*Psychiatria Danubina, 2021; Vol. 33, Suppl. 11, pp 52-57*
*© Medicinska naklada - Zagreb, Croatia*

*Conference paper*

# THE TRANSITION FROM CHILD AND ADOLESCENT MENTAL HEALTH SERVICES (CAMHS) TO ADULT MENTAL HEALTH SERVICES (AMHS): WHAT ABOUT AUTISM SPECTRUM DISORDER?

**Joana Reis [1,2,3], Simone Marchini [1,2,3] & Véronique Delvenne[1,3]**

[1]*Department of Child and Adolescent Psychiatry, Queen Fabiola Children's University Hospital, Brussels, Belgium*
[2]*Department of Child and Adolescent Psychiatry, Erasme Hospital, Brussels, Belgium*
[3]*Faculty of Medicine, Université Libre de Bruxelles (ULB), Brussels, Belgium*

## SUMMARY

***Background:*** *Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder and a long-term condition that may require psychiatric life-long care. Transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) possibly concerns a great portion of patients with ASD. This study focuses on transitional age youth (TAY) with ASD and proposes specific innovative tools to manage the transition process.*

***Subjects and methods:*** *This explorative study focuses on TAY with ASD. Data on socio-demographic characteristics and personal medical history was collected. Three self-rated questionnaires were used: the Health of The Nation Outcome Scales For Children And Adolescents (HoNOSCA-SR), to assess care need, the World Health Organization Quality of Life-BREF (WHOQOL-BREF) scale and the Transition Readiness and Appropriateness Measure (TRAM), to evaluate barriers to functioning.*

***Results:*** *The sample was composed of 10 patients with ASD aged from 17 to 18. The majority of them were male (70%) and born in Belgium (60%). The median (interquartile range) age of ASD diagnosis was 16 (13-17). The comorbidity rate was 60% for psychiatric disorders and 30% for somatic diseases; 80% of the participants were under psychotropic drugs. The average questionnaires scores were respectively: HoNOSCA-SR = 21.63 (±9.90), WHOQOL-BREF physical health = 50.88 (±19.14), psychological health = 36.13 (±13.97), social relationships = 48.50 (±18.23) and environment = 59.38 (±14.08); TRAM's number of barriers to functioning were 4.25 (±1.39).*

***Conclusions:*** *These preliminary data, accompanied by current recommendations, allow to clarify the strategies to an optimal transition in ASD. Special insight is given to strategies to reach a well-managed transition from CAMHS to AMHS, such as the assessment of psychiatric and somatic comorbidities, the care need continuity, the elaboration, in advance, of a transition plan, the assessment of the barriers to functioning, and the involvement of young patients and their families.*

***Key words:*** *transition – ASD – psychiatry – CAMHS – AMHS*

* * * * *

## INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by persistent and pervasive difficulties in social communication and by restricted and/or repetitive interests or behaviours (American Psychiatric Association 2013). By definition, ASD is a long-term condition that may require psychiatric life-long care (Colver et al. 2018).

Around the age of 18, in most European countries, a large proportion of patients with ASD face the artificial boundary between Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS). Transition from CAMHS to AMHS, defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health-care systems" (Blum et al. 1993), may represent a challenge for transitional age youth (TAY) with ASD (Swaran P. Singh et al. 2010), in particular for those presenting additional mental and physical health problems (King et al. 2020).

Several factors involved in this process may represent potential barriers to optimal transition. Some of these are common to all patients with a mental health condition experiencing transition from CAMHS to AMHS. For example, the adult services' threshold age to access to care varies greatly, from 16 to 21 years; additionally, young people feel that they are not familiar with existing care options (Swaran P Singh & Tuomainen 2015). Even if these obstacles are well-documented, it is still difficult to overcome them (Hovish et al. 2012).

