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Aldo Diavoletto
Unit Operational Neuropsychiatry Childhood Adolescence (UONPIA) Salerno, ASL Salerno, Via ML King SNC, Salerno, 84100 Italy

Franca Bottiglieri
Unit Operational Neuropsychiatry Childhood Adolescence (UONPIA) Salerno, ASL Salerno, Via ML King SNC, Salerno, 84100 Italy

Marianna Sessa
Unit Operational Neuropsychiatry Childhood Adolescence (UONPIA) Salerno, ASL Salerno, Via ML King SNC, Salerno, 84100 Italy

Anna Tortorella
Unit Operational Neuropsychiatry Childhood Adolescence (UONPIA) Salerno, ASL Salerno, Via ML King SNC, Salerno, 84100 Italy

Corresponding Author:
Aldo Diavoletto
Unit Operational Neuropsychiatry Childhood Adolescence (UONPIA) Salerno, ASL Salerno, Via ML King SNC, Salerno, 84100 Italy

Critical issues and methodologies of transition in autism spectrum disorders: A literature review

Aldo Diavoletto, Franca Bottiglieri, Marianna Sessa and Anna Tortorella

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Abstract
Background: This paper summarizes the operational and cultural challenges and challenges of transitioning responsibilities from child and adolescent services to adult services for autism. Challenges related to services and patient characteristics frequently lead to discontinuity of care during this phase, despite the significant intensity of clinical and care needs. It appears that there is a real risk of patients leaving the care system.
Purpose: The authors describe the transition modalities for patients with ASD from child care to adult care, highlighting their clinical and care characteristics. Methodologies shared in the literature are also presented.
Results: Individuals with ASD in transition are at increased risk for several comorbidities and should maintain continuity of care, with appropriate and necessary interventions. Many adults with autism or their families express a desire for independent living, academic or work integration, and social relationships, but often lack the skills and/or resources to successfully achieve these outcomes. Recent literature confirms the organizational and methodological challenges that hinder the transition from childcare to adult services, highlighting possible solutions and shared methodologies.
Conclusions: The transition to adulthood for patients with ASD necessitates providing support regarding community participation issues. To facilitate planning, this work should be planned well before the child reaches adulthood. Despite extensive literature, the transition of a patient with ASD from child and adolescent services to adult services still presents difficulties and, at times, confusion for the family. Therefore, it is essential to promote integrated procedures and joint training between the two types of services, allocating adequate resources to meet this significant care need.

Keywords: Transition, autism, developmental services, and adult services

Introduction
Current epidemiological evidence highlights worrying data regarding the mental health of children and adolescents and neurodevelopmental disorders. Meanwhile, the prevalence of autism spectrum disorder is constantly growing, with Italy reporting 1 case in 77 children between the ages of 7 and 9, while the CDC in Atlanta reports a figure of 1 in 36 [1].
These critical issues are paving the way for a progressive increase in access to adult services for a growing number of users with complex and specific needs, who require structured and personalized care. Receiving and addressing this enormous burden of suffering is a task that adult services can no longer avoid, beyond the standard operations typically focused on severe and chronic cases of psychosis. This will necessitate a reorganization of training and methodology.
Transition means the transfer of clinical-assistance skills from mental health and disability services in developmental age to services for adults [2, 3].
The transition phase is widely recognized as a critical moment, associated with a high risk of interruption and dispersion of care pathways; it is estimated that approximately 60% of patients lose contact with their care *teams* and continuity of care during this transition [4]. Further evidence indicates that approximately 50% of users experience discontinuity in the care-taking processes [5, 6].
Even young people with autism who transition into adulthood frequently show reluctance to seek support for their mental health, partly due to social stigma and uncertainty regarding

which services to turn to, resulting in worsening of symptoms [7, 8] and a marked feeling of abandonment and loneliness, also shared by the family unit.

In the long term, an inadequate transition is associated not only with a worsening of the clinical picture, but also with an often inappropriate use of emergency services, an increase in hospitalizations, the chronicization of the condition and an overall reduction in the Quality of Life (QoL) [9]. Several causes have been identified in the failure of the transition process: poor awareness of the problem and failure to ask for help, dissatisfaction with the quality, competence or perceived effectiveness of the healthcare system, fear of stigma or choice of self-management by the young person or the family unit [10, 11].

SCOPE

The aim of this paper is to present recent literature on transition in ASD and identify the main critical issues associated with this phase, summarizing the recommendations and methodologies proposed in the literature and in clinical practice.

