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Comparing residential programmes for adults with autism spectrum disorders and intellectual disability: outcomes of challenging behaviour and quality of life

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Abstract

Background Owing to methodological issues, little research has been conducted to examine quality of life (QoL) as a treatment outcome in autism spectrum disorders (ASD) and intellectual disabilities (ID). This study was conducted to combine QoL measures and objective observations of challenging behaviours (CB) in order to evaluate changes over time in adults with ASD and ID who were treated in two different residential programmes; we hypothesised that a decrease in CB would be related to an improved QoL.
Method In a longitudinal study (45 months), we followed 31 adults with ASD and ID who had been integrated into two residential programmes [Autism Programme with a Structured Method (PAMS) vs. traditional programme for ID (No-PAMS)] for 2–19 years. QoL [Quality of Life Inventory in a Residential Environment (IQVMR)] and severity of autistic features (Childhood Autism Rating Scales) were evaluated annually. CB, as measured by the Aberrant Behaviour Checklist (ABC), including stereotypic behaviour and inappropriate speech, were repeatedly assessed every 3 months.
Results Observed separately, the groups' results were different. In the PAMS programme, stereotypic behaviour and inappropriate speech (ABC scores) significantly decreased, and the IQVMR total score increased; in contrast, in the comparison group, ABC scores did not change and the IQVMR total score decreased. In all, three mixed-effect ANCOVAs partially confirmed that the PAMS programme had an effect on CB and that QoL improvement did not directly depend on the type of programme but on reducing CB as measured by the ABC.
Conclusion The PAMS programme has a positive and indirect influence on QoL by reducing CB.

Keywords Aberrant Behaviour Checklist, adults, autism spectrum disorders, challenging behaviours, intellectual disability, quality of life

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Introduction

Autism spectrum disorders (ASD) are a lifelong disability that requires treatment which is specific to each life stage. It is a spectrum of neurodevelopmental disorders; the core symptoms, called the triad of impairment (Wing 1988) (i.e. impaired communication, social impairments and repetitive/stereotyped behaviours), persist into adulthood (Billstedt *et al.* 2007; Matson *et al.* 2008). Across the world, one million children are diagnosed with autism (Burgess & Gutstein 2007), and prevalence rates are increasing (Chakrabarti & Fombonne 2005; Fombonne 2005; Baird *et al.* 2006; Rice 2009). Thus, it is important to focus on treatment, as these children will soon become adults. Moreover, the prevalence of intellectual disability (ID) among people diagnosed with ASD is high (Fombonne 2005). Consequently, this co-occurrence increases the risk of poor outcomes (Howlin *et al.* 2004) and behavioural problems like aggression, self-injury, tantrums and destruction (La Malfa *et al.* 2004; Billstedt *et al.* 2005; Allen 2008; Totsika *et al.* 2008) which, by extension, impact people's quality of life (QoL) (Allen 2008; Garcia-Villamisar & Dattilo 2010).

Many adults with autism did not benefit from early intervention during childhood because intervention did not exist at that time. This resulted in poor outcomes, as substantial behaviour problems were common and are cause for concern in adulthood (Billstedt *et al.* 2005). Behaviour problems, also called challenging behaviours (CB) (Emerson 2001), can be problematic when they are dangerous, their severity is inappropriate, they lead to an additional handicap, they result in the person being excluded from residential services, they cause significant stress to others, or they decrease the QoL (Allen 2008). QoL and CB are negatively correlated in the ID population (Symons *et al.* 1999; Emerson 2001; Robertson *et al.* 2004). In the ASD and ID populations, CB have been shown to be predictors of poor language expression, poor quality of social interaction and a previous diagnosis of autism/ASD (Murphy *et al.* 2005). This population is a significant challenge for staff in residential settings, as behavioural problems can be long-term (Van Bourgondien & Schopler 1990).

Studies and case reports on programme effectiveness in adults with ASD and ID illustrate different methods for measuring determinant outcomes, such as skill acquisition, autonomy or reduction of inappropriate behaviour (Van Bourgondien & Elgar 1990; Reese *et al.* 1998; Persson 2000; Van Bourgondien & Reichle 2001; Siaperas & Beadle-Brown 2006). For example, Van Bourgondien *et al.* (2003) observed a group of six adults with autism and moderate to profound ID living in a residential programme that was based on the Treatment and Education of Autistic and related Communications Handicapped Children (TEACCH) model. They compared this group to three other types of residential settings showing increased family satisfaction and decreased behavioural problems, but found no improvement on the Adolescent and Adult Psycho-Educational Profile (AAPEP) scores over time, regardless of the setting. They concluded that these positive changes reflected a better QoL.

Fox *et al.* (2009) emphasised the importance of multiple approaches for this challenging population and showed the efficacy of a community-based accommodation programme. They observed that the occurrence of CB decreased significantly for four adults with autism and severe to profound ID, and stated that the programme had a positive impact on QoL.

