

# From Policy to Practice: A Delphi Protocol on Life Projects for Autistic Adults

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## Abstract

This study presents a research protocol employing the Delphi method to develop a consensus-based definition of the Life Project (LP) for autistic adults in the Italian context. LPs, conceived as individualized, person-centered plans, aim to promote autonomy, social inclusion, and quality of life through coordinated health and social care interventions. Despite recent legislative and policy advancements in Italy a unified operational definition and implementation framework for LPs remains lacking. The protocol outlines a three-round Delphi process engaging a panel of 50–80 experts across clinical, social, legislative, and experiential domains. The initial survey will elicit qualitative data regarding current practices, challenges, and priorities in LP development. Second and third rounds will refine emerging themes and evaluate consensus using Likert-scale ratings, with consensus defined as  $\geq 80\%$  agreement. Data will be analyzed through thematic and descriptive statistical methods. The study has received ethical approval from the Comitato Etico di Ateneo per la Ricerca of the University of Modena and Reggio Emilia (Protocol Approval No. 46821; 17 March 2025). This protocol research is expected to produce a structured and actionable definition of the LP, as well as a consensus-based set of practices and principles to guide implementation. By involving stakeholders from diverse regions and disciplines, the study ensures ecological validity and responsiveness to local service delivery contexts. The outcomes aim to support LP practices across Italy and inform future research on their impact on the well-being of autistic adults.

## Keywords

autism spectrum disorder, life project, personal health budget, quality of life, integrated care, policy, Delphi method

## Background

Autism Spectrum Disorders (ASDs) are neurodevelopmental conditions characterized by impairments in social interaction, communication, and restricted, repetitive behaviors ([American Psychiatric Association, 2022](#)). Globally, approximately 61.8 million individuals are diagnosed with ASD, with an age-standardized prevalence of 788.3 per 100000 people. ASD accounts for 11.5 million disability-adjusted life years (DALYs), ranking among the top ten causes of non-fatal health burden in individuals under 20 ([Charman, 2025](#)). In Italy, ASD prevalence is estimated at 13.4 per 1000 ([Scattoni et al., 2023](#)). From now on, we are going to intentionally use the expression “autistic adults” rather than referring to ASD. This choice reflects the preferences of many within the autistic community and aligns with a neurodiversity-affirming perspective that

views autism as an integral aspect of identity, rather than a disorder to be separated from the individual

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Autistic people experience medical, neurological, and psychiatric comorbidities with high prevalence (Micai et al., 2023), which - considering their implications for health outcomes - must be carefully considered in the design and implementation of care plans (Lai et al., 2019). The complexity of needs requires improved access to healthcare, education, and social services. However, public services are challenged to meet these needs by implementing high-quality, integrated standards of care. Consequently, families are often forced to turn to private providers and bear high out-of-pocket costs, especially for therapeutic interventions (Micai et al., 2024). For autistic adults, the availability of services is even more limited, with a severe shortage of appropriate support options. Post-diagnostic support is rare, with less than 2% receiving comprehensive follow-up care (Scattoni et al., 2021). While recommended interventions exist, access remains inconsistent due to a lack of professional training, long waiting times, and the challenges of service implementation (Micai, Ciamarella et al., 2022; Micai et al., 2021). Despite international guidelines, a significant gap persists between recommendations and real-world service provision. Addressing these barriers requires enhanced professional training, expanded accessible services, and increased family financial support (Micai, Fulceri et al., 2022).

Designed to address complex needs in a flexible framework tailored to individual characteristics and care requirements, the Personal Health Budget (PHB) model has recently gained increased attention (Fulceri et al., 2023). PHBs allocate a predefined budget to individuals with disabilities or mental health conditions, granting them greater control over their care to support specific needs (Micai, Gila et al., 2022). The PHB integrates the individual's care plan with the Life Project (LP). In the literature, PHB programs have been implemented for individuals with severe mental health conditions, with studies documenting significant improvements in clinical outcomes (Elisa et al., 2024). Personalized, budget-based care models increase the quality of care and the overall well-being of individuals facing complex health challenges. Based on the assessments in all intervention areas (housing, work/training, social interactions, and learning/communication/expression), a tailored Individualized Therapeutic Rehabilitation Plan is developed in a participatory manner, considering the individual's preferences. This plan specifies actions and goals across all areas, aligning recovery-oriented care with the individual's LP. An LP is an existential pathway that reflects an individual's aspirations, needs, and possibilities (Corti et al., 2023). For autistic people, the LP ensures the value of their choices and desires, safeguarding their right to full self-determination and social participation (Ferrazzi et al., 2025). The LP is not merely a care plan but an approach that integrates personalized interventions, appropriate support, and enabling strategies to promote well-being and quality of life, focusing on equity and equal opportunities compared to the typically developing population (Cappa et al., 2020).

