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# Residential placement and quality of life for adults with severe autism spectrum disorders and severe-to-profound intellectual disabilities

Giuliana Galli Carminati, Federico Carminati, Rachel Lehotkay, Erica Nora Lorincz, Viviane Subirade-Jacopit, Elisa Rondini and Marco O. Bertelli

## Abstract

**Purpose** – The purpose of this paper is to evaluate the relationship between some main characteristics of different living arrangements and the quality of life (QoL) of their users with severe intellectual disability and low-functioning autism spectrum disorders.

**Design/methodology/approach** – Study participants were assessed for ASD severity through the Childhood Autism Rating Scale or the Vineland Adaptive Behavior Scales (VABS); for behavioral problems with the aberrant behavior checklist (ABC); for perception of efficacy and satisfaction with care, through an adapted Visual Analogue Scale; and for QoL with the QoL inventory in residential environments (validated in French as Inventaire de la Qualité de Vie en Milieu Résidentiel). Because the goal was to define a “residential profile (RP),” the authors evaluated each participating residence with the Working Methods Scale and the questionnaire on residential parameters.

**Findings** – The RP allowed for the classification of the residences into three clusters. The authors found no clear relationship between QoL and the RP clusters, but the authors found the RP clusters to be significantly correlated with ABC factors F1 (irritability, agitation, crying) and F2 (lethargy, social withdrawal), and VABS scores for living, socialization, and motor skills.

**Originality/value** – RPs were more strongly correlated with ABC items and the ability to cope with everyday life than with QoL. The authors hypothesize that RP is correlated with both aberrant behavior and the autonomy of residents and that QoL remains relatively stable. Therefore, RP is correlated with the status of the residents; however, this appears not to be correlated with their QoL.

**Keywords** Autism, Intellectual disability, Autonomy, Quality of life, Living arrangements, Residential profile

**Paper type** Research paper

The authors affiliations can be found at the end of this article.

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## Introduction

Autism spectrum disorder (ASD) is the DSM-5 term for the neurodevelopmental conditions previously defined as pervasive developmental disorders (PDD; DSM-IV-TR, American Psychiatric Association, 2000; ICD-10, World Health Organisation, 1993; Baird *et al.*, 2006). In the DSM-5, this disorder is included in the meta-structure of neurodevelopmental disorders, together with intellectual disability (ID), with which it shares onset before grade school, risk factors, clinical aspects (including co-occurrence), and developmental deficits determining impairments of functioning. ASD abnormalities focus on social interaction, patterns of communication, and repertoire of activities, while those of ID focus on cognitive and learning skill.

In the field of ASD/ID, where it is not possible to think about healing as restoring functional capacities to levels that are similar to those of the majority of people, outcome measures for therapeutic interventions based on the medical model for this population have often been

uncertain, symptomatic, restraining, or turned into basic care (Bertelli and Brown, 2006). Alternative outcome measures have been represented by the one centered on the individual well-being and individual quality of life (QoL). They surpass the criteria of normality and morpho-functional integrity, suggesting instead that value in a treatment is based on the person in his/her own physical and social complexity and not simply on the disorder symptoms affecting him or her.

Over the last three decades, the concept of QoL has been increasingly used in the field of ID and ASD to evaluate the overall condition of patients. QoL is a polysemic expression which defines a multidimensional concept, involving several definitions and applications (Brown and Brown, 2003; Schalock *et al.*, 2002; Schalock, 2005; Verdugo *et al.*, 2005; Bertelli and Brown, 2006). There is a general agreement that QoL refers to a wide variety of aspects, both qualitative and quantitative and should be assessed by considering objective and subjective variables (Schalock *et al.*, 2002; Summers *et al.*, 2005; Bertelli and Brown, 2006). Several authors believe that an evaluation of QoL must include at least psychological and social criteria (Schalock and Keith, 1993; Schwartz and Rabinovitz, 2003; Tremblay and Martin-Laval, 1997). Many measurement tools have been developed to evaluate QoL.

