Education Sciences & Society, 1/2025 ISSNe 2284-015X

Special Pedagogy trajectories in the Life Project: A scientific analysis starting from transition phases

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Abstract
Highlighting the relevance of a quality-of-life approach, this article reconstructs the transitional phases that characterize the life trajectories of people with complex disabilities.

More specifically, the analysis highlights the challenges that arise with regard to care strategies, which often lack long-term planning and an approach that can coherently and systematically support the delicate transition phases. In this direction, the article moves in the merit of a reflection on the Life Project as a crucial tool to ensure personalized and integrated support, allowing the person and his or her family to define goals and aspirations. Finally, the need to develop operational tools and strategies to effectively support existential transitions is emphasized, using the Quality of Life framework to ensure person-centred interventions.

Key words: Complex disabilities; Life transitions; Life Project

First submission: 18/03/2025, accettato: 23/05/2025

1. Introduction

In Special Pedagogy, adopting a Quality of Life-oriented perspective (Giaconi, 2015) implies a project-based approach that can offer meaningful opportunities to build unique and authentic life paths (Goussot, 2009). Accompanying a person with disability towards adulthood means supporting them through an existential path of both guided and self-directed orientation (Mura, 2016, p. 193). This process is realised through the temporal and material

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Doi: 10.3280/ess1-2025oa19771

gradualness of dreams, possibilities, needs, and constraints, which influence not only the individual but also their relational context (Mura, Tatulli, 2017).

Such an orientation presents significant challenges in caregiving for people with complex disabilities, whose functioning profile has long posed questions to professionals in formulating practices aimed at Quality of Life (Nakken, Vlaskamp, 2007; Goussot, 2011; D'Angelo, 2020).

As highlighted in previous works (D'Angelo, 2020), the increase in life expectancy of people with complex disabilities draws attention to the need of supporting their transition phases, dealing with such delicate existential passages that can impact the meaning that the person and their family attribute to their life experience (Giaconi, 2015). Studies show that many parents and siblings of people with complex disabilities experience anxiety regarding their future adult life (Lindahl et al., 2019; Davys et al., 2010; Lee & Burke, 2018). These family members often arrange a single emergency plan, which appears to be far from a long-term global care approach (D'Angelo, 2020; Lindahl et al., 2019; Blacher et al., 2010).

In this sense, transition phases can manifest significant challenges. s argued by Giaconi (2015), moments of change are often accompanied by uncertainties and difficulties that can increase without a consistent and long-term project thinking approach. Caldin and Friso (2022) emphasise how the guidance towards adulthood already begins with parents' reflections, highlighting the importance of a future-oriented perspective. However, such reflections must translate into concrete and systemic actions to avoid individuals with disabilities and their families finding themselves in situations of vulnerability or isolation (Goussot, 2011).

In this direction, it is necessary to strengthen the trajectories of continuity and transversality to build and ensure the right to a future. Programs and projects, along with the interventions they envision, should be verifiable in terms of results and contribute to the Life Project (D'Angelo, 2020; Cottini, 2024). Therefore, the questions that should arise in the logics of caregiving, also in the case of people with complex disabilities, address the perspectives of future wellbeing, personal growth and social inclusion of the person. For these reasons, not responding to these rights "means influencing the persons' life itself in terms of quality" (Giaconi, 2015, p. 125). As discussed in this contribution, supporting meaningful life paths for people with complex disabilities undoubtedly represents the main challenge of those who take care of them. Hence, also in light of recent regulations (Dl 62, 2024), we will examine the Life Project and the delicate transition phases that involve people with complex disabilities to explore possible quality trajectories.

2. The Life Project: from theoretical construct to operational dimension

Scientific literature in Special Pedagogy considers the Life Project as an operational trajectory to promote and develop participatory and collaborative action programs that are integrated and transversal to achieve personal objectives and enhance the person's active participation (Pavone, 2009; Giaconi, 2015; Cottini et al., 2016; Canevaro et al., 2021). The Life Project includes in a shared frame of reference a series of planned interventions aimed at ensuring and promoting competences, knowledge and skills that can lead to the achievement of a better Quality of Life (Giaconi, 2015; Cottini et al., 2016; Canevaro et al., 2021).

