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Challenging behaviours at early adulthood in autism spectrum disorders: topography, risk factors and evolution

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Abstract

Background—Challenging behaviours are highly prevalent in children and adolescents with autism spectrum disorders (ASD), but little is known about the prevalence and course of these behaviours during adulthood. The aims of this study were to describe the topography of challenging behaviours in a cohort of 106 young adults with ASD and to identify the risk factors for challenging behaviours. Our secondary objective was to study the changes in challenging behaviours from adolescence to early adult years.

Method—The present study uses data from the EpiTED prospective follow-up study in France. The presence of challenging behaviours was assessed by the Aberrant Behaviour Checklist (ABC) completed by parent informants. Several dimensions of behaviour were studied: irritability, stereotypy, lethargy, hyperactivity and self-injury. Clinical variables were collected on ASD symptom severity, cognitive and language levels, adaptive behaviours and comorbid medical disorders.

Results—The presence of challenging behaviours at early adulthood was related to the young adult's cognitive and language level, ASD symptom severity and comorbid gastrointestinal and sleep disorders. The main risk factor for challenging behaviours was ASD symptom severity. The level of language impairment was a significant predictor of self-injury. Gastrointestinal disorders were a significant predictor of stereotypy. The change in behaviour topography from adolescence to early adult years corresponded with decreased parent report of hyperactivity, but no significant decrease in parent reports of irritability, stereotypy, lethargy and self-injurious behaviours.

Conclusions—The challenging behaviours in individuals with ASD persist in early adulthood and are related to core symptom severity, levels of cognitive and language impairments and

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Conflict of interest

The authors have no conflicts of interest to report.

Supporting Information

Additional Supporting Information may be found online in the supporting information tab for this article.

medical comorbidity. The results emphasise the importance of early interventions for children with ASD to target cognitive and language abilities and to alleviate the severity of ASD symptoms. They also underscore the need to enhance opportunities for individuals with ASD to better communicate discomforts and pain in the context of medical illness.

Keywords

Autism spectrum disorders; Challenging behaviours; EpiTED cohort; Self-injurious behaviours; Young adult

Challenging behaviours are associated conditions noted that interfere with everyday activities of individuals with autism spectrum disorder (ASD) (American Psychiatric Association 2013). They include a varying degree of irritability, destructiveness, aggression, withdrawal, lethargy, uncooperativeness, hyperactivity as well as repetitive behaviours or self-injury. Many studies showed that challenging behaviours are more frequent among children with ASD than among children with intellectual disability (McClintock *et al.* 2003; Tonge and Einfeld 2003), with a prevalence estimated from 56 to 94% (Matson *et al.* 2007; Matson and Nebel-Schwalm 2007; Murphy *et al.* 2009; Mazurek and Kanne 2010; Matson and Kozlowski 2011; Kozlowski *et al.* 2012). Moreover, studies showed that among individuals with intellectual disability, a diagnosis of autism was associated with greater levels of challenging behaviours (Lundqvist 2013).

Little is known about challenging behaviours in the transition from adolescent to young adult years in ASD subjects. Some studies suggest that the prevalence of challenging behaviours increases with age during childhood, reaches a peak during adolescence and young adulthood and then declines at later adulthood years (Billstedt *et al.* 2007; Shattuck *et al.* 2007). Murphy *et al.* (2005) found a decrease in abnormal behaviours over a 12-year period in children with severe intellectual disabilities and/or ASD. A similar decline was described in a cohort of children and adults with ASD aged between 10 and 52 years, and the authors showed that the older participants were more likely to improve over the 4-year period of the study (Shattuck *et al.* 2007). In a sample of high-functioning individuals with ASD, Chowdhury *et al.* (2010) found a decline in restricted repetitive behaviours with the exception of self-injurious behaviours. Similarly, Richards *et al.* (2016) found no decrease in self-injury at adolescence during a 3-year period. Taylor and Seltzer (2010) described an overall improvement in internalised behaviours with age, but a slowing in improvement after leaving school, later in adolescence. Anderson *et al.* (2011) examined changes in maladaptive behaviours from mid-childhood to young adulthood and found that children and adolescents with more severe core symptoms of ASD had consistently higher irritability and hyperactivity scores over time. Overall, these results suggest that if there seems to be a consensus on a global decrease in challenging behaviours at adulthood, many questions remain unsolved regarding the type of challenging behaviours involved, the timecourse of these changes and the relationship between the decrease in challenging behaviours and the individual's cognitive and adaptive profile.

