# Diagnostic assessment, therapeutic care and education pathways in persons with autism spectrum disorder in transition from childhood to adulthood: the Italian National Ev.A Longitudinal Project

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**Abstract**
***Introduction.*** The transition from childhood to adulthood is one of the main critical points in the network of services for taking care of people with autism spectrum disorder (ASD). Within the framework of the national research programs on autism, an exploratory longitudinal multicentre study was conducted. This research program, called "Ev.A Project (Developmental and Adult Age)", was proposed by the Italian National Institute of Health (Istituto Superiore di Sanità, ISS) and the aim was the development and testing of a diagnostic, therapeutic, assistance and educational pathway (PDTAE) for autism.
***Aim.*** The present study aimed to evaluate two impact outcomes of the care protocol: the response obtained by the ASD person, and the perception of the change in the family context.
***Methods.*** Participants underwent an initial clinical evaluation and then after one year. Over the course of the year, participants undertook a program of intervention. The measures of adaptive functioning, need for support, psychiatric symptomatology and family quality of life were used for the outcome assessment. Linear mixed models were constructed for each measure to estimate the explanatory/predictive behavior of the intensity of the interventions, adjusted for the participant's level of symptom severity.
***Results.*** The results estimate a main effect of Intervention Group (b=-27.22, p<0.001) and severity level (b=-41.87, p<0.001) on the adaptive functioning of the ASD person, but no effect on performance on the dimension of Family Quality of Life (b=0.523, p=0.455).
***Conclusions.*** The most significant predictor of the impact on the ASD person is the activation of the service network, which must take into account the level of severity of the presented symptoms.

## INTRODUCTION

Autism spectrum disorder (ASD) represents an atypical and heterogeneous developmental condition that emerges early in life [1] but it has a life-long impact on an individual's development and adaptation [2]. Although there is an increasing competence of public mental health services in the early diagnosis and in structuring interventions to improve the treatment of the ASD person, the transition from developmental age to adulthood represents one of the main critical

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issues of the service network in caring for people with ASD.

The term "transition" generally refers to a planned and targeted process that addresses the needs of ASD young people (from the age of 16-18 years) holistically in the passage from a child to an adult-oriented health care system [3]. The number of ASD services decreases from childhood to adulthood and continues to decline into late adulthood, while the use of drugs and hospitalisation services increases [2, 4, 5]. Moreover, the transition from developmental age to adulthood represents a period characterised by significant changes in neurobiological and behavioral development [3] in which adolescents and young adults experience so-called "developmental challenges", such as the transition to secondary education, the conclusion of schooling, the access to employment, the acquisition of personal autonomy and the development of friendships and intimate relationships. These changes that occur during development are also made difficult by social interaction deficits [6], which become more evident with reaching adulthood, an age in which a person should achieve more independence.

Although the literature focusing on transition is still scarce, some studies emphasize that, at this stage, services should set a central objective to support adolescents with ASD in learning to "function as adults" [7, 8]. This aspect is of relevance as people with ASD show persistent impairments as well as regressions in functional and adaptive abilities in adulthood and high rates of mental health problems [5, 8, 9]. Moreover, they show a lower rate of independent living and employment opportunities [3, 10] and impairments in social cognition skills necessary for good social interactions, friendships and relationships [7, 11]. These aspects also appear to be associated with the severity of autism [12]. Generally, terms such as "high" and "low" functioning are used to define the symptom profile of persons with ASD. However, research supports the attribution of ASD severity by means of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), made based on the "intensity of support needs", differentiating into 3 severity levels (Level 1, 2 and 3) and considering impairments for social communication and restricted/repetitive behavior [1]. Analysing the support needed emphasises the impact of person-environment interaction, which is relevant for people with ASD who may be affected by the environmental context [13]. The severity level based on the intensity of support needs provides a picture of the ASD person's functioning, taking into account variables such as behavioral problems of cognitive and adaptive functioning, comorbidities and variables related to the context and environment. In fact, a worse transition outcome has a broader impact and is not only experienced by the person with ASD but also by their relatives who provide continuous support from adolescence to adulthood. Several studies show that caregivers of adults with ASD have more depressive symptoms, worse health, and lower functional capacity, leading to a negative impact on quality of life [14]. Based on these considerations, a successful transition should also be based on how relatives perceive this process and its outcomes.

