

Individual planning starts at school. Tools and practices promoting autonomy and supporting transition to work for adolescents with autism spectrum disorder

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Abstract

There is an increasing need for effective services and strategies to favor the transition from school to post-school/working experience for individuals with disabilities and specifically with autism spectrum disorder (ASD). Post-school options are still limited, and most adults with ASD struggle in finding adequate and stable job opportunities. This work analyzes the increasing number of laws issued in Italy in the last decades in order to improve social and working inclusion. The central role of the individual educational planning (IEP) as part of the broader individual project is discussed. Also the potential of pathways for transversal skills and orientation for future employment outcomes is taken into consideration. Good practices promoting autonomy and supporting transition to work starting from school years are reviewed. The international literature shows different models and tools, which could be applied to the Italian school. The COMPASS consultancy model could favor the achievement of individualized transition IEP goals. Peer mediated intervention could improve social skills, a core weakness in ASD, though a central element for success in the workplace. Another key element is the parental involvement in the construction of the future of their children with ASD.

Key words

- individual educational planning
- transition outcomes
- peer mediated intervention
- autism spectrum disorder
- adolescence

DISABILITY AND ITALIAN EDUCATIONAL POLICIES

Since the 1970s, Italy has initiated a process of inclusion of students with disabilities in mainstream schools and abandoned segregated educational practices. This change begins with Law 517/1977 [1] which establishes the right of students with disabilities to attend common schools and introduces a new philosophy of integration. Social debate begins to focus on the principles affirmed by the Italian Constitution [2]: equal social dignity (article 3) and the universal right to education (article 34). Fifteen years later, Law 104/1992 [3] is approved: this law becomes the main regulatory frame of reference for disability and is focused on assistance, social integration and the rights of people with disabilities. It reaffirms the importance of social and school integration for the protection of the human dignity of individuals with disabilities. The State is considered responsible

for removing the obstacles to the individual's development and for providing (re)habilitative interventions. This law considers the individual educational planning (IEP) and the dynamic-functional profile (PDF) as the expression of the right to education of the person with disability. Therefore, Law 104/1992 [3] emphasizes the principle of individualization in education and learning. In 2014, the Italian Government starts a renovation of the educational system, following the directives of the Convention on the Rights of Persons with Disabilities (article 24) [4]. Legislative Decree 66/2017 [5] on inclusive education is adopted in Italy in April 2017. This decree applies to all children with a certified disability from nursery school to secondary school.

According to this decree, schools can achieve inclusive education through educational and didactic strategies aimed at developing the potential abilities and aptitudes of each person. It promotes the definition and



sharing of the individual project among school, family and other public and private subjects, operating in the local area. The decree considers the participation of the family as fundamental in the school and social inclusion processes. Educational inclusion was originally born to guarantee the right to educational success of children with disabilities and today it represents a fundamental value of the identity of the educational institutions.

Legislative Decree 66/2017 [5] reaffirms the role of the IEP as one of the main inclusion tools. The IEP identifies tools, strategies and methods to achieve an optimal learning environment in the following dimensions: relationships, socialization, communication, interaction, orientation and autonomy. It also contains educational and evaluation methods in relation to individualized programming and defines the tools for the actual realization of “school-work alternating system”. The IEP is co-constructed, according to the individual functioning profile, by the student’s class teachers, the family and the specific professional figures inside and outside the school. The IEP is an integral part of the broader Individual Project (Law 328/2000 [6]), developed by the local authority to tailor social and health services to the specific needs of the person with disability. Therefore, the decree considers inclusive education as part of a broader individual strategy aimed at promoting social inclusion and autonomy for people with disability. School is formally integrated as part of the life project of the individual, endorsing a life course perspective.

In this decree, there are two main points which may play an important role in promoting independent living and supporting transition to work. First of all, the integration of the IEP in the broader individual project might facilitate the planning of the abilities which will be necessary in the working environment and should be developed starting from the school phase. Secondly, the definition of specific and individualized strategies and tools for the success of the school-work alternating system, included in the IEP, may allow an initial contact with work contexts.