Challenging behaviours were shown to be related to adaptive deficits, intellectual disability/intellectual developmental disorder (ID/IDD) as well as ASD severity (Baghdadli *et al.*

2003; Baghdadli *et al.* 2008; Cooper *et al.* 2009; Rojahn and Meier 2009; Baeza-Velasco *et al.* 2014). From a functional assessment perspective (O'Neill *et al.* 1997), challenging behaviour may be an individual's response to an environmental demand or other circumstance. In individuals with poor communication skills, challenging behaviours may be the most efficient way to express a need or a discomfort, to obtain reinforcement or to escape from a negative experience. Teaching functional communication as a replacement behaviour has consistently been associated with a lower level of challenging behaviour (Braithwaite and Richdale 2000; Durand and Merges 2001; Tiger *et al.* 2008). Chiang *et al.* (2008) showed that a high proportion of children with ASD with severe speech impairments used challenging behaviour as a form of expressive communication. Challenging behaviours can also increase when the environment is not congruent to the person's specific needs, for example, lack of daytime engagement (Bowring *et al.* 2017) and sensory overstimulation or understimulation (Goldschmidt 2016). For those reasons, challenging behaviours might increase at adulthood because of the lack of appropriate services and effective interventions (Barnard *et al.* 2001; Gerhardt and Lainer 2011; van Heijst and Geurts 2014). Finally, medical comorbidities, for instance epilepsy, pain, sleep or gastrointestinal disorders, are a frequent cause of challenging behaviours in persons with ASD (Molloy and Manning-Courtney 2003; Nikolov *et al.* 2009; Guinchat *et al.* 2015; Klukowski *et al.* 2015). One of the hypotheses to account for this is that the communication impairments may lead to unusual presentations of medical disorders and consequently to an absence of appropriate care by the health practitioners (Mannion and Leader 2013).

The term challenging behaviours is therefore a global description that encompasses several different behaviours. Many challenging behaviours are not part of ASD core symptoms but frequently co-occur with it, such as hyperactivity or self-injury (Baghdadli *et al.* 2008; Soke *et al.* 2016). Self-injury in particular has been shown to be related to cognitive level and syndromic severity and is a particular challenge among ASD subjects with associated ID/IDD (Emerson *et al.* 2001; Rattaz *et al.* 2015). Other challenging behaviours less prevalent but also associated in persons with ASD include property destruction as well as hurtfulness towards others (Shattuck *et al.* 2007). On the other hand, some challenging behaviours are part of the ASD core symptoms: These often include repetitiveness, stereotypy and social withdrawal under the 'restricted, repetitive and stereotyped patterns of behaviours, interests or activities' as described in the ICD 10. Shattuck *et al.* (2007) showed that one of the singularly most prevalent challenging behaviour in ASD was in fact unusual or repetitive habits, as well as withdrawal. Whether these behaviours, which are part of the ASD symptoms, must be characterised as challenging behaviours remains unclear. Nevertheless, at the phenomenological level, these behaviours can be stratified as related or unrelated to ASD core symptom domains. Mottron suggested that some kinds of repetitive behaviours (e.g. an early interest in letters, staring at objects for longer) are the manifestations of sophisticated information processing and cannot be considered as behaviours that need to be eliminated (Mottron 2017). Despite this variability in type and function, challenging behaviours are often studied as a global variable in the literature and studies about the topography of the different challenging behaviours are lacking.

The primary aim of the present study was to describe the topography, associated features and predictors of challenging behaviours in 106 young adults with ASD who are part of the

EpiTED cohort, a prospective follow-up study about developmental trajectories in individuals with ASD in France (Baghdadli *et al.* 2012). Our secondary aim was to describe the changes in challenging behaviours in the transition from adolescence (T3; 13–17 years) to early adulthood (T4; 18–23 years).

Methods

This research was approved by the Local Human Subject Protection Committee (CPP) and National Commission for Computing and Liberties (CNIL). All parents or guardians signed a consent form. EpiTED cohort is recorded on an online portal.