There is a growing recognition of the need for expertise and resources to provide accurate clinical assessment appropriate for adulthood, as well as appropriate intervention services for persons with ASD of all ages from a developmental perspective [3]. Currently, in Italy, the National Institute of Health (Istituto Superiore di Sanità, Italy) is working on national guidelines concerning the diagnosis and treatment of adults with ASD by existing legislation (national law on autism n. 134 of August 18, 2015, guidelines approved by the 2018 State-Regions Conference). Furthermore, guidelines are also available in the international context, such as in the USA, the UK and New Zealand, to improve access and involvement in interventions and services for persons with autism [15-18]. It is interesting to note that the different guidelines share the evidence that the transition care should start as early as adolescence and continue beyond the day of leaving the pediatric services and the involvement of all figures responsible for the well-being of the person with ASD.

Based on these premises, the present study was conducted as part of a larger multicentre project, namely the Ev.A Project (from developmental age to adulthood) proposed by the Italian National Institute of Health, commissioned and founded by the Ministry of Health, within the implementing framework of the national law on autism n. 134 of August 18th, 2015, and officially joined by the regions of Piedmont, Valle d'Aosta, Tuscany, Abruzzo, and the Autonomous Provinces of Trento and Bolzano. The general purpose of the Ev.A Project was the development and testing of a diagnostic, therapeutic, assistance and educational pathway (PDTAE) for autism, from the age of development to adulthood and the relative procedures and preparatory actions for its implementation. In particular, the PDTAE addressed the efficient and effective planning and management of the transition phase between adolescence and adulthood in ASDs.

Specifically, the present study aimed to assess the outcome by taking into account two levels of impact of the caring protocol: 1) the impact on the perception of the response obtained by the ASD person and 2) the impact on the perception of the change in the family context. Therefore, the study was conducted to assess the possible impact of the activation of the service network on young ASDs and the family context. For this purpose, the participants were divided into two groups based on the interventions activated during the trial, and measures of adaptive functioning, need for support, psychiatric symptomatology, and family quality of life were used for the outcome assessment.

## METHODS
### Participants and procedure

139 individuals with ASD and aged between 16 and 25 years participated in the study. The diagnosis of ASD was formulated by experienced clinicians according to the criteria of the DSM-5 [1], using the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) [19] and the Childhood Autism Rating Scale, Second Edition – Standard Version (CARS 2-ST) [20] for ASD individuals with communication

difficulties and intellectual disability. All participants with ASD were classified as Level 1, Level 2, or Level 3 according to DSM-5 criteria. An exploratory, pre-post treatment longitudinal study was conducted in which participants underwent an initial clinical evaluation (T0) and then after one year (T1). Over the year, the participants undertook a therapeutic and intervention pathway in collaboration with different services and institutions (health, social welfare, education, and training) involved in the clinical management of the patient in the transition phase.

At the beginning of the project (T0), participants underwent a cognitive assessment by Wechsler Adult Intelligence Scale, Fourth Edition, Italian version (WAIS-IV) [21, 22], and Leiter International Performance Scale, Third Edition (Leiter-3) [23], based on the ASD participants' language abilities. The inclusion criterion was the availability of pre (T0) and post (T1) observations and several missing values in the pre- and post-measurements not exceeding 10%. Thus, the final sample consisted of 112 subjects with a mean age of 20.05 years (SD=2.71) of which 89 were male and 23 female (*Table 1*).

All participants or their legal tutors (parents or others), when necessary, gave informed consent to participate in the study. The study was conducted according to the Declaration of Helsinki and the rules of good clinical practice and ethics in public mental health services.

### Therapeutic and intervention pathway

In the Ev.A Project, an individualised life plan was developed for each person involved based on the diagnostic process and support needs.

