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ABSTRACT

Orientation actions for future choices are put in place in secondary schools, which are difficult to implement for young adults with intellectual disabilities (ID). This dilemma underscores the importance of the Life Project. Drawing on the experiences of families of young adults with ID, this empirical study explores what role schools and teachers play in guiding and co-designing the adulthood of young adults with ID.

Nelle scuole secondarie vengono messe in campo azioni di orientamento alle scelte future, difficilmente realizzabili per i giovani adulti con disabilità intellettiva (DI). Questo dilemma sottolinea l'importanza del Progetto di Vita. Partendo dalle esperienze delle famiglie di giovani adulti con DI, in questo studio empirico si vuole esplorare quale ruolo hanno la scuola e gli insegnanti nell'orientare e co-progettare l'adultità dei giovani adulti con DI.

KEYWORDS

Orientation; Life Project; Intellectual Disability
Orientamento; Progetto di vita; Disabilità intellettiva

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Introduction

Transitioning from school to adult life for individuals with intellectual disabilities (ID) presents unique challenges, necessitating the mobilization of various resources. Individuals with intellectual disabilities often face multifaceted barriers spanning personal, cognitive, emotional, and physical realms, hindering their transition process (Dyke et al., 2013; Leonard et al., 2016; Gauthier-Boudreault et al., 2019). On a personal level, these individuals may possess varying degrees of self-awareness, self-advocacy skills, and comprehension of their own strengths and limitations. Empowering them to identify and leverage their strengths can significantly bolster their confidence and resilience throughout the transition. Addressing cognitive aspects, intellectual disabilities may impact memory, problem-solving, and decision-making abilities. Customizing transition programs to accommodate diverse learning styles and offering sustained support are instrumental in fostering essential skills for independent living, employment, and community engagement. Emotional well-being is paramount during the transition phase, as individuals with intellectual disabilities may grapple with anxiety, uncertainty, and apprehension about the future. Establishing a robust support network comprising family, friends, educators, and community members can provide invaluable emotional stability and encouragement. Additionally, ensuring access to adequate healthcare, transportation, housing, and assistive technology is imperative for their successful transition into adulthood. Collaborating with various stakeholders such as educators, healthcare professionals, social workers, policymakers, government agencies, advocacy organizations and the broader community, is crucial in ensuring that these resources are not only available but also tailored to meet individual needs effectively. In essence, by addressing these multidimensional challenges and leveraging diverse resources, individuals with intellectual disabilities can be better equipped to thrive in adulthood. By fostering inclusive environments and promoting equity, individuals with intellectual disabilities are empowered to achieve their full potential and lead fulfilling lives as active members of society (Dyke et al., 2013; Leonard et al., 2016; Redgrove et al., 2016).

Transitioning from school to post-school activities poses significant challenges for young people with intellectual disabilities also due to the intricate pathways and convoluted systems they must navigate. This transition period requires coordinated planning, collaboration, and decision-making among various stakeholders, including school staff, families, and community agencies (Forte et al., 2011; Leonard et al., 2016; Francis et al., 2019). The complexity of this transition arises from the

diverse needs and aspirations of individuals with intellectual disabilities, which often intersect with a multitude of services and support systems. The journey of navigating these paths can indeed be overwhelming for young people with intellectual disabilities and their families. They may find themselves in contexts where resources are scarce, making it challenging to access the support they need. Conversely, they may also encounter situations where there is an abundance of options, each accompanied by its own set of requirements and bureaucratic procedures. In both scenarios, the sheer complexity of the transition process can leave them feeling bewildered and uncertain about the best course of action. Balancing the need to explore opportunities with the practicalities of meeting bureaucratic demands can add an additional layer of stress to an already daunting experience. Thus, it is crucial to provide guidance, support, and streamlined pathways to help alleviate the burden and facilitate a smoother transition for individuals with intellectual disabilities and their families (Davies & Beamish, 2009; Forte et al., 2011). Effective transition planning necessitates a holistic approach that considers not only academic and vocational goals but also factors in personal preferences, social integration, and long-term aspirations. School staff play a crucial role in facilitating this process by providing tailored support, fostering self-advocacy skills, and connecting students with relevant resources and opportunities.

