

## **STEP INTO ADULTHOOD: EXPLORING TRANSITION EXPERIENCES OF YOUNG ADULTS WITH DISABILITIES THROUGH A NARRATIVE INQUIRY**

### **VERSO L'ADULTITÀ: ESPLORARE LE ESPERIENZE DI TRANSIZIONE DEI GIOVANI ADULTI CON DISABILITÀ A PARTIRE DA UN'INDAGINE NARRATIVA**

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#### **Abstract**

Transition to adulthood represents the transition to specific adult roles and responsibilities in close connection with life contexts. The literature in this area calls this phase *emerging adulthood* highlighting its complexity, uncertainty and problematic traits (Arnett, 2004). This process turns out to be more critical for persons with disabilities for whom, even today, the end of school is configured as a "leap into the void" urging for specific planning. The upper secondary school and the local services that act with it therefore play a crucial role in building this transition phase.

This contribution illustrates the outcomes of the exploratory phase of the STRADE project aimed at designing and experimenting a model of transition to adulthood that favors students with disabilities the acquisition of transversal and professional skills from a life plan perspective. For this purpose, the voices of young persons with disabilities and their families were collected through narrative-biographical interviews (Muylaert et al., 2014) and analyzed according to the criteria of thematic analysis (Green, Thorogood, 2004) in order to highlight the main personal/environmental factors characterizing the transition paths of students with disabilities as well as facilitators/barriers that have influenced the construction of their adulthood.

La transizione all'adulthood rappresenta il passaggio a ruoli e responsabilità specifiche dell'età adulta in stretta connessione con i suoi contesti di vita. La letteratura di settore denomina questa fase *emerging adulthood* evidenziandone i tratti di complessità, incertezza e problematicità (Arnett, 2004). Questo processo risulta essere maggiormente critico per le persone con disabilità per le quali, ancora oggi, la conclusione del percorso scolastico si configura come un "salto nel vuoto" che palesa l'urgenza di una specifica progettualità. La scuola secondaria di secondo grado e i servizi territoriali che con essa agiscono giocano, pertanto, un ruolo cruciale per costruire questa fase di transizione.

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<sup>1</sup> The paper was conceived, designed and realized by all the authors. Except paragraph n. 4 "Discussion" and "Conclusion" that were written by all the scholars, Mabel Giraldo wrote paragraph n. 1 "Persons with disabilities at the adulthood crossroad", Nicole Bianquin n. 2 "Study design" and Fabio Sacchi n. 3 "Results".

Il presente contributo illustra gli esiti della fase esplorativa del progetto STrADE finalizzato a progettare e sperimentare un modello di transizione all'adulthood che favorisca negli studenti con disabilità l'acquisizione delle competenze trasversali e professionali nell'ottica del progetto di vita. A tale scopo, le voci dei giovani con disabilità e le loro famiglie sono state raccolte attraverso interviste narrative-biografiche (Muylaert et al., 2014) analizzate secondo i criteri della *thematic analysis* (Green, Thorogood, 2004) al fine di evidenziare i principali fattori personali/ambientali caratterizzanti i percorsi di transizione degli studenti con disabilità nonché facilitatori/barriere che hanno influenzato la costruzione della loro adulthood.

### **Keywords**

transizione; età adulta; disabilità; intervista narrativa-biografica; analisi tematica  
transition; adulthood; disability; narrative-biographical interview; thematic analysis

### **Persons with disabilities at the adulthood crossroad**

The term “transition” has been commonly used to describe the step into specific adult roles and responsibilities (Morgan, Reisen, 2016). It represents a period of hopes and expectations balanced between the person's identity formation and social affirmation (Levine, 2005).

