

# Life project: a scoping review of assessment tools for persons with autism spectrum disorder

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## Abstract

**Background.** Persons with autism spectrum disorder (ASD) may face significant challenges during transition from adolescence to adulthood. This phase necessitates tailored support to address all needs, underscoring the importance of a comprehensive life project (LP) planning. This scoping review aims to identify methods and tools used in the development of LP for persons with ASD.

**Methods.** The preferred reporting items for systematic reviews and meta-analyses (PRISMA) extension for scoping reviews was used. The literature search was performed across Embase, Scopus, Web of Science, PubMed, CINAHL, and PsycINFO. The selection process involved screening titles and abstracts, followed by full-text reading, data extraction, and narrative synthesis of findings.

**Results.** A total of 899 records were identified, and 8 studies were included in the review. Preference assessment and ecological balance emerged as crucial elements in developing LP.

**Conclusions.** This review highlights the importance of tools that accurately capture individual preferences and support needs for persons with ASD but also reveals a gap in the literature concerning the development of tailored LP for this population.

## Key words

- life project
- autism spectrum disorder
- transition
- coping review
- person-centered plan

## INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by persistent and pervasive difficulties in social communication and by restricted and/or repetitive interests or behaviors which may be associated with different levels of disability [1]. Around the age of 18, in most European countries, a large proportion of people with ASD receiving mental health care have to cross the artificial boundary between child and adolescent mental health services (CAMHS) and adult mental health services (AMHS) [2]. The term “transition” specifically refers to the period when young individuals move from CAMHS to AMHS.

Transition from CAMHS to AMHS may represent a challenge for transitional age youth with ASD [3], in particular for those presenting additional mental and physical health challenges [4, 5]. Transition refers to the planned process that addresses the medical, psychosocial, educational, and vocational needs of adolescents

and young adults with long term physical, neurodevelopmental and medical conditions as they move from child-centered to adult-oriented health-care systems [6]. Transition is crucial for adult life fulfillment, which may include: obtaining a job, post-secondary education, attending a day habilitation program or maybe living outside of the family home [7]. Transition necessitates planning to ensure that ASD individuals receive support and services they will need as adults [8]: for this purpose, transition plans (TP) and life projects (LPs) are needed [9, 10]. TP is the document that outlines how transition should be managed, detailing the steps and support required to facilitate this change. TP is a comprehensive strategy designed to ensure that adolescents and young adults with long term physical, neurodevelopmental, and medical conditions, like ASD, receive the necessary support and services as they enter adulthood [11]. While TP encompasses a broad spectrum of needs and considerations, focusing on the individual's person-

al goals, preferences, and aspirations require additional planning, which in the Italian context is known as the LP. LP generally includes TP, referring to the broader process that goes beyond the immediate transition, encompassing all aspects of a person's life from adolescence onwards. The LP integrates educational, social, and professional goals, ensuring a comprehensive approach to an individual's development and well-being. It is a person-centered approach that considers the unique strengths and challenges of the person with ASD. LP is developed collaboratively, involving the individual, their family/caregivers, and relevant professionals. Despite referring to different concepts, an overlap exists between TP and LP, due to the timing of the transition and its integration within the broader design of the future LP. Both are crucial for ensuring a smooth and effective transition for ASD individuals as they navigate the challenging shift from child-oriented to adult-oriented mental health services. The seamless integration of the TP within the larger LP is essential for supporting these individuals through transition from adolescence to adulthood. LP aims to a comprehensive, personalized approach designed to support the individual's overall well-being, development, and integration into society across their lifespan. It encompasses various dimensions, aims and activities of life, including education, employment, health, social connections, leisure activities, and living arrangements [12]. The goal is to ensure that ASD individuals can achieve the highest quality of life (QoL) possible, according to their desires, strengths, challenges, and needs. The LP concerns the ASD population who, once they finish schooling (around age 18), find themselves having to reconsider and reorganize their daily lives, which the school institution previously contributed to manage and give structure to [13]. In doing so, LP emphasizes the individual's autonomy and personal definition of a fulfilling life [14].

Notably, in the Italian context, the concept of a LP has been particularly used during the transition from school to "adult life". This transition is not a simply chronological progression but a real transformation that necessitates a comprehensive reevaluation and adaptation of one's daily environment. The development of a personalized LP can help in overcoming the critical nature of this phase [15]. Although much literature on the transition to adulthood for ASD population is present [2, 6, 15-17], still little addresses issues around the concept, development and implementation of the LP [10]. In this context, Italian legislation has introduced specific measures to ensure greater autonomy and social integration for individuals, which further reinforced the concept of a LP. 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 for the first time specific protections for individuals with severe disabilities in Italy. The law aims to ensure maximum autonomy and independence for people with disabilities, enabling them, for example, to continue living in environments as close as possible to their family home even when their parents are no longer able to care for them. The goal is to ensure a high QoL in the community, in line with the

principles of the United Nations' Convention on the rights of persons with disabilities [18]. Thereafter the Italian State-Regions Unified Conference [19] on May 10, 2018, concerning the "Update of the guidelines for the promotion and improvement of the quality and appropriateness of care interventions in ASD" highlighted the need to train professionals to participate in the creation of individualized LP aimed at improving the QoL. The conference advocates for the incorporation of the LP into treatment strategies for ASD people, and to promote professional competencies for delivering therapeutic and habilitative/rehabilitative interventions based on the best available scientific evidence [20]. Moreover, in order to address social and healthcare needs of individuals with complex necessities, including ASD people, the personal health budget (PHB) has been implemented in various European countries [21]. The PHB is an integrated social-health tool designed to align the individualized therapeutic program with LP, promoting social inclusion and autonomy [22]. Guidelines have been established to support the development of LPs focused on improving QoL. Each Italian region and autonomous province, through regional centers and networks of community mental health services, rare disease programs, and adult disability services, promotes differentiated pathways tailored to individual needs. These pathways are based on varying levels of support required, adaptive functioning, and any associated diagnoses [23]. The guidelines (*linee di indirizzo*) for Italian regions and autonomous provinces for formulation of individualized LP, highlight the needs for its implementation [24, 25].

Overall the concept of a LP received increased attention, particularly following the release of the 2023 guidelines from the Italian National Institute of Health (Istituto Superiore di Sanità, ISS) [26]. At the moment there is an ongoing debate about the best assessments needed to support the development of LPs [23].

Recently the Italian government with the Legislative Decree 62 of May 3, 2024 introduced a comprehensive framework for defining disability conditions and establishing personalized LP for individuals with disabilities. This decree emphasizes a multidimensional assessment approach to create and implement individualized LP that focus on autonomy and social inclusion. Such legislative measures seem crucial for improving the QoL and promoting the independence of individuals with ASD [27].

The development and validation of assessment tools to accurately measure the needs, strengths, and goals of ASD individuals is urgent [28]. These tools should be adaptable to the diversity in the clinical presentation of ASD and flexible enough to accommodate changes over time. From that perspective, integrating LP with care programs through a unified, person-centered approach is essential. The aim of this scoping review is to identify evidence on the principal assessment tools in LP development for ASD individuals.

## MATERIAL AND METHODS

We used the preferred reporting items for systematic reviews and meta-analyses (PRISMA) extension for scoping review [29]. A comprehensive literature search

was performed across Embase, Scopus, Web of Science, PubMed, CINAHL, and PsycINFO, up to 11<sup>th</sup> April 2024.

The search terms included key phrases related to ASD, assessment tools, LP and related concepts. Boolean operators (AND, OR) were utilized to refine the search queries. The search string was defined and approved by the chief librarian from the authors' institution, who supervised its adaptation across the various databases searched. Details on the search strategies are shown in *Table 1*.

