem jautājumiem, norādot dažādām aktivitātēm atbildi, kas tevi vislabāk raksturo.

1 Vai atpazīstat dzīves vidi, vietas un ceļus, pa kuriem pārvietoties tajās?

A Jā, pat tajos, pie kuriem esmu bijis tikai dažas reizes.
B jā, bet ierastajā vidē, vietās un ceļos
C Man bieži vien ir vajadzīgas vadlīnijas, lai apzinātos un orientētos dzīves vidē.
D nē, man ir nepieciešama fiziska orientācija, lai apzinātos un orientētos dzīves vidē.
E nē, man nepieciešama pilnīga palīdzība un lielākoties neatpazīstu vidi, kurā atrodos.

2 Vai varat plānot savu ikdienas grafiku un aktivitātes?

A Jā, pat darbības, kas notiek ik pa laikam.
B Jā, tikai noteiktās konkrētās situācijās man var būt vajadzīga neliela palīdzība...
C Man ir nepieciešami virzieni (verbāli vai vizuāli), lai orientētu mani uz savas dienas notikumiem.
D Man bieži vien ir vajadzīgas norādes, lai uzklausītu savas dienas notikumus.
E Nepieciešama totāla palīdzība un lielākoties nevaru prognozēt savas dienas notikumus.

3 Kad jāveic svarīgs savas ikdienas uzdevums/aktivitāte...

A Es ar šo darbību veicu tik ilgi, cik vajadzīgs.
B Es šo darbību veicu kāda uzraudzībā.
C Man ir vajadzīgs kāds, kas man palīdzētu koncentrēties uz aktivitāti un virzīt mani pareizā secībā.
D Es tikai īsu brīdi esmu aizņemts un tad man vajag kādu, kas to pabeidz manā vietā.
E lielākoties es nespēju koncentrēties uz šo darbību, un man ir vajadzīgs kāds, kas to darītu manā vietā.

4 Kad tevi uzrunā cilvēki...

A ES saprotu verbālo valodu, kas saistīta ar saturu, pieredzi un personiskajām vajadzībām (pat ja man nepieciešams nedaudz vairāk laika).
B ES saprotu īsus teikumus vai vienkāršus vārdiskus izteicienus...
C ES pazīstu dažus vārdus, zīmes, žestus, kas atsaucas uz pamatvajadzībām vai vienkāršām komandām.
D ES atpazīstu, kad cilvēki mēģina ar mani komunicēt, bet es nesaprotu konkrēto saturu.
E ES nepazīstu, kad cilvēki mēģina ar mani komunicēt...

5 Kad tu runā...

A Varu izpausties skaidri un saprotami

B ES varu izpausties pat tad, ja ne tekoši.

C Varu uzrakstīt vienkāršus teikumus, bet man ir vajadzīga palīdzība, lai sevi saprastu...

D ES varu izrunāt tikai dažus vārdus un man ir jāpalīdz gandrīz pilnībā, kad jāliek sevi saprast...

E Mutiski neizpaužos.

6 Kad ir nepieciešams izteikt savas vajadzības...

A Varu brīvi izteikt citiem vajadzības un vēlmes

B Es varu izteikt vajadzības un vēlmes, bet tikai ar konkrētiem cilvēkiem.

C Varu paust tikai elementāras vajadzības (izsalkums, slāpes, mazgāšanās...) vai tikai konkrētas vēlmes.

D Es varu izrādīt vajadzības nepieciešamību, bet es nespēju to norādīt funkcionālā veidā (piemēram, kliedzu, situ sev, raudu...).

E Es nevaru izteikt vajadzības

7 Kad tu komunicē ar citiem cilvēkiem...

A Es spēju saprast, kādā sociālā kontekstā es atrodos un izmantoju atbilstošu uzvedību (piem: sveiciens, smaids, skatīšanās acīs).

B Es atpazīstu vairākas sociālas situācijas, kurās atrodos, bet reizēm man ir vajadzīgs kāds, kas atgādinātu par atbilstošu uzvedību (piemēram, sveiciens, smaidīšana, skatīšanās acīs, sarunu pavērsiena gaidīšana).

C Man ir vajadzīgas pastāvīgas vadlīnijas, lai izprastu veicamos sociālos kontekstus un uzvedību

D Es bieži vien nesaprotu, kādā sociālā kontekstā atrodos un man ir nepieciešama pastāvīga palīdzība, lai regulētu un kontrolētu savu uzvedību.

E Es nesaprotu to sociālo attiecību kontekstu, kurās dzīvoju, un atbilstošu uzvedību, ko šādās reizēs izmantot

8 Vai vari brīvi pārvietoties savā dzīves vidē?

A Es vienmēr pārvietojos patstāvīgi

B man ir vajadzīgs kāds, kas mani uzraudzītu noteiktās situācijās...