Currently literature promotes the passage from a traditional view of adulthood as a stable process with a predetermined end to multidimensional approaches reflecting the complexity of young people's life experiences (Furlong, 2009). The increasing period during which many youths remain in a state of semi-dependency have given rise to terms such as “yo-yo” or delayed transitions (Walther et al., 2006). These have led researchers to define a new life phase between youth and adulthood highlighting its traits of complexity (Furlong, 2009). For this reason, Arnett (2004) has introduced the concept of *emerging adulthood*: a new stage during which young people are able to “explore a wide range of different possible future paths” (p. 7). The challenges become even more relevant for young adults with disability (YAWD) for whom thinking about future often represents a source of disorientation and concern due to the sense of abandonment that, in many cases, accompanies this passage (Stewart et al., 2006). These concerns are also fueled by the concomitant request for adaptation to a new social, organizational and educational context which implies a reconfiguration of the person with disability's (PWD) life path and of services and welfare protections (McDonnell, Hardman, 2010). For these reasons, the transition of YAWD has often been reported by families and caregivers as a time of upheaval, stress and important decisions, and there is confusion about services available (Caton, Kagan, 2007). Its failure has been highlighted as a major cause of isolation and exclusion across all Western countries (UNCRPD, 2014).

Moreover the main difficulties encountered by YAWDs concern inclusion into the labor market, the living choice and the opportunities for independent life and social participation, continuing education and access to higher education programs (Lindsay et al., 2018). Furthermore, several studies indicate that the outcomes of these pathways are often determined by the type and severity of the disability (Canton, Kagan, 2007) as well as by the personal and environmental factors that characterize the life contexts (Stewart et al., 2006).

Evidence suggests that the difficulties are also linked with transition arrangements that are often absent, and, where present, they are uncoordinated (Kirk, 2008). In fact, a major challenge is the lack of collaboration and coordination between professionals involved in designing the transition (Bindels-de Heus et al., 2013). At last, the major critical concerns not involving YAWD in the process and considering them as passive recipients of support not empowering them to participate in it. In most cases transition occurs about the individual and not with the

individual (Butterworth et al., 1997) recognizing his/her right to participate, but not making him/her co-agents in the transition path.

All these challenges call for a more specific transition design in which upper secondary schools and the adult services may play a crucial role.

From this background, drawing on narrative-biographical interviews with YAWDs and their parents collected as part of a larger action research (AR) project entitled *STrADE - Supporting the Transition to Adulthood for persons with Disabilities from an Ecosystemic perspective*, this paper intends to explore transition directly from the voices of these protagonists. Starting from the thematic analysis of the collected material, the paper addresses the following questions:

Q1) What are the personal and environmental factors that characterize the transition to adulthood, from the perspective of YAWD and their parents?

Q2) Which of them are perceived as barriers/facilitators?

### **Study design**

This study is part of a larger research, entitled *STrADE* launched in October 2021 by the Chair of Special Pedagogy of the University of Bergamo. Adopting an ecosystemic approach (ICF; WHO, 2001) and a participatory design (McIntyre, 2007), this AR aimed at projecting and experimenting a model of transition to adulthood that supports YAWD in achieving adult outcomes associated with their life plan.

The narrative inquiry illustrated is the exploratory phase of *STrADE* project, aimed at defining and contextualizing the problematic areas on which to base the overall research. The steps of this phase are:

1. collecting the YAWDs and their parents' voices in relation to transition experiences;
2. examining the interviews individually and carry out a thematic analysis to identify barriers/facilitators;
3. elaborating a final report containing suggestions for the *STrADE* AR.

A qualitative interpretive approach (Thorne, 2008) was used to describe the relationships between different areas that help to understand transition.

Data collection was carried out through a narrative-biographical interview (Muylaert et al., 2014). Within idiographic-qualitative research, it aims at collecting stories (Atkinson, 2007) and obtain a first-person life account (Kaźmierska, 2004) enabling the researcher to formulate a construction of meaning and give voice to the interviewees to bring out the person's autobiographical story. By reconstructing the social events from the point of view of the people interviewed this tool allows to: a) analyse the social reality; b) understand the phenomena; c) figure out the connections of meaning reported by the narrators (Muylaert et al., 2014).

Then a thematic analysis was conducted (Green, Thorogood, 2004), properly chosen for this research, as it is a search for themes that emerge as being important to the description of the phenomenon. This method is a flexible tool for analyzing unstructured qualitative data (Richardson, 1996), like the ones analyzed here. The process involves the identification of themes through careful reading of the data.