The selection of studies was done by a single review Author (GF) using the web software Rayyan for the screening part of titles and abstracts. Rayyan's artificial intelligence (AI) tool aided in the screening process by learning from screening decisions made on a subset of articles. Once at least 50 studies have been manually reviewed, Rayyan's AI calculates the probability of inclusion or exclusion for each remaining undecided article [30, 31]. Rayyan assigns each record with one of the following ratings: 0.5 stars, 1.5 stars, 2.5 stars, 3.5 stars, or 4.5 stars. Records with a rating of 0.5 or 1.5 were considered ineligible according to the software guidelines available at the help center (<https://help.rayyan.ai>) as the optimal choice for records screening. Previous reports, suggested that at the threshold of <2.5 for exclusion, Rayyan showed 100% specificity compared to human decision, resulting in a reliable tool for excluding ineligible records in the screening process [32]. Selection by full-text reading and data extraction was performed by the same researcher (GF). An expert reviewer supervised the entire phase of study selection and data extraction. For each study, data were extracted regarding the study design, reported aims, country, LP, evaluation tool, and main results.

**Table 1**  
Database search strategy

| Database          | Search strategy 11 <sup>th</sup> April 2024   |
|-------------------|---|
| Embase            | ('life plan' OR 'personal development plan' OR 'life roadmap' OR 'person-centered plan*' OR 'support plan*' OR 'transition plan*' OR 'life project') AND 'autism'/exp                             |
| Web of Science    | "Life Plan" OR "Personal Development Plan" OR "Life Roadmap" OR "Person-Centered Plan*" OR "Support Plan*" OR "Transition Plan*" OR "Life project"  |
| Scopus            | "life plan" OR "personal development plan" OR "life roadmap" OR "person-centered plan*" OR "support plan*" OR "transition plan*" OR "life project" + "autism" OR "autism spectrum disorder"       |
| CINAHL & PsycINFO | ("Life Plan" OR "Personal Development Plan" OR "Life Roadmap" OR "Person-Centered Plan*" OR "Support Plan*" OR "Transition Plan*" OR "Life project") AND ("Autism" OR "Autism Spectrum Disorder") |
| PubMed            | ("Life Plan" OR "Personal Development Plan" OR "Life Roadmap" OR "Person-Centered Plan*" OR "Support Plan*" OR "Transition Plan*" OR "Life project") AND ("Autism" OR "Autism Spectrum Disorder") |

### Inclusion and exclusion criteria

Studies were included if they focused on developing LP for individuals of any age (both minor and adults) diagnosed with ASD according to diagnostic and statistical manual of mental disorders or international classification of diseases [33, 34], and explicitly discussing the assessment tools employed. All types of studies published in peer-reviewed journals were considered for inclusion. We excluded reviews and book chapters as these are not primary publications, conference abstracts and dissertations as these are not generally peer reviewed. Although no language or publication date restrictions were applied in the initial search, only English-language full texts were considered in the eligibility stage to ensure inclusion of studies accessible to an international audience. Studies that only addressed transition phases without mention to TP or LP and studies involving participants with different diagnoses than ASD (e.g., attention deficit hyperactivity disorder) were also excluded.

### Data extraction

Data extraction was performed by one review Author (GF) using a predefined form which was verified by a second reviewer [35]. Extracted information included study design, participant characteristics, LP assessment tools, and key findings related to the effectiveness of the tools in the LP development, realization and ongoing adaptation. Any discrepancies or uncertainties during the extraction process were resolved through discussions with the second review Author (GMG). A narrative synthesis approach was then employed to summarize and analyze the identified assessment tools. This involved categorizing the tools based on their focus areas, such as educational goals, life skills, and community integration.

### Quality assessment

The quality of the included studies was assessed using the Joanna Briggs Institute (JBI) critical appraisal tools [36]. One review Author (GF) conducted the initial assessment, and the results were checked by a second review Author (MM) to ensure accuracy and consistency in the evaluation.

## RESULTS

The first search identified 899 records. After duplicate removal 640 were eligible for screening. Following a preliminary screening of 50 records performed by a researcher to train the software, the subsequent screening was automated in Rayyan. Records with a rating of 0.5 or 1.5 were considered ineligible [32]. A total of 312 records remained and were screened by a human researcher (GF) on the title and abstract. Following this, 57 full texts were assessed for eligibility, leading to the selection of 8 studies which were included as the foundational literature for this paper. Most of the excluded studies (n=30) primarily focused exclusively on the transition period but not on LP or were based on the experiences of individuals with ASD or their caregivers, were therefore because "out of topic". Additionally, many of the excluded studies were dissertations or book

chapters, leading to their exclusion based on publication type ( $n=18$ ). The PRISMA flowchart summarizing the selection process is shown in *Figure 1*.

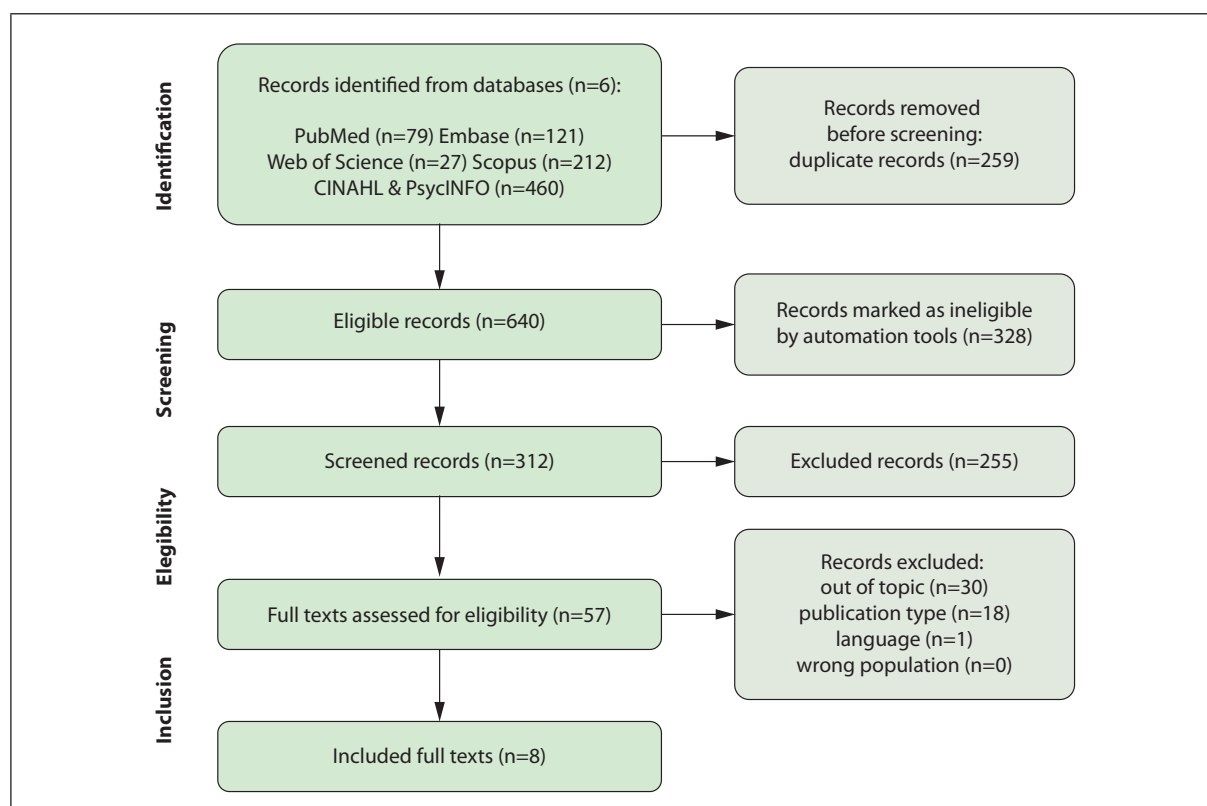
For each study included in the review, data on the aim of the study, type of study, tools used for the LP and the main results were extracted and summarized in *Table 2*. The included studies display a wide range of methodologies and objectives, emphasizing the complexity and individualized nature of planning LP for in the context of ASD.