1. Orientation and Life Project: from legislation to practice

The resolution of the Council of Europe of 21/11/2008 "Enhancing lifelong orientation in lifelong learning strategies" defines orientation as "a set of activities that enable citizens of all ages, at any time in their lives, to identify their own abilities, skills, interests; make informed decisions regarding education, training, employment; manage their personal life paths in learning situations, work, and in any other context in which such abilities and skills are acquired and/or developed". The "National Guidelines for lifelong orientation" affirm that orientation is no longer just a tool to manage the transition between school, training, and work, but it assumes a permanent value in every person's life, ensuring their development and support in decision-making processes with the aim of promoting active employment, economic growth, and social inclusion (MIUR, 2014). Schools are recognized as having a central role in guidance processes (from ages 3 to 19), and they are tasked with autonomously and/or in collaboration with other public and private entities, implementing guidance activities aimed at constructing and enhancing specific guidance skills (MIUR, 2014). Additionally, they have the responsibility to promote the development of basic guidance skills and propose

educational activities aimed at acquiring transferable skills that can be used throughout one's lifetime.

Schools are called upon to invest in designing interventions that allow students to become causal agents of their own existence (Mura, Tatulli, & Agrillo, 2021). The activity of school orientation, in its role as accompaniment, represents a privileged opportunity for self-design (Miatto, 2022). Therefore, it is necessary to promote a path of educational guidance "that takes into account the intimate and essential dimensions of the person (...) and that is able to respond to the perennial need for growth and development that characterizes and accompanies every human being, regardless of age and condition" (Mura, 2018).

In the 2021/2022 school year, there were over 316,000 students with disabilities attending Italian schools, accounting for 3.8% of the total number of students. Regarding secondary education, the percentage of students with disabilities stands at 3.1% of the total attendees (ISTAT, 2022). Students with intellectual disabilities represent 65% of the students affected by disabilities (Mura, Tatulli, & Agrillo, 2021).

The "Guidelines for the School Integration of Students with Disabilities" stipulate that each school should implement specific guidance actions to ensure continuity in the support of the individual by the subsequent school or chosen post-school path. Additionally, they underline the need to develop educational plans that, through guidance as well, outline the possible choices the student will make after completing their educational journey (MIUR, 2018).

The "Biennial Action Program for the Promotion of Rights and Integration of People with Disabilities" (2016) explicitly addresses the need to create continuity between guidance, education, transition to work, and access for adults with disabilities to lifelong education and training pathways (Mura, Tatulli, & Agrillo, 2021). These documents aim to provide opportunities for development and inclusion through educational and training pathways that enhance autonomy skills and the social and work inclusion of people with disabilities. For students with intellectual disabilities, it is essential to have skilled governance and teaching personnel who can provide opportunities for active self-discovery, promote the development of self-awareness, and foster the ability to make autonomous and self-determined decisions.

Schools play a crucial role in this transition process, serving as the focal point for orientation and skill development. They are responsible for fostering basic orientation skills and implementing educational activities aimed at acquiring essential skills applicable throughout life. Moreover, schools are mandated to

develop educational plans that outline potential pathways for students post-schooling (Mura et al., 2021).

In Italy, Law No. 328/00 ("Framework Law for the Establishment of an Integrated System of Social Interventions and Services") provides that in order to achieve full integration into school, work, social, and family life for individuals with disabilities, an individualized plan must be prepared for each person with a disability. Law No. 112/2016, "Provisions on Assistance for Persons with Severe Disabilities Lacking Family Support," commonly known as the "Law on Dying and After Us," specifically identifies the drafting of the life project as the starting point for activating the pathways provided by the same law.

The drafting of the life project for people with disabilities has been further addressed by the innovations introduced by the "Good School" Reform, particularly by Legislative Decree No. 66/2017 ("Rules for the Promotion of School Inclusion of Students with Disabilities, pursuant to Article 1, paragraphs 180 and 181, letter c) of Law No. 107 of July 13, 2015"), within which the drafting of the Individual Educational Program (IEP) and the consequent support interventions for the school inclusion of students with disabilities must now also be included.