### **Participants**

This study explored the perspectives of 2 young adults and their parents (see *Table 1*)

Name	Age	Gender	Disability
A.	20	Male	Cerebral palsy
S.	23	Female	Visual impairment
AP (A's parent)	47	Female	None
SP (S' parent)	45	Female	None

*Tab. 1: Participants Characteristics*

The participants were selected by the school institution they attended, also based on personal availability. The school is one of the partners of the project. Each participant was informed about the project objectives, the purpose of the interview and signed the informed consent.

### **Data Collection**

The narrative-biographical interview is part of the discursive interviews that are semi- or unstructured (Atkinson, 2007). Within this study, a semi-structured interview protocol was used inquiring the following areas:

- biographical information;
- occupation (job, higher formal education, vocational training, etc.)
- school career;
- student experience (roles, tasks, self-determination, participation, etc.);
- activities carried out by the school or/and by different actors;
- role of the school professionals and other actors;
- role of the family.

The interviews were conducted in December 2021 in presence at the school the young people attended. YAWDs and parents were interviewed separately.

### **Data analysis**

All interviews were transcribed by following the rules of clarity and completeness. The transcription process was conducted by researchers in a collaborative way: the recording narrative interview was listened to and strictly transcribed. The researchers manipulated the material as minimally as possible in order to recover the original meaning expressed by the narrators. Then the questions were eliminated to structure the person's autobiographical story (Atkinson, 2007).

The last stage concerns data interpretation. The retrieved material was subjected to a thematic analysis to identify specific areas and main evidence (Guest et al., 2012): each autobiographical story was analyzed by using inductive thematic analysis, in which analytical concepts and perspectives were derived from the data in a deliberate and systematic way. In examining these documents, the study interrogated the data to answer to the research questions.

This thematic analysis followed a four-step process, adapted from Braun and Clarke (2006):

1. each member of the research team familiarized independently with the autobiographical story;

2. the initial analysis was carried out by splitting the autobiographical story into units<sup>2</sup> from which to derive and develop principal themes (see *Table 2*);
3. each story was re-analysed and coded according to the identified themes in order to carry out a comparative analysis of the autobiographical stories;
4. the report was drawn up.

At stages 2, 3 and 4 the researchers worked collaboratively, advocating the value of dialogue and preventing bias and strengthening validity. The interpretations were continually challenged for alternative explanations and inter-rater reliability for code assignment to themes was tested by the research team (Graneheim, Lundman, 2004).

## **Results**

Starting from the transcripts, a synthesis of the YAWD' biographical stories arranged by the researchers will follow.

### **Young adults' biographical stories**

S. is a 22-year-old visually impaired girl, currently attending the master's degree in Social Psychology. She attended a business services course of technical high school. Although she was not interested in business subjects she completed her studies and, thanks to her determination and the aid of the support teacher and family, got the diploma. S. is also a professional swimmer of the Paralympic National team.

A. is 20 years old and has cerebral palsy. He attended, firstly, a visual communication and design course and then, social-health services course of a technical high school. Up to middle school he followed the mainstream curriculum. At the high school he had a differentiated curriculum obtaining a "skills certificate", instead of the diploma. This was experienced by A. as personal failures, requiring interventions by parents, teachers and psychotherapists. Currently, A. is temporarily employed as a waiter, waiting to access the supported employment services.

### **Dominant themes**

The dominant themes are presented in *Table 2*. Each theme was attributed by the research team to ICF contextual factors (both at the first and second level) and identified as barriers or facilitators.

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<sup>2</sup> A code is the smallest segment of the raw data that can be assessed in a meaningful way, without its initial context being lost. This may be a word, phrase, or whole passage and the unit will be physically cut up from one of the copies (Boyatzis, 1998).

RQ1			RQ2
Dominant themes	Correspondence to ICF categories 'contextual factors' (1 <sup>st</sup> level)	Correspondence to ICF categories 'contextual factors' (2 <sup>nd</sup> level)	Facilitators (F) / Barriers (B)
<i>Reasonable accommodations</i>	Products and technology	Products and technology for personal use in daily living	B
		Products and technology for education	B
		Products and technology for employment	B
<i>Transportation</i>	Products and technology	Products and technology for personal indoor/outdoor mobility and transportation	B
	Services, systems, and policies	Transportation services, systems, and policies	B
<i>Social relationships</i>	Support and relationships	Immediate family	F
		Friends	F + B
		Acquaintances, peers, colleagues, neighbors, and community members	F + B
		People in position of authority	F + B
		Health professionals	F
		Person care providers and personal assistants	F
		Other professionals	F + B
<i>Attitudes</i>	Attitudes	Individual attitudes of immediate family members	F
		Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	B
		Individual attitudes of people in position of authority	B
<i>Social systems and policies</i>	Services, systems and policies	Associations and organizational services, systems and policies	F
		Labor and employment services, systems and policies	B
<i>Educational systems</i>		Education and training services, systems and policies	B
<i>Choice, self-determination, participation</i>	Personal factors		F
Psychological characteristics	Personal factors		F