All included studies were published after the year 2000. Four were published between 2000 and 2010, two between 2010 and 2020, and the remaining two after the 2020. Seven out of the eight studies focused on the descriptive analysis regarding the LP, with only one study including participant data. Three studies were purely descriptive, three were conceptual analyses, one was a commentary, and the remaining one used a mixed-method design. Four studies addressed the topic of LP only for adults, three for adult and adolescents of which two considered also children, and one exclusively focused on adolescents.

Five studies out of eight used “person-centered planning” (PCP) [37-41]. Two Italian studies used “life project” [10, 42] and the last one [43] used the individualized education program (IEP). IEP is a term often used to refer to school programs [44], but in that paper, it is used in reference to post-school programming.

All the studies emphasize the importance of personalized design, which should be tailored to the individual's

characteristics, such as adaptive functioning and context, as well as the person's preferences. Ecological Balance, as an integrative tool for the assessment of the needs of an ASD individual, is mentioned in two studies out of eight [10, 37]. The “ecological life balance” serves as an integrative tool designed to harmonize various assessment systems and support methods for individuals with ASD and intellectual disabilities. The key components include: Assessment of Preferences and Values (procedures are tailored to accommodate the distinct characteristics of adaptive and communicative functioning in individuals with disabilities), Support Needs Assessment (tools for evaluating the support required by individuals to enhance their QoL promoting an “universal design” that accommodate different needs ensuring accessibility and inclusivity), Methods for defining life goals (providing positive behavior support as an example) and Monitoring and Verification (for continuously assessing and verifying the outcomes of the support plans). Indirect screening measures like the systematic psychopathological assessment for persons with intellectual and developmental disabilities-general screening (SPAIDD-G) [45] and the Italian version of the diagnostic assessment for the severely handicapped revised (DASH II) [46] were also implied to better understand support needs. Moreover, to achieve health and behavioral needs, has been recommended to complement these assessments with direct functional analysis tools for behavior, such the experimental functional analysis methods [47].



**Figure 1**  
PRISMA flow diagram of study selection for this review.

**Table 2**  
Synthesis of the main features of the studies included in the review

| First Author, year                  | Title  | Country | Focus of the study   | Publication type    | Participants                | LP evaluation tool  | Main conclusion   | Quality assessed |
|-------------------------------------|--|---------|--|---------------------|-----------------------------|---|---|------------------|
| Bui <i>et al.</i> , 2003 [40]       | East meets West: analysis of PCP in the context of Asian American values   | USA     | Evaluate the extent to which core values of PCP are consistent   | Conceptual analysis | Child, adolescent and adult | Specific approaches are used: Individual service design, person future planning, essential lifestyle planning, whole life planning, McGill action planning system, path, group action planning  | This paper emphasizes the importance of a value, culture-based PCP and highlights a gap in the literature about PCP for Asian American families   | Low              |
| Callicott <i>et al.</i> , 2003 [41] | Culturally sensitive collaboration within PCP  | USA     | This article provides background, and a description of PCP based on process, components, and outcomes and examines each in relation to working with individuals and families of other cultures and languages                       | Descriptive study   | Adult                       | The components necessary for PCP to be conducted smoothly involve organizing the logistics for the meeting, developing a personal profile for the individual on structuring a future vision, developing action sets, providing support, and evaluating ongoing implementation. Regardless of the steps or tools used, the essential components of PCP offer open communication for all participants involved in the focus person's life | The PCP effectively involves individuals with disabilities in planning their future by leveraging their strengths and needs and emphasizes the importance of cultural and linguistic sensitivity to enhance communication and support within families and communities   | Low              |
| Cappa <i>et al.</i> , 2020 [42]     | Network of services facilitating and supporting job placement for people with autism spectrum disorders. The experience of the ASL Piacenza, Italy | Italy   | Describe how to integrate job opportunity and LP for ASD individuals in ASL Piacenza, Italy  | Descriptive study   | Adult                       | Three different paths based on individual functioning: a) internship; b) social co-operative job fair and c) individual placement and support   | Psychiatric services must be able to provide different types of job opportunities and the possibility to switch from one to another when the patient desires it   | Low              |
| Corti <i>et al.</i> , 2023 [10]     | The life project of people with autism and intellectual disability: investigating personal preferences and values to enhance self-determination    | Italy   | Describe the six key phases and the corresponding evaluation to establish and implement the life project for people with ASD and intellectual disability, as conceptualized by the Italian Society of Neurodevelopmental Disorders | Descriptive study   | Adult                       | 1. PA; 2. assessment of necessary supports; 3. ecological life balance; 4. definition of existential goals; 5. implementation of the support plan; 6. monitoring and verification   | The development of LP for individuals with ASD and intellectual disabilities is essential for enhancing their quality of life, considering their unique communication and adaptive challenges. The LP implementation involves a detailed process of assessing preferences, values, support needs, and utilizing tools like the ecological life balance to harmonize the project. Continuous monitoring and evaluation of outcomes are critical to ensure that the LP remain aligned with the individual's goals | Low              |

Continues



**Table 2**  
*Continued*

| First Author, year                  | Title  | Country | Focus of the study   | Publication type    | Participants   | LP evaluation tool  | Main conclusion   | Quality assessed |
|-------------------------------------|--|---------|--|---------------------|--|---|---|------------------|
| Hagner <i>et al.</i> , 2014 [39]    | PCP for transition-aged youth with ASD   | USA     | Explore the effectiveness and adaptability of PCP for transition-aged youth with ASD   | Mixed-method design | Adolescent 47 participants enrolled from high schools in New Hampshire and Maine | The study includes an observational checklist called "How person-centered was this planning?" to assess the fidelity of the planning process. This checklist is used to ensure that the planning meetings are substantially person-centered. The checklist involves assessing various aspects of the meeting, including the extent to which the individual's preferences and choices are prioritized, the participation of the individual in setting goals, and the inclusivity of the meeting atmosphere | PCP can be effectively utilized for transition planning with ASD people. The process allowed these individuals to actively participate in developing their transition goals. Evidence of accommodation strategies was found for 29 participants (62%). There was a tendency for participants with lower levels of adaptive behavior to use accommodations more frequently, although this difference was not statistically significant | Medium           |
| Kim <i>et al.</i> , 2004 [38]       | Shifting toward person-family interdependent planning                              | USA     | Provide an overview of person-centered planning and family-centered planning approaches for young adults with severe ID linked to ASD, and propose a new, integrated approach called person-family interdependent planning | Conceptual analysis | Adolescent and adult   | Person-family interdependent planning should use comprehensive policies and programs providing social, emotional, and financial supports for young adults focusing on values with severe ID linked to ASD and their families should be implemented  | Person-family interdependent planning approaches emphasize thinking about transitions into adulthood from the perspectives of persons with disabilities and caregiver   | Low              |
| Renzaglia <i>et al.</i> , 2003 [37] | Promoting a lifetime of inclusion  | USA     | Assist parents and professionals in developing effective educational programs that promote a lifetime of successful inclusion for individuals with severe disabilities including ASD with ID                               | Conceptual analysis | Child, adolescent and adult  | PCP tool includes an ecological inventory process, self-determination values (focusing on teaching individuals to engage in goal-directed, autonomous behavior through personalized instruction and supportive environments). Positive behavior support is incorporated, using thorough functional assessments regular reviews and adjustments, along with feedback from individual and their network   | PCP and ecological assessment create an individualized picture of a person's goals and skills, and the supports needed to help reach meaningful goals   | Low              |
| Tullis <i>et al.</i> , 2019 [43]    | Incorporating PA into transition planning for people with autism spectrum disorder | USA     | Overview of the TP process, as well as how PA may enhance that process   | Commentary          | Adult  | Systematic PA involve direct observation of learner behavior to determine preferred items or activities and are valuable tools to determine preferred stimuli for learners with ASD across a variety of environments (e.g., school, clinic, community)  | PA and opportunities to express those preferences (i.e., choice) are one central component for the inclusion of people with ASD   | Low              |