C Pārvietojos ar pastāvīgu uzraudzību vai fizisku asistēšanu

D Veicu tikai nelielas kustības un lielākoties nākas saņemt fizisku asistēšanu

E Man ir pilnībā jāpalīdz pārvietojoties

9 Kad jāmazgājas...

A Darbību veicu pilnīgi patstāvīgi

B Es veicu darbību patstāvīgi un man ir vajadzīga tikai kāda norāde vai uzraudzība (piemēram, pienest, ūdens temp. kontrole,...).

C Man ir nepieciešama pastāvīga vadība un palīdzība (piemēram, pārvietojos, mazgāju un žāvēju,...).

D Varu paveikt tikai dažus nelielus uzdevumus un lielākajai daļai aktivitāšu nepieciešama fiziska palīdzība.

E Man ir jāpalīdz pilnībā

10 Higiēnas pašaprūpe (sejas un zobu mazgāšana, ķemmēšanās, skūšanās/ kosmētika, nagu griešana)

A Pats veicu visas nepieciešamās darbības

B Pats veicu darbības, bet man ir vajadzīga uzraudzība vai kaut kādas norādes.

C Veicu visvienkāršākās darbības (piem. roku mazgāšana), bet nepieciešamas palīdzība sarežģītākajās (piem. skūšanās/kosmētika).

D Man nepieciešama fiziska palīdzība lielākajā daļā aktivitāšu.

E Man ir jāpalīdz pilnībā

11 Vai var apģērbties un izģērbties?

A Darbību veicu pilnīgi patstāvīgi (arī kurpes, korsete, protēze,...)

B Veicu darbību pats, man vajag tikai kaut kādu norādi vai uzraudzību smalkiem uzdevumiem (piem., pogām, rāvējslēdzējiem)

C Es daru dažus darbus, man ir nepieciešama pastāvīga vadība un palīdzība.

D Varu paveikt tikai dažus nelielus uzdevumus un lielākajai daļai aktivitāšu nepieciešama fiziska palīdzība.

E Man ir jāpalīdz pilnībā

12 Kad jāēd...

A Es ēdu patstāvīgi, pareizi izmantojot galda piederumus (piemēram, griezt, atvērt burkas, ieliet ūdeni,...).

B Ēdu patstāvīgi, lietoju galda piederumus, bet reizēm man ir nepieciešama neliela palīdzība vai atgādināšana (nav nepieciešama citu klātbūtne)

C Es varu ēst, izmantojot galda piederumus, bet man nepieciešama pastāvīga vadība vai uzraudzība (personas klātbūtnē)

D Es veicu dažas darbības, bet man ir nepieciešama fiziska palīdzība (piemēram, pareizi turēt galda piederumus, ielikt ēdienu...).

E Man jāpalīdz pilnībā/mani baro mākslīgi.

13 Kad jāiet uz tualeti...

A Pareizi lietoju tualeti un patstāvīgi tīru
B Es pats to izdarīšu, bet man ir nepieciešama uzraudzība vai daži norādījumi
C Man nepieciešama palīdzība ar dažās darbībās tualetes izmantošanā vai tīrīšanas uzdevumos.
D Man jābūt līdzi un fiziski jāpalīdz tualetes izmantošanā un tīrīšanas uzdevumos.
E Neesmu spējīgs kārtīgi lietot tualeti un patstāvīgi tīrīt sevi

14 Gatavojot maltītes...

A Patstāvīgi
B Es pats to gatavoju, bet man ir vajadzīga kaut kāda vadība vai uzraudzība...
C Man ir vajadzīga pastāvīga vadība un palīdzība, kamēr esgatavoju.
D Varu veikt tikai atsevišķas darbības, nepieciešama palīdzība ar visu pārējo.
E Man vajag kādu, kas man gatavotu ēdienu.

15 Lai jūsu dzīves telpa būtu sakārtota un tīra (sakopt māju, sakārtot istabu un uzturēt kārtībā personiskās telpas...)

A Patstāvīgi
B Man vajag kaut kādas verbālas norādes vai uzraudzību
C Man ir vajadzīga pastāvīga vadība un palīdzība, kamēr es uzkopju.
D Varu veikt tikai dažas nelielas uzkopšanas daļas, nepieciešama palīdzība ar visu pārējo.
E Man vajadzīgs kāds, kas to darītu manā vietā.

16 Pārvietošanās uz pilsētu vai citu vietu...

A Es patstāvīgi pārvietojos
B Interesējošās vietas sasniedzu ar iepriekšējo sagatavošanos.
C Es dodos uz dažādām vietām, bet man ir nepieciešama pastāvīga uzraudzība un vadība.
D Sasniedzu dažas vietas, bet ar pavadoni
E Nevar parvietoties uz citu vietu

17 Kad iepērkaties...

A Darbību veicu pilnīgi autonomi (piemēram, veikala, preces un samaksas izvēle)
B Veicu darbību vienatnē, bet man vajag kaut kādu norādi vai uzraudzību (piem., saprast vērtību, saskaitītu pārējo)
C Man ir vajadzīga pastāvīga vadība un palīdzība, kamēr es daru savu darbu.
D Varu darīt vai sadarboties tikai vienkāršos iepirkumos, bet nepieciešama palīdzība ar visu pārējo.
E Man vajadzīgs kāds, kas varētu iepirkties manā vietā.