Furthermore, young people with ASD are less likely to make a transition to adult services (Swaran P. Singh et al. 2010), mainly due to ASD-related specific characteristics and needs. Communication impairments can represent a barrier to explain their-own mental health problems as well as to understand the need for a change in specialist help (Merrick et al. 2015). ASD patients are more likely to feel anxious when facing change in their routine (Leyfer et al. 2006). Caregivers, such as parents, represent a fundamental resource: their involvement has been proven to be correlated to greater scores in ASD youth well-being across transition from CAMHS to AMHS (Colver et al. 2018).

Smoothness in the transition process can also be disrupted by comorbidities (Bennett et al. 2018). These can vary from a broad spectrum of psychiatric disorders, such as depression, anxiety, obsessive compulsive disorder and attention deficit hyperactivity disorder (Leyfer et al. 2006), but also somatic ones (epilepsy, behavioural health disorders, gastrointestinal problems, allergies) requiring additional specialized care (Kuhlthau et al. 2016). Besides, during the transition from CAMHS to AMHS, ASD patients' quality of life is lower than in normative sample (Biggs & Carter 2016) but also than in other long-term condition such as diabetes and cerebral palsy (Merrick et al. 2015).

ASD specific training is lacking for AMHS professionals although they show interest to obtain it. Thus, AMHS professionals often feel that the clinical interventions they propose to young adult with ASD are inadequate (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012). In addition, provision of paediatric and adult services are lacking in transition resources for ASD patients and their specific needs (Ames et al., 2021), resulting in discontinuity of care for ASD young adults (Swaran P Singh et al. 2010).

This article aims to present socio-demographic and clinical data of a small sample of TAY with ASD facing the boundary between CAMHS and AMHS. Innovative standardized tools to manage the transition process were investigated in detail. The current recommendations to an optimal transition in ASD are discussed in the light of this preliminary data.

## SUBJECTS AND METHODS

As part of a larger longitudinal cohort study, the *Transition_psy* (Reis et al. 2021), this explorative study presents preliminary data on TAY (aged from 17 to 18 years old) who have been diagnosed with neurodevelopmental disorder, specifically ASD.

### Ethical considerations

The *Transition_psy* study protocol was reviewed and approved by the Institutional Review Boards of the Queens Fabiola Children's University Hospital, the Brugmann University Hospital and the Erasme Hospital, in Brussels, Belgium. Both parents or legal holder of parental authority and the participant must be able to provide informed and written consent.

### Procedure

Participants have been recruited in clinical settings, both outpatient and inpatient services, within the urban area of Brussels, Belgium, from June 2020 to October 2021. Participants included in the present study have been diagnosed with ASD meeting DSM-V criteria (American Psychiatric Association, 2013) by an ASD regional diagnosis team. Eligible participants are either male or female, 17 to 18 years old at the time of the inclusion phase and fluent in French. Participants with homogenous intelligence quotient (IQ) below 75, were excluded from de study, because of the impossibility to autonomously complete self-reported questionnaires. Participants completed self-report questionnaires through the secured Research Electronic Data Capture (REDCap©) platform.

### Materials

Data on socio-demographic characteristics, such as age, sex, civil and educational status, country of birth, housing composition, as well as personal medical history, including ASD diagnosis age, psychiatric and somatic comorbidities, and psychotropic medication were collected.

The self-rated Health of The Nation Outcome Scales For Children And Adolescents (HoNOSCA-SR) has been used to assess care need (Gowers et al., 1999). The HoNOSCA-SR focuses on clinically significant problems and symptoms, and consists of 13 self-reported scales, each rated from 0 (no problem) to 4 (severe to very severe problem). The total score, ranging from 0 to 52, represents the overall care need in mental health. Higher scores represent greater severity of the mental health problems.

Participants quality of life has been assessed through the World Health Organization Quality of Life-BREF (WHOQOL-BREF) scale (Skevington, Lotfy, O'Connell & WHOQOL Group, 2004). This instrument is a 26-item self-report questionnaire on a five-point scale. The WHOQOL-BREF measures four broad domains: physical health, psychological health, social relationships and environment. A score per each domain can be calculated out of 100. Higher scores represent better quality of life within the specific domain.