In a longitudinal and prospective study that lasted 3 years, Galli Carminati *et al.* (2007a,b) assessed changes in CB in adults with ASD and moderate to profound ID living in an individualised and structured residential programme. The authors used the Aberrant Behaviour Checklist (ABC) to evaluate CB of two groups of 10 residents each (Aman *et al.* 1985) and observed a significant decrease in the social withdrawal sub-scale for one of the two groups.

Quality of life for people with ASD and ID is also an important measure of treatment outcomes in residential settings, but little research has been conducted on this population (Burgess & Gutstein 2007; Gerber *et al.* 2008; Totsika *et al.* 2010). This is probably because behavioural challenges appear during the measurement of QoL, particularly among the severe and profound ID population who cannot understand or respond meaningfully to questions designed to gauge subjective QoL (Campo *et al.* 1997). To our knowledge, only two studies have addressed QoL outcomes and programme effectiveness. The first is a 2.5-year longitudinal study (Persson 2000), investigating the QoL of seven adults with autism and ID, as measured by the AAPEP scale, and indirectly examining behaviours, skills and independence (Mesibov *et al.* 1989a). The author found significant progression in each of the AAPEP scales for the seven men, regardless of their age or intelligence levels, indicating that behaviour and independence measures are related to how people feel, and concluding that the participants' functional QoL had improved through this programme.

The second study included 37 adults with ASD and ID, as compared to a control (waiting list) group in a repeated-measures design, via direct and proxy respondents (Garcia-Villamisar & Dattilo 2010). The study used an appropriate QoL instrument [Spanish version Quality of Life Questionnaire (QoL-Q)] to evaluate the QoL and stress effects of a 1-year group leisure programme. The authors found significant stress reduction and increased QoL total scores as well as increased satisfaction and competence sub-scale scores. However, they found no significant changes in the empowerment and social integration sub-scales. They stated that these results could be due to insufficiently long or intensive treatment, as these are a central characteristic of autism. These results might also be explained by Rapley *et al.* (1998), who showed that if proxy scores were used for QoL-Q completion, the empowerment sub-scale should not be employed and raw scores of the social integration sub-scale should be adjusted downwards.

In the same way, Plimley (2007) sheds some light on the difficulties inherent in measurements of the ASD population, including the lack of QoL instruments that suitably define real problems and overcome the obstacles associated with communicative difficulties or the absence of language. This implies that a scale that limits subjective variables has a better chance to constrain proxy interpretation (Cummins 2002); in this vein, Plimley (2007) emphasises that the Comprehensive Quality of Life scale for intellectual/cognitive disability (Cummins 1997) and the QoL-Q (Schalock & Keith 1993) appear to be valid instruments. The author also noted that ASD features specific to individuals could confound the reliability of the results; further, she showed that even if those QoL instruments were validated for individuals with ID, most of the outcomes were not adapted for ASD. To overcome this problem, this author proposed that ASD-specific QoL domain variables and outcome indicators could help create a tool inspired by the work of Groden *et al.* (2001) on stress factors in ASD, which is sensitive to specific differences experienced by many with ASD. Although the QoL of people with severe and multiple disabilities is under-researched (Brown & Brown 2005), it can be utilised as a method to interpret data. In fact, Petry *et al.* (2005) stressed that people with profound multiple disabilities (PMD) have learning disabilities of a magnitude unmeasurable by standardised tests; hence, direct observation by a proxy is a commonly employed solution (Cummins 2002). Petry *et al.* (2005) confirmed the validity of the basic domains of QoL (the development and activities of physical, material, social and emotional well-being), but concrete indicators need to be adapted to the specific needs and characteristics of people with PMD (e.g. hygiene, nourishment, rest, technical aids, communication, basic security and individual attention; Felce & Perry 1995). In spite of the progress in evaluating objective QoL in a way that is appropriate for PMD, the QoL-PMD (Petry *et al.* 2007) might not be valid for ASD with ID as they do not share the same severe neuromotor dysfunctions and sensory disabilities associated with PMD.

In conclusion, to measure QoL in an adult ASD population with ID, we must keep in mind several important issues. First, to overcome the problems inherent to the ASD population, including communication problems, limited capacity to make choices, and limitations produced by the triad of impairment, Schwartz & Rabinovitz (2003) demonstrate the importance of combining QoL evaluations with objective measures, such as challenging and adaptive behaviour scales. In maladaptive behaviours, the viewpoint of significant others is considered important (Nota *et al.* 2006). Further, Rapley *et al.* (1998) and Plimley (2007) indicate that we must carefully interpret some QoL sub-scales. Second, to constrain the interpretations of proxies, the QoL measure should include a large number of objective measures (Schalock 1993; Cummins 2002). Third, to overcome cross-cultural challenges, QoL measures have been translated; however, the translation of meanings can be problematic (Verdugo *et al.* 2005): hence, it is important to use a scale validated in the participants' language. Therefore, measuring the relationship between QoL and CB to evaluate programme effectiveness appears to be one way of responding to this challenge.