Piedaloties sabiedriskajās aktivitātēs (atpūtā, pulcēšanās, ballītēs...)
18 savā pilsētā

A Es pilnīgi autonomi piedalos aktivitātēs
B Varu būt pasākumā, bet man vajag kaut kādu virzienu vai uzraudzību.
C Nepieciešama noteikta veida palīdzība dažos gadījumos
D Bieži nepieciešams, lai kāds darbotos manā vārdā vai palīdzībā
E Man vajadzīgs kāds, kas darbotos manā vārdā vai palīdzētu man lielākoties.

3. Dzīves kvalitāte

Domājot par savu dzīvi pēdējo 6 mēnešu laikā, tagad centies atbildēt uz šādiem jautājumiem. Punktu skaits tiek dots, izmantojot Likert skalu no 1 līdz 5, kur 1 "pilnībā netabilst", bet 5 "pilnībā atbilst".

	Items	pilnībā netabilst (1)	(2)	(3)	(4)	pilnībā atbilst (5)
1	Vai jūtaties enerģisks un vitāls?	☐	☐	☐	☐	☐
2	Vai jūtaties atpūties?	☐	☐	☐	☐	☐
3	Vai jūtaties komfortabli, kur dzīvojat?	☐	☐	☐	☐	☐
4	Vai ir lietas (cilvēki, aktivitātes, notikumi), kas dara tevi laimīgu?	☐	☐	☐	☐	☐
5	Vai esat apmierināts ar lietām, ko darāt un kā pavadāt laiku savā ikdienā?	☐	☐	☐	☐	☐
6	Vai esat apmierināts ar personīgajām mantām vai lietām un to pieejamību?	☐	☐	☐	☐	☐
7	Vai ikdienas dzīves vide ļauj pabūt vienam (kad jābūt) vai aizsargāt savu privāto dzīvi?	☐	☐	☐	☐	☐
8	Vai jūsu dzīves vide ir pielāgota jūsu vajadzībām un vēlmēm?	☐	☐	☐	☐	☐
9	Vai jums ir attiecības ar cilvēkiem, kas dzīvo jūsu apkaimē/teritorijā (arī tad, ja atrodaties aprūpes iestādē)?	☐	☐	☐	☐	☐
10	Vai pakalpojumi, iespējas vai atpūtas vietas jūsu apkaimē/teritorijā (piemēram, veikali, bāri, baznīca, draudze, teātris, kino...) atbilst jūsu vajadzībām, interesēm, vēlmēm?	☐	☐	☐	☐	☐
11	Vai esat iesaistīts nozīmīgās aktivitātēs savā apkaimē/teritorijā (piemēram, atpūtā, sportā, brīvprātīgajā darbā...)?	☐	☐	☐	☐	☐
12	Vai jūtaties apmierināts ar attiecībām, kas jums ir ar ģimeni, vai ar aizbildņiem?	☐	☐	☐	☐	☐
13	Vai jums ir draugi, ar kuriem spējat uzturēt pastāvīgas attiecības (izņemot ģimenes locekļus, darbiniekus un brīvprātīgos)?	☐	☐	☐	☐	☐
14	Vai jums ir iespēja veikt sociālās aktivitātes, kas jums sagādā gandarījumu (piemēram, iziet pilsētā, piedalīties pasākumos...)?	☐	☐	☐	☐	☐

15 Vai jums ir iespēja pielietot to, ko protat (piemēram, instrumentu lietošana, datora lietošana, patstāvīgi veikt noteiktu darbu)?	☐	☐	☐	☐	☐
16 Vai esat apguvuši jaunas prasmes vai zināšanas (autonomijas prasmes, apmācības kursus...)?	☐	☐	☐	☐	☐
17 Vai jums ir bijusi iespēja piekļūt jaunām sociālām lomām vai jaunām dzīves iespējām (piemēram, mācībām, darbam, patstāvīgai dzīvošanai)?	☐	☐	☐	☐	☐
18 Vai jums ir iespēja kādam uzticēt savas vēlmes un priekšrocības?	☐	☐	☐	☐	☐
19 Vai dienas laikā jums ir iespēja izdarīt izvēli, kas saistīta ar jūsu aktivitātēm (piemēram, ko ēst, ko vilkt mugurā, ko darīt)?	☐	☐	☐	☐	☐
20 Vai jums ir iespēja izlemt, pie kā palikt, ar ko tikties, ko apmeklēt, ar ko veikt noteiktas aktivitātes?	☐	☐	☐	☐	☐

4. Iespējas

Arī atsaucoties uz pēdējiem 6 mēnešiem, pamēģiniet tagad padomāt, vai jums kādreiz ir bijusi iespēja...
Atbildi sniedz tikai atkarībā no iespējas biežuma neatkarīgi no jūsu prasmes un saņemtās palīdzības. Norādiet arī, vai esat faktiski izmantojis šo iespēju.