The Transition Readiness and Appropriateness Measure (TRAM), an innovative self-reported questionnaire developed by the MILESTONE European Project (Santosh et al. 2020), was also administrated. This clinical tool assesses whether transition is appropriate for youth approaching the CAMHS-AMHS boundary and whether they are ready for it. The youth version of the TRAM was administered in this study but only the section "barriers to functioning" was analysed. This section consists of 9 items, each rated from 0 (no barrier) to 3 (severe barrier), and includes: young people incapable to act as an independent adult; poor understanding their mental health condition or not being motivated to manage their condition; lack of knowledge on how to access services; poor adherence to medication; not wanting carers to be involved; lack of social support, difficulty building therapeutic relationships and difficulty repeating mental health history.

## Statistical analysis

Data were analysed using the Statistical Package for the Social Sciences version 27 (SPSS, Inc., Chicago, IL, USA). Descriptive statistic methods was used to characterize the study sample, including sociodemographic characteristics and personal medical history data. For numerical variables, the normality of the distributions was assessed with Shapiro–Wilk test. If the distribution was normal, mean and standard deviation were presented; if the distribution was asymmetrical, the median and interquartile range were displayed. Categorical variables were described with relative frequencies.

# RESULTS

## Sociodemographic characteristics and medical history

This preliminary study's sample consisted of 10 patients who already received a diagnosis of ASD in their life. Table 1 presents sociodemographic characteristics of the sample, recruited between June 2020 and October 2021.

The participants' age ranged from 17 to 18 years old. The majority of participants were male (70%) born in Belgium (60%). Every participant was single and engaged in an education activity (100%); 9 participants out of 10 were living with their parents, whereas only 1 with other people.

The participants' medical history details are resumed in Table 2. Concerning the age of ASD diagnosis the median was 16 (13-17). The psychiatric comorbidity rate was 60%, among which there were 2 cases of ADHD and 5 of anxio-depressive disorders. Somatic comorbidities (30%) included asthma (n=2) and chronic renal failure (n=1). The majority of patients were receiving one psychotropic medication (80%): 4 of them were on antidepressant, 2 psychostimulants, 1 antipsychotic and 1 anxiolytic agent.

**Table 1.** Summary of socio-demographic characteristics of the sample (n=0)

| Variable | Value |
|---|---|
| Age (Median (IQR)) | 17 (17-18) |
| Sex | |
| Male | 70.0% |
| Female | 30.0% |
| Civil status | |
| Single | 100% |
| Country of birth | |
| Belgium | 60.0% |
| Another country | 40.0% |
| Housing composition | |
| Lives with parents | 90% |
| Lives with other people | 10% |
| Educational status | |
| Education activity | 100 % |

Abbreviation: IQR - Interquartile range

**Table 2.** Data on personal medical history of the sample (n=10)

| Variable | Value |
|---|---|
| ASD diagnosis age [Median (IQR)]* | 16 (13-17) |
| Psychiatric comorbidities ¥ | 60.0% |
| Somatic comorbidities ¥ | 30.0% |
| Psychotropic medication ¥ | 80.0% |

Abbreviation: IQR - Interquartile range;
* cases missing data; ¥ 1 case missing data

## Self-reported questionnaires

Self-reported questionnaires scores are presented in Table 3. The average HoNOSCA-SR total score was 21.63 (±9.90). The average WHOQOL-BREF scores per each domain were respectively 50.88 (±19.14) for physical health, 36.13 (±13.97) for psychological health, 48.50 (±18.23) for social relationships and 59.38 (±14.08) for environment. The TRAM's mean number of barriers to functioning was 4.25 (±1.39). 3 barriers out of 9, including lack of knowledge on how to access services, not wanting carers to be involved and difficulty repeating mental health history, were present in at least 50% of the participants.