ASD: autism spectrum disorder; ASL: azienda sanitaria locale (local health unit); ID: intellectual disability; LP: life project; PA: preference assessment; PCP: person centered planning; TP: transition plan; USA: United States of America.

One article focused specifically on different paths to ensure employment [42]. The difference between three different ways of supporting employment in the Italian context based mainly on individual level of functioning was the specific framework discussed in the paper. These were: (1) internship which offers a practical work experience in a structured setting; (2) social co-operative jobs fair which provide opportunities for employment within cooperative social enterprises and (3) "Individual Placement and Support", a tailored job placement with ongoing support to ensure success in the free market workplace.

Hagner and colleagues showed that a PCP can be developed through a series of six meetings, guided by a specific checklist covering the following topics: introduction and personal history, career profile (skills, accomplishments, and personal qualities), career profile (preferences and aspirations), vision for the future, resources and barriers, transition and career goals, and career exploration and work experience action steps [39].

Three studies utilized personal values as an inner point to guide the PCP [38, 40, 41]. The first study presented the person-family interdependent approach, where both individual and family values contributed to shaping shared goals and enhancing overall QoL. The second emphasized culturally sensitive PCP, leveraging personal and cultural values to bridge communication gaps and foster inclusion. The third highlighted values within a cultural framework as a foundational element in developing effective PCP. Instead Tullis and colleagues more specifically focused on systematic preference assessments (SPAs) [43]. SPAs use direct observation of the behavior to identify preferred items or activities and serve for determining preferred stimuli for individuals with ASD across various environments (e.g., school, clinic, community).

PCP include different assessments helpful to highlight individuals needs and supports. Some examples are individual service design, person future planning, essential lifestyle planning, whole life planning, McGill action planning system, and group action planning. Although these are not direct or indirect measures, these can be used as a conceptual framework for developing a PCP by inspiring non-traditional strategies [40]. As such they ensure that PCP are focused on desires and preferences of the individual with higher needs and the collaborative efforts of those who care about them [48]. The individual is placed in the center of the planning process, with family members and close friends serving as key authorities in guiding the direction of their life [49].

One study also includes an observational checklist called "How person-centered was this planning?" to assess the fidelity of the planning process [39]. This criterion-referenced checklist ensures that planning meetings are substantially person-centered, with a score of 20 serving as the threshold to identify a PCP process. The checklist involves assessing multiple aspects of the meeting, including the extent to which the individual's preferences and choices are prioritized, the participation of the individual in setting goals, and the atmosphere of inclusivity of the meeting atmosphere.

The quality of the included studies was assessed using the JBI critical appraisal tool. Overall, the studies resulted of low, except one study which was rated as medium quality [39]. Notably, this study was the only one involving human participants and using a mixed-method design. The low quality across studies was primarily due to low scores in the items related to the alignment of methodology with objectives, researcher-research neutrality and inadequate participant representation.

## DISCUSSIONS

The aim of this scoping review is to identify evidence concerning methods and assessment tools helpful in the development of LP for ASD individuals.

The transition into adulthood means to become ready for several changes [50]. Transitioning typically involves moving from the structured environment of school to the more self-directed world of adulthood [51, 52]. The transition includes several key areas, such as moving to the workplace, shifting from living with family to more independent living situations, transitioning from pediatric to adult healthcare services, and developing and maintaining social relationships outside the school environment [53]. This phase can be particularly challenging due to difficulties in social communication, sensory sensitivities, and the need for an organized routine [54]. Most of the excluded literature for this review focused exclusively on the transition to adulthood as the movement from CAMHS to AMHS [15, 55]. Indeed, according to the findings published by Appleton in 2019, only a quarter of these young individuals moved to AMHS, and another quarter continued to receive care from CAMHS despite exceeding the age limit [55]. The transition to adulthood is particularly challenging, due to both the continuing dependency of many young ASD adults on their caregivers and the frequent loss of the social support they received during their childhood and adolescence also by mental health and social services [56].

Accordingly, LP planning becomes an essential process in order to ensure the optimal TP [57]. Moreover, TP and LP for ASD often overlap in several areas. For example, both emphasize a person-centered approach, tailoring strategies to the individual's unique strengths, needs, and preferences [10, 16, 23]. TP often begin with goal setting, which is a core component of LP [58]. These goals might include further education, employment, or independent living [59]. Skills required for successful transition, such as self-advocacy, communication, and daily living skills, are also essential for achieving long-term life goals [60]. Building and maintaining a support network is crucial during the transition and throughout life, as these networks provide emotional, social, and practical support [61]. Both processes require ongoing assessment and flexibility to adjust plans as needed [62]. On the other side LP is a proactive approach that involves setting goals and creating strategies to achieve a desired QoL [14]. A LP is not just about addressing immediate needs but also about a long-term path that includes personal, social, and professional aspirations [63]. According to the literature, LP involves establishing personal milestones such as ed-

ucation, employment, hobbies, and skills development [64]. It also requires to identify and build a network of support that includes family, friends, mentors and professional services [12, 65]. Additionally the review support the inclusion, within the LP, of financial planning, maintaining physical and mental health through regular medical check-ups, pharmacological therapy, and a balanced lifestyle [10, 37]. Finally the understanding and advocating for personal rights, including accommodations and anti-discrimination measures, also plays a pivotal role in LP [40]. In fact, as is widely acknowledged, ASD presents significant lifetime social costs, including expenses for specialized education, adult care and productivity loss [66, 67]. Our review highlights a geographic imbalance on LP or PCP development in low- and middle-income countries. The prevalence of American studies may be due to an established research infrastructure and a substantial financial investment in autism research and support services [68, 69]. Resource allocation may partly explain why high-income countries place a greater emphasis on comprehensive PCP approaches [70]. In contrast, in low and middle-income countries ASD support primarily addresses basic care needs, with limited resources [71, 72]. Moreover, in low-to middle-income countries, using the same methods and strategies as high-income countries may not be advantageous, effective, or sustainable.