When requested by the individual with disability or his/her parents or legal guardian, the city council and the local sanitary district cooperate to create the Individual Project, aimed at the full inclusion of the person with disability in family and social life, as well as in educational and working pathways. The local authorities activate the individual project, according to the available resources, on the basis of a diagnostic-functional evaluation. The individual project includes several services, i.e. care and (re)habilitation services, direct and indirect economic measures aimed at overcoming poverty and, when necessary, at recovery and social inclusion. Support can also be provided for the family of the individual with disability. This important document can be defined and implemented with the contribution of specific professional figures (i.e. psychiatrist, psychologist, social worker in the case of mental disability) who cooperate in order to guarantee the continuity of the habilitative process, especially during critical phases through the life of the individual, such as the transitions from a school level to another, or from school to work.

School-work alternating system (Legislative Decree 77/2005 [7] and Law 107/2015 [8]) is an innovative education method, addressed to students of upper secondary schools, that allows them to “alternate” periods of training in the classroom and inside work contexts (i.e. companies). The law establishes the minimum duration of these periods of training, leaving to the school the decision on the possibility to extend their time.

Article 4 of the Legislative Decree 77/2005 [7] requires that working pathways for individuals with disabilities should be carefully tailored in order to promote their autonomy and to prepare them to enter the world of work. Moreover, article 6 of this law highlights the importance of evaluating and certifying the skills acquired by students with disability during the school-work alternating system, according to the principles of Law 104/1992 [3] in order to facilitate future employability. School-work alternating system has been recently renamed as Pathways for transversal skills and orientation (Law 145/2018 [9]).

The recent Legislative Decree 96/2019 [10] integrates and modifies Legislative Decree 66/2017 [5]. The new decree affirms the role of the multidisciplinary evaluation unit of the local health services, that elaborates the functioning profile (which integrates the previous functional diagnosis and the functional dynamic profile), together with the family and a special education teacher of the school. The functioning profile follows the criteria of the bio-psycho-social model of the International Classification of functioning, disability and health (ICF) of the World Health Organization (WHO) [11]. The IEP is now exclusively defined as part of the individual project, ratifying the role of the individual project as an all-inclusive document of the interventions designed for the life project of the person with disability. Additionally, this legislative decree clearly affirms the importance of the active participation of the student with disability during the development of the IEP, in line with the principle of self-determination. The inclusion process is now considered, even more than before, as the product of a network action between the different local institutions.

The creation and development of this network, together with a detailed and updated functioning profile, may represent an essential link between childhood/adolescence and adult age, facilitating the transition from school to work.

GOOD PRACTICE SUPPORTING TRANSITION TO WORK FOR STUDENTS WITH AUTISM SPECTRUM DISORDER

The prevalence of ASD reported by Fombonne [12], in an analysis of epidemiological studies published between 1966 and 2001 was around 36/10 000. Reviews of Fombonne [13], Charles, Carpenter, Jenner and Nicholas [14] and Rapin and Tuchman [15] show an increase in the prevalence of autism spectrum disorder (ASD): around 60-70 cases in 10 000 people. A global review [16] confirmed this data, establishing a prevalence of 62/10 000. This increase in the number of individuals with ASD leads to a need for more services, especially as this population becomes older. Post-school

options are still limited, and most adults with ASD struggle in finding adequate and stable job opportunities. Additionally, studies conducted in various countries (the US, the UK, Australia and Canada) [17-20] showed high rates of unemployment in ASD compared to other disabilities.

Bennett and Dukes [21] analyzed studies focused on teaching employment skills to secondary students with ASD between the ages of 14-22. They found few studies targeting job specific skill instruction and no studies targeting social abilities necessary for employment. Much of this research examined strategies to increase independent employment skills through self-management packages or video modeling with promising results [22-24]. Another study with encouraging results [25] described an intervention package comprised of behavior skills training and text message cueing. Additionally, highly preferred items were more effective than less preferred items as a maintaining variable of task completion [26]. Bennett and Dukes [21] concluded that the paucity of research on secondary special education programming applied to students with ASD may contribute to their poor employment outcomes.