**Table 3.** Self-reported questionnaires scores of the sample (n=10)

| Variable | Mean (SD) | Min - Max |
|---|---|---|
| HoNOSCA * | 21.63 (9.90) | 8-38 |
| WHOQOL-BREF physical health * | 50.88 (19.14) | 19-89 |
| WHOQOL-BREF psychological health * | 36.13 (13.97) | 13-50 |
| WHOQOL- BREF social relationships * | 48.50 (18.23) | 19-75 |
| WHOQOL- BREF environment * | 59.38 (14.08) | 44-81 |
| TRAM – Barriers to functioning * | 4.25 (1.39) | 2-6 |

Abbreviation: HoNOSCA: Health of The Nation Outcome Scales For Children And Adolescents; SD - Standard deviation; TRAM: Transition Readiness and Appropriateness Measure; WHOQOL- BREF: World Health Organization Quality of Life-BREF;
* 2 cases missing data

## DISCUSSION

### Sociodemographic characteristics and personal medical history

This explorative study's sample was composed of 10 patients with neurodevelopmental disorders, specifically a diagnosis of ASD meeting the DSM-5 criteria (American Psychiatric Association 2013). Patient's inclusion age, between 17 and 18 years old, was specifically chosen taking into account the legal barrier between CAMHS and AMHS in Belgium (18 years old ± 3 years). In this sample, there is a higher percentage of male participants (70%). This findings are in accordance with a recent meta-analysis, suggesting a male-to-female ratio ranging between 4:1 and 3:1 in ASD patients (Loomes et al. 2017).

In the present study, the ASD diagnosis age is quite late, at the middle adolescence [*median (interquartile range)* = 16 (13-17) ], as all the participants had an IQ ≥ 75. Patients with both ASD and intellectual disability were excluded for participation in the *Transition_psy* study. These results are consistent with previous studies, demonstrating that lower IQ scores are associated with a younger age of ASD diagnosis (Shattuck et al. 2009).

Psychiatric comorbidities, mainly anxio-depressive disorders or other neurodevelopmental disorders, were frequently reported in this study's sample (60%) coherently with previous literature and guidelines (Leyfer et al. 2006, National Institute for Health and Care Excellence 2020). Simultaneously, a great portion of participants (80%) reported the use of psychotropic drugs, most frequently antidepressant or psychostimulant medication. These findings are consistent with the current recommendations encouraging the use of standardised tools to assess anxiety and depression in transitional-age patients with ASD. The goal is to identify the ones who are at greater risk of poor outcomes after transition (King et al. 2020).

Additionally, almost one third of the participants reported somatic comorbidities, including asthma and chronic renal failure. These results are crucial elements to consider in the transition plan, considering that the need for life-long care is highly associated with the presence and intensity of psychiatric or somatic comorbidities (King et al. 2020).

According to recent guidelines, comprehensive assessment should be performed as early as the age of 14 years, to evaluate whether the continuity of care in AMHS is needed (National Institute for Health and Care Excellence, 2020). Consequently, it is fundamental to plan in advance the possible transition from CAMHS to AMHS, before the child reaches adulthood (Bennett et al. 2018, National Institute for Health and Care Excellence 2020).

### Self-reported questionnaires

Additionally to a detailed clinical assessment of ASD patients, there are other factors to take into account to ensure the process of transition from CAMHS to AMHS.

In the present study, HoNOSCA-SR measures the severity of general health and social functioning problems of young people with ASD, and consequently care need (Gowers et al. 1999). In clinical population, higher scores therefore suggest higher care need and a greater probability of transitioning to AMHS. The recently developed instrument for assessing transition readiness and appropriateness, TRAM, assesses more specifically the need for transition from CAMHS to AMHS, but also includes the identification of frequent barriers to a successful transition process (Santosh et al., 2020). In our population, ASD patient present, in average, 4.25 barriers to functioning: Among 9 target-barriers, 3 moderate-to-severe barriers, including lack of knowledge on how to access AMHS services, not wanting carers to be involved and difficulty repeating mental health history, were present in at least half of the participants. These findings are consistent with recent guidelines encouraging clinicians from both sides of the transition to identify existing barriers and include target-solving strategies to care plan (National Institute for Health and Care Excellence, 2020).