According to Cummins (1995), individual's satisfaction with an aspect of life has to be mediated by the importance they ascribe to it. Thus, a comprehensive and useful assessment of QoL must aim to identify person's hierarchy of life areas which are considered to be relevant. For this purpose, it is necessary to include measures of both individual attribution of importance and individual perception of satisfaction in those areas of life with a qualitative value for everybody's existence (Becker *et al.*, 1993; Emerson *et al.*, 2004). The concept of whole-person QoL, as defined by Brown and Brown (2003), or generic QoL (G-QoL) is pertinent to the lives of all individuals, but it becomes especially appropriate when applied to ID or ASD.

Identification of choices can result from observation, above all when a patient is unable to verbalize, and choices can be overlooked (Brown and Brown, 2005). Lyons (2004) has proposed to question parents and other primary care providers about their observations of individual behavior to determine choice and satisfaction in individuals who are profoundly and multiply handicapped.

As mentioned above, QoL has a subjective nature and it should be performed through the self-perspective. Nevertheless, for most persons with severe ID the assessment can be challenging or impossible (Schalock *et al.*, 2002) and a proxy, for example, a family caregiver or a health care professional, may be asked to evaluate the patient's QoL. Proxy assessment involves several problematic issues. First of all, it may vary depending on many factors, such as individual characteristics, cultural level or the nature of the relationship with the person with ID or ASD (Pickard and Knight, 2005; Petry *et al.*, 2009).

Another major element is that the proxy can assess the patient as she/he considers the patient would evaluate him or herself (proxy-patient perspective), but it can also occur that the proxy adopts his/her point of view in evaluating the patient. Pickard and Knight (2005) defined these two distinct proxy perspectives "proxy-patient" and "proxy-proxy".

As reported by Lyons (2005) for individuals with severe ID, proxy-patient assessment is of controversial validity and reliability, and an accurate understanding of their wishes or interests continues to be a very troublesome challenge. The author therefore created a system to evaluate importance and satisfaction of this group of patients which is based on the attentive observation of their recurring behavioral pathways, and some other measurements have been developed to rate these aspects (Ross and Oliver, 2003; Petry and Maes, 2006).

Moreover, different proxies may have very different perspectives, kinds of information, perceptions, or evaluations of particular domains. For example, most research studies have shown that parents and relatives in general tend to attribute a lower level of QoL than health care workers (Rapley *et al.*, 1998; McVilly *et al.*, 2000; Shipman *et al.*, 2011). According to Cummins (2002), the accuracy of responses given by parents and relatives may be negatively conditioned by the tendency to underrate the perceived functional status of the person with ID, by the lacking knowledge of his/her experiences, and by the prejudice, while other studies have suggested that family members are more accurate in evaluating than other proxies (Andresen *et al.*, 2001; Cummins, 2002;

Schwartz and Rabinovitz, 2003). Finally, other authors have indicated that diversities in the assessment between different proxies are very limited (Stancliffe, 1999; McVilly *et al.*, 2000).

When the presence of a proxy (i.e. a person who answers in place of a target person) is necessary to evaluate QoL, it has been found that evaluations by parents are generally rather positive which may indicate a possible bias (Baker and Blacher, 2002; Blacher *et al.*, 1999; Seltzer *et al.*, 2001). In supported residential facilities, educators serve as good proxies (Schalock, 1990; Zetlin *et al.*, 1987) even if their answers may suffer from the same positive bias.

Accommodation plays a relevant role in any intervention oriented toward the improvement of QoL and it has important formative and rehabilitative implications. The QoL approach helps to put and keep the person on the line of development of skills for his or her satisfaction in life.

In a study by Bertelli *et al.* (2013), the authors identified some key factors associated with residential care and QoL, such as issues related to health status, behavioral problems and other personal factors (ageing, choice, and empowerment), family and peers, accommodation, architecture, urbanization, and technical aids, economic aspects, and social participation.