Recruitment

A cross-sectional subset of data from the EpiTED prospective follow-up study (Baghdadli *et al.* 2012) was sampled. The EpiTED study examines the developmental trajectories of children and adolescents with a diagnosis of ASD over the lifespan. All the children initially included in the cohort had a confirmed ICD-10 diagnosis of autistic disorder (WHO 1993) by means of the Autism Diagnostic Interview-Revised (Lord *et al.* 1994). The data presented here were collected during the third and fourth follow-up assessments, corresponding to 106 young adults with ASD (see Fig. 1).

Participants

The young adults' mean age was 20.6 years (± 1.5 years) at T4; the sex ratio was 6:1 (m : f). Majority of them met criteria for diagnosis of autistic disorder (77.4%), and 15.1% were diagnosed with atypical autism. Eight participants (7.5%) no longer met the criteria for an ASD diagnosis at the time of the follow-up assessment. Language was present at functional level in 50.9% of the participants, absent in 31.2% and limited to few words in 17.9% (see Table 1).

Measures

Challenging behaviours—These behaviours were assessed through the Aberrant Behaviour Checklist (ABC: Aman *et al.* 1985). The ABC is a 58-item rating scale used to measure behaviour problems across five domains: irritability (ABC1), lethargy/withdrawal (ABC2), stereotypy (ABC3), hyperactivity (ABC4) and inappropriate speech. Because many young adults of our cohort (31%) have an absence of an expressive language and 18% had only a few words, the domain 'inappropriate speech' was excluded from the analyses. Items are rated on a 4-point Likert scale (ranging from 0 [not at all a problem] to 3 [the problem is severe in degree]), with higher scores indicating more severe problems. The ABC was shown to have sound psychometric properties with high internal consistency among subscales (Cronbach alpha = 0.91), excellent test–retest reliability ($r = 0.98$) and acceptable interrater reliability ($r = 0.63$) (Aman *et al.* 1985). As the number of items is different in the four domains, scores were reduced to a scale of 100 in order to make comparisons (Baeza-Velasco *et al.* 2014). Thresholds have been created to facilitate the description of the four clusters. The scores indicate low (<20), medium (20–40) and high (>40) levels of aberrant behaviours. The ABC was shown to have moderate correlations with measures of adaptive behaviour ($r = 0.60$) (Aman *et al.* 1985). The ABC also allows to extract a self-injury factor,

which is part of the irritability subscale and is composed of the following items: 2 – *injures self on purpose*, 50 – *deliberately hurts himself/herself* and 52 – *does physical violence to self*. We defined three self-injurious behaviour (SIB) groups: without SIB, low SIB and high SIB. High SIB was defined as a total combined score of 3 or greater (Brinkley *et al.* 2007). This score could be obtained by the presence of at least one severe behaviour (score of 3 on any one item) or two or three self-injurious behaviours of lesser severity (i.e. minimum of three different items receiving scores of 1). Low SIB was defined as a total combined score of 1 or 2 on the three items above, and without SIB as a total score of 0.

Adaptive behaviours—These behaviours were assessed using the three subscales of the Vineland Adaptive Behaviour Scale (VABS): communication, daily living skills and socialisation (Sparrow *et al.* 1984). The VABS is a semi-structured interview which was administered to parents. Scores derived from this instrument have a mean of 100 and a standard deviation of 15 with a Cronbach α coefficient of 0.92. Age equivalent scores and standard scores were obtained for each domain. In the present study, the measures are expressed in age equivalents (months) to improve comparability across tests.

Cognitive level—Because of the variable abilities of the participants and differences in IQ test scores across age, the ‘best estimate’ intellectual functioning level was derived for each participant based on an age-appropriate test, from all the assessments available (Howlin *et al.* 2014). When standardised test could be administered, performance IQ (PIQ) was recorded; in other cases, when the participants could not understand test instructions or requirements, developmental quotient (DQ) was calculated according to Stern’s formula (1912) by dividing developmental age scores (based on clinical observation by a psychologist) with the chronological age $\times 100$. The best estimate intellectual functioning was based on DQ according to clinical observation ($N = 38$), Wechsler Adult Intelligence Scale (WAIS-IV; Wechsler 2008) ($n = 33$), Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III and IV; Wechsler 2002; Wechsler 2014) ($n = 19$) or Wechsler Intelligence Scale for Children (WISC-4; Wechsler 2005) ($n = 6$). We used four categories: without intellectual disability ($DQ \geq 70$), moderate intellectual disability ($55 \leq DQ < 70$), mild intellectual disability ($40 \leq DQ < 55$) and severe intellectual disability ($DQ < 40$).