Autism in adolescence and adulthood

The disorder takes on particular connotations in adulthood. Among the challenges are the identification of Level 1 forms that involve often underdiagnosed elements of suffering, and the identification of neurodivergent conditions bordering on diagnosis, which raises the question of a hypothetical boundary between neurodivergence and neurodivergence. subsyndromal and level 1 according to the DSM [12, 13].

The need for scientifically shared diagnostic protocols, addressing adult mental health and addressing individual knowledge and in-depth diagnostic testing with ad hoc testing, appears crucial. Equally crucial is the need for interventions to be tailored to the local context, as is typical for public services in the Italian National Health System.

A 2022 review [14] found that autistic adults had equal or higher healthcare utilization than non-autistic adults, with frequent emergency room and hospital visits. This finding suggests that routine outpatient care may not be adequate to fully meet their healthcare needs.

The clinical manifestations of ASD vary from individual to individual and at different stages of life, depending on numerous personal, family, and environmental variables. People with ASD typically exhibit poor cognitive and behavioral flexibility, sensory atypia, and difficulty regulating emotions.

A significant number of individuals with ASD experience difficulties adjusting to social, interpersonal, and work situations. This condition is often overlooked by healthcare providers and social workers, resulting in serious difficulties accessing the services needed to achieve complete independence. Furthermore, it should be noted that adults with ASD are more likely to suffer from other mental disorders and related physical problems, and it cannot be ruled out that they may be targeted by the criminal justice system, as perpetrators or victims of crime, precisely because of their poor interpersonal skills.

Many patients with ASD and their families express the desire to achieve an independent life, to participate in educational or work activities and to have social and sentimental relationships, however the skills and/or resources necessary to successfully achieve these goals are often lacking [15, 16].

There are widely varying data regarding screening and referral capacity, waiting times for a diagnosis, and care models for adults with ASD. These factors can lead to significant delays in diagnosis and access to appropriate and necessary support.

Clear evidence suggests that social-relational skills are deficient in subjects with autism and this difficulty persists in adolescence and adulthood, leading to a scarcity of relationships and friendly contacts [17].

As a consequence, school and academic maladjustment, socio-work exclusion, bullying victimization and possible development of comorbidities develop, in up to 70% of cases [18].

Recently, scientific research on psychosocial interventions for adults and adolescents with ASD has intensified, and literature data has highlighted that one of the key elements influencing the transition period towards better outcomes is parental involvement. They act as a fundamental support to promote the child's autonomy and allow the implementation of skills and abilities beyond school age; but it is equally important that family members are aware of the regulatory framework, their rights, and the different possible alternatives in the therapeutic field, and that they adequately support their children in the various paths [19]. Teacher support is also important for the transition as they can be a reference for identifying and promoting learning objectives and skills that will then be structured beyond the school period and in social life.

Maenner *et al*. 2020 report that 33% of subjects with ASD have an ID and 25% have an FIL [20]. Comorbidity is very frequent, the latter triggered by stressful events, among which cannabis use and bullying are the most cited. Therefore, in people with ASD, psychiatric disorders are present in comorbidity, 4-5 times more than in the rest of the population, and with an earlier onset: from 25 to 44% of ASD people present one psychiatric disorder, 21% present two and 8% present three [21, 22, 23, 24]. Anxiety and ADHD are the most present disorders, the latter decreasing with growth.

Comorbidity between AD and ID increases the risk of having a psychiatric disorder by 5 times compared to ID alone [21].

It has been reported that over half of adults with ASD do not have close friends [25] and children are bullied 4 times more than neurotypicals. Bullying is usually associated with depressed mood, suicide risk, poor academic results, and poor quality of life. Furthermore, it is reported that adults with autism have poor skills in sexuality, affection, and courtship.

Social skills enable positive personal relationships with family, friends, peers, and are crucial for managing complex interactions, such as cohabitation, collaboration with peers, work relationships, up to more specific *outcomes related to* QoL, self-esteem and happiness [26]. These *outcomes* also seem to be related above all to favourable interpersonal relationships: one or more friendships are believed to be sufficient to protect from the consequences of internalising disorders and bullying phenomena, and from failure in the socio-relational sphere [27].

We reiterate that there are significant elements of diagnostic and management difficulties in adult ASD. For example, comorbid symptoms manifest themselves in an atypical or incomplete manner, especially if an ID coexists [28, 29].

In level 1 forms, the so-called "masking" causes the symptoms to be hidden by a marked adaptive effort induced by the social context of reference, even if atypicalities of the disorder induce comorbid symptoms. Diagnosis is often problematic and even late [30, 31, 32].

Furthermore, we must not forget the problematic behaviors linked to autistic symptoms, which become visible in adolescents and adults especially when they are self- or hetero-aggressive, and in any case markedly dysfunctional with respect to the context.