1. Nekad
2. Mazāk nekā reizi mēnesī
3. Vismaz reizi mēnesī, bet ne katru nedēļu.
4. Vismaz reizi nedēļā
5. Katru dienu vai gandrīz katru dienu

Items	(1)	(2)	(3)	(4)	(5)	jūs izmantojāt iespēju		
						Nē	Ne pilnībā	Jā
1 Veikt personīgās aprūpes darbības?	☐	☐	☐	☐	☐	☐	☐	☐
2 Veikt dzīves vides uzkopšanas darbības?	☐	☐	☐	☐	☐	☐	☐	☐
3 Izmantot sadzīves tehniku vai instrumentus?	☐	☐	☐	☐	☐	☐	☐	☐
4 Pārvietoties pa teritoriju?	☐	☐	☐	☐	☐	☐	☐	☐
5 Izmantot kopienas pakalpojumus (piemēram, veikalus, birojus, kinoteātrus, sporta zāles)?	☐	☐	☐	☐	☐	☐	☐	☐
6 Piedalīties nozīmīgās kopienas pasākumos?	☐	☐	☐	☐	☐	☐	☐	☐
7 Apgūt prasmes patstāvīgai savas personas vadībai, izmantojot mērķtiecīgu apmācību?	☐	☐	☐	☐	☐	☐	☐	☐
8 Kognitīvo, izglītojošo vai tehnoloģisko prasmju (tālruņa, personālā datora utt.) apgūšana, mērķtiecīgi iesaistoties apmācībās?	☐	☐	☐	☐	☐	☐	☐	☐

9	Iesaistīties lomās, uzdevumos un aktivitātēs, kas noderēs cilvēkiem, ar kuriem kopā dzīvojat, kuri dzīvo tuvumā vai kuri apmeklē tavu dzīves vietu?	☐	☐	☐	☐	☐	☐	☐	☐
10	Iesaistīšanās uzdevumos, kas saistīti ar noteikta darba veikšanu (arī neapmaksātu)?	☐	☐	☐	☐	☐	☐	☐	☐
11	Meklēt vai veikt darbu?	☐	☐	☐	☐	☐	☐	☐	☐
12	Apgūt prasmes ārējai autonomijai, izmantojot mērķtiecīgu apmācības?	☐	☐	☐	☐	☐	☐	☐	☐
13	Socializēšanās/satikšanās ar jums svarīgiem cilvēkiem?	☐	☐	☐	☐	☐	☐	☐	☐
14	Piedalīties svarīgajās atpūtas vai socializācijas aktivitātēs?	☐	☐	☐	☐	☐	☐	☐	☐

5. Uzvedības traucējumi

Domājot par savu dzīvi pēdējo 6 mēnešu laikā, tagad mēģini atbildēt uz šādiem jautājumiem, norādot dažādām aktivitātēm atbildi, kas tevi vislabāk raksturo.
Izvēlieties reprezentatīvāko variantu, ņemot vērā atšķirīgās dzīves vides. Ja pastāv nenoteiktība starp diviem variantiem, norādiet lielākās intensitātes līmeni.

1 Heterotieša agresija

A attiecīgajā periodā nav tiešas rīcības pret citiem
B gadījuma rakstura kairinājums un kāds verbāls uzbrukums
C bieža verbāla agresija un reizēm agresīvi žesti
D fiziskas agresijas izpaušana, kas rada nelielas traumas un riskus citiem, kuriem profilaksei nepieciešama rūpīga uzraudzība
E fiziskas agresijas izpaušana ar sekojošām traumām un citiem svarīgiem riskiem, kam nepieciešama rūpīga uzraudzība

2 Pašvērsta agresija un paškaitējums

A attiecīgajā periodā nav paškaitējuma rīcības
B gadījuma paškaitējoša uzvedība (piem.:klapējot pa pieri...)
C biežs paškaitējums, neradot būtiskus bojājumus (piemēram, apsārtums, skrāpējumi utt.).
D paškaitējums ar risku bojājumiem, kas jebkurā gadījumā ir atgriezeniski un bez funkcijas zuduma (piemēram, griezumi, zilumi, matu izraušana utt.).
E paštraumējošas uzvedības risks, kā rezultātā rodas neatgriezeniski bojājumi un pastāvīgi funkciju zudumi (redzes traucējumi, pastāvīgas sejas rētas). Ieskaitot pašnāvības mēģinājumu