Existing literature fails to provide a coherent picture of the correlation of the QoL with the factors generally considered to be important for the organization of services, such as the number of residents and the ratio of the staff to residents. These parameters are correlated with measures of the QoL of residents in some studies but not in others. Emerson *et al.* (1999) and Felce *et al.* (2000) found that smaller groups are associated with greater opportunity to make choices, more individualization, and greater access to community and leisure activities, whereas Stancliffe and Lakin (1998) failed to find similar results. Moreover, neither Emerson *et al.* (1999) nor Felce *et al.* (2000) found that the number of educators was predictive of the level of participation in a given activity. In fact, most studies seem to demonstrate a rather weak correlation between staff resources (staff input) and the QoL of residents (Emerson *et al.*, 1999; Felce *et al.*, 2000; Stancliffe and Lakin, 1998). Even taking into account residents' skills, Emerson *et al.* (1999) noted a rather modest correlation between these markers and QoL, which suggests that there is not a single parameter influencing QoL.

According to Felce *et al.* (2002b), it seems likely that QoL is related to different elements in the configuration and functioning of residential services. Using the Working Methods Scale (WMS, Felce *et al.*, 1997), Felce *et al.* (2002a, b) explored the associations between the different types of services provided in the UK (state owned, private, and non-profit residences), and their internal organization, work habits, non-residential environment, number of staff, staff profiles and qualifications, staff activities, and the extent and nature of attention paid by staff to residents. Taking into account the results of other studies (Emerson *et al.*, 2000; Felce *et al.*, 1998, 1999, 2000; Jones *et al.*, 1999), Felce *et al.* (2002a) noted that staff activities are influenced by the interaction of several factors, such as service structure (e.g. size and composition of resident groups, structure of residences, number and qualifications of staff) and organizational aims and processes (e.g. operational philosophy, mission statement, job description, working methods, training, evaluation, and control procedures).

The results obtained by Felce *et al.* (2002a, b) are ambiguous, and those of the second study are contrary to the accepted idea that smaller groups are linked to better results. Some studies have confirmed this result (Emerson *et al.*, 1999; Felce *et al.*, 2000), but others did not (Stancliffe and Lakin, 1998). With respect to the ratio of staff to residents, Felce *et al.* (2002a) showed that the when this ratio is larger, the more residents receive attention and assistance. In contrast, Felce *et al.* (2002b) found a negative relationship between the size of the ratio and the level of attention and assistance, depending on the type of activity (domestic or community).

As far as the composition of the caregiving staff is concerned, a higher percentage of qualified personnel does not always seem to be a positive factor for QoL. The amount of staff members' professional experience is positively associated with them spending more time with and providing more assistance to residents and spending less time in other activities (e.g. administration) (Felce *et al.*, 2002a, b). These results are in concordance with those of Emerson *et al.* (1999). It is also interesting to note that although residents' skills are associated with more planned activities, they are also associated with less attention and assistance from staff (Felce *et al.*, 2002a).

As demonstrated by Mansell and Beadle-Brown (2012), better quality assistance could improve engagement in activities, even when variability of intervention quality is of concern, as noted by

other authors (Mansell *et al.*, 2008; Perry *et al.*, 2005). The reasons for variability in support quality are important issues when studying the QoL of persons with severe IDs (Mansell *et al.*, 2008; Perry *et al.*, 2005). In a recent paper on the QoL of people with ID and complex needs, Beadle-Brown *et al.* (2015) noted that the literature is not entirely satisfactory as it fails to provide firm evidence of the relationship between the nature of interventions and the effects of these interventions on the QoL of residents.

Persons with intellectual and developmental disabilities seem to remain disengaged and isolated (Mansell and Beadle-Brown, 2012; Mansell *et al.*, 2013; Netten *et al.*, 2010) despite relatively well-organized services and good facilities. As reported in the survey of Beadle-Brown *et al.* (2015), to understand the importance of skilled staff support, studies have described care practices as active support (Jones *et al.*, 1999; Mansell and Beadle-Brown, 2012; Mansell, Beadle-Brown, Ashman and Ockendon, 2005b; Mansell, Elliott and Beadle-Brown, 2005a; Stancliffe *et al.*, 2008), augmentative and alternative communication (Wilkinson and Hennig, 2007), positive behavior support (Koegel *et al.*, 1996), or as those provided in the National Autistic Society's "SPELL1" framework (Beadle-Brown and Mills, 2010).