The studies included in the current review provide only an initial understanding of different approaches and methodologies to support the life planning of individuals with ASD. LP is the term used in Italy but PCP seems to be the term most used in literature [37-41]. PCP is defined as a process for selecting and organizing the services and supports that an older adult or a person with disability may need to live in the community [73]. Most important, it is a process that is directed by the person who receives the support. A PCP process aims to discover how an individual desires to live their life and what may be needed to make that possible, with the aim of influencing positive change in the person's life and supporting services [74]. Similarly, the concept of LP in the Italian context emphasizes planning and supporting an individual's life needs [10, 14, 42]. Both frameworks prioritize the individual's preferences, goals, and active involvement in the planning process. The LP, like PCP, seeks to empower individuals by focusing on their personal desires and ensuring that the necessary resources and supports are aligned to help them achieving their desired life. Thus, while the terminology may differ, the core principles of enhancing personal autonomy, ensuring tailored support, and fostering positive life changes are shared between the LP and PCP. The LP appeared particularly beneficial for individuals with intellectual disabilities associated with ASD, as they often require extensive support in various aspects of life [75], including educational, social, and professional needs. The current review emphasized the LP should ensure personalized assistance to enhance individual's QoL and integration into society. Purposely the concept of QoL emerges as a pivotal construct in defining and guiding the implementation of LP, offering a multidimensional lens through which individual

well-being can be assessed and enhanced [10, 37-41, 43]. Defining that construct requires more than one explanation. Individual QoL is a multidimensional construct composed of core domains influenced by personal characteristics and environmental factors [76]. These core domains are the same for all people, although they may vary individually in relative value and importance [77]. Assessment of QoL domains is based on culturally sensitive indicators mostly related to perceptions, behaviors, and life conditions [78]. Adopting a QoL perspective may help services to understand what matters most to someone and how to make things better [79, 80]. From this review several key components emerged as crucial for developing a comprehensive LP:

1. *preference assessment*: systematic preference assessments involve direct observation of individual's behavior to determine preferred items or activities. These assessments are valuable tools for identifying preferred stimuli for individuals with ASD across various environments (e.g., school, clinic, community);
2. *assessment of necessary supports*: this involves identifying the specific supports required for an individual to enhance their QoL. Tools for evaluating support needs ensure that individuals receive the appropriate assistance to achieve their goals;
3. *ecological life balance*: this tool adds various assessment systems and support methods, focusing on achieving a balance that accommodates the distinct characteristics of adaptive and communicative functioning in individuals with disabilities;
4. *definition of existential goals*: this step involves defining life goals that are meaningful and personalized, ensuring that the planning process aligns with the individual's aspirations and desires;
5. *implementation of the support plan*: once goals are defined, a detailed support plan is implemented, incorporating strategies like Positive Behavior Support and other tailored interventions;
6. *monitoring and verification*: continuous assessment and verification of the support plan's outcomes are crucial to ensure that the individual's goals are met and adjustments are made as necessary.

Ecological balance was frequently reported among the selected studies [10, 37]. However, research would benefit from a better definition and agreement of the specific elements of this concept. For instance, personal values as discussed in three papers [10, 37, 38], can lead to understanding ecological balance. Values are crucial because they form the philosophical foundation of inclusion, which is essential for creating equitable, supportive, and empowering environments for ASD individuals [81]. These values emphasize equality, QoL and human rights, ensuring that ASD individuals can live lives similar to those without ASD, with access to the same opportunities and environments [82]. In a nutshell, LP could be defined by identifying supports, structures, and action plans suited to the individual's preferences. Moreover, the importance of preference assessment for the development of LP was also frequently discussed in the included studies [10, 43]. Preference assessment involved a multitude of procedures to determine preferred items or activities. Moreover, in



a therapeutic environment, a therapist might use these assessments to identify stimuli that can be used as positive reinforcement for clients working on behavior modification or skill development. Preference assessments can take various forms including direct observation, trial-based methods that involve the presentation of pairs [83], groups of stimuli [84], or survey methods [85].

Future studies should aim to develop and validate assessment tools that are capable of accurately capturing the complex and multifaceted nature of individual preferences and support needs through the LP process. Additionally, research should evaluate the long-term outcomes of LP implementation to determine their effectiveness and sustainability. This involves examining how LP plans influence clinical outcomes, QoL, independence, and community integration for ASD adults. By tracking these factors over an extended period, researchers could gain a deeper understanding of the true impact of LP and identify areas where improvements are needed. Assessing the cost-effectiveness of LP across diverse economic contexts and not only in high-income countries is essential. Given the global prevalence of ASD [86], future research should address this gap to provide a more comprehensive understanding of LP's benefits worldwide. Follow-up studies are crucial, not only for monitoring the progress and effectiveness of the work done but also for identifying limitations and shortcomings of the planning process. Through continuous assessment and adjustment, the LP process can be optimized to better support the long-term well-being and integration of ASD adults in the community. Future research should also aim to significantly improve articles quality. There should be a particular focus on improving methodological alignment, ethical rigor, and representation of participants' voices. Adopting mixed-methods approaches, as demonstrated in studies like Hagner *et al.*, could enhance methodological alignment by integrating quantitative data with qualitative insights [39]. To improve ethical value, studies might establish advisory boards that include stakeholders, such as ASD individuals and their families. Additionally, engaging individuals with ASD through participatory research methods, like focus groups or co-design sessions, would bring real-life perspectives, leading to findings relevant and applicable.

Several limitations of this review need to be acknowledged. First, due to the context specific nature of the LP, each country may refer to it differently, and there may not always be a direct English translation. This variation in terminology could have led to a significant

loss of information in the review. The different names and conceptual frameworks used across various cultures and languages might have caused some relevant studies and approaches to be overlooked, potentially limiting the comprehensiveness of the findings. While the American PCP construct overlaps significantly with the Italian LP concept, integrating these diverse paradigms as we did in this paper may lead to inconsistencies and practical challenges. For example, the cultural contexts and theoretical foundations from which the PCP construct arose may affect the effectiveness of LPs tailored for individuals with ASD in Italy adopting the PCP approach. Second, in May 2024 in Italy, the release of Decree 62 [27] more clearly defines what an LP is within the context of national policy and practice. This decree provides a clearer framework for developing and implementing LPs, aiming to enhance the QoL for individuals with disabilities. However, this decree broadly refers to LP for people with intellectual disability. Third, the selection of studies and data extraction were not conducted independently by two reviewers, which could increase the risk of selection bias [87]. Fourth the inclusion of primarily conceptual studies and only one study involving ASD participants limited the applicability of the findings to real-world scenarios. Sixth, the review was restricted to studies published in English, potentially overlooking relevant research in other languages. Finally, the small number of studies included in the review limited the generalizability and robustness of the conclusions.

## CONCLUSIONS

Our results pointed out that there were few studies focusing on the LP for people with ASD, on its definition and how to develop it. The lack of studies specifically addressing the development and implementation of LP for individuals with ASD underscores a critical gap in the current research landscape. Despite the recognized importance of tailored TP and LP development for enhancing the QoL and autonomy of individuals with ASD, there remained a significant need for more comprehensive, evidence-based approaches to guide these processes effectively.

## Conflict of interest statement

The Authors declare no conflict of interest.

Received on 3 August 2024.

Accepted on 6 December 2024.