3 Agresivitāte pret vidi vai lietām

A novērtēšanas periodā problēmu nav
B ir bijuši daži gadījumi
C būtiski ietekmē manu ikdienu
D ir ārkārtīgi būtiska ietekme uz manu un citu personu darbību, un tās prasa rūpīgu uzraudzību vadībai un profilaksei
E problēmas nopietni ietekmē ikdienas darbību, un to novēršanai nepieciešama pastāvīga uzraudzība vai fiziska iejaukšanās

4 Rituāli stereotipi un piespiedu uzvedība

A novērtēšanas periodā problēmu nav
B dažreiz notiek
C ir būtiska ietekme uz personas un citu darbības veikšanu
D ir ārkārtīgi būtiska ietekme uz citu personu darbību izpildi, un tās prasa rūpīgu uzraudzību vadībai un profilaksei
E problēmas nopietni ietekmē ikdienas darbību izpildi, un to novēršanai nepieciešama pastāvīga uzraudzība vai fiziska iejaukšanās

5 Neēdamu vielu uzņemšana

A novērtēšanas periodā problēmu nav
B ir gadījuma raksturs
C tam ir būtiska ietekme uz personas un citu darbības veikšanu
D ir ārkārtīgi būtiska ietekme uz personu un citiem cilvēkiem un tas prasa rūpīgu uzraudzību vadībai un profilaksei
E nopietni ietekmē ikdienas darbību izpildi, un to novēršanai nepieciešama pastāvīga uzraudzība vai fiziska iejaukšanās

6 Pretīgums

A novērtēšanas periodā problēmu nav
B ir gadījuma raksturs
C tam ir būtiska ietekme uz personas un citu darbības veikšanu
D ir ārkārtīgi būtiska ietekme uz citu personu darbību izpildi, un tās prasa rūpīgu uzraudzību vadībai un profilaksei
E problēmas nopietni ietekmē ikdienas darbību izpildi, un to novēršanai nepieciešama pastāvīga uzraudzība vai fiziska iejaukšanās

7 Sociāli neatbilstoša rīcība

A novērtēšanas periodā problēmu nav
B ir gadījuma raksturs
C tam ir būtiska ietekme uz personas un citu darbības veikšanu
D ir ārkārtīgi būtiska ietekme uz personas un citu personu darbību izpildi, un tās prasa rūpīgu uzraudzību vadībai un profilaksei
E nopietni ietekmē ikdienas darbību izpildi, un to novēršanai nepieciešama pastāvīga uzraudzība vai fiziska iejaukšanās

8 Nepiemērota seksuālā uzvedība

A novērtēšanas periodā problēmu nav
B ir gadījuma raksturs
C tam ir būtiska ietekme uz personas un citu darbības veikšanu
D ir ārkārtīgi būtiska ietekme uz citu personu darbību izpildi, un tās prasa rūpīgu uzraudzību vadībai un profilaksei
E problēmas nopietni ietekmē ikdienas darbību izpildi, un to novēršanai nepieciešama pastāvīga uzraudzība vai fiziska iejaukšanā

9 s traucējumi

A novērtēšanas periodā problēmu nav
B ir gadījuma raksturs
C tam ir būtiska ietekme uz personas un citu darbības veikšanu
D ir ārkārtīgi būtiska ietekme uz personas un citu personu darbību izpildi, un tās prasa rūpīgu uzraudzību vadībai un profilaksei

6. Veselība

1 - Slimības stāvokļu klātbūtne

Lūdzu, norādiet jebkādu slimību klātbūtni dažādajās ierosinātajās jomās. Ja tā, norādiet problēmas smaguma pakāpi no 1 līdz 4 (1: viegla; 2: vidēji smaga; 3: smaga; 4: ļoti smaga). Norādiet arī, vai tiek veikta terapija, un autonomijas līmeni, izvēloties no dažādām piedāvātajām alternatīvām (A: terapija netiek veikta; B: neatkarīgs; C: dažos gadījumos saņem palīdzību vai ir nepieciešams atgādinājums; D: intensīvā aprūpe: saņem palīdzību visos gadījumos; E: pilnībā atkarīgs).

Slimības stāvoklis	Klātbūtne (Ja JĀ atzīmēji et rūtiņu)	Problēmas nopietnības līmenis (Ja ir klāt slimības stāvoklis)				Jebkādas "ārstēšanas uzņemšanas" klātbūtne un autonomijas līmenis (Ja ir klāt slimības stāvoklis)				
		1	2	3	4	A	B	C	D	E
Sirds	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Hipertensija	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Asinsvadu	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Elpošanas	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Acs, auss, deguns, rīkle un balsene	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Augšējā kuņģa-zarnu trakta	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Apakšējā kuņģa-zarnu trakta daļa	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Aknas	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Nieres	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Urogenitālā sistēma	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Skeleta muskuļi	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Nervu sistēma	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Endokrīnā sistēma	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Psihopatoloģiska/uzvedības	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

2 - Sāpju novērtēšana

Runājot par veselības problēmām, cik stipras sāpes jūs šobrīd jūtat?

