



UNIVERSITY OF PADOVA

Department of General Psychology*

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Final dissertation

**Autism Spectrum Disorder:
Proposal for a Program Designed to Improve the Quality of
Life in Adults with Autism**

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** No more than two people.

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Abstract

Over the past several decades, individuals with autism and other intellectual disabilities have experienced a significant increase in life expectancy, from 18 years in 1961 to over 60 years in 2011 (Dieckmann, Giovis, & Offergeld, 2015). This improvement is attributed to societal acceptance, better medical care, mainstream education, and family-based upbringing, contrasting with past practices of institutionalization. As a result, these individuals now spend the majority of their lives as adults, presenting new challenges for social services originally designed for children.

This paper examines the care and support needed for adults with intellectual disabilities, with a particular focus on Autism Spectrum Disorder (ASD). It addresses critical areas such as guardianship, community involvement, and cultural stereotypes. Additionally, it proposes a project aimed at enhancing the quality of life (QoL) for adults with ASD, equipping them with skills for independent living and integration into mainstream society.

To contextualize the QoL project, the paper provides a brief history of autism and its treatments. Autism existed long before it was formally recognized, with early descriptions dating back to the 1700s. Significant contributions came from figures like Jean-Etienne Dominique Esquirol and Grunya Sukhareva, whose work laid the foundation for modern diagnostic criteria. The most detailed early descriptions of ASD were provided by Leo Kanner and Hans Asperger in the 1930s and 1940s.

Applied Behavior Analysis (ABA), based on early 20th-century behaviorism, plays a key role in ASD treatment, using positive reinforcement to teach effective behaviors and improve lives. The proposed QoL project leverages ABA principles to support young adults with ASD, addressing the gap in services for adults and ensuring they receive continued support into adulthood.

Introduction

There are people of all ages with intellectual disabilities, cognitive deficits, and other intellectual challenges, and over the past several decades, their average life expectancy has increased from 18 years in 1961, to more than 60 years in 2011 (Dieckmann, Giovis, & Offergeld, 2015). Because of acceptance into society instead of placing them in mental hospitals or orphanages, because most families now raise their children with disabilities in the home environment with their other children, because they are mainstreamed into traditional academic classrooms, and because they are the recipients of much better medical care than when they were institutionalized, these people with serious intellectual disabilities live longer than they ever have before, and so they spend most of their lives as adults.

Therefore, this growing population of adults with intellectual disabilities has significantly stressed social services; these services historically have not been designed with them in mind. Several questions emerge from this simple fact:

- What does it mean to care for an adult with intellectual disability?
- Who does the caring? Who arranges guardianship?
- Who can assist the guardian in accessing necessary services?
- Is the community able to provide appropriate support to people with intellectual disabilities at all stages of life?

These questions in turn recall some fundamental themes, such as:

- A. The transition to adult life appears to be difficult both due to clinical-functional obstacles and linked to the health conditions of the individual and due to contextual and socio-cultural components.
- B. The cultural level between attitudes and stereotypes: some beliefs (charitable, infantilizing, overprotective, substitutive, repulsive) persist today and are revealed in the different levels of the social system, influencing the way of thinking about disabilities, the actions taken, policy decisions, programs and interventions that are implemented in a given society. These cultural stereotypes may represent strong obstacles to the processes of inclusion and access to adult life.
- C. The community or territory proposes actions that are not concentrated on the characteristics of adulthood but focus on childhood; this results in little effort toward the promotion of interventions and significant outcomes in those factors that play a fundamental role in the development and access to the typical roles of adult life.

Thesis Statement

The increasing life expectancy of individuals with intellectual disabilities, now averaging over 60 years, underscores a significant shift in societal integration and improved medical care. However, this demographic's growth has strained social services, which were not originally designed to support adult life stages for those with intellectual disabilities. Addressing the care and support for these adults necessitates understanding their unique needs, the role of guardians, and community involvement. This paper explores these critical questions, examines cultural stereotypes hindering inclusion, and proposes a project aimed at equipping adults with Autism Spectrum Disorder with the skills and support needed for independent living and improved quality of life in mainstream society.