In the last decade, the Italian government has introduced specific measures to promote the Life Project (LP) as a central

element of their care and well-being. In line with the United Nation's Convention on the Rights of Persons with Disabilities (McCusker et al., 2023), the Italian Law 112/2016, titled "Provisions on Assistance for People with Severe Disabilities Lacking Family Support," commonly known as the "After Us Law", introduced specific protections for individuals with severe disabilities. In 2018, the Ministry of Health, in collaboration with the Italian National of Health (Istituto Superiore di Sanità - ISS), the Regions, and representative associations of autistic individuals, updated the guidelines aimed at promoting and improving the quality and appropriateness of care in ASD (Ceccherini, 2009). These guidelines, calling for professional training in individualized LP to enhance the Quality of Life (QoL), were approved on May 10, 2018, at the State-Regions Unified Conference (Presidenza del Consiglio dei Ministri, 2018). In 2019, the ISS established a working group on the Life Project, including administrative representatives at national and regional levels, national experts on autism, intellectual disability, and social-health integration, and representatives from the most prominent national associations in the field of ASD. The working group developed Guidelines to define and implement the LP based on the "Quality of Life" framework. Since 2019, the Ministry of Health has allocated funds for Regions and Autonomous Provinces to ensure that the LP has a coordinated set of objectives and strategies to achieve through a cohesive and non-fragmented approach (Osservatorio Nazionale Autismo, 2022a; 2022b). Further, the recommendations of the evidence-based guidelines on diagnosing and treating ASD in adults published by the ISS in 2023 underlined this approach, emphasizing the role of the LP based on quality of life and individual preferences (Linea Guida sulla diagnosi e sul trattamento di adulti con disturbo dello spettro autistico, 2023). In this context, it is essential to reach a consensus on the most effective assessments to support the development of LPs for autistic individuals (Valenti et al., 2023).

Recently, with Legislative Decree No. 62 of May 3, 2024, the Italian government introduced a clear framework for defining disability conditions and establishing personalized LP for individuals with disabilities. This decree describes a multidimensional assessment to create and implement individualized LP focusing on autonomy and social inclusion (Italy, 2024, Legislative Decree No. 62). The LP is a highly detailed process involving interconnected and sequential components. Whereas in the developmental age, (re)habilitative projects have the primary function of empowering the person by increasing their functional competencies to allow the best possible adaptation and inclusion, in the LP, this rehabilitative function, that is always present when needed, must become more focused on the pursuit of the existential priorities of autistic individuals. For this reason, accessing what is meaningful and preferred by the person (Virués-Ortega et al., 2014) is essential. This information will be the basis for identifying the stimuli, activities, opportunities, desires, expectations, preferences, values, and relationships considered

crucial for the person and should be the priority elements on which to define existential goals, aim to be pursued together with the definition of a support plan.

Despite significant advancements in the field, a unified consensus on the pragmatic definition of an LP remains elusive. In this context, applying methods that prioritize the perspectives of experts directly involved in developing LPs, such as the Delphi method, presents a valuable approach. The Delphi method is esteemed for its efficacy in cultivating consensus among experts and facilitating the iterative refinement of ideas and priorities (Fink-Hafner et al., 2019). Its structured nature ensures that the voices of diverse stakeholders—including autistic individuals, their families, and professionals—are incorporated. This methodology is particularly relevant when addressing complex, multifaceted topics like the LP, where diverse perspectives and interdisciplinary professional collaboration are essential (Ismail & Taliep, 2023).

## Aim

This paper's main aim is to present the research protocol designed to establish a consensus on the conceptual and operational definitions of LP for autistic adults in the Italian context. As a secondary objective, the study seeks to identify key elements and principles that should inform LP co-construction for autistic adults and contribute to the identification of practical, actionable definitions and guidelines for implementing LPs.