In their systematic review, Hedley *et al.* [27] analyzed a number of studies that, overall, supported the use of technological aides and behavioral strategies in improving workplace skills in adults with ASD. Nevertheless, the large range of skills taught in the studies considered in this review and the reduced number of individuals involved limit the generalizability of these results.

An important point to address is the lack of evidence-based transition interventions to improve post-school outcomes and the absence of transition planning processes with empirical support [28]. Therefore, the need for studies of empirically-supported approaches for improving transition planning and outcomes for students with ASD is a critical issue, as observed by the Inter-agency Autism Coordinating Committee [29].

To help improve transition planning and outcomes, Ruble *et al.* [30] designed a randomized control trial (RCT). These authors adapted the Collaborative Model for Promoting Competence and Success (COMPASS) [31], a consultation intervention [32, 33] that has proved to be successful in improving achievement of goals in pre-school and elementary school. In this RCT, twenty teachers and 20 students and their parents participated; 11 dyads were assigned to the experimental group and 9 to the comparison group. The teachers in the comparison group received online training on three evidence-based practices in autism. The results showed that Individualized Education Program goal accomplishment was higher for students in the COMPASS group. This indicates that COMPASS was able to support teacher-student dyads to achieve transition goals.

Social and interaction deficits are a core aspect of ASD [34] and represent one of the main obstacles to community inclusion, including finding and maintaining a gainful job [35, 36]. Among the strategies used to improve social skills in ASD, Peer mediated intervention (PMI) is a promising practice that can be conducted in meaningful real-world contexts. In this approach, typically developing peers are taught effective strategies

to interact with and help children and adolescents with ASD gain social skills by increasing social opportunities. In their systematic review, Watkins and colleagues [37] analyzed fourteen PMI studies which included children and adolescents from preschool to high school age. Most of these studies showed that it is possible for children and adolescents with ASD to make significant changes in their social skills in inclusive settings as reported by parents, teachers, researchers, and children and adolescents themselves. Nevertheless, only few studies specifically targeted middle or high school age children. As the social context dramatically changes between elementary and high school, it would be important to establish specific guidelines for selecting peer buddies for adolescents with ASD.

HOW COLLABORATIVE MODEL FOR PROMOTING COMPETENCE AND SUCCESS CAN IMPROVE THE TRANSITION OUTCOMES

The international literature shows different models and tools, which could be applied to the Italian school. The COMPASS consultancy model could favor the achievement of individualized objectives as an integral part of the IEP. An extended application of the PMI could equip high school students, strengthening their weaker social skills, which are a central element for success in the workplace. The use of technological tools, such as video-modeling, could favor the acquisition of specific work skills, which could be implemented and tested in the pathways for transversal skills and orientation, during the last high school years.

These elements offered by international literature require more in-depth analysis. It will be important to design and conduct longitudinal studies analyzing the school-work transition and evaluating the effectiveness of the proposed models.

Ruble and colleagues provide a strong rationale for the importance of a collaborative approach to interventions in schools, for improving teaching quality and student learning and transition outcomes [30, 31]. The Compass is a manualized teacher-parent consultation intervention for students with autism that was translated and adapted in Italian context. There is a first step (Step A) of the consultation plan where the consultant meets the teacher and caregivers for obtaining a clear picture of the student with ASD thanks to Compass profile that includes questions about different domains: adolescent's strengths, preferences, fears, frustrations, adaptive functioning, problem behaviors, social and communication skills, and learning skills. In this first phase we added different instruments for identifying in the next step, IEP goals related to the social, communication, and work skills.

Both parents and teachers complete the Social Responsiveness Scale (SRS) [38], that is a 65-item rating scale measuring the severity of autism spectrum symptoms as they occur in natural social settings. The SRS provides a measure of the adolescent's social impairments, assessing social awareness, social information processing, capacity for reciprocal social communication, social anxiety/avoidance, and autistic traits.