Scientific Background

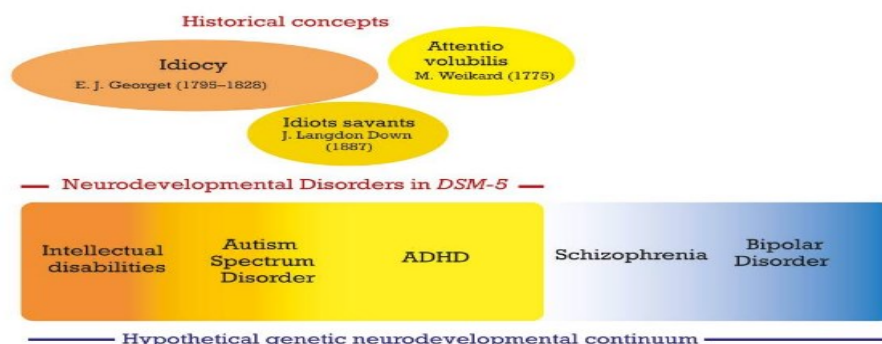
Neurodevelopmental Disorders: terminology

In the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), neurodevelopmental disorders (NDDs) are defined as a group of conditions with onset in the developmental period, resulting in deficits that cause impairments in functioning. NDDs include intellectual disability (ID); communication disorders; autism spectrum disorder (ASD); attention-deficit/hyperactivity disorder (ADHD); neurodevelopmental motor disorders, including tic disorders; and specific learning disorders.

“Developmental disorders” were included for the first time in DSM-III, published in 1980, within the category that comprised autistic disorder (Morris-Rosendahl & Crocq, 2020). The term “neurodevelopmental disorders” (NDDs) was introduced as an overarching category in DSM-5, published in 2013 (Morris-Rosendahl & Crocq, 2020). Figure 1 outlines the main categories comprising neurodevelopmental disorders in DSM-5, their historical background, and the hypothesis of the genetic spectrum of neurodevelopmental disorders, which will be discussed later in this article.

Figure 1

Main Categories of Neurodevelopmental Disorders in DSM-5



The validity of neurodevelopmental disorders (NDDs) as a construct is supported by the high rates of comorbidity observed among various disorders within this diagnostic grouping. For instance, several studies have demonstrated that 22% to 83% of children diagnosed with autism spectrum disorder (ASD) also exhibit symptoms meeting the DSM-IV criteria for attention-deficit/hyperactivity disorder (ADHD), and conversely, 30% to 65% of children with ADHD display clinically significant symptoms of ASD (Morris-Rosendahl & Crocq, 2020). Additionally, although not included in the criteria for ASD, accompanying intellectual or language impairments are common in individuals with ASD, and their presence must be specified. Neurodevelopmental disorders also share the characteristic of being diagnosed more frequently in males than females; DSM-5 mentions male-to-female ratios of 4:1 for the diagnosis of ASD, 2:1 for the diagnosis of ADHD in children, and 1.6:1 and 1.2:1 for mild and severe intellectual disability (ID), respectively.

Historical Perspective on Therapy For NDD

The best early modern descriptions of what we currently consider autism spectrum disorder, also known as ASD, came from two doctors in the 1930s and 1940s: Leo Kanner and Hans Asperger. Both were Austrian by birth, but Kanner moved to the United States before World War II and conducted most of his professional work there. They described children who were very asocial, severely speech-delayed, and managed new stimuli poorly, thriving best in stable environments. Ironically, Kanner proposed the term “Asperger syndrome” for those patients who had high intellectual functioning, whereas most of the early patients he described had severe developmental delays (Kanner, 1943). Asperger, working independently, described a similar condition in children who had specific difficulties in social integration but preserved cognitive and language skills.

Each new edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) has changed the terminology and the diagnostic criteria for Autism based on ongoing research in the epidemiology, prevalence, and causes of ASD. The DSM-5, published in 2013, eliminated the term “Asperger syndrome,” which had sometimes been referred to as “high-functioning autism.” This decision was based on the concept of a spectrum of symptoms and developmental problems, where each person with ASD fits along a range of symptoms. These symptoms, while present to a small degree in many people who do not meet the criteria for an ASD diagnosis, are much more pronounced and problematic in individuals with ASD. As the diagnostic criteria have been refined and widely disseminated, the prevalence of the condition has steadily risen. Once considered an exceedingly rare and severely disabling condition, ASD is now recognized as encompassing a much broader

spectrum, with both severe and mild cases. Mild cases receive services in school through programs designed to mainstream and support them, facilitating their integration into society during adulthood. In contrast, more severe cases also receive services during preschool and school years, but opportunities for continued support in adulthood are often less well developed.