The treatment and intervention pathways in the PDTAE included:
- *medical-psychiatric interventions*: consultations and follow-up visits to monitor any psychiatric comorbidities and any pharmacological therapies;
- *psychological-psychotherapeutic interventions*: psycho-educational counseling of family members, teachers, and other caregivers; supportive interviews (acceptance/awareness of the diagnosis), individual cognitive-behavioral psychotherapies for the treatment of anxiety and/or depressive symptoms, social skills training groups; neuropsychological skills enhancement;
- *educational interventions*: for persons with intellectual disability, it concerns the cognitive enhancement and promotion of personal and domestic autonomy, and basic social skills through the use of structured educational strategies; for persons with good cognitive functioning or mild intellectual disability, it concerns the enhancement of emotional-social and communicative pragmatic and self-regulation skills;
- *social welfare and social inclusion interventions*: coordinated by the social worker, with the aim of providing the person with an experience of social inclusion, within everyday social contexts and typical functioning peer groups, by accompaniment of the person by a trained worker (e.g., "adult buddy"); in the school setting, provide for the involvement of trained peers (peer-mediated education);
- *employment interventions*: training courses aimed at occupational guidance, employability assessment, and professionalization;
- *parent-training and sibling programs*: they aim to create a space for emotional sharing, to make parents as aware as possible of their adolescent or young adult child's difficulties and abilities. They provide information on psycho-educational aspects and the implementation of intervention techniques. Siblings can also present different forms of psychological distress, so through group meetings with other siblings it is possible to share experiences and emotions in a protective and pleasant context.

The *Table 1S* available as *Supplementary Material* shows the percentages of activated interventions for the total sample.

### Outcome measures for ASD person
#### Adaptive functioning

The Adaptive Behaviour Assessment System-II (ABAS-II) [24] and the Vineland Adaptive Behavior Scale II (VABS-II) [25] were used to assess the adaptive functioning of participants with ASD. Both measures are interviews with caregivers and assess the person's adaptive behavior, i.e., the activities habitually performed to meet expectations of autonomy and social responsibility. The scales investigate 4 domains respectively: communication/conceptual (expressive and receptive language skills, school skills), daily life (self-care, life at home, community) social (socializing, leisure), and motor skills. Only three domains were used in the study (communication/conceptual, daily life, and social). Both measures provide a standard score (M=100, SD=15) and a higher score indicates better functioning. In the course of the trial, the participating regions used both measures. For the study, as the measures assess the same construct (adaptive behavior) and domains, providing a standard score of equal magnitude, they were considered as a single index of adaptive functioning in the analysis.

**Table 1**

Mean scores of clinical and cognitive data of ASD (autism spectrum disorder) participants

|  | Mean (SD) |
|---|---|
| Chronological age | 20.05 (2.71) |
| Gender (F; M) | 23; 89 |
| **ADOS-2 MODULE 4** | |
| SA | 12.22 (4.04) |
| RRB | 2.06 (1.69) |
| Total | 12.22 (4.04) |
| **CARS 2-ST** | 33.39 (6.54) |
| **Total IQ** | |
| Verbal IQ | 83.78 (24.79) |
| Non verbal IQ | 71.57 (27.77) |

SA: social affect; RRB: repetitive and restricted behaviors; Total: total ADOS-2 score.

*Support intensity scale*

The Support Intensity Scale (SIS; Thompson *et al.*) [26] is a semi-structured interview with caregivers useful for assessing the support needs of persons with intellectual disabilities in medical, behavioral, and living activities. The scale consists of 49 items on life activity support needs and is divided into six subscales: home life activities, community life activities (e.g., going shopping) learning activities, work activities (e.g., learning and using specific work skills), health and safety activities (e.g., taking medication) and social activities (e.g., socializing within the family).

The items are scored on a 5-point scale about frequency (0=none or less than once a month; 1=monthly; 2=weekly; 3=daily; 4=hourly), daily support time (0=none; 1=less than 30 minutes; 2=between 30 minutes and 2 hours; 3=between 2 and 4 hours; 4=4 hours or more) and type of support (0=none; 1=monitoring; 2=verbal or gestural prompting; 3=partial physical assistance; 4=full physical assistance). The subscale scores are obtained by summing the ratings of frequency, daily care time, and type of care and transformed to obtain the standard scale scores. Finally, the standard scale scores can be converted into a Support Needs Index. A higher score indicates a greater need for support.