The Italian form of the Vineland Adaptive Behavior Scales - Second version [39] is used to assess the adaptive functioning of the student with ASD. Three VABS skill domains are evaluated: communication (receptive, expressive, and written language skills), daily living (personal self-care, domestic living skills, and community living skills), and socialization (interpersonal skills, play and leisure, and coping skills). In order to ensure higher reliability, we prefer administering the interview form. The consultant interviews each participant's parent.

Teachers are asked to complete the Italian form of the ABAS-II [40] to assess the adaptive functioning of their students with ASD. Three ABAS-II skill domains are analyzed: conceptual (communication, functional academics, and self-direction), social (leisure, and social), and practical (community use, home living, health and safety, and self-care).

The TEACCH transition assessment profile (TTAP) is used to evaluate abilities for transition planning from school age to adolescence and adulthood [41]. TTAP test items cover the six functional areas of vocational skills, vocational behavior, independent functioning, leisure skills, functional communication, and interpersonal behavior, with an observation of the performance of students in several tasks, and with an interview for teacher and parents to evaluate abilities related to school and family context. For each ability it is possible to evaluate the performance of the student with a 3-point scale of P (pass), E (emerging), or F (fail).

In the Step B the profile is shared with teachers, parents and paraprofessionals and the aim of the meeting is to analyze the student's current personal and environmental challenges and the personal and environmental supports necessary for success. Then, the consultant, caregiver, and teacher prioritize goals, write measurable objectives, and develop the teaching plan and identify environmental supports for each objective [31-33]. A Goal Attainment Scale is created: the expected outcomes are defined on a 5-point scale from -2 (outcome much less than expected), -1 (less than expected), to 0 (expected outcome) to +1 (better than expected), and +2 (much better than expected). As reported in other studies [42], for vocational skills and vocational behavior, the consultant set the goals for each subject in the areas where the performance of the student is emerging.

The intervention consists of four 1-1.5 h coaching sessions conducted in-person at the school within the first and second semester of the school year.

The application of the COMPASS in the Italian context has shown promising results. After their experience with the COMPASS, most parents and teachers considered Step A very useful to define the objectives of the IEP. The definition of a detailed profile describing the abilities of the students in the different areas was particularly appreciated, as it allowed them to define the goals they wanted to achieve. Additionally, they found the analysis of environmental challenges and resources very useful for the planning of activities aimed at reaching the established goals. The main obstacles were the definition of the objectives according to the Goal Attainment Scale and the planning of the activi-

ties after defining the goals. The monitoring of goals can also be considered a critical point: teachers who are not used to being observed, for instance through video units, sometimes experienced the observation as a test instead of a way to think over the process together with the consultant.

In the Italian context, providing training for teachers on targeted intervention practices and on autism is particularly important, because support teachers do not necessarily receive a specific training on ASD and may not be experienced in working with individuals with this condition.

HOW PEER MEDIATED INTERVENTION CAN HELP THE STUDENTS WITH ASD TO ACQUIRE ABILITIES RELATED TO INDEPENDENT FUNCTIONING AND VOCATIONAL SKILLS

In the literature, peer-mediated intervention (PMI), a treatment approach in which classmates are trained to act as the intervention agents, has been demonstrated to be useful to promote social behavior and enhance scholastic achievement. Inclusive classroom environments may produce positive benefits to social development and adjustment of adolescents with autism. However, the simple exposure to peers' interactions is not sufficient to promote social skills in adolescents with autism, but highly structured training programs with systematic procedures are required.

The benefits of PMI also depend on the strategies used to choose peers. Previous research has provided some support for the use of sociometric status, but some risks need to be understood. Adolescents who engage in antisocial behavior may be popular in the classroom because of their social influence on peers. Hence, new strategies to identify peer buddies are reported.