Recent research highlights the importance of addressing the quality of life for individuals with ASD. Studies emphasize the benefits of early behavioral interventions, which have been shown to significantly improve social skills, communication, and overall well-being in individuals with ASD (Reichow, 2012). Moreover, comprehensive reviews have demonstrated that quality of life for children with ASD is influenced by factors such as physical health, emotional well-being, social functioning, and family dynamics (Kuhlthau, 2010). These findings underscore the need for tailored interventions that address the diverse needs of individuals with ASD across different stages of life.

Additionally, the quality of life in adults with ASD is significantly affected by factors such as employment, independent living, social relationships, and mental health. Research has shown that many adults with ASD face challenges in these areas, which can impact their overall quality of life (Ayres, 2018). Interventions aimed at improving employment opportunities, enhancing independent living skills, and providing mental health support are crucial for helping adults with ASD achieve a higher quality of life. Furthermore, ongoing support and community involvement play critical roles in fostering a sense of belonging and enhancing social integration for adults with ASD (Anderson, 2020). By addressing these factors, we can better support individuals with ASD in leading fulfilling lives and participating fully in society.

Applied Behavioral Analysis (ABA)

Behavior analysis is the science of behavior, with a history extending back to the early 20th century. Its guiding philosophy is behaviorism, which is based on the premise that attempts to improve the human condition through behavior change (e.g., education, behavioral health treatment) will be most effective if behavior itself is the primary focus. To date, behavior-analytic scientists have conducted thousands of studies to identify the laws of behavior—the predictable ways in which behavior is learned and how it changes over time. The underlying theme of much of this work has been that behavior is a product of its circumstances, particularly the events that immediately follow the behavior. Behavior analysts have used this information to develop numerous techniques and treatment approaches for analyzing and changing behavior, and to improve lives. Because this

approach, Applied Behavior Analysis (ABA), is largely based on behavior and its consequences, techniques generally involve teaching individuals more effective ways of behaving through positive reinforcement and working to change the social consequences of existing behavior (Institute for Credentialing Excellence, 2024). Treatment approaches based on ABA have been empirically shown to be effective in a wide variety of areas (see ABA Subspecialty Resources).

ABA is a therapy that has been shown to help children with autism learn skills and decrease or extinguish problematic behaviors, such as self-harm or severe tantrums. Its effectiveness has been demonstrated by hundreds of studies. All forms of ABA are based on the idea that rewarding certain behaviors will lead children to repeat those behaviors. Early forms of ABA focused on breaking skills into exceedingly small steps and rewarding children for doing each step correctly. In the past, they might also have been punished for doing a step incorrectly. Punishment is no longer used in any form of ABA. Other forms of ABA are much less structured. Instead, they are based on play and other activities that are part of kids' normal lives. One form is called Pivotal Response Treatment (PRT). In PRT, the clinician praises the child when they engage in an important behavior (like making eye contact), using the child's interests and attention to guide learning. Over time, the reinforcement helps the child remember and use those skills.

Finally, there is the Early Start Denver Model (ESDM). ESDM uses play, like PRT, but it also includes more traditional ABA at times. It usually includes more than one goal for each activity, which can be harder for therapists but may help kids build skills quickly. Research supports the efficacy of ESDM in improving cognitive, language, and adaptive behavior skills in young children with ASD. A study by Dawson et al. (2010) found that children who received ESDM showed significant improvements in IQ, language, and adaptive behavior compared to those who received typical community-based interventions. These findings highlight the potential of ESDM to facilitate early developmental progress and improve long-term outcomes for children with ASD.

Receiving an autism diagnosis for your child can leave any parent overwhelmed. There seem to be a vast number of treatments available, from aggressive dietary restrictions to music therapy. It is hard to know what will help your child and what is going to be a waste of crucial time and money. But the evidence-based therapy most widely accepted is Applied Behavior Analysis, better known as ABA. ABA has been shown to help autistic children develop needed skills and minimize undesired behaviors such as self-injury, and it has been shown to be successful for children across the autism spectrum, from mild to severe.

Moreover, long-term studies have demonstrated that children who receive intensive ABA therapy early in life often achieve significant improvements in intellectual and adaptive functioning, enabling many to integrate into mainstream educational settings (Lovaas, 1987; Sallows, 2005). These outcomes underscore the importance of early and sustained intervention to maximize the potential benefits of ABA for individuals with ASD.