☐ 0 (nav sāpju) ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 (maksimālas sāpes)

Ja pacientiem ir nopietni kognitīvi traucējumi vai komunikācijas grūtības, izpētiet šādas 5 uzvedības jomas:

2.01 Elpošana
0 Normāls
1 Elpas trūkums
2 Trokšņaina un sēcoša elpošana, pārmaiņus apnojas un polipnejas periodi

2.02 Vokalizācija
0 Nav problēmu
1 Neregulāra stādīšana vai kurnēšana
2 Atkārtota kliedzieni vai vaidēšana

2.03 Sejas izteiksmes
0 Smaidošs vai neizteiksmīgs
1 Skumjas vai sarauktas skropstas
2 Grimases

3.04 Ķermeņa valoda
0 Atslābināts
1 Saspringts
2 Stīvs ar aizvērtām dūrēm vai mēģinājums sist

4.05 Mierinājums
0 Nav nepieciešams mierināt
1 Apjukusi un meklē mierinājumu
2 Nespēj novērst uzmanību un/vai rast mierinājumu

3 - Elpošanas palīdzība
☐ Jā ☐ Nē
Ja jā,
☐ Inhalācijas terapija vai skābekļa terapija
☐ Invazīva mehāniski atbalstīta plaušu ventilācija
☐ Nepārtraukta neinvazīva mehāniski atbalstīta plaušu ventilācija
☐ Posturālā drenāža
☐ Fizioterapija krūšu kurvja sekrēta drenāžai
☐ Bronhu un trahejas atsūkšana
☐ Traheostomijas aprūpe

4 - 77 — Elpošanas palīdzība
☐ Jā ☐ Nē
Ja jā,
☐ Mutes dobuma stimulācija vai žokļa pozicionēšana
☐ Barošana caur zondi (piemēram, nazogastrālā)
☐ Parenterāla barošana (piemēram, intravenoza)
☐ Slimības diēta
☐ Barošana

5 - Stājas palīdzība spiediena traumu profilaksei

☐ Jā ☐ Nē

Ja jā,

☐ Rotācija vai pozicionēšana

☐ Spiediena čūlas pārsējs

6 - Urīna nesaturēšanas problēmas

☐ Jā ☐ Nē

Ja jā,

☐ Patstāvīga iekšējo/ārējo urīnceļu palīglīdzekļu (prezervatīvu, autiņbiksīšu u. c.) lietošana

☐ Nepieciešama uzraudzība urīnceļu palīglīdzekļu lietošanai

☐ Nepieciešama fiziska palīdzība palīglīdzekļu lietošanā (parasti sauss dienas laikā, bet ne naktī)

☐ Nepieciešama fiziska palīdzība palīglīdzekļu lietošanā (vienmēr)

☐ Nesadarbojošs

7 - Kuņģa-zarnu trakts

☐ Jā ☐ Nē

Ja jā,

☐ Spēj uzlikt svecītes vai veikt klizmas

☐ Nepieciešama uzraudzība, lietojot svecītes, klizmas un autiņbiksītes.

☐ Nepieciešama fiziska palīdzība ierīču lietošanā

☐ Nesadarbojošs

8 - Rehabilitācijas procedūras

☐ Jā ☐ Nē

Ja jā,

☐ Specializēta individuālā fizioterapija

☐ Specializēta grupu fizioterapija

☐ Elpošanas fizioterapija

☐ Speciālistiska logopēde

☐ Citi specializētās rehabilitācijas veidi (piemēram, ergoterapija)

9 - Citi veselības aprūpes intervenču veidi

☐ Jā ☐ Nē

Ja jā,

☐ Infekcijas slimību profilakse

☐ Krampju ārstēšana

☐ Stomu pārsēšana

☐ Fizioterapijas intervences

☐ Specializētas terapeitiskās aktivitātes

☐ Farmakoloģiskā ārstēšana ar insulīnu

10 - Cita veida veselības aprūpes intervences klātbūtne

☐ Jā ☐ Nē

Appendix 3
Raw data tables

(Created by the researcher)