## Explanation and Justification of Method

The development and implementation of LPs for autistic adults in Italy require a shared understanding and consensus among the policy makers, professionals, and stakeholders directly involved in their design and execution. Within the local context, practitioners, social workers, educators, healthcare professionals, family members, and the person play a pivotal role in constructing and applying LPs (Italy, 2024, Legislative Decree No. 62). Therefore, achieving consensus from the ground up represents the cornerstone for ensuring consistent and effective applicability of LPs across different regional and local contexts.

The complexity and variability of needs among autistic adults necessitate a bottom-up approach that prioritizes the voices and experiences of those directly engaged in LP co-construction and delivery. This strategy fosters greater inclusivity and ownership and ensures that the resulting definitions and guidelines are context-sensitive, pragmatic, and aligned with the realities faced by professionals and families. To achieve this, the study will employ the Delphi Method, a consensus-building methodology. This methodology is well-suited for synthesizing people's perspectives and identifying consensus among experts in a particular field. The Delphi Method will facilitate structured rounds of consultation,

allowing participants to review, refine, and prioritize key elements and principles for LP development.

The local dimension will be further emphasized by involving representatives from different regions/autonomous provinces and service networks, ensuring a wide and balanced representation of perspectives. This participatory approach will help identify both shared priorities and region-specific challenges, contributing to the creation of operational guidelines that are both nationally coherent and locally adaptable. Engagement of the professionals by involving them in the path of LP definition will raise active participation and application of LP in clinical practice.

The **main purpose** of the present survey is to engage high-level policymakers, professionals, and stakeholders in defining the essential elements of an integrated care pathway for autistic adults that is practical and feasible for the specific region involved. This approach ensures that the pathway is tailored to the local context, effectively addressing unique challenges and capitalizing on available resources. By grounding the research from a local perspective, this study aims to bridge the gap between theoretical frameworks and practical implementation, fostering a shared and actionable definition of LPs for autistic adults that can effectively guide professionals, institutions, and policymakers across Italy.

## Materials and Methods

### Study Design

A Delphi method approach (De Villiers et al., 2005) will be followed, which uses rounds of surveys to reach consensus (Thompson, 2009). The Delphi Method gathers expert opinions and achieves consensus on complex topics. It involves multiple rounds of anonymous surveys or questionnaires, where a panel of experts provides their insights on a specific topic. After each round, a facilitator summarizes and analyzes answers. This process continues until a consensus or a clear understanding of the LPs is reached.

We will conduct three rounds of a survey using an online questionnaire on the Red Cap Platform (Harris et al., 2009, 2019). The first round will enable us to ask questions to generate insights about the LP's practices and tools.

The study is designed to last for a total of 12 months. The 12-month period allows sufficient time to conduct the research thoroughly, gather necessary data, analyze the results, and prepare final reports and publications. Specific milestones include completed initial setup, participant recruitment, data collection, interim analysis, and final analysis.

### Development of Questionnaire Items

The development of the questionnaire items followed a collaborative process. Initially, two researchers (M.M. and G.F.) with expertise in the study's thematic area were tasked with

drafting the preliminary set of questionnaire items. This phase involved an extensive literature review of the research topic, ensuring the items are theoretically grounded and practically applicable. Once the initial draft is completed, the questionnaire was submitted for review to senior researchers (M.L.S., G.M.G., and L.G.) with substantial experience in survey methodology and/or the subject matter. Their role was to critically assess the items for content validity, phrasing clarity, and alignment with the study's goals. Specific attention was given to ensuring that the items were free from ambiguity, culturally sensitive, and suitable for the target population.

The finalized questionnaire for the first round will include three stimuli featuring open-ended and multiple-choice questions. This combined format will enable participants to provide detailed insights through open-ended responses while ensuring ease of participation and structured data collection through multiple-choice options.

### Expert Identification

The Delphi method involves engaging experts who meet specific inclusion criteria relevant to the research topic. Although there is no universally agreed-upon size for a Delphi expert panel, previous studies in health sciences suggest that an effective panel size ranges between 50 and 80 participants (Niederberger et al., 2024).

Experts were selected based on their expertise in key areas of the Health Budget, including Training/Work, Housing, Socialization, and Health Interventions, with consideration given to both leadership/coordinative and clinical/operational roles. To integrate the perspective of autistic individuals, stakeholders such as caregivers, autistic people, and representatives from local associations were also involved. Additionally, healthcare economists, legislators, and managers from health and social sectors across Italian regions/autonomous provinces or local psychiatric units were included. Given the context-specific nature of the Life Project, participants are required to have proficiency in Italian.