In this study, quality of life of TAY with ASD was evaluated by the WHOQOL-BREF, a complete and cross-culturally valid assessment of quality of life, measuring physical health, psychological health, social relationships and environment (Skevington, Lotfy, O'Connell, & WHOQOL Group, 2004). The highest quality of life was scored in the environment domain, followed by physical health and social relationship domains. The lowest quality of life was found in psychological health. Scores in each domain where significantly lower than those found in general adult population (Skevington, Lotfy, O'Connell, & WHOQOL Group 2004), but also in Taiwanese ASD adults (Lin 2014). A recent longitudinal observational cohort study including 118 TAY with ASD demonstrated a strong association between appropriate parental and carers involvement and higher wellbeing scores. However, one of the most frequent barriers detected in this sample was "not wanting carers to be involved" in the transition process. Thus, recent guidelines also point out the involvement of young patients and their families as key factors in the elaboration the transition plan (National Institute for Health and Care Excellence 2020).

## CONCLUSION

This exploratory study focuses on TAY diagnosed with ASD. The analysis of these preliminary data, accompanied by the current recommendations, allows to clarify the fundamental components of an optimal transition in ASD. The transition from CAMHS to AMHS for patients with ASD represents a complex intervention that should be programmed and structured. Complementary strategies to achieve these aims should include a comprehensive assessment of psychiatric and somatic comorbidities and of care need continuity at the adolescence, an anticipatory and practical transition plan, a detailed evaluation of the barriers to functioning and the involvement of young patients and their families.

**Acknowledgements:**

The study was carried out as part of the University Chair "Psychiatry in Transition in a World in Transition" (Université Libre de Bruxelles - ULB) with the support of Julie Renson Fund, the Queen Fabiola Fund and the King Baudouin Foundation.

**Conflict of interest:** None to declare.

**Contribution of individual authors:**

Joana Reis: conceptualization and design; statistical analyses; interpretation of the findings; draft preparation; editing.

Simone Marchini: conceptualization and design; interpretation of the findings; draft preparation; editing.

Véronique Delvenne: conceptualization and design; revision.

All authors have read and agreed to the published version of the manuscript.