On the Need for a Quality-of-Life Program for Adults with NDD

Contributions provided in the literature promote and highlight significant changes on:

- the cultural and value vision (e.g., the United Nations Convention on the Rights of Persons with Disabilities, 1993): the vision of the person with disability is now included in principles and rights of equality, dignity, and inclusion.
- the ecological and biopsychosocial conception of disability: the focus is now no longer on the pathology but on the interaction between personal and environmental characteristics, as a determinant of individual functioning (World Health Organization 2001). That is, it involves placing the person and their interactions within context at the center of the vision, and no longer the diagnosis as the only source of information on the subject. There are currently two scientifically validated models that reflect this approach: the International Classification of Functioning, Disability and Health (ICF) model, and the model proposed by the American Association on Intellectual and Developmental Disabilities (AAIDD).
- the paradigm of supports: a psychological construct that represents the gateway to a "person-centered" approach in which those who propose a given service do so from the starting point of the needs and preferences of the individual subject. Supports are the resources and strategies that aim to promote the development, personal well-being, and quality of life (QoL) of a subject, and that increase human functioning in its complex interaction with living environments. That is, the analysis of support needs becomes indispensable for QoL-oriented programming.
- the systemic model of quality of life: this constitutes a new interpretative horizon through which to consider the existence of people and therefore rethink community-based interventions. It is a multidimensional construct with a high semantic and conceptual complexity that needs precise definitions and validated models to be operationalized.

Regarding QoL studies addressing autistic people, there is a good study that evaluates the World Health Organization Quality of Life Measure (WHOQoL-BREF), published in

2022 (Mason, et al., 2022). In this study, 352 autistic adults were evaluated using the WHOQoL-BREF questionnaire, and four separate discussion groups of twenty adults each were used to validate the questionnaire. In this way, the study collected both quantitative data and qualitative data, and was able to validate the questionnaire in this population. The conclusion of the study, indicated in the chart below, was that the WHOQoL-BREF had acceptable validity and reliability when used with autistic adults.

Table 1

Participants' Demographic Information

Characteristic	Range	Mean	SD
Age in years	18–80	42.29	±14.22
Male	18–74	43.87	±15.31
Female	18–80	41.15	±12.63
Age at diagnosis in years	2–74	37.82	±16.30
Male	2–74	38.33	±17.95
Female	4–69	38.21	±13.39
SRS total score	18–178	111.65	±28.66
	N	%	
Gender			
Male	189	53.7	
Female	150	42.6	
Other / Rather not say / Not reported	13	3.7	
Current employment status			
Employed (inc. self-employed)	141	40.1	
Other ^a / Not reported	211	59.9	
Educational qualifications			
Higher ^b education qualifications	129	36.6	
Other / Not reported	223	63.4	
Current mental health condition diagnosis			
Yes	262	70.8%	
No	81	21.9%	
Not reported	27	7.3%	

^a "other" includes being a carer for a relative, long term illness, being a full time student, or unable to work; ^b "higher education" is first degree level qualification or above

SRS: Social Responsiveness Scale (Constantino & Gruber, 2012)