Panel members were identified among experts from the National Observatory on the Condition of People with Disabilities, the 'Life Project national working group' established by the ISS, the technical committee for drafting the Legislative Decree on Disability (62/2024), and the professional team of the project 'Subject, Person, Citizen: promoting the well-being and social inclusion of people with mental disorders through the health budget,' a collaborative agreement between the Ministry of Health's General Directorate of Health Prevention and the Emilia-Romagna Region. The panel was integrated by representatives from both public and private sectors, including members from public agencies, professionals in personalized budgeting, and autism specialists. The National Autism Observatory (Osservatorio Nazionale Autismo - OssNa), coordinated by the Istituto Superiore di Sanità (ISS), will oversee the regular evaluation and monitoring of procedures.

Two independent researchers (M.M. and G.F.) reviewed the curricula of the experts and assigned each person to their area of expertise based on the relevant domains (housing, work/training, social interactions, and learning/communication/expression). Any disagreements were discussed, and a third expert reviewer (F.M.) provided the final decision on the assignment to each domain (Nasa et al., 2021).

### Enrollment of the Participants

All identified experts will be invited to participate via e-mail. The participants will receive materials to inform them of the study objectives and design and the commitment required for participation. They will be sent an invitation letter with information and a participant consent form. Participants will be asked to commit to participating in all rounds of the Delphi technique required to develop the prescribing criteria. Participants will be provided with a clear explanation of the anticipated process and an explanation that participation would be required over 3 months with three or more rounds of questions and feedback.

If the participants choose to participate, they will access the provided link, which will redirect them to the REDCap platform to complete the questionnaire. A customized email address will be available for any inquiries ([qualipra@unimore.it](mailto:qualipra@unimore.it)).

The software RedCap will be used to administer the surveys and ensure the anonymity of participants throughout the study. This platform allows for secure, General Data Protection Regulation compliant, data collection and management, maintaining the confidentiality of participant responses by assigning random codes to each participant, which will not be disclosed to the participants or the research team (Harris et al., 2019).

The iterative nature of the Delphi method means that participants are anonymous to each other but not to the researcher (Hasson et al., 2000). This has been termed quasi-anonymity (Keeney et al., 2006). After the process, participants who have responded in each round will be offered the choice to remain anonymous or receive acknowledgement in the publication for their participation (Rowe & Wright, 2011).

### Data Handling/Analysis

The data collected will undergo a qualitative and quantitative analysis to ensure the validity and reliability of the findings (Nha, 2021). Given the iterative nature of the Delphi method, different analytical techniques will be employed at each stage to systematically identify, refine, and prioritize key themes related to LP.

### Round 1

Open-ended responses from the first round will be analyzed using thematic analysis (35), a method suitable for

identifying, analyzing, and reporting patterns (themes) within the data. Thematic analysis is a qualitative analysis method used in the social sciences to identify and present recurring patterns or themes in data (Kiger & Varpio, 2020, p. 131). It involves carefully reading the material to extract meaning and understand different subjects and interpretations (Naeem et al., 2023). Thematic analysis develops meaning from data and encompasses the pinpointing, sharpening, recording, and/or evaluation of recurring themes. The identified themes will serve as the foundation for the subsequent rounds of the Delphi process (Humble & Mozelius, 2022).

### Round 2

In subsequent rounds, participants will be asked to rate the importance and relevance of the themes identified. The themes for the second round will be derived from the thematic analysis conducted on the open-ended responses collected in Round 1 (Bingham, 2023). This will be done using qualitative scales, such as a Likert scale (1 to 5). The analysis will explore the percentage of agreement for each item, with consensus defined as  $\geq 80\%$  of participants rating their agreement as “Agree” (4) or “Strongly Agree” (5) (Richards et al., 2022).

Themes not meeting the consensus threshold will not be included in LP definitions.

### Round 3

In round 3, participants will rate their level of agreement with the proposed final conceptual and operational definitions of LP using a 5-point Likert scale (from 1 = Strongly Disagree to 5 = Strongly Agree).

As done in Round 2, the analysis will explore the percentage of agreement for each definition, with consensus defined as  $\geq 80\%$  of participants rating their agreement as “Agree” (4) or “Strongly Agree” (5).

If necessary, additional rounds will be conducted since consensus is reached.