ID_Rif	S1	S2	S3	S4	S5	S6	S7	S8	S9	S10	S11	S12	S13	S14	S15	S16	S17	Q1	Q2	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	O1	O2	O3	O4	O5	O6	O7	O8	O9	O10	O13	O14
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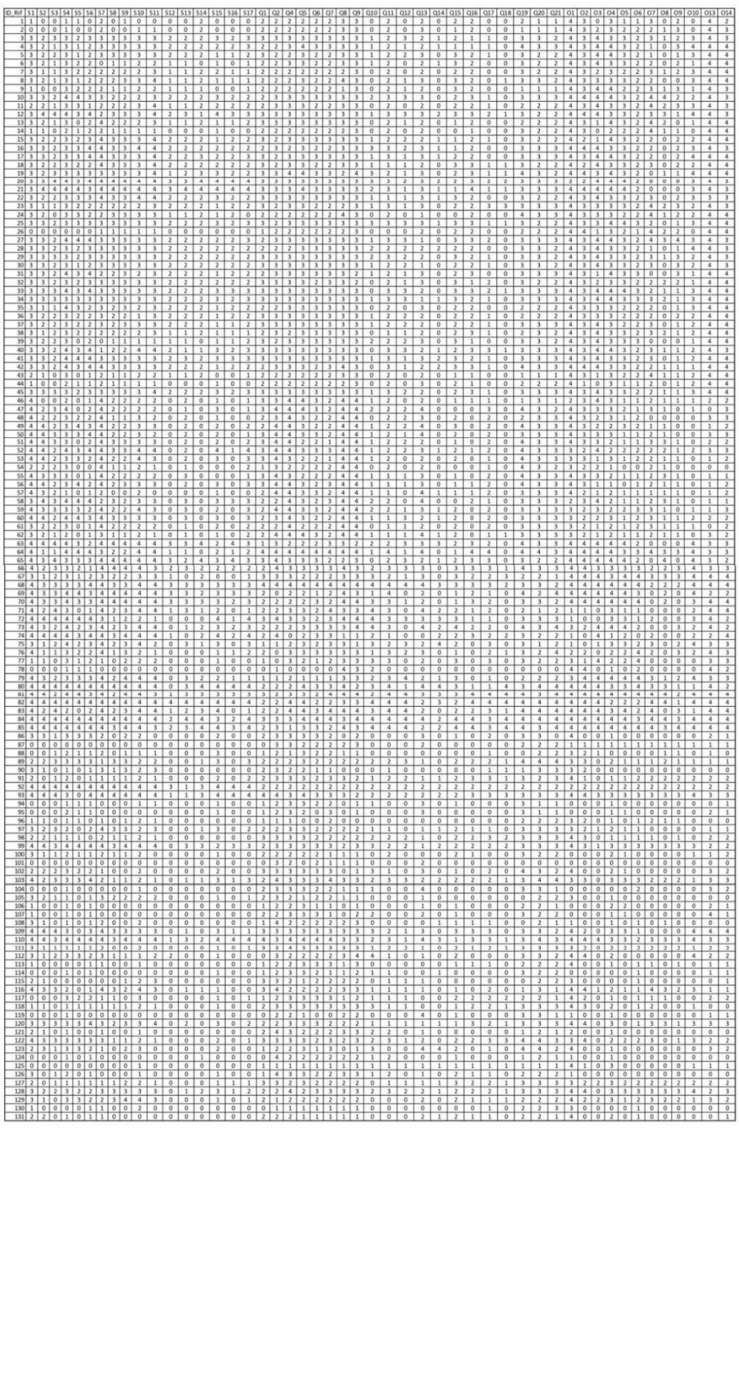