In Friuli Venezia Giulia (a north-east region of Italy), the Law No. 16 of November 14th, 2022, defines the life project as a tool aimed at realizing the goals of individuals with disabilities according to their desires, expectations, and choices. It aims to improve their personal and health conditions and enhance their quality of life across different spheres. The life project identifies barriers and facilitators within living contexts in accordance with the principles outlined in the UN Convention on the Rights of Persons with Disabilities. It also outlines measures necessary to compensate for activity limitations and facilitate participation in various aspects of life, including work, school, cultural and sports contexts, and other contexts of social inclusion. This project should create differentiated formulas of training provision, in order to avoid educational flattening and welfare, but promote an individualized, constructive experience capable of generating the future.

For students with intellectual disabilities (ID), these principles underscore the importance of having competent governance and teaching staff who can facilitate opportunities for active self-discovery, self-awareness, and decision-making. Achieving integration across various life domains—be it in school, work, social, or family settings—demands the development of individualized projects that are finely tuned to the unique needs and aspirations of each person with disabilities

(Miatto, 2022). Central to this approach is the recognition of the diverse strengths, preferences, and potential of students with ID. Educators and support personnel must adopt inclusive teaching strategies that promote autonomy, agency, and skill development. By fostering an environment that encourages active participation and self-expression, students can explore their interests, cultivate self-confidence, and take ownership of their learning journey (Miatto, 2022). Individualized projects tailored to the specific needs and goals of each student serve as a roadmap for their transition into adulthood. These projects may encompass vocational training, social skills development, independent living skills, and access to community resources. By tailoring interventions to the unique strengths and challenges of each individual, educators and support personnel can maximize the likelihood of successful outcomes and long-term integration into society. In essence, the journey towards integration for students with ID requires a multifaceted approach that prioritizes individualization, empowerment, and collaboration. By championing these principles, educational institutions and communities can create inclusive environments where every individual has the opportunity to thrive and contribute meaningfully to society (Turnbull et al., 2020).

2. Methodology

The research reported in this paper focuses only on the qualitative component of the larger study. The aim of this empirical study was to investigate the role of schools and teachers in guiding and co-designing the transition to adulthood for young adults with intellectual disabilities (ID).

An interpretative descriptive approach (Thorne, 2016) was chosen to describe, explain, and highlight the importance of the role of schools and teachers in planning the transition from school to adulthood for young people with intellectual disabilities. This methodological approach also allowed for the consideration of human subjectivity (Thorne, 2016), providing an in-depth understanding of the experiences of young adults and their families. The use of a qualitative design was central to understanding parents' perspectives through their discourse.

This study includes the perspectives and experiences of 15 parents (14 mothers and 1 father) of young adults with ID. Their sociodemographic characteristics are summarized in Table 1 and Table 2.

Characteristics		N=15
Age	50-65 years	12
	66 years or older	3
Gender	Female	14
	Male	1
Parental Relationship	Mother	14
	Father	1
Nationality	Italian	14
	Other	1
Marital Status	Married	8
	Separated	5
	Widowed	2
Educational level	Middle School	4
	High School	8
	University Degree	3
Occupational Status	Working	12
	Retired	3
Other sons/daughters	Yes	11
	No	4

Table 1. Sociodemographic characteristics of the parents interviewed

Characteristics		N=15
Age	20 years or less	4
	21-25 years	3
	26-30 years	3
	31-35 years	5
Gender	Female	9
	Male	6
Primary Diagnosis	Spastic Tetraparesis	3
	Intellectual Disability	6
	Prader Willy Syndrome	1
	Down Syndrome	2
	Rare genetic disease	1
	Autistic spectrum	1
	Post-natal brain hemorrhage (cause unknown)	1
Timing of Diagnosis	Before the birth	1
	Within the first year of life	9
	After the first year of life	5
Severity of Disability	Requires little assistance	5
	Requires moderate assistance	5
	Requires significant assistance	4
	Requires assistance for all activities	1
Primary Residence	In family	14
	Outside family	1

Table 2. Characteristics of young people with intellectual disabilities

The parents were contacted through collaboration with a local foundation that operates in the field of intellectual disabilities. A summary document of the research project was delivered to two members of the foundation. They verified which families met the inclusion criterion, namely being the parent of a young adult (aged 18-35 years) with intellectual disabilities. The identified families were provided with the researcher's email and phone contacts (specifically created). The researcher, after providing the families with more detailed information about the study, proceeded to schedule the interview if they were still interested.