The organisational and professional implications of the Life Project align with fundamental pedagogical principles, such as: continuity (in undertaking, in the critical and dynamic pursuit of goals), integrity (in defining the evaluations), breadth and depth (in the vision, the analysis of contexts, and the definition of methods to guarantee the person and their family's engagement to the greatest extent possible) (Pavone, 2014).

In the Italian context, the recent Legislative Decree No. 62 of May 3rd, 2024 (effective from June 30th, 2024), aligns with the findings of Special Pedagogy research, confirming a system of assessment and support centered on the person and oriented towards their well-being (Del Bianco, 2024). By actively involving the person with disability in the definition of contents and realisation of the project, a personalised and participatory approach can be promoted, taking into consideration their needs and desires (Shogren, & Plotner, 2012). A central aspect of the new decree on the Life Project is related to ensuring that the person with disability has control over their choices, thereby fostering project continuity and promoting alignment among supports. This approach underlines a person-centred collaborative process that involves the individual, their family, and professionals (Bianquin & Besio, 2021). The goal is to develop an integrated plan that addresses the person's needs and aspirations in various areas of life, such as education, employment, social participation, and independent living. This framework highlights the importance of empowering individuals with disabilities to define their own futures.

As previously mentioned, the functioning profile of people with complex disabilities presents unprecedented challenges regarding this right. Recent literature on the topic underscores the adoption of an ecological and Quality of Life-oriented perspective to address such complexities. These approaches allow the adoption of a life cycle perspective (Caldin & Giaconi, 2021), considering transitions not as isolated events, but rather as complex processes that unfold over time and involve multiple systems and levels. By implementing evidence-based strategies that prioritize the needs and aspirations of people with complex disabilities as well, these studies highlight the importance of continuous research and the development of more effective transition programs. Such a trajectory ensures that the Life Project is embedded in meaningful perspectives (Giaconi, 2015; D'Angelo, 2020; Jacobs et al., 2018; Bianquin & Besio, 2021).

To address the highlighted challenges with a project-based perspective, it is crucial to focus on the distinctive elements of the transition phases experienced by people with complex disabilities.

3. The transition phases in the Life Project

Transitions are crucial moments in the lives of all people, but for those with complex disabilities, they take on greater significance and complexity (D'Alonzo, 2011). In this context, the transition to adulthood is particularly meaningful as it involves a shift in personal roles and in the family's support needs. As individuals with complex disabilities age, outliving their parents, significant concerns about future care and supports emerge (Taggart et al., 2012; Kruithof et al., 2022). The challenges of this transition may include finding appropriate housing solutions, community integration, and employment, which can significantly impact the person's Quality of Life. As highlighted in previous works (D'Angelo, 2020; Giaconi et al., 2021), scientific literature highlights the importance of planning during the moment of "During Us" (Giaconi, 2015) to understand and address the needs of people with complex disabilities and their families, whose challenges and needs may significantly vary over time, from the initial diagnosis to the transition to adulthood and beyond.

The evolution path of people is, indeed, characterised by a series of crucial phases that present both opportunities and challenges. Such transitions, which span from childhood to adulthood, require careful planning and adequate support to ensure the wellbeing and participation of the person throughout their life (Pavone 2009; Miatto, 2022; Kruithof et al., 2022).

With the aim of retracing the main transition phases and challenges in the life cycle of a person with complex disabilities, we will present the key research lines that address this topic in the following paragraphs.

3.1 Transition from school to adulthood services

The transition from adolescence to adulthood represents a significant challenge for individuals with complex disabilities, marking the passage from a structured school environment to a less predictable adult context. This change implies an adaptation to the loss of school services, creating new support systems, and achieving goals related to independent living, employment, and community integration. For those with complex disabilities, this process can turn out to be particularly critical (Jacobs et al., 2018). The complexity of this transition requires careful planning and effective coordination among families, schools, and services (Wehman, et al., 2014; Kruithof et al., 2022). Similarly, researchers characterise the importance of this phase, describing it as a potential "turning point" that can significantly influence the individual's development towards adulthood (Ezerins et al., 2024). The challenges that individuals with complex disabilities and their families face during this transition are multiple and demanding (Luitwieler et al., 2024). The loss of established services and family support can be destabilising, forcing families to adapt to new systems and resources. Additionally, entering adulthood can raise new concerns, such as managing sexuality and planning for future care (Hendricks & Wehman, 2009).