## REFERENCES

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. Washington DC: American Psychiatric Association; 2013.
2. Maurice V, Russet F, Scocco P, McNicholas F, Santosh P, Singh SP, Street C, Purper-Ouakil D. Transition from child and adolescent mental health care to adult services for young people with attention-deficit/hyperactivity disorder (ADHD) or autism spectrum disorder (ASD) in Europe: Barriers and recommendations. *L'Encéphale*. 2022;48(5):555-9. doi: 10.1016/j.enceph.2022.01.012
3. Singh SP, Paul M, Ford T, Kramer T, Weaver T, McLaren S, Street C. Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study. *Br J Psychiatry*. 2010;197(4):305-12. doi: 10.1192/bjp.bp.109.075135
4. Reis J, Marchini S, Delvenne V. The Transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS): What about autism

- spectrum disorder? *Psychiatr Danub.* 2021;33(1):52-7.
5. Howlin P, Magiati I. Autism spectrum disorder: outcomes in adulthood. *Curr Opin Psychiatry.* 2017;30(2):69-76. doi: 10.1097/YCO.0000000000000308
6. Fortune J, Murphy P, Merchant N, Kerr C, Kroll T, Walsh A, Kelly G. Transition from child-centred to adult-oriented healthcare systems for young people with neurodisability: a scoping review protocol. *HRB Open Res.* 2020;3:61. doi: 10.12688/hrbopenres.13095.1
7. Keller TE, Cusick GR, Courtney ME. Approaching the transition to adulthood: distinctive profiles of adolescents aging out of the child welfare system. *Soc Serv Rev.* 2007;81(4):453-84. doi: 10.1086/519536
8. Pillay Y, Brownlow C, March S. Transition approaches for autistic young adults: A case series study. *PLoS One.* 2022;17(5): 20267942. doi: 10.1371/journal.pone.0267942
9. Colver A, Rapley T, Parr JR, McConachie H, Dovey-Pearce G, Couteur AL, McDonagh JE, Bennett C, Maniopoulos G, Pearce MS, Reape D, Chater N, Gleeson H, Vale L. Facilitating transition of young people with long-term health conditions from children' to adults' healthcare services – Implications of a 5-year research programme. *Clin Med.* 2020;20(1):74-80. doi: 10.7861/clinmed.2019-0077
10. Corti S, Cavagnola R, Carnevali D, Leoni M, Francesco F, Galli L, Alzani L, Michelini G, Miselli G, Chiodelli G. The life project of people with autism and intellectual disability: investigating personal preferences and values to enhance self-determination. *Psychiatr Danub.* 2023;35(Suppl. 3):17-23.
11. Mubanga N, Baumgardner DJ, Kram JJJ. Health care transitions for adolescents and young adults with special health care needs: where are we now? *J Patient-Centered Res Rev.* 2017;4(2):90-5. doi: 10.17294/2330-0698.1406
12. Fulceri F, Gila L, Caruso A, Micai M, Romano G, Scattoni ML. Building bricks of integrated care pathway for autism spectrum disorder: A systematic review. *Int J Mol Sci.* 2023;24(7):6222. doi: 10.3390/ijms24076222
13. Laghi F, Trimarco B. Individual planning starts at school. Tools and practices promoting autonomy and supporting transition to work for adolescents with autism spectrum disorder. *Ann Ist Super Sanità.* 2020;56(2):222-9. doi: 10.4415/ANN\_20\_02\_12
14. Perego C, Oberti I, Pavesi AS. "Progetto di Vita" and universal design for persons with disabilities. *Stud Health Technol Inform.* 2022;297:201-8. doi: 10.3233/SHTI220840.
15. Appleton R, Canaway A, Tuomainen H, Dieleman G, Gerritsen S, Overbeek M, Maras A, van Bodegom L, Franić T, de Girolamo G, Madan J, McNicholas F, Purper-Ouakil D, Schulze UME, Tremmery S, Singh SP. Predictors of transitioning to adult mental health services and associated costs: a cross-country comparison. *BMJ Ment Health.* 2023;26(1):e300814. doi: 10.1136/bmj-ment-2023-300814
16. Westbrook JD, Fong CJ, Nye C, Williams A, Wendt O, Cortopassi T. Transition services for youth with autism: a systematic review. *Res Soc Work Pract.* 2015;25(1):10-20. doi: 10.1177/1049731514524836
17. Hatfield M, Falkmer M, Falkmer T, Ciccarella M. Evaluation of the effectiveness of an online transition planning program for adolescents on the autism spectrum: trial protocol. *Child Adolesc Psychiatry Ment Health.* 2016;10:48. doi: 10.1186/s13034-016-0137-0
18. McCusker P, Gillespie L, Davidson G, Vicary S, Stone K. The United Nations Convention on the rights of persons with disabilities and social work: evidence for impact? *Int J Environ Res Public Health.* 2023;20(12):6927. doi: 10.3390/ijerph20206927
19. Ceccherini E. Intergovernmental relations in Italy: the permanent state-regions-autonomous provinces conference. Intergovernmental relations in Italy: the permanent state-regions-autonomous provinces conference. Genova: Università di Genova; 2009. p. 216-38.
20. Presidenza del Consiglio dei Ministri (PCM). Aggiornamento delle linee di indirizzo per la promozione ed il miglioramento della qualità e dell'appropriatezza degli interventi assistenziali nei disturbi dello spettro autistico. Roma: PCM; 2018. Available from: <https://www.trova-norme.salute.gov.it/norme/renderNormsanPdf?anno=2018&codLeg=66884&parte=1%20&serie=null>.
21. Jones K, Forder J, Caiels J, Welch E, Glendinning C, Windle K. Personalization in the health care system: do personal health budgets have an impact on outcomes and cost? *J Health Serv Res Policy.* 2013;18(1):59-67. doi: 10.1177/1355819613503152
22. Presidenza del Consiglio dei Ministri (PCM). Linee programmatiche: progettare il budget di salute con la persona-proposta degli elementi qualificanti. Roma: PCM; 2022. Available from: <https://siep.it/wp-content/uploads/2022/07/BdS-Intesa-sancita-il-6-luglio-2022-Rep.-Atti-n.-104CU.pdf>.
23. Valenti M, Mazza M, Arduino GM, Keller R, Le Donne I, Masedu F, Romano G, Scattoni ML. Diagnostic assessment, therapeutic care and education pathways in persons with autism spectrum disorder in transition from childhood to adulthood: the Italian National Ev.A Longitudinal Project. *Ann Ist Super Sanità.* 2023;59(4):304-12. doi: 10.4415/ANN\_23\_04\_10
24. Osservatorio Nazionale Autismo (OssNA). Linee di indirizzo per le regioni e province autonome finalizzate alla definizione e implementazione di percorsi differenziati per la formulazione del progetto di vita basato sui costrutti di "Quality of Life" e tenendo conto delle diverse necessità di supporto, livello di funzionamento adattivo e disturbi associati delle persone con ASD, con particolare attenzione alla fascia d'età dai 16 anni in su. Roma: OssNA; 2022. Available from: [https://osservatorionazionaleautismo.iss.it/documents/20126/170236/Linee+di+Indirizzo\\_Progetto+di+vita\\_16\\_anni\\_in\\_su.pdf/fac22cca-7b9b-6011-f6b9-ed842754c0e5?t=1648042142393](https://osservatorionazionaleautismo.iss.it/documents/20126/170236/Linee+di+Indirizzo_Progetto+di+vita_16_anni_in_su.pdf/fac22cca-7b9b-6011-f6b9-ed842754c0e5?t=1648042142393).
25. Osservatorio Nazionale Autismo (OssNA). Linee di indirizzo per le regioni e province autonome finalizzate alla definizione e implementazione di percorsi differenziati per la formulazione del progetto di vita basato sui costrutti di "Quality of Life" e tenendo conto delle diverse necessità di supporto, livello di funzionamento adattivo e disturbi associati delle persone con ASD, con particolare attenzione alla fascia d'età 7-21 anni. Roma: OssNA; 2022. Available from: [https://osservatorionazionaleautismo.iss.it/documents/20126/170236/Linee+di+Indirizzo\\_Progetto+di+vita\\_7-21anni.pdf/2671fbdd-5a9b-0983-ec97-b33306739e82?t=1648042138144](https://osservatorionazionaleautismo.iss.it/documents/20126/170236/Linee+di+Indirizzo_Progetto+di+vita_7-21anni.pdf/2671fbdd-5a9b-0983-ec97-b33306739e82?t=1648042138144).
26. Istituto Superiore di Sanità (ISS). Linea guida sulla diagnosi e sul trattamento di adulti con disturbo dello spettro autistico. Roma: ISS; 2023. Available from: [https://www.iss.it/documents/20126/8968214/Linea\\_Guida\\_ASD\\_adulti\\_dic2024.pdf/2f89bd78-d44b-f8da-5de7-f1e69b62974c?t=1734950813404](https://www.iss.it/documents/20126/8968214/Linea_Guida_ASD_adulti_dic2024.pdf/2f89bd78-d44b-f8da-5de7-f1e69b62974c?t=1734950813404).
27. Italia. Decreto legislativo 3 maggio 2024, n. 62. Definizione della condizione di disabilità, della valutazione di base, di accomodamento ragionevole, della valutazione multidimensionale per l'elaborazione e attuazione del progetto di vita individuale personalizzato e partecipato. *Gazzetta Ufficiale – Serie Generale n. 111, 14 maggio 2024.*