*Psychiatric symptomatology*

The Brief Psychiatric Rating Scale Version 4.0 (BPRS 4.0) [27, 28] is a semi-structured interview containing 24 items, translated into Italian by Morosini and Casacchia [29] that assesses 24 psychiatric symptoms. The presence and severity of psychiatric symptoms are assessed on a Likert scale with a range from 1 (no symptoms) to 7 (extremely severe symptoms). The final score ranges from a minimum of 24 to a maximum of 168, with lower scores indicating less psychopathological severity.

### Outcome measure in family

Family quality of life was assessed through the administration of the Italian translation of the Family Quality of Life Survey - 2006 (FQoLS) [30], named Strumento d'Indagine della Qualità di vita della Famiglia (SIQF). It is a questionnaire composed of 9 domains covering specific areas of family life, such as health, economic well-being, family relationships, support from others, support from services, the influence of values, career, time for oneself, fun, and integration in the community. Each domain contains two sections: section A, which contains questions that gather some general information and provide context, and section B, which contains questions on six key concepts: importance, opportunity, initiative, achievement, stability, and satisfaction. The items in section B are rated on a 5-point Likert-type scale from 1 to 5, where 1 expresses "not at all" and 5 "very much". The overall QoL scores are calculated by weighting the satisfaction scores with the importance scores [31]; thus, the maximum QoL score results from the maximum importance value and the maximum satisfaction value; the minimum score, on the other hand, results from the maximum imbalance, i.e., the highest importance value and the lowest satisfaction value in a range between -10 and +10.

### Statistical analysis

For the analysis and given the sample size, treatment intensity was categorized using the maximum value of the frequency distribution of activated treatments during the study (i.e., at least 3 activated interventions). In this way, two groups were formed: Group 1 (n=49; 40 males and 9 females) with 3 or more activated interventions and Group 2 (n=63; 49 males and 14 females) with less than 3 activated interventions.

Firstly, an exploratory univariate analysis (t-test paired samples) was used to explore whether there were any differences in performance on the measures considered between T0 and T1 for the two groups.

Secondly, linear mixed models (SIS) were constructed given the longitudinal nature of the experimental design, taking into account confounding variables (number or intensity of intervention and level of severity). For each model, the probability of introducing a random slope along with the random intercept was analyzed to estimate the random effects; the fitting of the model was assessed using the Wald Test. To assess the impact of the caring protocol, we included the symptom severity of the ASD participants in the analysis in addition to the intensity of the intervention. Examining the influence of the level of severity on the basis of the required support according to the DSM-5 has implications for clinical and research practice in treatment planning, activation of necessary services and the prognosis of the ASD person. So, the models estimated the explanatory/predictive behavior of the intensity of the interventions on the outcome measures considered, adjusted for the participant's level of symptom severity (DSM-5). The effect of the interaction between the intensity of the activated intervention and the level of severity was also estimated (see *Table 2S* available online as *Supplementary Materials)*.

Analyses were conducted using STATA (version 17.0).

## RESULTS

### Differences in outcome measures between time points

About measures directed at the ASD person, t-test paired samples revealed only a significant reduction in SIS scores in Group 1 (t(48)=2.26, p=0.026). No significant differences emerged in Group 2. Regarding the family context, the results also show no significant differences in the SIQF within the two groups. Results of t-test paired samples are reported in *Table 2*.

### Outcomes linear mixed models
*Adaptive functioning*

About the impact on the ASD person, the results obtained from the LMMs show ($\chi^2_{df=5}$ = 50.49, p<0.001) a main effect of treatment intensity (β=-27.22, p<0.001) and severity level on adaptive functioning, in particular, level 3 appears to have a significant influence (β=-41.87, p<0.001).

The adjusted multivariate analysis supports the conclusion that belonging to the group with a lower intervention intensity (<3), presents a worsening of adaptive abilities compared to the group with a higher intervention intensity; this change is also explained by the Level of severity ranging from 2 to 3, compared to Level 1.