Research highlights the need to conceptualise this transition not as an isolated event, but rather as a complex process that involves multiple systems and levels: from the family to the school, from local services to national policies.

Ideally, the preparation for this transition should start long before the end of the school path, involving the person with disability, their family, and all relevant professionals. This process should consider not only practical aspects – such as choosing the most suitable service or day activity – but also the emotional and relational dimensions of such a change.

Research underlines how there is often a discontinuity in the transition from school services to adult services, causing potential stress and disorientation for the person with a disability and their family. Studies stress the crucial role of the family in this context, as parents often represent the primary support to their children, coordinating the various actors involved. However, this role can generate additional stress for parents, who find themselves navigating a complex and fragmented scenario.

To mitigate such difficulties, a greater continuity can be ensured through the introduction of new coordination roles (Dl 62, 2024) or structured protocols for information transfer between services. Systemic actions to identify and implement personalised support strategies can contribute to reducing the criticalities associated with this transition and maximise the opportunities for an inclusive and satisfying life.

3.2 Transitions within adult services

The second transition phase analysed by scientific literature refers to the changes that occur in adulthood, with a focus on the transfer from family home to residential services (Beadle-Brown et al., 2023; Jacobs et al., 2018). This transition raises relevant questions regarding the concept of “adulthood” for individuals with complex disabilities. Traditionally, one’s moving from their parents' home is seen as a crucial step toward adult independence. However, for those who would always require intense support in their life, this perspective might be questionable.

Studies show that this transition is often driven more by external factors (such as the aging of one’s parents or their passing) rather than proactive choices made by the person and their family (Miatto, 2022; Bigby, & Beadle-Brown, 2018; Giaconi, 2015). This considerations raise ethical issues in supporting self-determination and facilitating informed choices for people with complex disabilities (Wehmeyer & Abery, 2013). An additional critical aspect characterising this transition phase is the maintenance and development of meaningful relationships (Simplican et al., 2015). The transition from family home inevitably leads to changes in relational dynamics. Research emphasises the importance of adopting approaches that not only provide adequate care but also promote and expand the individual's relational networks (Kamstra et al., 2019). Studies also explored various housing support models, highlighting related potentials and challenges (Bigby & Beadle-Brown, 2018). Among the innovative approaches that were considered, we can mention shared living models, in which people with disability and caregivers live together in community settings (Giaconi, 2012). These approaches can foster more authentic relationships and continuous support (Clement & Bigby, 2010).

Personalization appears to be crucial in this transition phase (Stancliffe et al., 2011). In this sense, housing and support solutions should be tailored to the needs, preferences, and aspirations of people with disabilities, requiring creative and flexible approaches to balance care needs with the promotion of autonomy and Quality of Life (Bigby & Beadle-Brown, 2018).

Research has also highlighted the challenges in managing risks in this transition, as moving to a new living environment inevitably leads to uncertainties and potential difficulties. However, it is essential to find a balance between protection and the promotion of opportunities for personal growth. In this sense, some authors (Douglas & Bigby, 2020) underline the need for flexible and personalised approaches to risk management, which can support informed and proactive choices.

3.3 Transitions in advanced age

The final transition phase analysed is related to the aging of individuals with complex disabilities, a topic of increasing importance given the rising life expectancy (Shogren & Wehmeyer., 2017; Haveman et al., 2010). Aging brings new challenges related to the increase of healthcare needs, changes in the functioning profile, and the necessity of adapting supports. It is essential to pursue a proactive approach to aging, which considers the needs of elders with complex disabilities and aims at maintaining Quality of Life even in advanced age (Jacobs et al., 2018). In this context, a critical issue is related to healthcare services accessibility and the management of complex health needs (Heller & Sorensen, 2013). People with complex disabilities often present unstable health conditions, making diagnosis and treatment challenging (Nakken & Vlaskamp, 2007). In this direction, operators and healthcare professionals' training gains centrality to properly address their needs. It is therefore crucial to promote an integrated approach that considers the interaction between complex disability and aging (Bowers, Webber & Bigby, 2014).