Individual semi-structured interviews with 15 parents of young adults with ID were utilized for collecting data. Questions were compiled based on a review of the literature. The interview guide included questions that allowed participants to describe their experiences as they related to the young adult's transition into adulthood across a range of life domains. In particular, participants were prompted to discuss their experiences in various content areas, including family management practices, school experiences, community connections, family support, and long-term planning.

Written informed consent was obtained from each participant before the start of each interview.

The interviews were conducted individually in a reserved room within the Department of Human Studies at the University of Trieste (Italy). The interviews took place between July 2023 and March 2024. The interviews were conducted by the author of this paper. The average duration of the interviews was 62 minutes (range: 32-94 minutes). All interviews were recorded and transcribed verbatim. To ensure anonymity, all names used are fictitious.

In addition to the interviews, participants were administered a brief sociodemographic questionnaire asking about: parent's age, parent's gender, parent's education level, parent's occupational status, parent's marital status, age of the child with disabilities, gender of the child with disabilities, primary diagnosis, timing of diagnosis, severity of disability, primary residence of the person with disability, and presence of other sons/daughters.

Data analysis was conducted using NVivo 14 software.

Reflexive thematic analysis (Braun & Clarke, 2019 and 2021) was used to systematically identify and organize patterns of meaning within the qualitative data. The analytical process began with a thorough review of the transcripts to gain familiarity with the data. In order to maintain the perspectives of parents, each

transcript generated from the interviews was initially coded inductively. Subsequently, the researcher categorized data with conceptual similarities under broader codes aligned with the research aims. A thematic map was created to visually represent the prospective themes and their interrelationships (Braun & Clarke, 2021). The initial themes were then reviewed in the context of the entire dataset, the research question, and broader objectives, and were further refined based on this review. Finally, themes were revised and defined to weave together the narrative conveyed by the data concerning the research question in a final written interpretation (Braun & Clarke, 2019).

Due to the limited sample size, no statistical analysis was conducted on the survey data.

The study has been conducted in accordance with the ethical standards outlined in the ethical code for research in Pedagogy.

Ethics approval for all aspects of the study, inclusive of the qualitative component of the research, was obtained from the Ethics Committee of the University of Trieste (Italy).

3. Results

During the pivotal period of transition from secondary school to adulthood, parents of young adults with intellectual disabilities often find themselves navigating a labyrinth of uncertainty and doubt. This journey is fraught with challenges, primarily stemming from a glaring lack of accessible information and adequate support systems. One of the most profound struggles faced by these parents is the pervasive feeling of being adrift, as they grapple with the myriad decisions and pathways that lie ahead for their child. The transition period represents a central juncture where the familiar structures of secondary education give way to a nebulous landscape of adult responsibilities and opportunities. Without clear guidance and resources tailored to their child's unique needs, parents are left to navigate this terrain largely on their own. The absence of robust support networks exacerbates the sense of isolation experienced by many parents during this time. Moreover, the pervasive uncertainty surrounding their child's future can take a toll on parents' mental and emotional well-being. The constant worry about whether their child will find meaningful employment, secure stable housing, or forge social connections weighs heavily on their minds, leading to heightened levels of stress

and anxiety. In the absence of adequate support structures, these feelings of uncertainty can quickly spiral into frustration and despair.

"As a parent you feel abandoned, you don't find answers, you don't get information, you have to make a huge effort and that exhausts you, I was and still am very stressed" (Mother 11).

"I realize that the same sense of emptiness I experienced six years ago when my daughter finished high school, parents are feeling now. The sense of emptiness, of feeling abandoned, of 'what do I do now?' is there now just as it was 20 years ago" (Mother 6).