28. Ratto AB, Bascom J, daVanport S, Strang JF, Anthony LG, Verbalis A, Rosen W. Centering the inner experience of autism: development of the self-assessment of autistic traits. *Autism in Adulthood*. 2023;5(2):93-105. doi: 10.1089/aut.2021.0099
29. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, Morrison C. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med*. 2018;169(7):467-73. doi: 10.7326/M18-0850
30. Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A, Shafer D. Rayyan – a web and mobile app for systematic reviews. *Syst Rev*. 2016;5(1):210. doi: 10.1186/s13643-016-0384-4
31. Hamel C, Hersi M, Kelly SE, Tricco AC, Straus S, Wells G, Goldstein J. Guidance for using artificial intelligence for title and abstract screening while conducting knowledge syntheses. *BMC Med Res Methodol*. 2021;21(1):285. doi: 10.1186/s12874-021-01451-2
32. Valizadeh A, Moassemi M, Nakhostin-Ansari A, Hosseini Asl SH, Saghab Torbati M, Aghajani R, Jafari K. Abstract screening using the automated tool Rayyan: results of effectiveness in three diagnostic test accuracy systematic reviews. *BMC Med Res Methodol*. 2022;22(1):160. doi: 10.1186/s12874-022-01631-8
33. Pompili E, Biondi M, Nicolò G, editors. *DSM-5-TR: manuale diagnostico e statistico dei disturbi mentali*. Milano: Raffaello Cortina; 2023.
34. World Health Organization (WHO). *ICD-11: international classification of diseases (11<sup>th</sup> revision)*. Geneva: WHO; 2022.
35. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Kastner M, Straus SE. A scoping review on the conduct and reporting of scoping reviews. *BMC Med Res Methodol*. 2016;16(1):15. doi: 10.1186/s12874-016-0116-4
36. Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc*. 2015;13(3):179-87. doi: 10.1097/XEB.0000000000000062
37. Renzaglia A, Karvonen M, Drasgow E, Stoxen CC. Promoting a lifetime of inclusion. *Focus Autism Other Dev Disabl*. 2003;18(3):140-9. doi: 10.1177/10883576030180030201
38. Kim KH, Turnbull AP. Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Res Pract Pers Severe Disabil*. 2004;29(1):53-7.
39. Hagner D, Kurtz A, May J, Cloutier H. Person-centered planning for transition-aged youth with autism spectrum disorders. *J Rehabil*. 2014;80(1):4-10.
40. Bui YN, Turnbull A. East meets West: Analysis of person-centered planning in the context of Asian American values. *Educ Train Dev Disabil*. 2003;38(1):18-31.
41. Callicott KJ. Sensitive collaboration with person-centered planning. *Focus Autism Other Dev Disabl*. 2003;18(1):60-8. doi: 10.1177/108835760301800108
42. Cappa C, Figoli M, Rossi P. Network of services facilitating and supporting job placement for people with autism spectrum disorders. The experience of the ASL Piacenza, Italy. *Ann Ist Super Sanità*. 2020;56(2):241-6. doi: 10.4415/ANN\_20\_02\_14
43. Tullis CA, Seaman-Tullis RL. Incorporating preference assessment into transition planning for people with autism spectrum disorder. *Behav Anal Pract*. 2019;12(3):727-33. doi: 10.1007/s40617-019-00353-6
44. Woods AD, Ireland MC, Murphy KA, Lancaster HS. Go beyond compliance: use individualized education programs to answer strategic questions and improve programs. *Lang Speech Hear Serv Sch*. 2024;55(2):249-58. doi: 10.1044/2023\_LSHSS-23-00084
45. Bertelli M. *Systematic psychopathological assessment for persons with intellectual and developmental disabilities-general screening*. Firenze: Private Edition; 2019.
46. Guaraldi G, Ruggerini C, Neviani V, Vicini S. La scala DASH-II (diagnostic assessment for the severely handicapped) per la valutazione dei disturbi mentali nei ritardati mentali gravi. *Quaderni Italiani di Psichiatria*. 2002;21(1):39-45.
47. Beavers GA, Iwata BA, Lerman DC. Thirty years of research on the functional analysis of problem behavior. *J Appl Behav Anal*. 2013;46(1):1-21. doi: 10.1002/jaba.30
48. Abery B, McBride M. Look and understand before you leap. *Impact*. 1998;11(2):2-26.
49. O'Brien J, Lovett H. Finding a way toward everyday lives: The contribution of person-centered planning. Ontario Independent Facilitation Network (OIFN); 1992. Available from: [http://www.oifn.ca/wp-content/uploads/2016/10/everyday\\_lives.pdf](http://www.oifn.ca/wp-content/uploads/2016/10/everyday_lives.pdf).
50. White SW, Smith IC, Miyazaki Y, Conner CM, Elias R, Capriola-Hall NN. Improving transition to adulthood for students with autism: a randomized controlled trial of steps. *J Clin Child Adolesc Psychol*. 2021;50(2):187-201. doi: 10.1080/15374416.2019.1669157
51. Gerhardt PF. Effective transition planning for learners with ASD. *Exceptional Parent*. 2007;37(9):26-7.
52. Gabriels RL. Review of universal design for transition: A roadmap for planning and instruction. *J Autism Dev Disord*. 2010;40(5):651-2. doi: 10.1007/s10803-009-0838-9
53. Rehm RS, Fuentes-Afflick E, Fisher LT, Chesla CA. Parent and youth priorities during the transition to adulthood for youth with special health care needs and developmental disability. *Adv Nurs Sci*. 2012;35(3):e57-72. doi: 10.1097/ANS.0b013e3182626180
54. Stromberg M, Liman L, Bang P, Igelstrom K. Experiences of sensory overload and communication barriers by autistic adults in health care settings. *Autism in Adulthood*. 2022;4(2):66-75. doi: 10.1089/aut.2020.0074
55. Appleton R, Connell C, Fairclough E, Tuomainen H, Singh SP. Outcomes of young people who reach the transition boundary of child and adolescent mental health services: a systematic review. *Eur Child Adolesc Psychiatry*. 2019;28(11):1431-46. doi: 10.1007/s00787-019-01307-7
56. Marsack-Topolewski CN, Church HL. Impact of caregiver burden on quality of life for parents of adult children with autism spectrum disorder. *Am J Intellect Dev Disabil*. 2019;124(2):145-56. doi: 10.1352/1944-7558-124.2.145
57. Chancel R, Miot S, Dellapiazza F, Baghdadli A. Group-based educational interventions in adolescents and young adults with ASD without ID: a systematic review focusing on the transition to adulthood. *Eur Child Adolesc Psychiatry*. 2022;31:1-21. doi: 10.1007/s00787-020-01609-1
58. Hutchinson SL. Lifestyle planning in the transition to retirement. *JAR Life*. 2024;13:30-2. doi: 10.14283/jar-life.2024.4
59. Nell-Rood C, Ruble L, Kleinert H, McGrew JH, Adams M, Rodgers A, Goodman J. Stakeholder perspectives on transition planning, implementation, and outcomes for students with autism spectrum disorder. *Autism*. 2020;24(5):1164-76. doi: 10.1177/1362361319894827
60. Wehman P, Schall C, Carr S, Targett P, West M, Cifu G. Transition from school to adulthood for youth with autism spectrum disorder: what we know and what we need to know. *J Disabil Policy Stud*. 2014;25(1):30-40. doi: 10.1177/1044207313518071
61. Bauer A, Stevens M, Purtscheller D, Knapp M, Fonagy