**Table 2**
Mean scores and comparison between the two time points (T0 and T1) of outcome measures in the two groups

|  | Group 1, three or more interventions (n=49) | | | | Group 2, less than three interventions (n=63) | | | |
|---|---|---|---|---|---|---|---|---|
|  | Mean (SD) T0 | Mean (SD) T1 | t | *p* | Mean (SD) T0 | Mean (SD) T1 | t | *p* |
| Adaptive index | 64.79 (28.22) | 68.60 (31.49) | -1.82 | 0.075 | 49.95 (23.93) | 50.79 (25.86) | -0.498 | 0.621 |
| Comunication skills | 68.53 (24.63) | 70.87 (25.67) | -1.36 | 0.179 | 55.84 (23.69) | 57 (24.44) | -0.643 | 0.621 |
| Daily life skills | 71.09 (27.66) | 72.74 (27.96) | -0.992 | 0.372 | 67.51 (22.02) | 67.90 (22.72) | -0.297 | 0.768 |
| Socialization skills | 62.60 (21.98) | 64.87 (23.6) | -1.72 | 0.091 | 49.46 (22.86) | 48.80 (24.14) | 0.358 | 0.721 |
| SIS | 87.21 (18.94) | 83.69 (19.16) | 2.26 | **0.028** | 87.87 (15.19) | 85.97 (15.42) | 1.58 | 0.119 |
| BPRS | 49.48 (15.65) | 47.21 (17.22) | 1.81 | 0.076 | 47.07 (16.86) | 44.92 (17.21) | 1.47 | 0.147 |
| SIQF | 1.76 (2.66) | 2.22 (2.33) | -1.14 | 0.260 | 1.69 (2.27) | 1.76 (2.52) | -0.310 | 0.758 |

Significant differences (p<0.05) are reported in bold. Group 1: group with more than 3 interventions activated; Group 2: group with less than 3 activated interventions. SIS: Support Intensity Scale; BPRS: Brief Psychiatric Rating Scale; SIQF: Strumento d'Indagine della Qualità di vita della Famiglia (Family Quality of Life Survey).

Analyzing the components of the adaptive index communication/conceptual skills, practical/everyday life skills, and social skills), the results show that belonging to the group with lower intervention intensity significantly predicts a worsening of communication/conceptual skills ($\beta$=-22.05, p=0.001), daily life skills ($\beta$=-13.64, p=0.021) and social skills ($\beta$=-22.34, p=0.001) compared to belonging to the group with higher intervention intensity (see *Table 3*).

There is also a main effect of severity level, in particular, presenting a severity Level 3 significantly predicts lower scores in communication/conceptual skills ($\beta$= -35.78, p<0.001), daily life skills ($\beta$=-46.94, p<0.001) and social skills ($\beta$=-20.30, p=0.007) compared to severity Levels 2 and 1. However, these changes do not seem to be explained by the interaction between severity level and intervention intensity (*Table 3*).

*Psychiatric symptomatology*

The LMM results show a main effect of severity level on the possible change in psychiatric symptomatology over the course of the trial. Specifically, the results show that Level 3 influences the increase in score on the BPRS compared to Level 1 symptomatology ($\beta$=15.17, p=0.004). It would appear, on the other hand, that membership in the intervention group does not significantly influence the possible change in symptoms ($\beta$=0.569, p=0.907). The interaction between the intervention group and the level of severity also did not appear to be significant (*Table 3*).

*Support index*

A main effect of both intervention group membership and severity Level 3 ($\beta$=32.611, p<0.000) on the need for support is shown. Specifically, the results show that belonging to the group with the lowest intervention intensity ($\beta$=10.364, p=0.007) requires more support. It would also appear that presenting a severity Level 2 ($\beta$=22.719, p<0.000) or 3 ($\beta$=32.611, p<0.000) influences the increase in the support index in comparison to participants with Level 1. The results also show a significant influence of the interaction between the intervention group and severity level; participants with Level

2 and belonging to the group with lower intervention intensity would show a decrease in the score on the SIS scale ($\beta$=-15.51, p=0.003) (*Table 3*).

***Outcome LMM in quality of life of family***

The fitting of the model does not reach statistical significance ($\chi^2_{df=5}$=4.36; p=0.498) and the predictors are not statistically significant (see *Table 3*). The model does not provide evidence for a predictive role in the perceived quality of the family about the intervention, the level of severity as well as about any interaction between severity and the intervention administered.