Table 2

Factor Loadings for items of the WHOQoL-BREF

		Phys	Med	Env	Soc	Psych
3	To what extent do you feel that (physical) pain prevents you from doing what you need to do?	-0.07	0.73	0.16	-0.02	-0.03
4	How much do you need any medical treatment to function in your daily life?	0.06	0.97	-0.08	0.01	-0.01
5	How much do you enjoy life?	-0.02	0.01	0.19	0.06	0.81
6	To what extent do you feel your life to be meaningful?	0.012	-0.06	0.10	0.14	0.62
7	<i>How well are you able to concentrate?</i>	0.59	-0.06	-0.02	0.06	0.04
8	How safe do you feel in your daily life?	0.28	0.01	0.50	0.07	-0.01
9	How healthy is your physical environment?	0.28	0.05	0.48	0.12	-0.00
10	Do you have enough energy for everyday life?	0.74	0.08	0.04	0.00	0.14
11	<i>Are you able to accept your bodily appearance?</i>	0.31	-0.06	0.09	0.11	0.26
12	Have you enough money to meet your needs?	0.17	-0.10	0.61	0.09	-0.09
13	How available to you is the information that you need in your day-to-day life?	0.30	-0.09	0.54	0.08	-0.03
14	To what extent do you have the opportunity for leisure activities?	0.33	0.10	0.41	0.09	-0.04
15	<i>How well are you able to get around?</i>	0.49	-0.09	0.46	-0.07	-0.09
16	How satisfied are you with your sleep?	0.54	0.08	0.10	-0.11	0.15
17	How satisfied are you with your ability to perform your daily living activities?	0.79	0.06	0.09	0.02	0.06
18	How satisfied are you with your capacity for work?	0.67	-0.09	0.02	0.06	0.16
19	How satisfied are you with yourself?	0.29	-0.02	-0.15	0.02	0.79
20	How satisfied are you with your personal relationships?	-0.07	0.06	0.13	0.77	0.18
21	How satisfied are you with your sex life?	0.03	-0.03	-0.10	0.87	-0.08
22	<i>How satisfied are you with the support you get from your friends?</i>	-0.05	0.06	0.34	0.31	0.18
23	How satisfied are you with the conditions of your living place?	-0.07	0.04	0.73	-0.13	0.22
24	How satisfied are you with your access to health services?	-0.05	0.09	0.68	0.07	0.17
25	How satisfied are you with your transport?	0.09	-0.05	0.65	0.03	-0.02
26	<i>How often do you have negative feelings such as blue mood, despair, anxiety, depression?</i>	0.09	0.08	-0.18	0.16	-0.17

NB Items in italics do not load as expected from WHOQoL-BREF structure. Bold numbers indicate strongest factor loading per item (all above 0.40, except for items 11, 22 and 26). Items 1 and 2 are not included in the EFA as they are global QoL items and so do not load onto facets of QoL.

Objectives

For all these reasons listed above, it seems obvious that there is a need to launch a QoL promotion process. What does it mean to promote quality of life interventions in people with disabilities? QoL may be defined by the extent to which a person, based on their functioning profile, deficits, skills, and competences, considering their life path, supports and barriers present, is able to satisfy expectations, desires, and personally significant needs. The constituent elements are outlined as follows:

- Functioning profile (deficits, skills, and competences).

- Life context (supports, barriers).
- Ability to satisfy personally significant expectations, desires, and needs.

These elements require the path to:

- Include personalized strengthening interventions on the individual profile.
- Provide for a specific structuring of the supports and supports needed by the person.
- Organize the path within a life project that gives personal meaning to the various objectives.

It is also conceptually evident that a quality life implies self-determined choices, that is, free as much as possible from constraints imposed by the context or by the personal condition itself. In this regard, the need arises to clearly differentiate:

- autonomy implies the subject's possession of the skills necessary to respond to the demands of the life context, without the need for continuous assistance from third parties. In this sense the concept strongly recalls that of adaptation.
- self-determination implies the subject's awareness of their own preferences regardless of internal and external conditioning, as well as the ability to communicate such preferences to obtain their satisfaction.

Hence, it's conceivable for a person to possess autonomy without being self-determined, and conversely, one might exhibit a strong capacity for self-determination despite lacking sufficient autonomy. Therefore, there's a crucial need to develop a comprehensive approach that targets both aspects—self-determination and autonomy—as part of the pathway towards enhancing Quality of Life (QoL). What attributes should the objectives embody to effectively elevate an individual's QoL? Adams, Beadle-Brown, and Mansell (2006) provide valuable insights by outlining key "quality indicators," including the relevance, observability, age appropriateness, necessity, timeliness, developmental suitability, measurability, and realism of the individual's goals within their unique life circumstances.

In light of these considerations, the proposed project aims to enhance QoL for adults with moderate-severe Autism Spectrum Disorder (ASD).

Project “Adult Identity”

After an analysis of the changes that have occurred in the economic, social, cultural, and scientific fields, we can see the need to develop a path that promotes improvements in Quality of Life (QoL) for people with neurodevelopmental disorders.

What does it mean to promote QoL in people with disabilities?

To answer this question, the terms must be defined:

QoL is described by the extent to which a person, based on their functioning profile, deficits, skills, and competences, considering their life path, supports and barriers present, can satisfy expectations, desires, and personally significant needs (World Health Organization, 2024).

The constituent elements are outlined as follows:

- functioning profile (deficits, skills, and competences).
- life context (supports, barriers).
- ability to satisfy personally significant expectations, desires, and needs.