Although considerable evidence documents the importance of long-term CB management as a way to enhance QoL, it has not been explored in people with ASD and ID; specifically, the relationships between these variables in two types of residential programmes for this population have never been explored in the literature. By extension, this allows us to understand what long-term programmes and types of staff training and support are most effective for this challenging population.

This study aimed to explore whether adults with ASD and ID, who were treated for several years in two different types of residential programmes [the Programme Autisme Méthode Structurée (Autism Programme with a Structured Method) PAMS programme vs. the traditional programme (No-PAMS)], benefited with respect to CB and QoL. The main hypothesis was that a more structured residential programme is positively associated with a more substantial decrease in CB and a better QoL outcome. A prospective and repeated-measures design was used during the 4 years, and we explored: (1) changes in CB in both programmes; (2) changes in the QoL scores in both programmes; and (3) whether changes in QoL occurred directly or through CB.

Methods

Participants

In this study, 31 adults (23 men, eight women) were included. The participants lived in two different residences: PAMS ($n = 20$) and No-PAMS ($n = 11$). Ages ranged from 24 to 62 years (mean = 39.7 ± 10.5). There was a significant difference in the ages of the two groups at the time of their inclusion in the study ($F_{1,30} = 10.002$; $P = 0.004$; PAMS mean age = 43.6 ± 9.5 years; No-PAMS mean age = 32.6 ± 8.4 years). All participants met the diagnostic criteria for pervasive developmental disorders (PDD) and ID, as described by the International Classification of Diseases ICD-10 of the World Health Organization (1994). Diagnoses were established via clinical evaluation by an experienced clinical psychologist and were confirmed by a second independent evaluation made by a senior psychiatrist, who was independent from the present study. The Childhood Autism Rating Scale (CARS) (Schopler *et al.* 1988) was used to confirm the diagnoses and establish a symptom severity rating for each participant. Cut-off references were based on a study by Mesibov *et al.* (1989b) using CARS with adults. No between-groups differences in the total CARS scores were found at the time of their inclusion in the study ($F_{1,30} = 0.146$; $P = 0.705$). The CARS total scores ranged from 30 to 52 (mean = 40.6 ± 6.2). Among our ASD participants, on the basis of the ICD-10 diagnostic criteria, childhood autism represented 48% (15/31) of the sample; unspecified PDD, 35% (11/31); fragile X syndrome, 10% (3/31); and other childhood disintegrative disorders, 7% (2/31). Moreover, according to ICD-10, ID was moderate for four participants (13%), severe for 20 (64%) and profound for seven (23%). The male-to-female ratio was 2.7:1, comparable to studies on autism prevalence for severe to profound ID (Yeargin-Allsopp *et al.* 2003; Matson *et al.* 2008).

The Ethical Committees of the University Hospitals of Geneva and of the Wallis District approved the study protocol. A precise and in-depth oral explanation of the purpose of the study was provided to participants' families during individual sessions. They were also informed that if they did not consent, their diagnosed family member would not be included in the study but would still be included in the residential programme. All the participants had next of kin who could legally provide consent on their behalf.

Measures

Quality of Life Inventory in a Residential Environment

The 'Inventaire de Qualité de Vie en Milieu Résidentiel' [Quality of Life Inventory in a Residential Environment (IQVMR)] (Tremblay & Martin-Laval 1997) was chosen to measure QoL because it was written in the relevant language and because it had been psychometrically validated. This inventory was elaborated for individuals of any age who were in need of substantial support and who lived outside the family environment, and it specifically addressed the needs of people with severe and profound ID. Tremblay & Martin-Laval (1997) were guided by studies by Caldwell & Bradley (1979), Heal & Chadsey-Rusch (1985) and the Institut Québecois de la Déficience Intellectuelle (1989). Their questions aim to determine if the system of assistance and support has been adapted to physical or intellectual disability. The inventory comprises 80 items and covers eight different general categories – individuality, self-determination, environment, health/security, social integration, leisure/recreation, specific needs, and staff training/supervisory control – from which a total score is calculated. Responses are graded on a 3-point scale, in which 0 = unattained goal, 1 = partially attained goal and 2 = attained goal. Each domain has 10 questions and a domain sub-score ranges from 0 to 20 points. The total score ranges from 0 to 160; the higher the scores, the higher the QoL. The IQVMR score was calculated for each participant by an experienced psychologist who collected the staff evaluations (a consensus of two referents). We controlled for respondents who had supported each individual for at least 6 months and who were in regular, close contact.

Tremblay & Martin-Laval (1997) document the scale's construct validity using factor analysis. It confirmed the structure with satisfactory loadings for each factor, ranging from 0.81 to 0.98, and reported an adequate internal reliability (Cronbach's $\alpha = 0.90$; inter-rater agreement = 0.80; test–retest reliability = 0.84).