## References

1. *American Psychiatric Association (Ed.): DSM-5-Diagnostic and Statistical Manual of Mental Disorders (5th ed.). Arlington: American Psychiatric Publishing, 2013*
2. *Ames JL, Massolo ML, Davignon MN, Qian Y, Cerros HJ & Croen LA: Transitioning youth with autism spectrum disorders and other special health care needs into adult primary care: A provider survey. Autism 2021; 25:731–743*
3. *Bennett AE, Miller JS, Stollon N, Prasad R & Blum NJ: Autism Spectrum Disorder and Transition-Aged Youth. Current Psychiatry Reports 2018; 20:103*
4. *Biggs EE & Carter EW: Quality of Life for Transition-Age Youth with Autism or Intellectual Disability. Journal of Autism and Developmental Disorders 2016; 46:190–204*
5. *Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP & Slap GB: Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. The Journal of Adolescent Health : Official Publication of the Society for Adolescent Medicine 1993; 14:570–576*
6. *Bruder MB, Kerins G, Mazzarella C, Sims J & Stein N: Brief report: The medical care of adults with autism spectrum disorders: Identifying the needs. Journal of Autism and Developmental Disorders 2012; 42:2498–2504*
7. *Colver A, McConachie H, Le Couteur A, Dovey-Pearce G, Mann, KD, McDonagh JE, ... Parr JR: A longitudinal, observational study of the features of transitional healthcare associated with better outcomes for young people with long-term conditions. BMC Medicine 2018; 16:111*
8. *Gowers, S. G., Harrington, R. C., Whitton, A., Lelliott, P., Beevor, A., Wing, J., & Jezzard, R. (1999). Brief scale for measuring the outcomes of emotional and behavioural disorders in children. Health of the Nation Outcome Scales for children and Adolescents (HoNOSCA). The British Journal of Psychiatry : The Journal of Mental Science, 174, 413–416*
9. *Hovish, K., Weaver, T., Islam, Z., Paul, M., & Singh, S. P. (2012). Transition experiences of mental health service users, parents, and professionals in the United Kingdom: A qualitative study. Psychiatric Rehabilitation Journal, 35(3), 251–257*
10. *King, C., Merrick, H., & Le Couteur, A. (2020). How should we support young people with ASD and mental health problems as they navigate the transition to adult life including access to adult healthcare services. Epidemiology and Psychiatric Sciences, 29*
11. *Kuhlthau, K. A., Delahaye, J., Erickson-Warfield, M., Shui, A., Crossman, M., & Van Der Weerd, E. (2016). Health care transition services for youth with Autism Spectrum Disorders: Perspectives of caregivers. Pediatrics, 137(February 2016), S158–S166*
12. *Leyfer, O. T., Folstein, S. E., Bacalman, S., Davis, N. O., Dinh, E., Morgan, J., ... Lainhart, J. E. (2006). Comorbid psychiatric disorders in children with autism: Interview development and rates of disorders. Journal of Autism and Developmental Disorders, 36(7), 849–861*
13. *Lin, L.Y. (2014). Quality of life of Taiwanese adults with autism spectrum disorder. PLoS One, 9(10):e109567*
14. *Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. Journal of the American Academy of Child and Adolescent Psychiatry, 56(6), 466–474*
15. *Merrick, H., McConachie, H., Le Couteur, A., Mann, K., Parr, J. R., Pearce, M. S., ... Thalange, N. (2015). Characteristics of young people with long term conditions close to transfer to adult health services. BMC Health Services Research, 15(1), 1–11*
16. *National Institute for Health and Care Excellence. (2020). Managing autism spectrum disorder in under 19s. NICE Pathways, (August), 1–14*
17. *Reis, J., Marchini, S., De Leeuw, A., Slama, H., Leys, C., Delhaye, M., ... Delvenne, V. (2021). Study Protocol : Transition _ psy A multicenter prospective interventional youth in Belgium. Frontiers in Psychiatry, 12(June), 1–10*
18. *Santosh, P., Singh, J., Adams, L., Mastroianni, M., Heaney, N., Lievesley, K., ... Singh, S. (2020). Validation of the Transition Readiness and Appropriateness Measure (TRAM) for the Managing the Link and Strengthening Transition from Child to Adult Mental Healthcare in Europe (MILESTONE) study. BMJ Open, 10(6), e033324*
19. *Shattuck PT, Durkin M, Maenner M, Newschaffer C, Mandell DS, Wiggins L, ... Cuniff C: Timing of Identification Among Children With an Autism Spectrum*

*Disorder: Findings From a Population-Based Surveillance Study. Journal of the American Academy of Child & Adolescent Psychiatry 2009; 48:474–483*

20. *Singh SP, Tuomainen H, Bouliotis G, Canaway A & Girolamo GD: Effect of managed transition on mental health outcomes for young people at the child – adult mental health service boundary : a randomised clinical trial, 2021*
21. *Singh, Swaran P., Paul, M., Ford, T., Kramer, T., Weaver, T., McLaren, S., ... White, S. (2010). Process, outcome and experience of transition from child to adult mental healthcare: Multiperspective study. British Journal of Psychiatry, 197(4), 305–312*
22. *Singh Swaran P, Paul M, Ford T, Kramer T, Weaver T, McLaren S, ... White S: Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study. The British Journal of Psychiatry : The Journal of Mental Science 2010; 197:305–312*
23. *Singh Swaran P & Tuomainen H: Transition from child to adult mental health services: needs, barriers, experiences and new models of care. World Psychiatry : Official Journal of the World Psychiatric Association (WPA) 2015; 14:358–361*
24. *Skevington SM, Lotfy M, O'Connell KA & WHOQOL Group: The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group. Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation 2004; 13:299–310*

*Correspondence:*

*Joana Reis, MD*
*Department of Child and Adolescent Psychiatry, Queen Fabiola Children's University Hospital*
*Avenue Jean Joseph Crocq 15, 1020 Brussels, Belgium*
*E-mail: joana.figueiredooliveirareis@huderf.be*