And these elements require the Project to:

- include personal improvement interventions based on the individual's profile.
- provide for a specific structuring of the supports needed by the person.
- organize the path within a life project that gives personal meaning to the various objectives.

It is also conceptually evident that improvements in QoL imply self-determined choices, i.e., free as much as possible from constraints imposed by the context or by the personal condition itself. In this regard, we need to define the following concepts:

- Autonomy implies the subject's possession of the skills necessary to respond to the demands of the life context, without the need for continuous assistance from third parties. In this sense the concept strongly recalls that of adaptation.
- Self-determination implies the subject's awareness of their own preferences regardless of internal and external conditioning, as well as the ability to communicate such preferences to obtain satisfaction.

Therefore, a person can be autonomous but not self-determined; vice versa, we could witness a good capacity for self-determination in the absence of adequate levels of autonomy. It is therefore necessary to build a project which leads toward improved QoL by conducting educational actions, both in terms of self-determination and autonomy.

Purpose and Recipients

With these premises and objectives, the Project promotes activities which favor the disabled person and their living context, to:

- acquire skills at an individual level.
- recognize and function as a person with a unique identity (hobbies, work, history, preferences, etc.)

- generalize these outcomes to the plurality of the subject's life contexts, as relates to the person.
- understand one's role in the subject's life plan.
- legitimize, support, and stimulate the subject's life plan, as it relates to the living context.

These are the two projects under proposal.

The “I Choose” Project

The objective is to assist the subject in his/her life context to develop motivation to exercise the ability to choose by integrating the development of precise skills (in areas such as: money management, self-care, organization of events, behavior in shops, etc.) with the construction of an adult identity.

The “I Live” Project

The aim is to make the subject learn all the specific skills related to life and managing a home by integrating them with the development of awareness and self-determination.

Methodology

We choose to work from design to implementation, including evaluation, following some key principles, such as:

- **graduality:** to support the processes of building a life project it is important that the experience is in line, in content and rhythm, with the feelings and thoughts of both the subject involved and his life context.
- **personalization:** despite having a frame of reference, it is person-centered, and therefore tailor-made for each person in his/her specific life context.
- **defined beginning and end:** we must precisely know the starting point (with a detailed assessment of the person and their life context) and the arrival point (with objectives defined in behavioral terms).
- **organization:** we must define an organized work plan with a series of aspects (techniques, places, times, people involved, available resources, verification tools, and methodologies).
- **teamwork:** to guarantee the definition and implementation of objectives based on QoL, sharing is crucial both at a micro and macro level, both between the various professions and with the other actors in the life context of the individual involved.

Practicalities for the Project

The Project, therefore, thinks of a circular process between the subject and the life context, in which it is essential to refer to: the QoL construct, a person-centered and ecological approach, the definition and programming of supports, the definition of personal functional and clinical outcomes. The theoretical and operational models are defined in the individual projects.

Table 3

An overview of the intervention levels considered.

Cognitive Skills	Social-Emotional Skills	Adaptive- Integrating Skills
<ul style="list-style-type: none"> ● global intellectual level ● attentional and amnesic functions ● perceptive and practical skills ● instrumental reading and writing skills 	<ul style="list-style-type: none"> ● temperamental characteristics ● self-awareness and emotional self-regulation ● social-relational skills ● presence of psychopathological disorders 	<ul style="list-style-type: none"> ● ability for personal autonomy ● social autonomy skills ● communication skills ● presence of problem behaviors ● self-determination skills

THE “I LIVE” PROJECT

Who will use the Project? What are the Project’s goals?

The “I Live” Project intends to teach all those salient skills when thinking about oneself and managing one's life in and through the place of home. It conducts actions aimed at the participant and the family in a crescendo of skills which are divided as follows for simplicity of description:

Table 4

Crescendo of skills

	Knowing	Knowing How	Knowing When
PARTICIPANT	a.e. know how to prepare toasted bread	a.e. Make Toasted bread	a.e. Deciding what to eat, choosing the toast and organizing yourself to do it, deciding to share the moment with a friend, etc...