ASD symptom severity—The Childhood Autism Rating Scale (CARS) (Schopler *et al.* 1988) was assessed based on observational data from a 20-min video recording of the participant interacting with a psychologist. The CARS consists of 15 items intended to measure the presence and severity of ASD. The participant is rated on each item based on the clinician’s observation of his behaviour. Each item is scored on a scale from 1 (normal) to 4 (clearly abnormal). The CARS includes items on socialisation, communication, emotional responses and sensory sensitivities. The CARS classifies an individual as having mild, moderate or severe ASD, or no ASD, with a cut-off of 30 for the presence of ASD.

Expressive language and speech—Expressive speech was also assessed based on observational data from video recording. We used three levels: (a) spontaneous, functional speech with sentences, (b) utterances or phrase speech including at least five different words and (c) use of fewer than five words.

Medical comorbidities—Epilepsy, gastrointestinal and sleep disorders were recorded from an extensive standardised close-ended parental questionnaire based on the listing and codes of ICD10 (see Supporting Information Table S1).

Statistical analysis

Descriptive statistics of the data collected at last assessment point was computed using means and standard deviations. Median and interquartile (25th–75th quartile or IntQ) were computed for quantitative variables and proportions for categorical ones. The bivariate relationships between ABC, SIB and other study variables were assessed. Multiple linear regressions and multivariable logistic regression were run separately to determine the relative contributions of the variables within each of the four ABC domains (i.e. irritability, lethargy, stereotypy and hyperactivity) and the presence of SIB. Variables that were significant predictors of ABC at the 0.05 level within each domain were selected and included in the final regression models. Data at T3 and T4 were compared for challenging behaviours using the Wilcoxon signed ranks test for continuous data. All hypothesis tests were two-tailed with a significance level of $P < .05$ and analyses utilised procedures from SAS version 9.3 for Windows (SAS Institute Inc., Cary, NC).

Results

Challenging behaviours at early adulthood (T4)

At T4, the ABC median scores were 17.8 (IntQ = 4.4; 33.3) for the irritability domain, 27.1 (IntQ = 12.5; 45.8) for the lethargy domain, 23.8 (IntQ = 9.5; 47.6) for the stereotypy domain and 17.7 (IntQ = 8.3; 37.5) for the hyperactivity domain. Irritability and hyperactivity are in the low (0–20) range, whereas lethargy and stereotypy are in the medium (20–40) range of challenging behaviours. As regards self-injurious behaviours, 19 participants (18%) had a high level of SIB, 17 (16%) a low level of SIB and 68 (65%) did not present any SIB.

Challenging behaviours were significantly related to the participants' cognitive level for the irritability ($P < .0001$), stereotypy ($P < .002$) and hyperactivity ($P < .0001$) domains, with more challenging behaviours among the young adults who had a lower cognitive level (see Table 2). There was no significant link between the lethargy domain and the participants' cognitive level. Similarly, the young adults who had no functional language were more likely to display irritability ($P < .009$), stereotypy ($P < .005$) and hyperactivity ($P < .001$), but not lethargy. There was a significant relationship between challenging behaviours at early adulthood and the CARS score for irritability ($P < .0001$), lethargy ($P < .001$), stereotypy ($P < .0001$) and hyperactivity ($P < .0001$). Gender was not related to challenging behaviours, but we found a significant link between sleep disorders and irritability ($P < .005$), stereotypy ($P < .002$) and hyperactivity ($P < .02$), as well as between gastrointestinal disorders and stereotypy ($P < .002$).

Self-injurious behaviours were significantly related to the participants' language ($P < .001$) and cognitive ($P < .004$) levels, as well as to the CARS score ($P < .0001$) (Table 3). Gender,

sleep or gastrointestinal disorders and epilepsy were not significantly related to the presence of SIB.