Children's services and adult services: issues and solutions

Transition must be conceived as an operational modality aimed at ensuring continuity of care through a planned and personalized process, capable of responding to the specific individual needs of each user.

Adolescence is a period of extreme vulnerability, during which constitutional, emotional, and social factors shape each individual's health or illness in a way that is often complex and difficult to predict.

It is widely believed that during adolescence and before the age of 18, managing and treating neurodevelopmental disorders is a challenging time, as goals need to be redefined and family grief recurs. As peers begin to separate and develop sexual and socio-emotional maturity, these patients experience difficulties as much as, if not more so, than at previous ages.

The feelings of frustration, failure and depression expressed by parents become more acute and are associated with a sense of loss, determined by the loss of support from their *parents. managers* who have assisted them for a long time and the lack of clarity regarding the health services in which the necessary assistance for the children can be guaranteed [33].

Advancing and completing school deprives adolescents of a system—the school system—which, despite its weaknesses, represents, especially in Italy, an experience of protection, inclusion, and anchoring in social interaction and peer relationships. This raises the need to address the issue of potential job placement or pre -work training, where possible.

Furthermore, adolescence is frequently the age of onset for numerous psychiatric conditions, such as mood disorders and psychotic disorders, which can comorbidly coexist with ASD. It is often at this age that multimodal therapies, including pharmacological therapies, must be initiated and implemented, which can be challenging in terms of overall management.

In Italy, the transition and related critical issues are also influenced by the cultural and operational specificities that characterize Child Neuropsychiatry (NPIA) and Adult Psychiatry.

The comparison between Psychiatry and NPIA can represent an opportunity for mutual enrichment for both disciplines, provided that it occurs on an equal footing and is oriented towards a mutual educational exchange. Frequent operational opportunities arise that favor the comparison between the two branches: among other things, the data published in 2022 in the Lancet underline a substantial continuity between mental disorders and neurodevelopmental disorders, also documenting that the peak incidence of the onset of a mental disorder coincides with late adolescence (17-19 years) [34].

Therefore, special care must be taken to transition ASD cases from child services to adult services, primarily psychiatry, upon reaching the age of 18. However, one might wonder what should be addressed: psychiatric comorbidity or the patient's overall needs. Emergency admissions of adolescents with ASD and behavioral problems to adult psychiatric facilities are also common, given the shortage of beds dedicated to developmental neuropsychiatry.

Furthermore, there are marked cultural differences between adult psychiatry and NPIA: In Italy, [35] NPIA has jointly maintained the neurological and psychiatric skills of developmental age, with a solid foundation in the psychological and pedagogical models of child development. The NPIA approach is oriented towards a developmental dimension in the management and formulation of diagnoses, with a strong emphasis on cognitive problems and scholastic pathways, which are essential in the clinical practice of the discipline. Furthermore, a problematic management of emergency situations and complex clinical cases is frequent, often faced with difficulty and reluctance, also due to a diversified distribution of resources across the territory. The activity of the Italian NPIA is strongly influenced by Law 104/92, which constitutes the main regulatory reference and significantly impacts on daily operations, sometimes to the detriment of adaptation to changing epidemiological conditions and new healthcare needs.

Italian psychiatry, likewise, born and developed in the wake of Law 180/78, which abolished psychiatric hospitals and focused on psychosis and chronic conditions, has found itself having to manage the transition from a role historically characterized by social control, progressively addressing new types of patients, such as youth, the elderly, individuals with *addiction disorders*, and immigrants. However, a structural difficulty persists in accommodating nuanced clinical conditions, so-called minor disabilities, as well as specific conditions requiring a high level of care, such as severe disabilities and autism spectrum disorders, which typically begin and manifest during preschool or school age. Indeed, these have only recently been included within the scope of adult psychiatry, despite the recommendations of various international documents and programs.

In 2021 and 2025 Myers *et al.* [36] administered questionnaires to the operators, from which the embarrassment in talking about transition and in adequately directing patients and families still emerges, but the key role of the operators themselves regarding the future of these users and their care path also emerges. The theme of the questionnaires was above all autonomy and transport, the importance of understanding the motivations of adolescents, the approaches to prepare the *caregivers* of children to undertake driving and the role of the operators in promoting the agreement between adolescents and *caregivers*.

We then proceed to review the main critical factors found in the late adolescence phase in patients with ASD: possibility of late or incorrect diagnosis of ASD; interruption of care with limited planning; insufficient transmission of information to families and reduced involvement of *caregivers* in therapeutic projects; discontinuity of care between services, attributable to cultural, logistical, organizational and communication factors [37]. Communication difficulties between services for developmental age and those for adulthood are frequent,

often aggravated by mutual prejudices regarding the respective specificities; significant differences in the training curricula of operators, in particular with regards to skills relating to developmental age, management of chronicity, developmental psychopathology, the relational dimension, the use of psychotropic drugs and the management of emergency situations.