The final results will be presented in a narrative format, highlighting the level of consensus achieved, the key themes that emerged from the qualitative feedback, and the analysis of the Likert scale results. The document, summarizing the themes and consensus reached in previous rounds, will be shared with participants before the final phase. This ensures transparency and allows participants to review, refine, and validate the proposed conceptual and operational definitions before concluding the Delphi process (Chalmers & Armour, 2019). Any revisions made to the definitions based on participant comments will be documented, along with the rationale for these changes.

### Ethics

The study described in this protocol does not involve sensitive data collection. The study has received ethical approval from the Comitato Etico di Ateneo per la Ricerca of the University of Modena and Reggio Emilia on 17 March 2025 (Protocol Number: 46821), ensuring compliance with all ethical guidelines, the confidentiality and anonymity of participants, and adherence to data protection regulations. The CEAR provides a technical-advisory function and issues opinions on ethical aspects of research projects involving human participants, excluding those under the jurisdiction of Healthcare-Hospital Ethics Committees.

### Practical Implications/Discussion

This paper details the protocol of a study using the Delphi method to address consensus among LP definitions for autistic adults in Italy. This study seeks to develop a structured and shared framework for LP implementation by engaging an expert panel in an iterative process of feedback and rating. The results will contribute to creating a consensus-based list of explicit practices to ensure that LPs effectively support autonomy, inclusion, and QoL for autistic individuals.

Although the specific findings of this study cannot be known in advance, the process of reaching a shared conceptual and operational definition of the LP for autistic adults holds significant potential for advancing both clinical practice and policy development. By establishing a consensual framework that is both theoretically grounded and pragmatically oriented, this work is expected to offer concrete guidance for professionals involved in the co-construction of individualized and person-centered planning processes. A shared LP definition may contribute to enhancing the quality, coherence, and responsiveness of care pathways, particularly in their capacity to reflect the preferences, values, and aspirations of autistic individuals. For autistic people and their families, the expected impact lies in the potential for more participatory, meaningful, and autonomy-oriented planning processes, with increased recognition of individual agency and self-determination.

However, for these outcomes to become actionable and sustainable in a real-world context, further steps will be required. These include the translation of consensus definitions into operational tools, the development of targeted training for service providers and the integration of LP principles within existing regulatory and organizational frameworks. Moreover, effective implementation will depend on sustained political commitment, inter-institutional coordination, and investment in capacity-building at both the individual and system level.

There are methodological strengths and limitations associated with using the Delphi technique in this study. One primary strength is obtaining input from experts and stakeholders across different regions/autonomous provinces of Italy, ensuring a diverse and representative range of perspectives. The anonymity of panel members prevents any single individual from dominating the discussion, reducing the

risk of bias and encouraging independent contributions. Additionally, the iterative nature of the Delphi process allows for progressive refinement of opinions, leading to a more robust and well-rounded consensus.

However, there are inherent limitations to the Delphi technique. Since it relies on expert opinion rather than empirical data collection, it does not generate new evidence but instead synthesizes existing knowledge and professional experience. While this method is valuable for consolidating expert insights, the validity of the findings depends on the composition and engagement of the expert panel. Under these circumstances, the selection of participants is crucial, as their expertise and willingness to participate in multiple rounds of surveys directly impact the quality and reliability of the final consensus. In this study, the sample was carefully selected among experts who played a key role in developing the personalized health budget in Italy and other relevant frameworks, such as disability legislation and policymaking, ensuring a high level of domain-specific knowledge and practical experience. The stakeholders, individuals with lived experience, and caregivers were selected based on their pivotal roles in national and local autism associations.

The findings of this study will have practical implications for clinical practice, social services, and policy development. A consensus-based definition of LP will serve as a reference point for professionals in both clinical and social domains, enhancing the coherence and applicability of LP. This shared framework will facilitate more structured planning and implementation, ensuring that interventions are aligned with the real needs of autistic adults. Moreover, it will provide policymakers with shared consensus-based definitions that help shape legislation and resource allocation, improve service provision and support strategies across different life contexts. The resulting consensus can support professionals in the co-construction of LPs, ensuring they are evidence-informed and practically feasible.


Future research should explore the long-term impact of consensus-based LPs on the QoL and social inclusion of autistic adults through rigorous methodologies such as randomized controlled trials (RCTs) and longitudinal studies, allowing for empirical validation and continuous refinement of the approach.

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