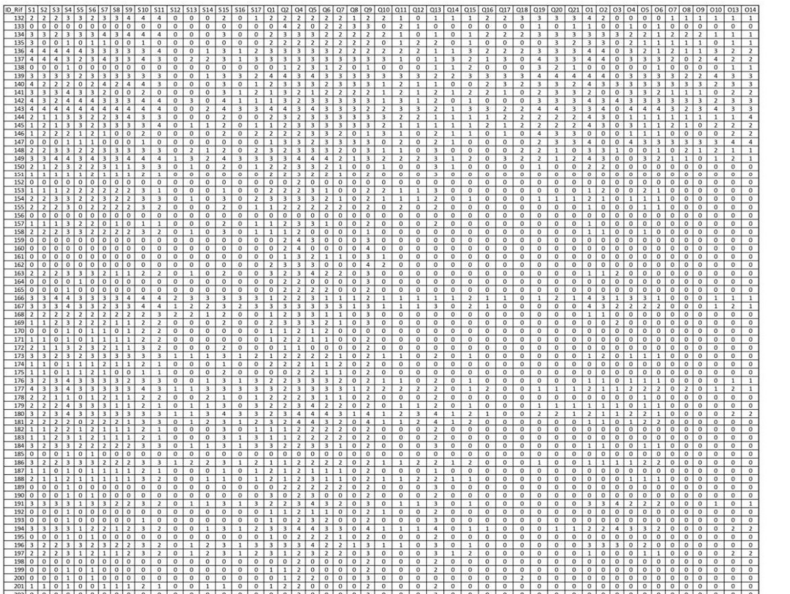

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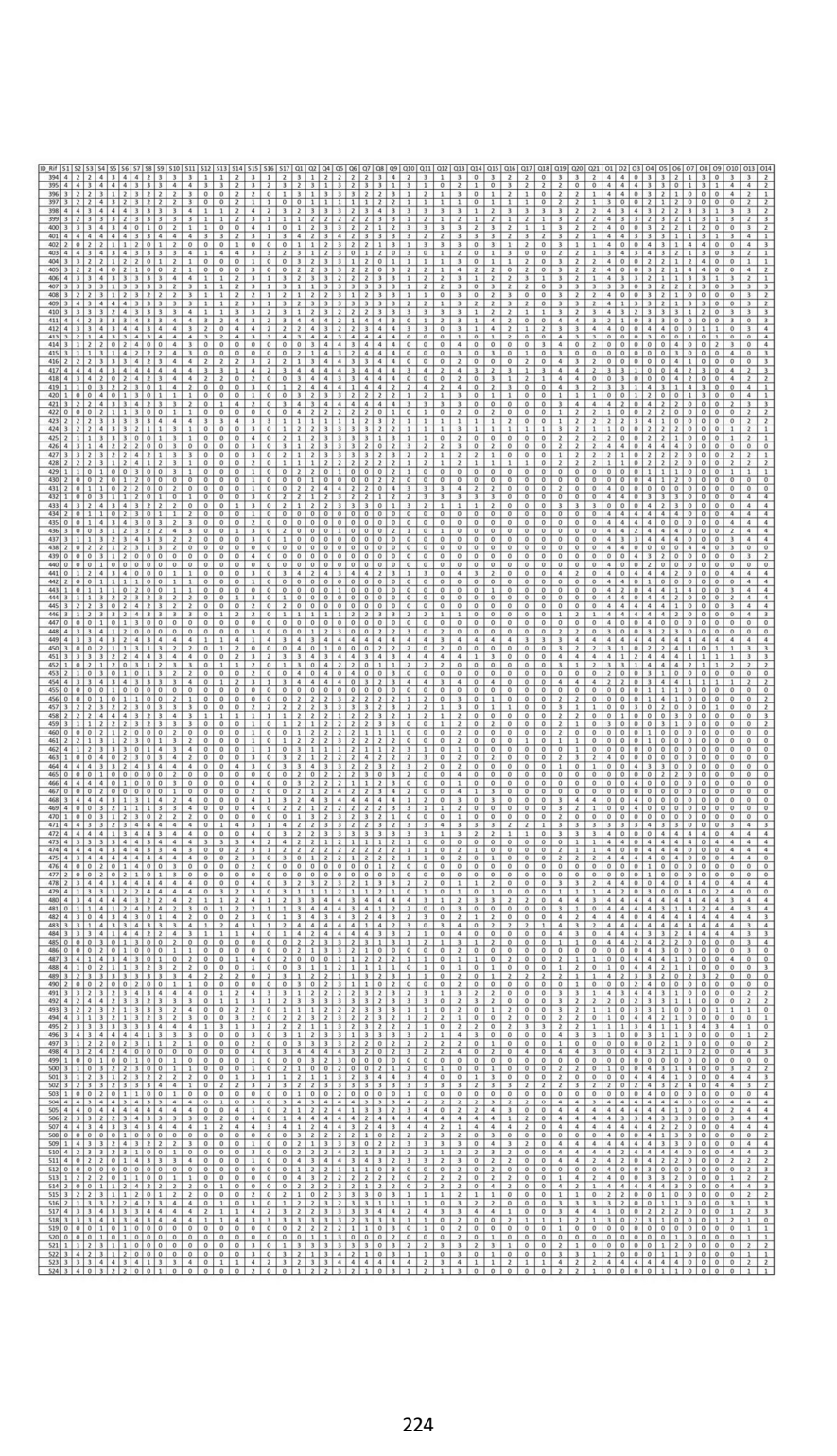

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Simone Zorzi was born on June 17, 1976, in Gorizia, Italy. He obtained his Master's degree in Psychology (2002) from the University of Trieste. He later completed a four-year specialisation in Cognitive-Behavioural Psychotherapy and earned a postgraduate Master's degree in Applied Behaviour Analysis, obtaining a qualification as a Behaviour Analyst. Since 2019, he has served as Director of Disability Services at the Azienda Sanitaria Universitaria Friuli Centrale, where he leads and coordinates the regional network of socio-health services. He is also an adjunct professor of Special Pedagogy and Psychology of Disabilities at the University of Udine and Vice President of the Ecoistituto del Friuli Venezia Giulia. His professional expertise focuses on the design and implementation of psychoeducational interventions for individuals with intellectual disabilities and autism, integrating evidence-based behavioural models with digital technologies. His research addresses disability, social inclusion, and the application of digital technologies in support services.