FAMILY	a.e Thinking about the child's autonomy	a.e. take concrete actions that promote the child's autonomy	a.e. confront the child about autonomy, feel what it feels like in the child's new configuration of autonomy, etc.
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Objectives for Subjects:

Specific Skills to Improve:

1. Personal hygiene: shower, dressing, body care (hair, nails, etc.)
2. Domestic hygiene: washing, changing sheets, cleaning the bathroom, etc.
3. Prepare meals.
4. Morning routine (wake up)
5. Evening routine (going to sleep)

Transversal:

1. Time management: read now, plan your time, etc.
2. Money Management: Compare money, stick to a budget, etc.
3. Free time management: playing sports, choosing how to spend your time, etc.
4. Self-determination skills: knowing one's preferences, implementing actions aimed at satisfying one's needs, solving problems.
5. Self-narrative and identification processes: self-narrative with focus on fears, needs, critical issues, objectives, motivations, permissions also with respect to the family of origin, etc.

Furthermore, we need to remember that the project has two populations of targeted users: the participant, and his parents. Therefore, the implementation of a series of actions capable of reorienting family habits with a QoL perspective, specifically from the subject's point of view, is to be strived for.

Table 5*Implementation of series of actions*

		2 0 2 4	2025											
Project Phases	Time development	D	J	F	M	A	M	J	J	A	S	O	N	D
		e	a	e	a	p	a	u	u	u	e	c	o	e
		c	n	b	r	r	y	n	l	g	p	t	v	c
1. Start														
2. Initial Assessment														
3. Implementation of the intervention														
4. Generalization of the intervention														
5. Review and Final Evaluation														
6. Closure and Perspectives														

Project Phases

The “I Live” Project may be divided into six phases, each characterized by different purposes and actions.

1. Start

It is the initial part of the work where all those actions aimed at defining the candidates for the project and the work team are activated.

2. Initial-Assessment

It is the dynamic and multidimensional evaluation of the person's deficits and residual abilities both at an individual level and embedded in the surrounding living environment.

3. Implementation Of the Intervention

When the correspondence between the entry levels of the activity and the prerequisites possessed by the subject is recorded, we can organize the actual educational intervention which will have to be divided into a series of points: techniques, times, places, materials, people involved.

The intervention of the Project includes two sub-routes:

- A1, Circle Participant, Housing Autonomy
- A2, Triangle Participant, Preparatory steps to independent living:

In details, the Circle participant will leave his home and will be followed day and night from Monday to Friday. The timetable will be developed around the participant's weekly activities to teach all the necessary skills in the circumstances of his/her daily life, thus facilitating him/her to learn how to carry them out more independently.

The Triangle participant will work individually or in some circumstances in pairs, at specific times depending on the objective. A fixed weekly scheme will be developed where they will have the opportunity to go inside the house to begin to learn the idea of a detached family life progressively and adequately.

4. Generalization Of the Intervention

This is a phase in which the participant is trained to exercise the skills acquired, in the intervention phase, in gradually different and increasingly complex conditions.

5. Review And Final Evaluation

In this phase, after an initial moment of evaluation of the state of learning, we continue with training of learning. That is, the participant will remain inside the house to maintain and improve his skills and the integration of the same on an emotional and identity level.

6. Closure And Perspective

This is the phase in which possible short- and medium-term prospects are outlined based on the information that emerges from the final evaluation. That is, it is a matter of building a vision with the participant, the family, and the team that on the one hand can welcome and enhance the learning obtained and on the other stimulate and support new ones.

“I Choose” Project

Purpose

Adult identity is a construction process that needs to be crossed and constituted through steps: development, roles, and contexts. That is, it is not so much an achievement linked exclusively to age or rather the abandonment of some roles in favor of others, but rather the possibility of developing self-awareness and fulfilling oneself through choices in everyday life. The Project promotes self-determination as awareness on the part of the subject of their own preferences regardless of internal and external conditioning, as well as the ability to communicate such preferences to obtain their satisfaction.

Recipients & Objectives

Start:

The purpose of this phase is to lay the foundations for mutual knowledge between the recipients of the Project. 2.

Evaluation:

This is the phase dedicated to knowledge between the participants, parents, educators, and the Project itself. In this phase, actions are carried out aimed at: or team (weekly meetings, individual supervision, training meetings, compilation of observation grids, etc.); participants (small, medium and large group outings; with the activity on a weekly basis); or parents (with structured interviews held by the coordinator with the aim of bringing out the parent's point of view on the child and his role as a parent).

3. Drawing Up the Educational Project:

This is the phase dedicated to defining and sharing the objectives. We therefore proceed with:

- Definition and articulation of the objectives for each individual participant, of the possible obstacles and of the expected performances as a result in different steps of the activity.
- Identification of effectiveness measures and expected performance as a result in different steps of the activity.
- Choice of two objectives by the participant.