**Tab. 2: Dominant themes and ICF sub-themes extracted by biographical stories**

## Discussion

This study aims to identify what are the contextual factors (WHO, 2001) characterizing the transition to adulthood of YAWDs. According to the literature, the research highlighted several multifaceted issues associated with this phenomenon.

### Environmental factors

ICF environmental factors include physical, social and attitudinal environment in which people live. They can either act as barriers or facilitators to the individual's functioning.

### **Reasonable accommodations**

UN *Convention on the Rights of Persons with Disabilities* (2006) defines reasonable accommodations as “necessary and appropriate modification and adjustments [...] to ensure to persons with disabilities the enjoyment or exercise [...] of all human rights and fundamental freedoms” (art. 2). They can be applied to living contexts and their related physical elements. ICF presents two categories of environmental factors: the natural environment and human-made changes and products and technologies. From the first one the following topics emerge.

*In the canteen the menu is written on the paper, you choose what you want to eat, you get a number, the screen rings but it does not say the number (S)*  
*Because of his motor difficulties and the fact that there are no kitchens equipped for him, we, with the support teacher, suggested him another school course (AP)*

Products and technologies are also identified as problematic with respect to their availability and usability. Mainly S talks about the products she uses in her daily life (e.g. adapted books, magnifiers and vocal screens).

*Difficulties, for example, in finding books (S)*  
*Our magnifiers, she used it all the time at school; obviously at the request of the family the school permits to transfer it to this company and use it (SP)*

These units reveal how the right of PWD to obtain reasonable accommodation is not yet fully recognized.

### **Transports**

Transports emerge as essentials for a successful transition (Graham et al., 2018) to guarantee personal mobility and inclusion and participation. They assume a strategic role also by the narrative inquiry, in a double perspective.

The first concerns what the ICF identifies as “products and technologies for personal indoor and outdoor mobility and transportation”. For instance, S reports her difficulties especially concerning accessibility and usability of transport and paucity of resources to assist.

*In small stations like that of my town there is no assistance [...] I often have to wait even 3 or 4 hours at the station (S)*

Moreover, the stories highlight the need of vehicles equipped with adaptations making them usable for PWDs. Punch and Duncan (2020) recommend integrating alternative forms of communication in addition such as audio and verbal announcements and real time information (Park et al., 2017).

The second barriers concern what ICF called “transportation services, systems and policies” in relation to location and connections of the public transport network particularly in rural area.

*In my opinion the big problem is the transport in the small town where we live. There isn't a bus line for train station. I always take her to the station (SP)*

Also A states that, although he was accepted into the secondary catering school he wanted, the distance and the lack of the public transport lines effectively prevented him from attending it.

Mobility and transport policies are strategic and their limited implementation can preclude the concrete possibilities of leading an independent life (Kamruzzaman et al., 2016).

### **Social relationships**

ICF social relations refer to people that “provide practical physical or emotional support, nurturing, protection, assistance and relationships” (p. 187). In the narrative inquiry, these include: immediate family; friends; acquaintances, peers, colleagues, neighbors, and community members; people in position of authority; health professionals; care providers and personal assistants; other professionals.

Immediate families play a significant role and appear as positive resources.

*My parents always told me to follow my passions and do what I felt and wanted to do (S)  
I have to thank my family (A)*

Parents’ support is crucial for the transition to adulthood, especially in guiding and supporting the life choices of the PWDs and accompanying them in these critical phases (Lyndsay et al., 2018). Families’ involvement is the most cited predictor of a successful transition as well as their collaboration with different professionals (Foley et al., 2012).