- P, Evans-Lacko S, Paul J. Mobilising social support to improve mental health for children and adolescents: A systematic review using principles of realist synthesis. *PLoS ONE*. 2021;16(5):e0251750. doi: 10.1371/journal.pone.0251750
62. Wehman PH, Schall CM, McDonough J, Kregel J, Brooke V, Molinelli A, Smith AC. Competitive employment for youth with autism spectrum disorders: Early results from a randomized clinical trial. *J Autism Dev Disord*. 2014;44(3):487-500. doi: 10.1007/s10803-013-1892-x
  63. Bernhardt JB, Lam GYH, Thomas T, Cubells JF, Bohlke K, Reid M, Green W. Meaning in measurement: evaluating young autistic adults' active engagement and expressed interest in quality-of-life goals. *Autism Adulthood*. 2020;2(3):227-42. doi: 10.1089/aut.2019.0081
  64. Benevides T, Watling R, Robertson SM. Person-centered interventions for autistic adults ages 18+ (2013-2021). *Am J Occup Ther*. 2023;77:1-8. doi: 10.5014/ajot.2023.77S10023
  65. Edelson SM, Nicholas DB, Stoddart KP, Bauman MB, Mawlam L, Lawson WB, McCauley JB. Strategies for research, practice, and policy for autism in later life: a report from a think tank on aging and autism. *J Autism Dev Disord*. 2021;51(2):382-90. doi: 10.1007/s10803-020-04514-3
  66. Cakir J, Frye RE, Walker SJ. The lifetime social cost of autism: 1990-2029. *Res Autism Spectr Disord*. 2020;72:101502. doi: 10.1016/j.rasd.2019.101502
  67. Matin BK, Byford S, Soltani S, Kazemi-Karyani A, Atafar Z, Zereshki E, Mokhayeri Y, Vafae R, Tabrizi R, Asadollahi M. Contributing factors to healthcare costs in individuals with autism spectrum disorder: a systematic review. *BMC Health Serv Res*. 2022;22(1):604. doi: 10.1186/s12913-022-07932-4
  68. Cervantes PE, Matheis M, Estabillo J, Seag DEM, Nelson KL, Peth-Pierce R, Kantarovich K, Pulido N, Kelly M. Trends over a decade in NIH funding for autism spectrum disorder services research. *J Autism Dev Disord*. 2021;51(8):2751-63. doi: 10.1007/s10803-020-04746-3
  69. Harris L, Gilmore D, Longo A, Hand BN. Short report: patterns of US federal autism research funding during 2017-2019. *Autism*. 2021;25(8):2135-9. doi: 10.1177/13623613211003430
  70. Zablotsky B, Maenner MJ, Blumberg SJ. Geographic disparities in treatment for children with autism spectrum disorder. *Acad Pediatr*. 2019;19(7):740-7. doi: 10.1016/j.acap.2019.02.013
  71. McConkey R. Responding to autism in low and middle income countries (Lmic): what to do and what not to do. *Brain Sci*. 2022;12(11):1475. doi: 10.3390/brain-sci12111475
  72. Zhou E, Kyeong Y, Cheung CS, Michalska KJ. Shared cultural values influence mental health help-seeking behaviors in asian and latinx college students. *J Racial Ethn Health Disparities*. 2022;9(3):1325-34. doi: 10.1007/s40615-021-01073-w
  73. McCausland D, Murphy E, McCarron M, McCallion P. The potential for person-centred planning to support the community participation of adults with an intellectual disability. *J Intellect Disabil*. 2022;26(4):603-23. doi: 10.1177/17446295211022125
  74. Sanderson H, Thompson J, Kilbane J. The emergence of person-centred planning as evidence-based practice. *J Integr Care*. 2006;14(1):18-25. doi: 10.1108/147690182006000014
  75. Waizbard-Bartov E, Fein D, Lord C, Amaral DG. Autism severity and its relationship to disability. *Autism Res*. 2023;16(4):685-96. doi: 10.1002/aur.2898
  76. Schalock RL, Verdugo MA, Gomez LE, Reinders HS. Moving us toward a theory of individual quality of life. *Am J Intellect Dev Disabil*. 2016;121(1):1-12. doi: 10.1352/1944-7558-121.1.1
  77. Schalock RL, Verdugo M. Handbook on quality of life for human service practitioners. Washington, DC: American Association on Mental Retardation; 2002.
  78. Grabowska I, Antczak R, Zwierzchowski J, Panek T. How to measure multidimensional quality of life of persons with disabilities in public policies – a case of Poland. *Arch Public Health*. 2022;80(1):230. doi: 10.1186/s13690-022-00981-5
  79. Bertelli M, Francescutti C, Brown I. Reframing QoL assessment in persons with neurodevelopmental disorders. *Ann Ist Super Sanità*. 2020;56(2):180-92. doi: 10.4415/ANN\_20\_02\_08
  80. Evers K, Maljaars J, Schepens H, Vanaken G, Noens I. Conceptualization of quality of life in autistic individuals. *Dev Med Child Neurol*. 2022;64(8):950-6. doi: 10.1111/dmcn.15205
  81. Petersson-Bloom L. Equity in education for autistic students: professional learning to accommodate inclusive education; 2022. Available from: <http://urn.kb.se/resolve?urn=urn:nbn:se:mau:diva-55508>.
  82. Hasson L, Keville S, Gallagher J, Onagbesan D, Ludlow AK. Inclusivity in education for autism spectrum disorders: Experiences of support from the perspective of parent/carers, school teaching staff and young people on the autism spectrum. *Int J Dev Disabil*. 2024;70(2):201-12. doi: 10.1080/20473869.2022.2070418
  83. Fisher W, Piazza CC, Bowman LG, Hagopian LP, Owens JC, Slevin I. A comparison of two approaches for identifying reinforcers for persons with severe and profound disabilities. *J Appl Behav Anal*. 1992;25(3):491-8. doi: 10.1901/jaba.1992.25-491
  84. DeLeon IG, Iwata BA. Evaluation of a multiple-stimulus presentation format for assessing reinforcer preferences. *J Appl Behav Anal*. 1996;29(4):519-32. doi: 10.1901/jaba.1996.29-519
  85. Wine B, Reis M, Hantula DA. An Evaluation of stimulus preference assessment methodology in organizational behavior management. *J Organ Behav Manag*. 2014;34(1):7-15. doi: 10.1080/01608061.2013.873379
  86. Zeidan J, Fombonne E, Scora J, Ibrahim A, Durkin MS, Saxena S, Zhao Y, Brown C, Mucic D. Global prevalence of autism: A systematic review update. *Autism Res*. 2022;15(5):778-90. doi: 10.1002/aur.2696
  87. Afifi M, Stryhn H, Sanchez J. Data extraction and comparison for complex systematic reviews: a step-by-step guideline and an implementation example using open-source software. *Syst Rev*. 2023;12(1):226. doi: 10.1186/s13643-023-02322-1