**DISCUSSION**

Awareness of the importance of establishing pathways for clinical assessments and providing appropriate intervention services for adults with ASD has increased in recent years; however, the transition from childhood to adulthood represents one of the main critical points in the network of care services for people with ASD.

This study examines the impact of a large multicentre project, namely the Ev.A Project, on the outcome of the ASD person and family context. Specifically, the general aim of the research program was to develop a protocol of evaluative and diagnostic instruments focused on the general functioning of the ASD person in order to estimate the impact of the activation of rehabilitation services both on the individual and on the quality of life of the family context.

During the project's experimental phase, different interventions for participants with ASD and their families were planned and implemented in cooperation with territorial institutions, such as health, social welfare, education, and training services. Our analyses examined the outcome of individual participants with ASD and the family context, that were divided into two groups based on the number of interventions activated. In addition, we estimated the explanatory/predictive behavior of the intensity of the interventions on the measures considered, adjusted for the participant's level of symptom severity, and estimated the effect of the interaction between the intensity of the activated intervention and the level of severity.

**Table 3**
Outcome LMM (linear mixed model) in ASD (autism spectrum disorder) person and in quality of life of family
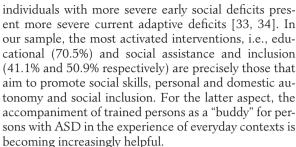
| | Adaptive index | | | Comunication skills | | | Daily skills | | | Social skills | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | β | SE | p | β | SE | p | β | SE | p | β | SE | p |
| **Predictors** | | | | | | | | | | | | |
| Intervention group | -27.22 | 7.35 | **<0.001** | -22.05 | 6.71 | **0.001** | -13.64 | 5.92 | 0.021 | -22.34 | 6.94 | **0.001** |
| Severity level | *Reference* | | | | | | | | | | | |
| *Level 2* | -23.97 | 7.75 | **0.002** | -18.91 | 7.10 | **0.008** | -25.59 | 6.24 | **<0.001** | -11.06 | 7.32 | 0.131 |
| *Level 3* | -41.87 | 7.98 | **<0.001** | -35.78 | 7.31 | **<0.001** | -46.94 | 6.43 | **<0.001** | -20.30 | 7.54 | **0.007** |
| Group Intervention*severity level | | | | | | | | | | | | |
| *Group 2 x Level 2* | 14.25 | 10.11 | 0.159 | 11.03 | 9.27 | 0.234 | 13.54 | 8.15 | 0.097 | 10.90 | 9.55 | 0.254 |
| *Group 2 x Level 3* | 18.20 | 11.14 | 0.102 | 14.51 | 10.23 | 0.156 | 11.61 | 9.00 | 0.197 | 14.40 | 10.54 | 0.172 |
| *Wald Chi² Test* | $\chi^2_{df=5}$ = **50.49; p<0.001** | | | $\chi^2_{df=5}$ = **43.32; p<0.001** | | | $\chi^2_{df=5}$ = **86.42; p<0.001** | | | $\chi^2_{df=5}$ = **19.42; p=0.001** | | |

| | SIS | | | BPRS | | | SIQF | | |
|---|---|---|---|---|---|---|---|---|---|
| | β | SE | p | β | SE | p | β | SE | p |
| **Predictors** | | | | | | | | | |
| Intervention group | 10.36 | 3.84 | **0.007** | .56 | 4.89 | 0.907 | 0.523 | 0.700 | 0.455 |
| Severity level | | | | | | | | | |
| *Level 2* | 22.71 | 4.05 | **<0.001** | 15.27 | 5.09 | **0.003** | .857 | 0.738 | 0.245 |
| *Level 3* | 32,61 | 4.17 | **<0.001** | 15.17 | 5.25 | **0.004** | 1.20 | 0.759 | 0.112 |
| Group Intervention*severity level | | | | | | | | | |
| *Group 2 x Level 2* | -15.51 | 5.29 | **0.003** | -7.12 | 6.59 | 0.280 | -0.788 | 0.957 | 0.410 |
| *Group 2 x Level 3* | -8.92 | 5,82 | 0.126 | 3.00 | 7.27 | 0.679 | 1.866 | 1.05 | 0.076 |
| *Wald Chi² Test* | $\chi^2_{df=5}$ = **100.09; p<0.001** | | | $\chi^2_{df=5}$ = **25.14; p<0.001** | | | $\chi^2_{df=5}$ = 4.36; p=0.498 | | |