Predictors of challenging behaviours among young adults

Multiple linear regression and logistic regression were conducted to identify factors associated with the four ABC domains and the presence of SIB. All independent variables (best estimate DQ, CARS score, expressive language, sleeping disorders and gastrointestinal disorders) were introduced in the model. Only CARS score remained in the final regression model as a predictor of irritability ($R^2 = .283$, $F = 9.0$, $P < .0001$; $\beta = .86$), hyperactivity ($R^2 = .338$, $F = 1.2$, $P = .0002$; $\beta = .86$), lethargy ($R^2 = .165$, $F = .99$, $P = .0086$; $\beta = .99$) and stereotypy ($R^2 = .287$, $F = 6.5$, $P = .01$; $\beta = 1.1$). Gastrointestinal disorders remained in the final model as a predictor of stereotypy ($R^2 = .287$, $F = 4.75$, $P = .03$; $\beta = 10.9$).

The results of the logistic regression for SIB showed that the risk to have SIB was multiplied by 1.8 for the children who had a higher CARS score at T4 (IORa1 = 1.8; CI95% = [1.2–2.6]; unit = 5; $P < 0.001$). The risk to have SIB was also multiplied by 3.7 for children who used few words as compared to children who had a functional language at T4 (IORa1 = 3.7; CI95% = [1.0; 14.6]; $P = 0.02$). The percentage of concordance between the observed and predicted values is 78.3% and P value of Hosmer–Lemeshow goodness-of-fit test is 0.2 which shows good adequacy of our models.

Changes in challenging behaviours between adolescence (T3) and early adulthood (T4)

The scores at the ABC four factors were compared at T3 and T4. Results show no significant difference for the irritability/aggressiveness, lethargy/withdrawal and stereotypy domains. There was a significant decrease in the hyperactivity domain from T3 to T4, $P = .02$ (Table 4).

We also examined the qualitative changes in the ABC items from T3 to T4. Results showed a significant decrease in the items 39 (*will not sit still for any length of time*, $P = .025$) and 54 (*tends to be excessively active*, $P = .012$), which are part of the hyperactivity domain. We also found a significant decrease in the items 29 (*demands must be met immediately*, $P = .002$), 34 (*cries over minor annoyances and hurts*, $P = .004$) and 57 (*throws temper tantrums when he/she does not get own way*, $P = .022$), which are part of the irritability domain. Finally, there was an increase in only one item of the ABC, 32 (*sits or stands in one position for a long time*, $P < .001$), which is part of the lethargy domain.

Discussion

This study yields several insights regarding our understanding of the topography of challenging behaviours at early adult years in individuals with ASD. The results confirm the expectation that young adults with ASD display a range of challenging behaviours with about a third of subjects exhibiting self-injury. The severity of ASD (as measured on CARS) was significantly related to the four ABC domains of irritability, stereotypy, hyperactivity and lethargy, as well as to presence of self-injury, consistent with previous studies (Baghdadli *et al.* 2003; Baghdadli *et al.* 2008; Rojahn and Meier 2009). We observed significant relationships between the young adult's cognitive and language level and the

presence of challenging behaviours with respect to the three ABC domains of irritability, stereotypy, hyperactivity, as well as self-injury. There was no observed relationship between the cognition and language levels and the ABC lethargy domain. These observations suggest that lethargy, which refers to withdrawal, isolation and lack of emotional reactivity, behaviours that are likely to be part of the core ASD features, do not vary according to cognitive and language levels. In contrast, since irritability, hyperactivity and self-injury are not part of the core ASD symptoms, they are likely to represent features related to communicative deficits, difficulties in the environment or experiencing conditions that may cause physical discomfort and pain. As such, these behaviours are more likely to be related to cognitive and language levels. The stereotypy domain refers to repetitive motor behaviours that are often described in people with IDD, and, as the present findings suggest, seems to be mostly related to cognitive level.

The finding of sleep and gastrointestinal disorders being related to stereotypy is of particular interest. As suggested by Goldschmidt (2016), such challenging behaviours can be significant indicators of health care problems rather than a direct manifestation of the ASD condition. Finally, sleep disorders were related to irritability and hyperactivity which can easily be explained by the impact of these disorders on the ASD subject's state of arousal impacting daily activities.