Aberrant Behaviour Checklist

The ABC (Aman *et al.* 1985) was designed for a population of individuals with medium to profound ID. It includes 58 items graded on a 4-point scale, from 0 (the behaviour is not at all a problem) to 3 (it is a very significant problem), and it covers five factors, including irritability, lethargy, stereotypic behaviour, hyperactivity and inappropriate speech. The higher the score, the greater the behaviour problem. The ABC has good internal consistency (α range: 0.86 to 0.94), inter-rater reliability (r range: 0.55 to 0.69) and test–retest reliability (r range: 0.96 to 0.99). The ABC was completed for each participant by an experienced psychologist who collected the staff evaluations.

Childhood Autism Rating Scale

The CARS (Schopler *et al.* 1988) was developed to identify children with autism and to provide a differential diagnosis compared to developmental disorders without the autism symptoms. This scale consists of behavioural evaluation by a psychologist, as well as observations provided by educational staff in 15 dimensions, including human relatedness, relation to objects and adaptation to change; it also provides a total severity score. These dimensions are evaluated on a 4-point scale, from 1 = normal behaviour to 4 = severe behaviour problem. The total score indicates one of three diagnostic categories: non-autistic (0–26), moderate autism (26.5–33) and severe autism (33.5–60). Cut-offs were validated on adult scores (Mesibov *et al.* 1989b) (Cronbach's $\alpha = 0.90$; inter-rater agreement = 0.80; test–retest reliability = 0.84).

French versions of these scales were used in this study.

Intervention/programme characteristics

Autism Programme with a Structured Method

Autism Programme with a Structured Method was a 24-h residential programme for low-functioning adults with ASD. It provided several apartments for six to eight residents, and the staff intervened in both the residential homes and workshops to provide continuity in the environment and enhance time management and strong team coherence. The team was composed of educators with specific theoretical and practical ASD training. At the beginning of this study, the PAMS residents had been participating in the PAMS programme for an average of 3.5 years (range: 2.0–5.0 years). Objectives were chosen to strengthen the development of autonomy.

Autism Programme with a Structured Method is inspired by several models. First, PAMS contains the three typical components of the TEACCH model by Schopler & Mesibov (1985), including structural teaching that focuses on independent work skills, strategies to enhance visual processing to clarify space (spatial boundaries) and time (individualised visual schedule), and a communication system based on gestures or pictures. The residents' capacities are determined via the French version of the Psycho-Educational Profile – Revised (Schopler

& Tréhin 1994) or AAPEP (Mesibov *et al.* 1997). Then, an adapted programme for their day-to-day activities, leisure and residential environment is implemented. It is important to note that there is often too much pressure on persons with ASD to fit into a programme. In contrast, the PAMS philosophy was for the structure to adapt itself to the resident. The programmes included domestic activities such as eating breakfast, bathing, walking or watching TV, or educational activities such as basic constructions and categorisation of objects (Galli Carminati *et al.* 2007a). PAMS programme was based on individualised representations of objects, including pictures or pictograms, depending on the cognitive and developmental level of the resident. Ultimately, it aimed to find the correct stimulation to gain the desired results; for example, if Cathy walked around and hyperventilated during the hour before lunch, structured leisure activities during this period helped her to reduce those behaviours. This programme was used with 100% of the participants.

Second, PAMS worked with the Picture Exchange Communication System (PECS) (Bondy & Frost 1998), which is a form of augmentative and alternative communication (AAC) created over 20 years ago. AAC is a broad term for forms of communication, including electronic devices, picture boards or sign language, which supplement or enhance speech. PECS provides a functional communication system on the basis of the philosophy that, to ensure that a person learns to take the initiative in communicating spontaneously, one should avoid anticipating their needs and wishes and instead create opportunities for communication. It first teaches ways of approaching the communicative partner and delivering a message in exchange for something that is reinforcing. Its second focus is on enhancing spontaneity. Then, it teaches the individual to discriminate between symbols, by increasing the number of pictures available and monitoring the accuracy of use via frequent correspondence checks. Finnegan *et al.* (1987) demonstrate how teaching adolescents with autism to use PECS had a rapid impact on reducing the rate of aggression and similar problem behaviours, including their occurrence in community settings. For example, to start his breakfast, John learned to ask by spontaneously showing pictures of a knife, bread, butter and jam; after advanced learning, he associated the words with the pictures. PECS was used with 10% of participants, those who presented lower verbal ability (e.g. non-functional and echolalic expressive communication or severe expressive communication deficit).

Third, PAMS was inspired by Willaye & Magerotte (2008), who based their intervention manual on the research conducted by Borthwick-Duffy and the Hester Adrian Research Center. The authors proposed a model providing a functional assessment tool, such as an observation checklist, to analyse the behavioural environments, precursors, behaviours and consequences. They then suggested that strategies should be individually designed to create a predictable environment and to prevent or decrease the frequency of CB. Strategies could include changing the environment, teaching new skills, providing structured adaptive activities and reinforcers and providing positive behavioural support to the person. For example, just after waking up, Mark would address the first educator and ask, ‘Counting mamy?’ When the educator delayed in responding to his demand, he repeated this question loudly to all the residents until someone responded. An analysis showed that he remained anxious until he had counted the days before he could see his mother; thus, an individualised anxiety reduction programme was developed. First, he ate his breakfast; then, he spent an individualised moment with an educator and his diary, in which he counted the days until he could see his mother and was asked questions about his counting. This supportive process was used with 100% of the participants.