*Interaction between the intensity of the activated intervention and the level of severity; significant differences (p<0.05) are reported in bold.
SIS: Support Intensity Scale; BPRS: Brief Psychiatric Rating Scale; SIQF: Strumento d'Indagine della Qualità di vita della Famiglia (Family Quality of Life Survey).

Our results showed that both the activation of rehabilitation services and the level of severity predicted the support the individual needs in daily life. In fact, the activation of more interventions and, consequently, a more comprehensive approach would seem to improve the person's autonomy. However, it must be considered that the type and intensity of support the ASD person needs varies according to the level of severity as defined by the DSM-5 [1]. Furthermore, the interaction between the intervention group and severity level was found to be significantly predictive of the intensity of the support needs, showing that ASD persons with severity Level 2 who received fewer interventions would have a lower need for support in daily life. Although this result could be considered counterintuitive, it could be traced back to the clinical characteristics of Level 2. Compared to Level 1, which is generally attributed to the so-called "high functioning", and Level 3, which includes the most severe degree of autistic symptomatology, ASD persons with Level 2 generally exhibit emerging abilities that need to be acquired, as well as greater variability in clinical presentation. We believe that this result can be interpreted as an incentive to intensify intervention since the activation of some services already shows a trend toward a perceived improvement in the family's need to support the person.

The level of severity and intensity of the intervention also appears to influence the adaptive behavior of the ASD person. As we expected, the group with fewer interventions would present lower abilities in all domains of adaptive behavior, i.e., in communication, daily life and socialisation abilities. Moreover, people with Level 3 would show almost twice as much impairment as Level 2 in adaptive functioning, particularly if we take social skills into account. Adaptive behavior is defined as the extent to which a person is able to be self-sufficient in real-life situations, including the functional use of communication, socialisation, daily living and motor skills [8, 25]. Our findings are in line with evidence in which continuity of services and interventions appear to be crucial in ASD persons, in whom regression of adaptive abilities in the transition phase is not uncommon [8, 32]. The acquisition of adaptive skills in young adults with autism is largely dependent on their inclusion in intensive and routine rehabilitation programs and the stabilisation of daily life routines [8]. This would be of particular importance for ASD persons with Level 3 severity, in which according to DSM-5 criteria, they present severe deficits in communication and social interaction, as well as resistance to change and repetitive behavior that significantly interferes with general functioning. This may be especially true for social skills, as

individuals with more severe early social deficits present more severe current adaptive deficits [33, 34]. In our sample, the most activated interventions, i.e., educational (70.5%) and social assistance and inclusion (41.1% and 50.9% respectively) are precisely those that aim to promote social skills, personal and domestic autonomy and social inclusion. For the latter aspect, the accompaniment of trained persons as a "buddy" for persons with ASD in the experience of everyday contexts is becoming increasingly helpful.

In the assessment of psychiatric symptomatology evaluated by BPRS, in which scores are taken from direct observation of the person, the results show that the increase in psychiatric symptomatology is associated with the severity of the level, independently of the intensity of the intervention. Although psychiatric symptoms are common in young ASDs, at a significantly higher rate than in non-autistic populations [5, 35], this result confirms the importance of monitoring psychiatric symptomatology even in lower-functioning ASDs, as it would appear that both lower IQ and adaptive functioning are risk factors in obtaining higher scores on psychiatric scales [36].

Our analysis shows that psychological-psychotherapeutic interventions account for 63.4% and psychiatric and pharmacological interventions for 61.6% and 15.2% respectively. Pharmacological and psychiatric interventions seem to be more frequent in Level 2 and 3 participants and less so in Level 1 (7.9%), while psychological-psychotherapeutic interventions are, as one would expect, more frequent for Level 1 and 2 people (84.2% and 66.6% respectively) and less so for Level 3 (31.03%). We also analysed the perceived quality of life in the family context. Our results show that there are no perceived changes in this dimension, and it does not seem to be influenced either by the intensity of the support from the intervention or by the level of severity presented by the ASD person.