As in child subjects with ASD, the present study affirmed that the ASD symptom severity among adult subjects was a significant predictor of co-occurrence of challenging behaviours (Baghdadli *et al.* 2003; Baghdadli *et al.* 2008). Another significant predictor was the presence of gastrointestinal disorders. This is consistent with reports of a high correlation between the presence of pain and the frequency and severity of stereotypes (Courtemanche *et al.* 2016), as well as challenging behaviours in general (Chaidez *et al.* 2014). Nevertheless, these variables together only explained at most 30% of the developmental variance observed in our study sample. Invariably, this means that other variables, not identified here, might explain the presence of challenging behaviours in adults with ASD. Additional research is needed to examine other influences, with particular relevance for the services and intervention in the community provided. The predictors of SIB were ASD symptom severity and level of language impairment, findings congruent with the prior reviews (Howlin *et al.* 2000; Murphy *et al.* 2005; Shea and Mesibov 2005; Murphy *et al.* 2009; Richards *et al.* 2012; Rattaz *et al.* 2015). It is of interest that in the previous collection times of the EpiTED cohort, when the participants were children (Baghdadli *et al.* 2003; Baghdadli *et al.* 2008), the main risk factors for SIB were ASD symptom severity and cognitive level. However, in the present study, if symptom severity remained a significant risk factor, language skills instead of cognitive skills predicted the presence of SIB. One possible explanation for this might be that self-injurious behaviours at adulthood are a symptom of underlying communicative deficits. These results emphasise the crucial role of communicative abilities and underlie many behavioural interventions for children with ASD aiming at developing communication in order to prevent subsequent challenging behaviours.

Our secondary study aim examining the effect of transition from adolescence to early adulthood on challenging behaviours showed no significant decreases in irritability, stereotypy, lethargy and self-injury across the 5-year follow-up period, with the exception of

decrease in hyperactivity. Anderson *et al.* (2011) has also described a decrease in hyperactivity, also noted among other neurodevelopmental diagnoses involving developmental delay. The qualitative analysis yielded a significant improvement in two items in the hyperactivity scale: *will not sit still for any length of time and tends to be excessively active*. These items refer to the motor control, an ability that improves with age in the typical development but at an earlier stage. Contrary to the Anderson *et al.* study (2011), there was no significant decrease in the irritability domain, but improvement was noted for three items: *demands must be met immediately, cries over minor annoyances and hurts and throws temper tantrums when he/she does not get own way*. For individuals with ASD, these items reflect promising ability to tolerate frustration that also has been noted to increase over chronological age during development, which may reflect a delayed course as compared to general population. As regards to lethargy, we did not find an increase as was noted in the Anderson *et al.* study (2011), but rather a global stability of lethargy scores. However, there was a significant increase in one item of the lethargy domain: *sits or stands in one position for a long time*. This item refers to idiosyncratic catatonia-like symptoms that may be seen among subjects with severe IDD. We can hypothesize that this may have also increased in our study population as many young adults had co-occurring severe IDD. This may be due to the fact that when the EpiTED study began 20 years ago, early diagnosis and intervention were not the norm in France and more severe forms of ASD were likely to be diagnosed and included. We found no decrease in the stereotypy domain, suggesting that there is no decline in repetitive behaviours from adolescence to young adulthood in our population. The same result was found in a study by Piven *et al.* (1996) in adolescents and young adults without ID/IDD; these authors suggested that the proportion of subjects showing improvement in communication and social behaviours was significantly higher than the proportion showing improvement in ritualistic and repetitive behaviours. An alternative hypothesis is that such a decline exists, but appears later in the life course, in middle adulthood (Shattuck *et al.* 2007). Finally, as regards self-injury, we found no decrease from adolescence to early adulthood. Congruently with our results, a few studies reported no decrease in self-injury at adolescence (Richards *et al.* 2016). Some authors even suggested that adults with ASD had increased risk for engaging in self-injury as compared to adolescents (Maddox *et al.* 2017). However, studies about the topography of SIB in ASD in adulthood remain rare, and future work is required to help elicit an improved understanding of the course of SIB symptoms in adulthood.

There are several limitations to the present study. First, the data presented here consists of a cross-sectional and longitudinal subset from a much larger EpiTED cohort; the observations are part of a prospective follow-up study whose aims were to examine the heterogeneity of developmental trajectories among ASD subjects (Baghdadli *et al.* 2012). Although there is inevitably potential bias linked to the fact that the subjects were not recruited at random and data reflect period effects, the diagnoses of ASD, cognitive level and language were confirmed as part of this study. Second, the ABC was intended as a measure of symptom changes in response to drug trials and not as a descriptive measure of problem behaviour, although many studies use it this way. Moreover, the set of variables inherent in the ABC domains reflect reports by parent informants rather than direct and blinded observation by trained raters. Inevitably, caution is advised in interpretation of the ABC reports as they

reflect a degree of parental subjectivity. Nonetheless, they represent the closest naturalistic reports of home behaviours ascertained by means of a structured checklist validated in the French (international) language. Third, our measure of the cognitive level was not made using state of the art measures, as in cases in which an assessment could not be completed, a best clinician estimate of developmental level was made. This limitation is due to the fact that the existing psychometric tests are not well adapted to all individuals with ASD.