"After finishing school, what do we do? There's a big problem. I was very concerned about life after school because, clearly, another chapter opens, of course, but it also opens up a black hole because one doesn't know, hasn't been prepared, guided by anyone" (Mother 1).

The role of schools and teachers in facilitating the transition for students with intellectual disabilities is crucial, yet frequently falls short of expectations. Despite the significance of this period in shaping the trajectory of these students' lives, the support provided by educational institutions often lacks depth and effectiveness. One prominent deficiency lies in the absence of comprehensive school orientation programs tailored specifically for students with intellectual disabilities. These programs are essential for providing students and their families with essential information about available resources, potential pathways post-schooling, and how to navigate the transition process effectively. Without such orientation initiatives, families are left to navigate the complex transition landscape on their own, often feeling overwhelmed and ill-equipped to make informed decisions. Moreover, the role of teachers in guiding and co-designing the transition is frequently limited by various factors. While teachers undoubtedly play a vital role in the academic development of students, their training and expertise in addressing the unique needs of individuals with intellectual disabilities may be insufficient. As a result, they may struggle to provide tailored support and guidance to students during this critical phase of their lives.

"Everything was left to the parents and their abilities; we were not being oriented" (Mother 5).

"Everything was left to the parents and their abilities, there was no guidance, there was no orientation. So, there was no possibility to discriminate one structure from another considering the person's issues" (Mother 15).

Teaching staff are often perceived as unskilled and untrained in the opportunities available for young people with ID. This results in a lack of structured life projects and guidance, leaving families to fend for themselves. Without adequate training and awareness, teachers may struggle to provide appropriate support and resources for students with ID as they transition into adulthood.

As a result, families frequently find themselves navigating the intricacies of transition planning independently, lacking the necessary orientation, guidance and expertise from educational institutions. This places a significant burden on families and can lead to feelings of frustration, isolation, and uncertainty about the future.

"School doesn't direct you; I mean it was like a parking lot, it wasn't preparatory to doing anything, absolutely nothing" (Mother 3).

"As a parent, I expected the school to propose alternatives, strategies instead I was the one who proposed. I expected the school to give us directions instead it was us parents giving directions to the school. It's not that I expected them to give answers to everything, but school today is really very impersonal" (Mother 8).

Despite these challenges, parental agency and family proactivity emerge as a central resource in enabling young people with ID to carve out a future for themselves. Parents actively seek out opportunities and create projects tailored to the interests and abilities of their sons and daughters. Recognizing the limitations within the educational system, these parents take on the role of advocates for their children, tirelessly advocating for the support and resources they need to become adults. Through their proactive approach, parents often collaborate with

community organizations, service providers, and employers to create customized opportunities for their children. Whether it's through vocational training programs, job placements, or independent living arrangements, parents work tirelessly to ensure that their children have access to the resources and support they need to pursue their goals and aspirations.

"To occupy the time, after school, with the xx cooperative and educators, we came up with many projects targeted for my daughter. She started with painting and had great satisfaction (...) You have to assert your rights because first of all you are a person. Then you have a disability. You can't walk, ride a bike, ski, swim but you are a person and for that, you must have the best possible life and future" (Father 1).

"I consider myself an active mom, although I'm starting to feel worn out and quite tired. But I've always come up with things to do with my daughter, to have her try a thousand things, even new experiences, because it's not just about filling time. It shouldn't be just a filler, it should be experiences that always help her to grow. Because now, for example, she's finished school, and I've noticed that she's also declining cognitively, in reading, in understanding a conversation, in understanding a movie, she can't follow it. She's losing these skills, and I try to take her to the theater, take her here, take her there, show her a movie. But it's always me who does, proposes, invents, and I'm tired, but I can't stop because if I don't do these things, no one else will" (Mother 12).

4. Discussion

The research outlined in this paper highlights the complex challenges surrounding the transition from secondary school to adult life for young individuals with intellectual disabilities (ID) and their families. It emphasizes the feelings of abandonment, the absence of tailored programs, and the inadequacy of training and information, all of which contribute to a sense of disorientation among families. Consequently, families are often left with no choice but to improvise plans for their children's futures. This underscores the urgent need for more comprehensive support systems and resources to address the diverse needs of individuals with ID and their families during this critical transition period. The factors identified in this study align with those identified by other researchers,

highlighting the challenges associated with accessing information and services post-schooling. International studies have consistently pointed to issues such as non-systematic transition planning, limited services inadequately tailored to individuals with ID, and a lack of coordination among transition planning services (Heller et al., 2015; Gauthier-Boudreault et al., 2017; Gauthier-Boudreault et al., 2019; Morgensen et al., 2023).