4. Intervention on Objectives:

This is the phase in which the intervention is conducted to bring the participants to achieve the chosen objectives. Actions are conducted at the level of:

- team (with an increase in planning, training, and supervision meetings).
- participants (with weekly activities, evening outings in small-medium-large groups).
- parents (with the organization of micro group meetings of parents, additional individual interviews on request, distance tutoring, etc.)

Conclusion

In conclusion, the remarkable increase in life expectancy for individuals with autism and other intellectual disabilities—from 18 years in 1961 to over 60 years in 2011—highlights the substantial progress made in societal acceptance, medical care, mainstream education, and family-based upbringing (Dieckmann, Giovis, & Offergeld, 2015). This shift has transformed the lives of these individuals, who now spend most of their lives as adults,

thus necessitating a reevaluation and expansion of social services originally designed for children.

This paper has examined the multifaceted care and support required for adults with intellectual disabilities, with a special focus on Autism Spectrum Disorder (ASD). It has explored essential areas such as guardianship, community involvement, and the dismantling of cultural stereotypes. Furthermore, it has proposed a Quality of Life (QoL) project aimed at equipping adults with ASD with the skills necessary for independent living and successful integration into mainstream society.

The historical context provided in this paper underscores the evolution of autism recognition and treatment. From early descriptions in the 1700s to the foundational work of Jean-Etienne Dominique Esquirol and Grunya Sukhareva, and the comprehensive early 20th-century descriptions by Leo Kanner and Hans Asperger, our understanding of ASD has grown significantly. This evolution has paved the way for modern diagnostic criteria and treatment approaches.

Applied Behavior Analysis (ABA), grounded in early 20th-century behaviorism, remains a cornerstone of ASD treatment. By employing positive reinforcement to teach effective behaviors, ABA has proven instrumental in improving the lives of individuals with ASD. The proposed QoL project leverages ABA principles to address the gap in services for adults with ASD, ensuring they receive continued support into adulthood.

To further enhance the quality of life for adults with ASD, several changes can be made in clinical, educational, and rehabilitation contexts:

1. Clinical Interventions:

- a. **Personalized Care Plans:** Develop individualized care plans that cater to the unique needs of adults with ASD, incorporating regular assessments and adjustments.
- b. **Integrated Health Services:** Foster collaboration between mental health professionals, primary care providers, and specialists to provide comprehensive healthcare tailored to ASD-related challenges.
- c. **Advanced Training for Healthcare Providers:** Enhance training programs for healthcare providers to improve their understanding of ASD and their ability to deliver effective care.

2. Educational Enhancements:

- a. **Lifelong Learning Programs:** Establish educational programs that extend beyond childhood, focusing on vocational training, life skills, and continuing education for adults with ASD.
 - b. **Inclusive Education Models:** Promote inclusive education models that integrate individuals with ASD into mainstream classrooms and workplaces, providing necessary support and accommodations.
 - c. **Awareness and Sensitivity Training:** Implement widespread training programs for educators and peers to foster a more inclusive and supportive educational environment.
3. **Rehabilitation and Social Integration:**
- a. **Community-Based Support Systems:** Develop robust community support systems that facilitate social engagement, vocational opportunities, and recreational activities for adults with ASD.
 - b. **Residential and Day Programs:** Create residential and day programs that offer structured environments, promoting independence while providing necessary supervision and support.
 - c. **Family and Caregiver Support:** Offer resources and training for families and caregivers to better support adults with ASD, emphasizing collaborative approaches to care.

The project in the paper indicates that each young adult effected by Autism will participate in one of the sections of “Adult Identity” where they will work on salient skills needed to manage one's life in and through the place of home, and the possibility of developing self-awareness and fulfilling oneself through choices in everyday life. With the increase of these abilities, there will be an improvement of the quality of life of the participants, creating more independents. This could lead to a final goal of finding a solution to the question “What will happen when we will not be here anymore?” which families with disabilities and especially Autism, faces every day.

By embracing these changes, we can create a more inclusive and supportive society for adults with ASD. Ensuring they receive comprehensive and continuous support will not only enhance their quality of life but also enable them to contribute meaningfully to their communities. As we move forward, it is crucial to remain committed to research, innovation, and advocacy to meet the evolving needs of this growing population.

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