We ask adolescents to provide their contact information if they are interested in learning what they thought about the possibility to help a peer with ASD in their classroom. Because first session is initiated, permission is obtained from parents. We think that the voluntary adhesion to the project is not enough to guarantee the effectiveness of the intervention program. It is important to evaluate the specific characteristics of peer buddies, to ensure that these are suitable for adolescents with ASD. For this reason, the introduction meeting is devoted to have a deep knowledge of students who want to become a peer buddy for a student with autism. We describe briefly the key variables that we evaluate and may be considered by scholastic psychologists and teachers when a peer mediated intervention is planned: mind reading abilities, prosocial behavior, and peer buddy nomination. We use the Reading the Mind in the Eyes' Test revised version [43], that is a standard test of advanced "theory of mind" which measures the ability to decipher mental states from 36 photographs of the eye region alone. Participants are required to select which of four complex mental state descriptors (one target word and three foil words) best describes the thoughts or feelings expressed by different individuals. Prosocial behavior, a construct that includes behaviors as helping, sharing, cooperating, and comforting, is

evaluated with the Italian version of Strength and Difficulties Questionnaire [44]. Peer Buddy Nomination is a technique where adolescents nominate three classmates they would “choose as a peer buddy” and three classmates they would “not choose as a peer buddy” to help the adolescent with ASD in the classroom. Students also circle the person that would make the “best peer buddy”.

We think that these constructs are very important because, as demonstrated in previous studies [45], the classmates's social use of their mind reading abilities is recognized by peers but using a measure of prosocial behavior we can analyze the social use of mind reading abilities and understand if the potential peer buddies employ these abilities for prosocial goals. After this phase of knowledge of the classmates, all students are trained in four training session. Each training session is conducted during scholastic period and lasted no more than 3 hours.

In the first session of training students are provided with a rationale for helping a student with ASD and guided in a discussion about “challenges and resources” asking students their strengths, preferences, fears, and frustrations, and the preference, strengths and areas of need of the classmate with ASD. The trainer uses video clip, books and slides to explain the characteristics of autism spectrum disorder. The aim of this phase is to help the classmates that all students have resources and areas of need.

In the second session, following Owen-DeSchryver *et al.* [46], we use the same five central themes, except for the fourth theme that was adapted for work abilities: 1) When can you share activities and talk to (name of the student) at school?; 2) What are some topics you can talk with him/her?; 3) What are some activities that you can do with him/her during the recess?; 4a) How can you help him/her learn to acquire a work skill during activities in laboratory (only for students that attend laboratories at school); or 4b) How can you help him/her learn a social or communication ability (the ability can be chosen thanks to Compass profile administered to parent and teacher); 5) What can you do if he/she doesn't cooperate and shows unusual behaviors?

After the discussion, the trainer shares potential techniques that can be used and facilitate a discussion on times that they can be involved in activities for helping the classmate with ASD. The purpose of this phase is providing meaningful opportunities for students to help the classmate with ASD.

In the third and fourth session, the aims of the training are to discuss any barriers and provide support to students as needed related to the difficulties that they meet during the activities.

The application of PMI in the Italian context [47] has shown that this model was very positively received by both teachers and classmates, who defined the intervention as useful and effective in improving social and communication abilities of students with ASD. The possibility of experiencing this intervention within the classroom was appreciated by students and teachers. In the same research study [47], classmates maintained they felt comfortable in the relationship with the

students with ASD and they enjoyed interacting with them, showing that PMI can be considered a successful strategy for inclusion.

HOW THE PARENTAL INVOLVEMENT CAN BE A SOURCE FOR THE TRANSITION OUTCOMES OF STUDENTS WITH ASD: THE SOCIAL COOPERATIVE GIUSEPPE GARIBALDI

A group of parents of high school students with ASD requiring very substantial support, who later founded the Social Cooperative Giuseppe Garibaldi, started their journey together while their children were attending the Agricultural High School “Istituto Tecnico Agrario (ITA) Giuseppe Garibaldi” in Rome. During high school, this group of adolescents with ASD experienced a school-based intervention aimed at improving working and social skills using behavioral strategies in a peer-mediated model [48]. This PMI intervention, monitored by the Department of Developmental and Social Psychology (“Sapienza”, University of Rome), laid the groundwork for the continuity of social and working inclusion during the transition from school to post-school experience.