In summary, the results of the present study indicate that challenging behaviours persist throughout adulthood, with no significant decrease in challenging behaviours from adolescence onwards, except for hyperactivity. The severity of ASD is a key risk factor for co-occurrence of challenging behaviours, and the lower degree of language attainment is a risk factor for self-injurious behaviours. The presence of gastrointestinal disorders predicts stereotypy, reflecting the specific influence of medical comorbidities on challenging behaviours in ASD. These results underscore the need to enhance opportunities for ASD subjects to better communicate their discomforts and pain. Overarching general principle in interventions ought to be development of 'ASD friendly environments' suitable to an individual subject's cognitive and language abilities. Such an optimised intervention program is more likely to mitigate and prevent the secondary effects of challenging behaviours in ASD across the lifespan.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.
Flow chart of the EpiTED cohort.

Table 1 :

Young adult's characteristics at T4

	Mean $\pm$ SD
<i>Age (years)</i>	20.6 $\pm$ 1.5
	Median (IntQ *)
<i>Vineland (month)</i>	
Communication	29.5 (16;91)
Socialization	24.0 (9;73)
Daily Living Skills	49.5 (30;95)
<i>Autism severity (CARS total score)</i>	35 (25.5;42) %
<i>Gender</i>	
Boy	84.9
Girl	15.1
<i>Best estimated IQ</i>	
1. Severe Intellectual Disability (DQ < 40)	64.7
2. Moderate Intellectual Disability (40 $\leq$ DQ < 55)	5.9
3. Mild Intellectual Disability (55 $\leq$ DQ < 70)	3.9
4. Without Intellectual Disability (DQ $\geq$ 70)	25.5
<i>Educational level</i>	
Without qualification	83.8
Vocational/technical school	5.7
High school diploma	7.6
College / University	2.3
<i>Expressive speech</i>	
Functionnal language	50.9
Words	17.9
Mute	31.2
<i>Sleeping disorders</i>	
Presence	39.6
Absence	60.4
<i>Gastrointestinal disorders</i>	
Presence	35.85
Absence	64.15
<i>Epilepsy</i>	
Presence	15.1
Absence	84.9

* IntQ = (Q25; Q75)

Table 2

Relationship between challenging behaviours and clinical variables at T4

	Irritability		Lethargy		Stereotypy		Hyperactivity	
	Median (IntQ [*])	P value	Median (IntQ)	P value	Median (IntQ)	P value	Median (IntQ)	P value
Best estimate DQ								
1. Severe intellectual disability (DQ < 40)	24.4 (11.1; 42.2)	.0001	31.25 (14.6; 47.9)	0.3	38.1 (14.3; 57.1)	0.002	29.2 (12.5; 45.8)	.0001
2. Moderate intellectual disability (40 < DQ < 55)	12.2 (8.9; 17.8)		29.2 (22.9; 35.4)		16.7 (9.5; 38.1)		12.5 (8.3; 16.7)	
3. Mild intellectual disability (55 < DQ < 70)	4.4 (1.1; 18.9)		17.7 (6.25; 31.25)		23.8 (9.5; 38.1)		13.5 (3.1; 29.2)	
4. Without intellectual disability (DQ ≥ 70)	4.4 (0.0; 13.3)		25.0 (8.3; 41.7)		14.3 (0.0; 23.8)		8.3 (4.2; 14.6)	
Expressive language								
Speech	13.3 (4.4; 28.9)	0.009	27.1 (12.5; 45.8)	0.4	19.05 (9.5; 38.1)	0.005	14.6 (6.25; 31.25)	0.001
No speech	26.7 (12.2; 42.2)		33.3 (14.6; 45.8)		47.6 (11.9; 57.1)		33.3 (15.6; 51.0)	
Gender								
Man	17.8 (4.4; 33.3)	0.7	27.1 (12.5; 45.8)	0.8	23.8 (9.5; 47.6)	0.5	18.75 (8.3; 37.5)	0.6
Woman	22.2 (2.2; 44.4)		27.1 (10.4; 45.8)		38.1 (0.0; 52.4)		14.6 (8.3; 33.3)	
Gastrointestinal disorders								
Absence	15.6 (4.4; 31.1)	0.1	25.0 (12.5; 41.7)	0.2	19.1 (9.5; 38.1)	0.002	16.7 (6.25; 37.5)	0.2
Presence	20.0 (11.1; 35.6)		33.3 (12.5; 47.9)		42.9 (19.1; 57.1)		21.9 (12.5; 43.75)	
Sleeping disorders								
Absence	11.1 (2.2; 31.1)	0.005	25.0 (14.6; 41.7)	0.4	14.3 (9.5; 38.1)	0.002	14.6 (6.3; 31.3)	0.02
Presence	24.4 (13.3; 40.0)		33.3 (10.4; 47.9)		38.1 (19.1; 57.1)		22.9 (12.5; 47.9)	
Epilepsy								
Absence	15.6 (4.4; 33.3)	0.4	29.2 (16.7; 45.8)	0.3	23.8 (9.5; 47.6)	0.8	16.7 (8.3; 37.5)	0.3
Presence	22.2 (6.7; 40.0)		12.5 (8.3; 35.4)		23.8 (4.8; 57.1)		33.3 (8.3; 47.9)	
	$r(\text{Spearman})^{\dagger}$	P value	$r(\text{Spearman})$	P value	$r(\text{Spearman})$	P value	$r(\text{Spearman})$	P value
Symptom severity	0.52	.0001	0.32	0.001	0.50	.0001	0.54	.0001