The transition to adult services is often determined by the formal diagnosis, rather than guided by the patient's specific clinical and care needs. Furthermore, there is a discrepancy between the increased demand for child and adolescent services and the scarcity of resources, which hinders healthy transition processes, which are often perceived as a "luxury" by various providers in both services.

A further critical issue is the lack of integration with social services and other local resources, which could serve as a liaison and "bridge" between the various agencies responsible for treatment. The role of general practitioners, pediatricians, and primary care psychologists, as well as hospital and university departments, must also be defined. These are often key stakeholders at various stages of the treatment process, especially if the clinical situation is complex, potentially requiring hospitalization, or if the symptoms are subtle and may worsen.

Regarding the timing of the transition process, it is frequently observed that it is reduced to the last 2–3 months of the process within the developmental age service, a period during which neither the family nor the patient are adequately prepared or informed. It is therefore essential to identify, within both services, a dedicated team, as well as—where possible—a case manager for each of the two entities, capable of collaborating in an integrated and continuous manner during the transition phase.

To summarize, what are the elements that contribute to the success of the transition process?

From systematic reviews available in the literature [38], it emerges that empirical data on the effectiveness of transition models are still limited, a criticality that persists over time despite the extensive scientific production and numerous operational recommendations on the topic. A quality transition often remains entrusted to the individual initiative of the professionals involved, the availability of those responsible for the services and the solidity of the respective organizational cultures.

Overall, on the basis of a now extensive literature on the subject [39, 40], it is possible to outline a structured transition model, whose fundamental components can be summarised as follows:

Appropriate organizational policies, resource implementation, and operator training; adequate patient monitoring, with careful attention to databases; adequate preparation of the patient and family with detailed information and separation planning; involvement of the child and parents in this process and in subsequent therapeutic decisions; gradual and flexible transition timing. Planning interventions by precisely identifying operators and roles, including case *studie. Manager* to refer to; personalized treatment plan oriented to goals and life contexts. The two services must be considered as a continuum, with periodic meetings in the form of *micro-teams.* dedicated; parallel care work between the two services. Subsequent formal transition and completion of the transfer of care, with information sharing and ongoing contact between the two services; patient and family involvement in the post-transition period, and increasing encouragement of the child in decision-making and consent to treatment.

The practices described represent an opportunity to apply the community psychiatry model to the transition process in patients with ASD. This model "accompanying" the patient throughout their lives requires an integrated consideration of key individual and family bio - psycho -social variables, the relevant socio-relational context, and the need to create an integrated network of services capable of providing comprehensive and complex responses to the needs of each individual patient. Applying the concept of a life plan, using tools such as a health budget, can provide guidance within the Italian regulatory context.

Last but not least, there is a need to identify appropriate outcome indicators of the transition process. To this end, it is possible to hypothesize assessments relating to adaptive functions, the level of severity of the disorder or the presence of specific ASD symptoms. Tools such as the CGI (*Clinical Global Impression)* [41] can be useful, as it allows the expression of a global clinical judgement divided into three areas: the severity of the disease, the overall improvement and the index of therapeutic efficacy. Also worthy of mention is the Disability Scale – DISS [42], a self-assessment scale that uses an analogue format (from 0 to 10) to measure the degree of functional impairment attributable to mental disorders in the areas of work functioning, interpersonal relationships and family life. A scale also used in mental health to subjectively evaluate an individual's psychosocial functioning is the WHODAS scale referred to the DSM-5, which is more detailed [43, 44].

Conclusions

Child and adolescent services must dedicate part of their resources, methodological vision, and operational capabilities to the transition process for patients with ASD. It's not enough to simply report patients or provide parents with brief information about the next steps; appropriate procedures with appropriate steps must be structured.

The relevant literature documents numerous experiences and operational practices related to transition, yet significant weaknesses persist both in the overall treatment of transition in ASD and in the definition of quality and outcome indicators. This area therefore remains largely undeveloped, both in scientific research and clinical practice.

While treatment for ASD in childhood requires timely and early intervention, it is equally important to optimize interventions in adolescence and early adulthood, ensuring continuity of care, and ensuring access to all necessary psychosocial interventions. A community psychiatric approach, which safeguards comprehensive care by focusing on the individual characteristics of each child with ASD, as well as their family context, can make a significant contribution to the management of these cases.

Above all, we believe it is necessary to overcome the current organizational and training issues of the services in order to ensure the real applicability of the operational models widely described in the international literature.

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