For S and A, health and social professionals are important facilitators. According to the literature (Kochhar-Bryant, Greene, 2009), one of the key features in fostering transition is the wide range of professionals and services supporting YAWDs throughout this process. As confirmed by the stories, these figures help PWDs and their families by informing and guiding them in the choice of specific services meeting their needs.

*And luckily for me I have a social assistant who is very skilled ... who listens to my needs. The social assistant helped me a lot more than the teachers (A)*

The teachers are perceived by YAWDs and their parents both as facilitators and barriers; in particular support teachers are crucial for supporting students.

*Thanks to the support teacher and educator who have given him important roles within the school (AP)*

Contrary, class teachers are mainly perceived as barriers due to their limited awareness and understanding of the difficulties associated with disability.

*The first year I had to change the course because class teachers didn't understand my difficulties and they even reprimanded my support teacher: they said that while she was working with me, she was disturbing the other students (A)*

This is a crucial issue: many class teachers would appear not to have the adequate knowledge/skills to understand disability and implement curriculum and instructional strategies to guarantee a successful transition (Clements et al., 2021).

Classmates and friends result as barriers and facilitators too.

*It is fundamental to have friendships: you cannot always and only rely on your parents (S)  
Last summer I argued with my best friend: at a certain point he told me “You can't do it, that's enough”. This didn't help me psychologically because made me conclude that I was a failure (A)*

Friendships are crucial for supporting the transition to adulthood: thanks to them, YAWD are more likely to “experience a high quality of life post high school, as defined by self-sufficiency,

community living skills, post high school education, financial independence, and social contacts” (Test et al., 2009:170).

### ***Attitudes***

Significant environmental factors influencing transition to adulthood are attitudes: “the observable consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs” (WHO, 2001:190).

Closely related to “social relationships”, the autobiographical stories reveal prejudices and stereotypes generating forms of discrimination, stigmatization and marginalization, in particular at school.

*There was no dialogue with classmates, disability was ghettoized in one part of the class (A)  
He looked at me because of my disability. This distanced me (S)*

Negative attitudes towards disability are confirmed by some research showing how teachers’ perception about PWD is still largely negative and impacting on the possibilities of choice, participation, and autonomy for YAWDs (Pruett et al., 2008).

*Some teachers told me in the early years: “You can’t go to university because you have difficulties with STEM subjects (S)*

### ***Social system and policies***

This theme includes “benefits, structured programs and operations, in various sectors of society, designed to meet the needs of individuals” (WHO, 2001:192).

In the stories, social systems and policies represent both barriers and facilitators.

*The library for blind people has been very helpful; suggested by Dr B. and the local blind association (SP)*

*Since September I started working from mid-November because bureaucracy has slowed down... (A)*

Literature acknowledges that transition to adulthood is more than just a service approach as it involves a process of gradual adoption of new roles and modification of existing roles (King et al. 2006). It implies a lifelong and participatory approach focused on the inter-play between personal and social contexts and transforming YAWDs into active subjects, empowering them to participate in the design and assessment of their own needs (Pearson et al., 2021).

### ***Educational systems and policies***

In the stories, educational policies are relevant. They refer to the “education and training services, systems and policies”. These factors mainly appear as barriers, related to the inadequate designing attention.

A first feature is the use of standardized activities, mainly limited to the usual institutional proposals addressed to all students (e.g. selected university invitations and presentation at school) offered during the last year.

*There were several days dedicated to the universities to give a general presentation; while the presentations of individual courses were chosen and managed by the individual student (S)*

*The school has offered me, especially in the last few years, some internships to build my life after school...(A)*

Research emphasizes the importance of starting transition planning at the beginning of high school to accompany YAWDs in different experiences, even personalized ones, and to enable them through a gradual process of awareness (Izzo, Lamb, 2003).

A second aspect concerns the choice of activities and internships often determined not based on YAWDs' interests, needs, aspirations, but on previous experiences of other students and informal network of some teachers (Jacobs et al., 2018). What emerged proves the paucity of forms of personalization in the transition planning of A and S that lead these paths not to be significant (e.g. S's internship during the third/fourth year).