Significant associations (P value < .05) are presented in bold.^{*} IntQ = (Q25; Q75).[†] r = Spearman's rank correlation.

Table 3

Relationship between SIB and clinical variables at T4

At time 4	1. Without SIB			2. Low SIB			3. High SIB			P value	Post hoc test (Bonferroni)
	N	Median (IntQ*)	%	N	Median (IntQ*)	%	N	Median (IntQ*)	%		
Autism severity (CARS total score)	66	28.7 (25;37)		17	38.5 (37;42)		19	44 (32;48.5)		.0001	1 2.3
Best estimate DQ											
1. Severe intellectual disability (DQ < 40)	34	52.3		14	87.5		17	89.5		.004	1 2.3
2. Moderate intellectual disability (40 < DQ < 55)	4	6.2		2	12.5		—	—			
3. Mild intellectual disability (55 < DQ < 70)	4	6.2		—	—		—	—			
4. Without intellectual disability (DQ ≥ 70)	23	35.4		—	—		2	10.5			
Expressive language											
Functional language	43	63.2		4	23.5		6	31.6		.001	1 2.3
Words	7	10.3		8	47.1		4	21.1			
Mute	18	26.5		5	15.6		9	47.4			
Gender										.05	
Male	62	91.2		12	70.6		15	78.9			
Female	6	8.8		5	29.4		4	21.1			
Gastrointestinal disorders										0.4	
Absence	43	63.2		9	52.9		14	73.7			
Presence	25	36.8		8	47.1		5	26.3			
Sleeping disorders										0.5	
Absence	44	64.7		9	52.9		10	52.6			
Presence	24	35.3		8	47.1		9	47.4			
Epilepsy										0.3	
Absence	58	85.3		13	76.5		18	94.7			
Presence	10	14.7		4	23.5		1	5.3			

Significant associations (P value < .05) are presented in bold.

* IntQ = (Q25; Q75).

Table 4

Changes in the four ABC domains between T3 and T4

	T3 (<i>n</i> = 106)		T4 (<i>n</i> = 104)		Change (T4 – T3) <i>n</i> = 104	
	Median	IntQ	Median	IntQ	Mean	<i>P</i> value
Irritability/aggressiveness	17.8	(8.9–37.8)	17.8	4.4–33.3	–2.6	17.6 0.1
Lethargy/withdrawal	25	(14.6–37.5)	27.1	12.5–45.8	2.6	20.9 0.2
Stereotypy	28.6	(14.3–47.6)	23.8	9.5–47.6	–1.3	25.7 0.6
Hyperactivity	22.9	(10.4–45.8)	17.7	8.3–37.5	–5.0	21.1 0.02

IntQ, interquartile (Q25; Q75).