During the trial, parent-training programs were activated for 53.6%, while programs including siblings were activated for only 9.8%. Parents in our sample perceive the quality of life as problematic (*Table 2*) [37]. This result is in line with existing literature, showing that families often perceive an imbalance between the degree of importance and satisfaction in specific areas of family life, such as health, economic well-being, family relationships, support received from the social context and services, as well as personal values, career, time for oneself and community and leisure activities [14, 38]. Parents are usually directly responsible for the ASD person and experience negative transition outcomes, face ongoing challenges that may affect their family life and require support to achieve a better quality of life [14, 38]. Many families require transition planning to adulthood with increased support for social skills, life skills training and employment support. Currently, the literature regarding the transition phase of ASD persons is scarce, but it points out that a greater understanding of risk and protective factors at the level of families is needed to develop and plan a functional transition [14]. Although we are aware that 12 months is a short timeframe in which to perceive changes in an

intervention, quality of life assessment in clinical practice would also make it possible to identify needs, plan interventions and mobilise resources in the most useful way to increase satisfaction in the most important areas of people's lives.

To date, few evidence-based services exist to support people with ASD in the transition phase and the literature on this is developing slowly [18, 39]. Despite this, intervention programs for people with ASD in transition age that focus on adaptive skills, social skills, and self-determination, as well as programs that specifically target work and university employment are also proposed in the international landscape [18, 39, 40]. To our knowledge, the Ev.A Project represents one of the first studies in assessing the impact of care protocol on people with ASD and caregivers in the transition phase including all levels of severity of the condition. Furthermore, our results seem to support and be in line with the international scenario. In fact, many of the available documents (UK, USA, Australia) recommend planning and coordination of the transition at least from the end of adolescence (12-14 years), that each young ASD has a "named worker", involvement of family members, sharing of information with the general practitioner, creation of a 'transition team' involving children and adult services [18].

In conclusion, our results suggest that one of the most significant predictors of the impact on the ASD person is the activation of the service network, which must take into account the level of severity of the presented symptoms and support the idea that intervention planning should be based on evidence. However, the study is not without limitations. Except for the BPRS, the outcome measures used for the assessment of adaptive behavior (ABAS-II and VABS-II) and the need for support (SIS) represent indirect measures of the ASD person, as they represent information reported by the parents.

With regard to our sample, there is a predominance of the male gender, however, this is characteristic of the clinical condition [8]. In addition, the participants came to the care services consecutively, so it was not possible to carry out a gender balance. The PDTAEs were activated by the territorial structures and services of each region that participated in the Ev.A Project through organisational practices already in use (e.g., the transition to the Multidisciplinary Disability Assessment Unit). Consequently, each participant is subject to more than one intervention within the PDTAE. So, no analysis was conducted to assess the effect of the type of intervention proposed to the participants, as the effect (improvement or worsening) could be associated with one intervention rather than another.

Future studies should take these aspects into account controlling for the variables just mentioned. This would make it possible to analyse possible gender differences and the effectiveness of the type of intervention on the outcome of the ASD person. A strength of the present project is that it included all three levels of severity, considering that many existing studies do not include persons with intellectual disabilities. We believe that our results provide an important contribu-

tion to the scenario of the care and management of people with ASD, highlighting how the activation of the network of territorial services represents the main predictor in the improvement of the symptomatology and functional abilities of the ASD person. Communication between child and adult services is in fact one of the main components in the planning and coordination of the transition phase, but it does not disregard direct work with people with ASD, carers, and their support network.

### Authors' contributions

MV, MM, GMA, and RK conceived the study, designed the research protocol, and drafted the manuscript; FM and ILD analyzed the data and gave a substantial contribution to the manuscript; GR and MLS coordinated the project data collection protocol and gave a substantial contribution to the manuscript.

### Conflict of interest statement

The Authors declare no conflict of interest.

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