Morgan and Reisen (2016) argued that planning should not be limited to "a summary list of activities" (p. 107) but should consider numerous factors and a person-centered approach (Kaehne, Beyer, 2014). It requires that youths, parents, school, educators, and adult service professionals come together to match between YAWDs' skills, needs, preferences and the demands of the adult environment (McDonnell, Hardman, 2009). This confirms an often-limited awareness by both teachers and school. As emerged from the inquiry, this aspect often compromises the construction of a network of those stakeholders who, in various capacities and alongside the school, should be involved to support the transition and respond in a coherent and meaningful way to the needs, interests and aspirations of that YAWD.

S and A and their parents don't mention any assessment tools and instructional strategies, aspects for designing a functional and effective transition process (Test et al., 2009), specifically used for "gathering and analyzing information of knowledge, skills, needs, preferences and interests so that a student and the transition" (Morgan, Reisen, 2016: 82).

### ***Personal factors***

ICF personal factors are the background of an individual's life and the overall behavior pattern and psychological assets. In this research they refer to two dominant themes.

#### ***Choice, self-determination and participation***

Self-determination is the capacity to act as a primary causal agent able to make decisions for his/her life according to preferences, desires and values (Wehmeyer, 2005) promoting the active participation in the community life (school, work, local organizations, services, etc.) (Bianquin, 2020). According to an ecosystemic approach, self-determination implies both skills connected to the personal experience and the result of a dynamic relation to the whole factors which, in different ways, can affect self-determined action (Giraldo, 2020).

Decision making is one of the strongest themes according to S and A.

*I chose to go to university (S)*

*The work I am doing today is partly my choice and partly not (A)*

Self-determination is a critical element in achieving adult outcomes in the process of transition for students with disabilities (Foley et al., 2012): transition planning and program development should provide important opportunities to foster self-determination skills (goal setting, decision making, problem solving, self-advocacy, etc.) in YAWDs (Wehmeyer, 2005). Despite this, current research suggests that teachers are almost unfamiliar with this and the related instructional strategies to promote it (Grigal et al., 2003).

#### ***Psychological characteristics***

Psychological characteristics are crucial facilitators to overcome difficulties in the transition to adulthood (Sevak et al., 2017). Self-esteem, motivation, self-efficacy and locus of control

emerge by the students and parents' voices as the main individual features that helped S and A to address the transition process and related adult outcomes.

*I have always been quite obsessed in the sense that if I should do something, I have to do it at the best as possible (S)*

*He can adapt well to any situation, even the most difficult ones, and he can find the most suitable solutions (AP)*

Self-esteem and self-efficacy are crucial personal factors for achieving adult outcomes: they can be affected by both discriminatory attitudes experienced by PWD in various life contexts, in particular in the family and school, and unsuccessful and frustrating work or job search experiences (Noel et al., 2017). This has a negative impact on the PWD by limiting or preventing the transition to adulthood and the realization of his/her life plan.

It is essential to offer training courses, transition plans and vocational experiences to help students to acquire greater awareness of their limits/skills and to improve their self-efficacy and self-esteem.

## **Conclusion**

The paper presents the main results of the exploratory phase of STrADE project and highlights a range of complex issues still related to the transition to adulthood for YAWDs. The ICF framework permits to classify and analyze the contextual factors that characterize this life stage as well as facilitators/barriers, as emerged from the voices of YAWDs and their families. The narrative inquiry highlighted qualities and gaps connected to the transition to post-school confirming what literature underlined.

One of the strengths concerns the role assumed by some crucial actors emerging as facilitators: support teachers, health and social professionals, and, in particular, families. Personal factors, and specifically self-esteem, motivation and self-determination are essential for a successful transition. On the contrary, the critical points are mainly represented by environmental accessibility and products and technologies' availability and usability for both education and daily life (e.g. reasonable accommodation, transports). The research also underlined that systems and policies represent barriers, e.g. the lack of an effective network and collaboration between schools and adult services undermining the transition process, the achievement of adult outcomes and, in general, the right of educational and social inclusion.

The overall features resulting from the autobiographical stories recall that YAWDs' transition requires a personalized, participatory and lifelong planning supported by a shared methodological itinerary based on their life plan in respect to the PWD's characteristics and rights, the whole contexts and possibilities and the different dimensions and social roles of being adult.

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