No-PAMS

The comparison group, No-PAMS, was a 24-h residential programme and was part of a major medico-social institution for children and adults with ID; it provided a traditional programme of care/treatment. No-PAMS was composed of two apartments for 8–10 residents, and there were two different staff groups for residential and work/leisure activities. No-PAMS residents had lived in their residential homes for an average of 10.8 years (range: 5.5–19.17 years), since childhood. Day-to-day activities occurred in groups and objectives were chosen to strengthen the processes of socialisation.

No-PAMS was based on systemic pedagogy (Borel *et al.* 1998) and a variety of approaches, including the developmental approach (Lelord *et al.* 1989; Luissier & Flessas 2001) and individualised approach (Montreuil & Magerotte 1994). In some cases, TEACCH and functional assessments were used, but these were not as systematic as in PAMS. PECS was not used at all. No-PAMS was inspired by treatment adapted to PMD; programmes were individualised and adapted to the cognitive level, and they aimed to decrease stimulation as much as possible.

Procedure

The present study extended previous longitudinal studies in which authors explored the changes in CB after implementation of PAMS treatment (Galli Carminati *et al.* 2007a,b), and the CB and QoL levels in residential programmes were evaluated by family members and programme staff (Gerber *et al.* 2008). It was not possible to randomly assign the residents to study groups because participants in the No-PAMS group lived in a different district from those in the PAMS group. Several institutions were asked to participate as a control group. A single positive response was obtained for the No-PAMS group. Our study of QoL began in March 2005 and ended in December 2008.

We included participants who underwent treatment for a minimum of 2 years. For the PAMS group, one of the 20 participants was included in the study after 2005, and four were excluded from the study before 2008. In the No-PAMS group, two of 11 participants were included after 2005, and two were excluded.

Staff members were blind to the study's hypothesis and were allowed to change programmes and activities depending on the residents' needs.

Data collection for the ABC was carried out at 3-month intervals. All participants were observed by the socio-educational team for 1 week, and the ABC was completed by a psychologist. The IQVMR was completed at the beginning of the study, after the first year, and at the end of the study. The CARS was completed approximately once a year.

The psychotropic medication taken by each participant was recorded every 3 months. Treatment was stable, reduced, increased, introduced or discontinued depending on the participant's clinical state. To simplify these data, in this report, only two occurrences were analysed for each participant, the first at the beginning of the study in March 2005, and the second at the end of the study in December 2008. For ethical reasons, the protocol did not impose any treatment restrictions. Moreover, our study did not aim to measure the impact of the psychotropic treatment, even if it had a potential effect on CB. Only the psychotropic medications were recorded, even though some participants were also taking medications for somatic or physical problems.

Data analysis

We first verified changes in the ABC, CARS and IQVMR scores for each of the two groups – PAMS and No-PAMS – using non-parametric tests owing to the heterogeneity of the variance; we used the Wilcoxon signed-rank test for intra-groups repeated measurements (2005 vs. 2008) and Mann–Whitney *U*-tests for between-group measurements. For an easier comparison of the five ABC factors, we divided the sum for each factor by the number of items belonging to each factor (e.g. 15 items in irritability factor and four items in inappropriate speech). To evaluate the direct or indirect effects of the treatment on QoL, we used three mixed linear models with the subject as the random effect. As each subject was measured several times in our repeated-measurement design, we used a mixed-effect ANCOVA, and all analyses were adjusted for age. The first (a Crude Model) included only treatment as the fixed effect; the second (a Crude Model) included only the CB: the five factors of the ABC; and the third (a Full Model) included both the treatment and the CB. Thus, if the PAMS treatment influenced QoL through its effect on CB, treatment should be significant in the first model but not in the Full Model, and CB should be significant in the second and third analyses.

Results

Table 1 summarises the average scores for each of the ABC factors, CARS total score and IQVMR total score.