Research has also examined the impact of aging on the person's support networks. As people age, significant changes may occur in significant relationships (Taggart et al., 2012). The loss of primary caregivers raises questions about ensuring the continuation of support as well as the advocacy strategies fostered in the relational proximity with the person (Skarsaune & Hanisch, 2023; Shogren & Wehmeyer, 2017).

Another crucial aspect in the reflections surrounding the care of elderly people with complex disabilities concerns care planning and decisions on end of life (Kirkendall, et al., 2017). This process is particularly delicate in the case of people with complex disability, as they may have limited capacities to express their wishes (Tuffrey-Wijne et al., 2017).

Research also highlighted the importance of considering not only the functional and healthcare aspects of aging, but also the social and spiritual dimensions of it (Desai et. al, 2024). As a result, it is necessary to adopt holistic approaches that can favour an active and meaningful aging path, providing opportunities for social engagement and personal fulfillment, line with one's capacities and interests (Buys et al., 2012; Bigby et al., 2020).

In conclusion, the aging of individuals with complex disabilities requires a multidimensional and personalised approach that acknowledges the connections between disability, health, and aging, aiming to promote Quality of Life and wellbeing throughout all stages of adulthood (Giaconi, Caldin, 2021; Bigby, 2008).

Conclusions

The analysis of transition phases highlights the complexity and interconnection of the changes that individuals with complex disabilities face throughout adulthood. In fact, transitions are not isolated events, but rather complex processes involving various stakeholders and systems that require continuous planning (Giaconi, 2015). The discontinuities emerging from the reconnaissance of scientific literature underline the need for personalised and flexible approaches based on an ecological and longitudinal perspective of the life cycle (Caldin & Giaconi, 2021; Dew et al., 2019). This reinforces the importance of continuity, depth, and breadth of project action (Pavone, 2009).

In this context, the Life Project emerges as a fundamental tool for ensuring integrated and personalised support, aimed not only at the continuity of caretaking, but also at the promotion of ecological and longitudinal actions.

Guiding a person with a disability in their life path means directing project initiatives towards significant trajectories that can "guarantee adequate levels of Quality of Life in terms of independence, social participation, and wellbeing" (Giaconi, 2015, p. 127). Specific complexities arise in orienting people with complex disabilities in the implementation of the Life Project (D'Angelo, 2020). It is therefore crucial to implement transition programs that facilitate the active participation of the individual and their family network in defining aspirations and decision-making processes (Giaconi et al., 2021). In this direction, the Legislative Decree No. 62/2024 provides a legal basis to support and promote a cultural and operational shift in designing and implementing the Life Project.

The definition of the Life Project proposed in the decree embodies the reflections and trajectories that have been long promoted by Special Pedagogy scholars. By renewing the individual, personalised and participatory nature of such a tool, it emphasises the importance of identifying the desires and preferences of the person, moving towards a unified existential vision. The goal is to improve one's Quality of Life, develop their potential, and ensure choices in living contexts under conditions of equal opportunity.

Such considerations lead to the centrality of a systemic and integrating caretaking in such project actions (Pavone, 2009; Giaconi, 2015; Galanti, 2020). Sucrequires common languages and the sharing of best practices to overcome the fragmentation of interventions. Shared project horizons can be redefined through the interaction among different domains of daily life.

Finally, a pedagogical reflection is necessary regarding the alignment of professional plans to create a sustainable and meaningful Life Project. The need to develop tools and operational strategies to support transitions calls for the adoption of ecological approaches that translate theoretical demands into practical actions. A useful operational construct is represented by the Quality of Life framework (Schalock & Verdugo Alonso, 2002; Verdugo Alonso et al., 2014), which promotes a common understanding of goals and facilitates dialogue between professionals and families. This approach serves as a unifying element for planning person-centered interventions and monitoring their impact, ensuring alignment with personal preferences and needs while promoting strategic alliances to integrate and coordinate support.

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