An important goal of the scientific collaboration between the Department of Developmental and Social Psychology, ITA Garibaldi and Garibaldi Cooperative was to set up a network of services for the inclusion of the students with disability. The Province of Rome, the local sanitary districts, the Municipalities and the associations working for the adolescents with ASD attending ITA Garibaldi participated in the protocol which made the PMI intervention possible. This collaboration also allowed the activation of parent training and self-help interventions for parents and the monitoring of the specific objectives in each area of development indicated in the IEP.

Parents and children obtained the management of a part of the field of their former school ITA Garibaldi, thus they had the chance to develop the Cooperative, where the young adults with ASD, after graduating from high school, can maintain and keep developing the working and social abilities they had started to strengthen during the school years. The Cooperative is a real agricultural and agritourism enterprise. Half of its members are young adults with ASD requiring very substantial support. Together with their individual tutors, they sell agricultural food products in the city farmers markets and serve the tables in the Cooperative restaurant, which allows them to interact with their colleagues and with their clients every day. The creation of urban vegetables garden in the field managed by the Cooperative provides another chance of interaction and social inclusion in the local community. The Cooperative also receives students attending near schools for their pathways for transversal skills and orientation.

Monitored by the Department of Developmental and Social Psychology, the Cooperative has adopted an adapted version for young adults and working contexts of the COMPASS [31]. This model allows an individualized rehabilitative planning: the goals and the tactics to achieve them are tailored on the specific individual's

needs and abilities, considering her/his strengths and weaknesses, and regularly verified and updated. The participation of parents and tutors in the individual planning is a core element of the model. One of the main obstacles in the adaptation of the COMPASS in the working context of the Cooperative is the availability of tutors who are experienced and trained in working with adults with ASD. Specific training on ASD and on intervention practices is often necessary. The active participation in planning and monitoring the habilitative goals can also be challenging for some parents when individuals with ASD become adults.

KEY ELEMENTS ASSOCIATED WITH A REAL-LIFE PROJECT AND FAVORABLE TRANSITION OUTCOMES

This overview highlights the increasing need for specific services and shared strategies of proven effectiveness to favor the transition from school to post-school/working experience. From a legislative viewpoint, in the last decades, an increasing number of laws have addressed the themes of disability and inclusion in order to improve the quality of life of individuals with different disabilities in Italy. However, the actual school conditions do not always allow a full implementation of the legislation in the interest of the students with disabilities. We try to describe the key elements, in our experience, that are associated with favorable transition outcomes.

The first key element is the involvement of parents and teachers for evaluating strength and challenges and for defining transition outcomes of the student with ASD. We know that parents serve as key support for increasing abilities across life skills that continue long past school age, as reported by Rubles and colleagues [32], and teachers can be a source to teach learning objectives and life-skills. Following the COMPASS model, both parents and teachers are involved in the first phase of consultation, and the discussion on the profile allows the development of an individualized set of goals

for each student and a personalized teaching plan for each goal. Parents and the student, when possible, answer additional questions about post high school goals. Thus, plans are also generated for the achievement of post-school goals. After the first consultation, the consultant meets with the parents, the teacher and the student, when possible, for four coaching sessions to review data on the student's progress toward the goals and the tactics to accomplish the goals. Cooperative problem-solving on issues which may obstacle the goal achievement is also an important part of the model. If the students with ASD have the possibility to develop work abilities thanks to the design of high school internships they are more likely to be employed as adults, as reported by Schall *et al.* [49].

The second key element is the power of the classmates, because many activities can be done in general education settings where students with ASD can receive the help of classmates, if they are trained as peer buddies. The school setting can be a fertile ground where adolescents with ASD may experience social interactions in a positive way if structured procedures and training are provided to peers.

The third key element is the parental involvement in the construction of the future of their son or daughter with ASD. The experience of Cooperative Garibaldi is an example of how the individual project (Law 328/2000 [6]) can support an individual with disability, by creating a network among the available health and social services and integrating the specific tools accessible during each life phase. The individual project is also essential for the continuity of the habilitative process during life transitions.

Conflict of interest statement

The Authors declare that they have no competing interests.

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