Table 1 Mean scores (SD) on the ABC by factor, CARS and IQVMR in 2005 and 2008

	2005		**2008**		**Wilcoxon signed-rank test**	
	n	**Mean (SD)**	***n***	**Mean (SD)**	***Z***	***P***
PAMS group						
Irritability	19	0.69 (0.6)	16	0.53 (0.6)	–0.980	0.327
Lethargy	19	0.75 (0.6)	16	0.58 (0.4)	–0.944	0.345
Stereotypic behaviour	19	1.14 (0.7)	16	0.62 (0.4)	–2.993	0.022*
Hyperactivity	19	1.00 (0.8)	16	0.55 (0.5)	–1.413	0.158
Inappropriate speech	19	0.89 (0.9)	16	0.81 (0.8)	–1.980	0.048*
CARS	19	41.9 (7.2)	16	42.3 (5.7)	0.596	0.551
IQVMR total score	19	131.1 (11.5)	16	148.2 (10.5)	2.841	0.004**
IQVMR individuality	19	18.42 (1.2)	16	19.38 (1.3)	2.525	0.012*
IQVMR self-determination	19	13.95 (4.4)	16	16.12 (3.6)	2.033	0.042*
IQVMR environment	19	17.00 (2.1)	16	18.5 (1.2)	1.902	0.057
IQVMR health/security	19	18.79 (1.0)	16	19.8 (0.5)	2.546	0.011*
IQVMR social integration	19	12.42 (3.8)	16	17.31 (1.9)	2.703	0.007**
IQVMR leisure/recreation	19	14.79 (3.2)	16	17.7 (2.7)	2.133	0.033*
IQVMR specific needs	19	19.68 (0.8)	16	19.8 (0.5)	0.680	0.496
IQVMR staff training/ supervisory control	19	16.05 (2.0)	16	19.56 (1.5)	2.680	0.007**
No-PAMS group						
Irritability	9	0.55 (0.4)	9	0.40 (0.3)	–0.943	0.345
Lethargy	9	1.11 (0.4)	9	0.79 (0.4)	–1.532	0.125
Stereotypic behaviour	9	1.24 (0.5)	9	1.06 (0.3)	–0.954	0.340
Hyperactivity	9	1.02 (0.7)	9	0.72 (0.4)	–1.261	0.207
Inappropriate speech	9	0.14 (0.3)	9	0.25 (0.5)	1.342	0.180
CARS	9	41.2 (6.3)	9	43.0 (7.0)	1.727	0.084
IQVMR total score	9	132.9 (3.2)	9	125.9 (7.1)	–2.670	0.008**
IQVMR individuality	9	17.11 (0.9)	9	15.20 (0.9)	–2.701	0.007**
IQVMR self-determination	9	17.78 (0.7)	9	13.44 (3.1)	–2.680	0.007**
IQVMR environment	9	15.78 (0.4)	9	15.33 (0.7)	–1.633	0.102
IQVMR health/security	9	19.00 (0.0)	9	19.78 (0.7)	2.333	0.20*
IQVMR social integration	9	12.44 (1.4)	9	11.22 (1.5)	–1.845	0.65
IQVMR leisure/recreation	9	15.78 (2.2)	9	13.89 (2.2)	–2.329	0.20*
IQVMR specific needs	9	20.00 (0.0)	9	20.00 (0.0)	1.000	–
IQVMR staff training/ supervisory control	9	15.00 (0.0)	9	17.00 (0.0)	3.000	0.003**

* Significance $P < 0.05$; ** Significance $P < 0.01$.

ABC, Aberrant Behaviour Checklist; CARS, Childhood Autism Rating Scales; IQVMR, Quality of Life Inventory in a Residential Environment; PAMS, Autism Programme with a Structured Method.

For the PAMS group, stereotypic behaviour was significantly higher in 2005 (mean = 1.14) than 2008 (mean = 0.62; $z = -2.993$; $P = 0.022$). This is also true for inappropriate speech, which was higher in 2005 (mean = 0.89) than 2008 (mean = 0.81; $z = -1.980$; $P = 0.048$). Changes observed on other ABC sub-scales were not significant. For the No-PAMS group, no significant reduction on ABC sub-scales was observed (Table 1).

The level of autism remained stable over time (Table 1), and the severity of autism was identical between groups in 2005 ($z = 0.372$; $P = 0.730$) and 2008 ($z = 0.340$; $P = 0.760$). For the IQVMR, the staff evaluation's total score increased significantly over time for the PAMS group ($P < 0.01$), whereas it decreased significantly for the No-PAMS group ($P < 0.01$). For the IQVMR sub-scales for the PAMS group, the Wilcoxon signed-rank test revealed significant increases between 2005 and 2008 on most sub-scales except environment and specific needs. For the No-PAMS group, we observed significant increases in staff training and health/security sub-scales and significant decreases in individuality and leisure sub-scales (see Table 1).

Treatment (PAMS vs. No-PAMS), when adjusted for age, was a significant predictor of QoL, in that being treated via PAMS increased QoL by 9.23 points (see Table 2). Further, increased lethargy, stereotypic behaviour and hyperactivity led to lower QoL. Almost certainly, owing to a small sample size, only stereotypic behaviour itself led to a significantly lower QoL; 1 additional point in stereotypic behaviour decreased QoL by 6.12 points. On the other hand, an increase in irritability was significantly associated with an elevated QoL. When treatment and CB were analysed together, only stereotypic behaviour remained significant. Thus, the effect of the PAMS treatment seemed to be on CB, and it only indirectly increased the QoL.

Such a decrease in stereotypic behaviours in the treatment group confirmed our hypothesis that a more structured environment is more strongly associated with a decrease in CB, even if a statistically significant decrease is observed in only one of the five factors.