Qualitative studies have emphasized that the transition to adulthood represents a critical and highly stressful period for parents of young adults with ID, as they are often ill-prepared for the end of schooling and the transition to adult services. The findings indicate a clear necessity for offering both material resources and information to aid parents in managing the numerous challenges they encounter as their children transition from school to adulthood (Francis et al., 2019). This underscores the importance of establishing support structures that can provide tangible assistance and guidance to parents as they navigate this complex process with their sons and daughters (e.g., Miatto, 2022; Morgensen et al., 2023).

Addressing the lack of training and awareness among teaching staff is essential for improving the transition experience for young people with ID and their families. By providing teachers and educators with the necessary tools and resources, we can ensure that all students, regardless of their abilities, have the support they need to achieve their full potential and lead fulfilling lives.

Schools and teachers must recognize the importance of transition planning for students with intellectual disabilities and take proactive steps to address their unique needs. This includes providing individualized transition planning that considers the strengths, interests, and goals of each student, as well as involving parents and educational staff as equal partners in the process. Additionally, schools should offer comprehensive vocational training and job readiness programs tailored to the abilities and interests of students with intellectual disabilities (Lascioli and Traina, 2022). These programs should focus on developing practical skills, building self-confidence, and facilitating meaningful employment opportunities within the community. Furthermore, schools can play a crucial role in facilitating connections with community organizations, service providers, and employers to create a supportive network for young adults with intellectual disabilities. By fostering collaboration and partnerships, schools can help ensure that these individuals have access to the resources and opportunities they need to thrive in adulthood.

Effective transition planning requires a multidisciplinary approach, involving not only teachers but also special education professionals, families, and administrators.

However, in many cases, there is a notable absence of cohesive efforts to pool expertise and resources, leading to fragmented support systems that fail to adequately meet the diverse needs of students.

Parental agency and family proactivity play pivotal roles in empowering young individuals with intellectual disabilities (ID) to surmount obstacles and forge meaningful paths for their futures. By actively engaging in advocacy, seeking out resources, and advocating for their children's needs, parents can significantly impact their children's opportunities and outcomes. This proactive approach fosters independence, resilience, and self-determination in young people with ID, ultimately enabling them to pursue fulfilling and purposeful lives.

Conclusions

The study's findings underscore the urgent need for a tool that facilitates several key functions. Firstly, it should enable a comprehensive survey of the current landscape within the regional territory, identifying existing resources, gaps, and areas for improvement. Secondly, the tool should support the enhancement of available services by aligning them with the specific training and educational offerings that best cater to the needs of individuals with intellectual disabilities. This involves ensuring that services are tailored to address the unique challenges and aspirations of these individuals as they transition into adulthood. Lastly, the tool should facilitate the dissemination of gathered information to relevant stakeholders involved in supporting young people with intellectual disabilities during this critical phase of their lives. By providing valuable insights and fostering collaboration among educators, service providers, families, and community members, such a tool can significantly contribute to improving outcomes for individuals with intellectual disabilities as they navigate the transition from school to adult life. Secondary school teachers stand to benefit greatly from this tool, as it equips them with guidelines to effectively guide young adults with intellectual disabilities and their families. Equipped with extensive knowledge about post-schooling options within their community, teachers can offer personalized assistance, guiding each individual with intellectual disabilities to make informed decisions about their future paths. This tool not only enhances teachers' ability to support students but also positions them as crucial facilitators in ensuring smooth transitions. Moreover, by actively involving parents and community members, educational institutions create a collaborative environment where the diverse needs of these individuals are met. Through this inclusive approach, institutions

foster empowerment, enabling young adults with intellectual disabilities to lead fulfilling lives imbued with satisfaction and purpose.

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