Psychotropic treatment did not change during the study for two participants (10%) in the PAMS group, and for three (27%) in the No-PAMS group.

In brief, for the PAMS group, anxiolytics were stable for 30% of participants, increased or introduced for 15%, and discontinued for 5%. Atypical neuroleptics were stable for 45% and were decreased or discontinued for 50%. Typical neuroleptics were stable for 35%, increased or introduced for 25%, and decreased or discontinued for 20%. Antidepressants were stable for 20%, introduced for 20%, and decreased or discontinued for 10%. Mood stabiliser/antiepileptics are used for both conditions in the ASD population as epilepsy is frequent in this population (Danielsson *et al.* 2005); they were stable for 45%, increased or introduced for 25%, and decreased for 5%.

For the No-PAMS group, no anxiolytics were used. Atypical neuroleptics were stable for 10%. Typical antipsychotics were stable for 35%, increased for 20%, and decreased or discontinued for 20%. Antidepressants were stable for 20% and

Table 2 Mixed linear regression models evaluating the relationships between treatment, ABC scores and QoL

Treatment and ABC scores by factor (2005, 2006, 2008)	**Model 1 for QoL (adjusted for age, including treatment)**			**Model 2 for QoL (adjusted for age, including ABC)**			**Model 3 for QoL (adjusted for age, including treatment and ABC)**		
	Adjusted coefficient	***P***	**95% CI**	**Adjusted coefficient**	***P***	**95% CI**	**Adjusted coefficient**	***P***	**95% CI**
Treatment (PAMS vs. No-PAMS)	9.23	0.001**	(3.65; 14.81)				5.89	0.11	(−1.33; 13.10)
Irritability				7.71	0.04*	(0.42; 14.99)	6.95	0.06	(−0.31; 14.22)
Lethargy				−3.61	0.24	(−9.73; 2.51)	−1.99	0.54	(−8.36; 4.38)
Stereotypic behaviour				−6.12	0.02*	(−11.30; −0.94)	−5.72	0.03*	(−10.86; −0.58)
Hyperactivity				−5.06	0.12	(−11.43; 1.31)	−4.51	0.16	(−10.84; 1.83)
Inappropriate speech				0.03	0.91	(−3.32; 3.72)	−0.17	0.57	(−4.95; 2.72)

Significance * $P < 0.05$; ** $P < 0.01$.
ABC, Aberrant Behaviour Checklist; QoL, quality of life; PAMS, Autism Programme with a Structured Method.

introduced for 20%. Mood stabiliser/antiepileptics were stable for 20% and increased or introduced for 30%.

Discussion

Our findings showed that residential programmes have an impact on CB; treatment via the PAMS programme significantly decreased stereotypic behaviour and inappropriate speech after almost 4 years of observation, whereas no changes in CB were observed in the No-PAMS group. The lack of changes in ABC scores in the No-PAMS group confirmed our hypothesis, in the sense that no specific treatment maintained CB stability; instead, only specific treatment, such as PAMS, decreased specific persistent CB, such as stereotyped behaviours.

At the same time, the IQVMR total scores showed that staff evaluations increased in the PAMS group, whereas it decreased in the No-PAMS group. It is possible that, for the No-PAMS group, the fact that CB did not change after 3 years led the staff to assess a lower QoL; at the same time, in the PAMS group, a decrease in CB led to the evaluation of a better QoL. To test this relationship between CB and QoL levels, we conducted tests with mixed effects. Of the six sub-scales that significantly increased in the PAMS group, Rapley *et al.* (1998) explain that the empowerment (self-determination in the IQVMR) and social integration sub-scales should be interpreted with caution; moreover, while the health/security and staff training/supervisory control sub-scales increased significantly for the No-PAMS group, it appears that the sub-scales most sensitive to PAMS intervention were individuality and leisure/recreation.

These CB results cannot be explained by a change in ASD symptoms as, in both groups and throughout the study, the severity of the autistic symptoms, as measured by CARS, remained stable. However, interpretation of the results must include the significant differences in age between the treatment and non-treatment groups: the PAMS residents were significantly older than the No-PAMS residents. We were unable to determine predictive factors for age-related changes in CB, so it is possible that age had an impact on these results, although there are contradictory results in the literature. A study by Tonge & Einfeld (2003) shows that behavioural problems became less prevalent with maturity; however, their cohort was younger (8–18 years old) than the sample in our study. In a more recent study, Totsika *et al.* (2010) found that the lower skill levels observed in older adults (age > 50) with ID and ASD were not due to ageing but instead were associated with initially observed differences in behavioural problems and QoL assessments.

Therefore, ANCOVA, adjusted for age, showed that a decrease in CB could be related to an improved QoL as measured with the IQVMR. Interestingly, our results showed that high irritability was associated with a high QoL when considering both groups together. One explanation could be that irritability is a form of communication between the caregiver and the individual with ASD, even if it is inappropriate. This form of communication could lead to better quality of care from the caregiver and, consequently, to a better QoL for the resident.

The third analysis supported the hypothesis that, when considering CB, group effects were no longer present, suggesting that stereotypic behaviour directly influenced QoL. Thus, the group effect had an influence, but only through the CB. Thus, the PAMS programme did not directly influence QoL, although it probably promoted a decrease in stereotypic behaviours, which then played a significant role in increasing QoL. One explanation could be that the PAMS treatment had an impact on emotional regulation as stereotypic behaviours can be seen as a strategy to modulate arousal and maintain homeostasis (Hutt *et al.* 1964). Schopler & Olley (1982) also proposed that the TEACCH programme might be effective in reducing repetitive behaviours in autism. Another explanation could be that PAMS is adequately stimulating residents with an interesting environment. As we know, impoverished environments have often been associated with repetitive behaviour (Wurbel 2001); conversely, environmental complexity has an impact on brain structure and ameliorates abnormal repetitive behaviour (Lewis & Kim 2009). This result is interesting given that Howlin *et al.* (2004) show that communication generally was impaired in adults and that stereotyped behaviours persisted into adulthood even in ASD with high IQ.

Our study has several limitations. First, the participants were not randomly assigned to the different study groups, which increased the possibility that the observed differences were due to subject selection and not to differences in programmes; this is a consistent problem in studies of residential services. A second problem was that the participating institutions were not randomly chosen; they voluntarily participated. We also acknowledge that, at the beginning of the study, the residents had been living in the two environments for a number of years and thus had been receiving interventions for several years; therefore, we do not have baseline data. The numerous statistical tests posed a problem as well, as they increased the risk of type I errors, detecting an effect that is not real, whereas the small number of participants in each group increased the risk of type II errors, missing a real effect.

The fourth problem was the psychotropic medication. During the study, each participant's treatment was modified when necessary, which undoubtedly influenced individual presentations. As Rogé *et al.* (2008) report, however, medication must be used to respond to a crisis, which is defined as a disorganised state with cries, threats and aggression towards others and towards objects. Once the crisis has passed, the efficacy of maintaining a medication must be examined. In our study, we cannot exclude that long-term medication use, as well as occasional adaptations throughout the study, reduced the CB more particularly in the PAMS group which received, on average, more molecules and more modification than the No-PAMS group. This is not surprising as regular fine-tuning is one of the benefits of the PAMS programme. However, the results of this study showed that stereotypic behaviour and inappropriate language had significantly decreased. Few medications have a direct impact on CB; rather, they are described as effective on irritability, aggression and self-injurious behaviours, whereas symptoms that need specific skill remediation are usually non-responsive to medication (Potenza *et al.* 1999; Santosh & Baird 2001; Carminati *et al.* 2006; Mohammadi & Akhondzadeh 2007; Myers 2007; King *et al.* 2009; Akhondzadeh *et al.* 2010). However, as very few behavioural research studies clearly describe medication treatment (Weeden *et al.* 2010), it seemed important to note that there might have been medication effects.

The first strength of our study is its longitudinal and prospective design of over 4 to 8.5 years, and its focus on individuals with ASD with severe to profound ID (87%). Such a lengthy observational period has the advantage of illuminating the developmental evolution of this challenging population. Another major advantage of our experimental design is that no extra contacts were made with residents; this is less stressful for them as changes in their environment are a source of anxiety (Fox *et al.* 2009). This study also engendered staff discussions within and between the residences and helped enhance the sophistication of their knowledge base and skill set.

Past studies have shown that residents benefit from highly structured and specific interventions such as TEACCH to decrease CB or increase autonomy and cognitive competencies (Persson 2000); researchers concluded that QoL was, by extension, improved. The current findings explore the link between CB and QoL. These results show that specific residential supports can decrease CB in the long term, and that this has the effect of improving the overall QoL. This type of study also shows that long-term studies are possible but must take into account two factors reducing the experimental cohort: the mortality and ageing of the ASD population. Indeed, people with ASD also have different needs relative to ageing; in fact, several participants (4/20 in the PAMS group and 2/11 in the No-PAMS group) joined their residential settings with fewer educative needs and were better suited to the meeting of somatic needs.

Given the results of this study, it is clear that individualised support is essential but not sufficient. A multiple and specific approach (Fox *et al.* 2009) is required to reduce CB in the long term. In the future, the No-PAMS group will benefit from the results of this study and will incorporate specific elements of the PAMS programme.

Further studies should identify indicator variables (e.g. age, rate of CB, severity of autism, intelligence quotient measures and adaptive behaviours) for prognoses regarding changes across the lifetime, as well as treatment effectiveness. Further studies should also compare different ASD and ID residential programmes to highlight how characteristics at the structural and organisational levels are related to CB and the efficient improvement of QoL. Despite a number of follow-up studies on older adolescents or adults with autism, information about prognosis remains uncertain because of the heterogeneity of subjects and the variability of outcome measures (Howlin *et al.* 2004). Totsika *et al.* (2010) also discussed the need for longitudinal studies to understand the ageing process of the ASD population as compared with people who only have ID.

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