Several authors have underlined that even if active support has a positive impact on individuals, improvement is usually related to behavioral disorders rather than to QoL (Allen *et al.*, 2005; Carr *et al.*, 1999; MacDonald and McGill, 2013; Mansell and Beadle-Brown, 2012; Stancliffe *et al.*, 2008). The results of the present study support this observation. Thus, despite some contradictory findings, it seems that several factors and, above all, their interactions have an influence on the care provided to residents and therefore on their QoL.

Several studies have shown the importance of programs adapted for persons with ASD to improve their QoL and to control their behavioral disorders. A well-known example is the Treatment and Education of Autistic and Related Communication Handicapped Children (Reichler and Schopler, 1976) method, originally developed to help parents teaching their children with ASD and later applied to classrooms and eventually to residential homes. This method is applicable throughout an individual's lifespan and features basic elements to manage ASD (Panerai *et al.*, 2002; Van Bourgondien *et al.*, 2003). Research on the QoL of persons with ASD and severe-to-profound ID in residential placement has shown the influence of structured care and environment and a high correlation between QoL, behavioral disorders, and the skills of residents (Galli Carminati, Constantin, Gerber, Carminati Garbino, Schaya, Legay and Baud, 2004; Galli Carminati, Constantin, Schaya, Gex-Fabry, Kummer and Canellas, 2004; Galli Carminati, Gerber, Constantin, Carminati Garbino and Baud, 2004; Galli Carminati *et al.*, 2005; Galli Carminati, Gerber, Baud and Baud, 2007; Galli Carminati, Gerber, Constantin and Baud, 2007; Gerber *et al.*, 2008; Lehotkay *et al.*, 2009).

The results of the present study are meant to highlight characteristics of different living arrangements at structural and organizational levels, as measured by a residential profile (RP) described in the methods section, and their relations to the QoL and status of residents for persons with severe ASD and severe-to-profound ID. We investigate the correlation between the living arrangement profile and the residents' behavioral problems, the appreciation of educators, the residents' autonomy, and their QoL, with the latter correlation being either director via behavioral problems, appreciation of educators, and autonomy.

It is important to note that the distribution of the participants in the living arrangements is governed by socioeconomic and cultural factors well beyond our control. This may introduce a bias in our results that, in the context of the present study, we cannot determine or correct for, and limits our conclusions to the observation of correlations, preventing us from drawing any conclusion on the possible causal relations.

## Method

### *Design*

This is an observational descriptive cross-sectional study, where a group of people with a diagnosis of low-functioning autism spectrum disorder and/or severe ID were consecutively recruited to undergo the process of ethical approval and complex assessment.

## Population

The participants of this study were 101 residents (71 males and 30 females) of 15 residences located in three French-speaking countries (Belgium, France, and the French-speaking region of Switzerland), aged between 18 and 45 years (see Table I). Different institutions have different logistic organizations. In the institution with around 100 or more residents, the people participating to the research live in ASD-dedicated apartments, with facilities open to all the residents. The smaller institutions are entirely dedicated to residents with ASD. Institutions E–I are the exception, where the residents with and without ASD live together. The majority of the institutions have almost exclusively single rooms as institutions C, G, I, M, N, and O have also some double rooms. All institutions have a more or less large protected park with vegetation and trees where to walk and meet with the family.

The participants had a diagnosis of severe ASD, which is the common clinical term for PDD, described in the classification systems (World Health Organisation, 1993; American Psychiatric Association, 2000; Baird *et al.*, 2006). According to the ICD-10 (World Health Organisation, 1993), all participants had to have a minimum score of 33.5 (value consistent with existing literature: Chlebowski *et al.*, 2010) on the Childhood Autism Rating Scale (CARS; Schopler *et al.*, 1988) to meet the criteria for severe ASD. The persons included in this study also had severe-to-profound ID (diagnostic codes F72 or F73 according to the ICD-10). Their age equivalent was less than or equal to 36 months, as assessed by the Vineland Adaptive Behavior Scale (VABS) (see Table I). This explains the low ratio of cases vs residents.

The tests are always answered by a proxy (the educator), as people involved in the study cannot speak or read and are cannot be cognitively tested with the WAISS test. Ethically the consent is given by the guardians or the families. In our study, there were no refusals or drops out, and indeed families were quite happy to be part of the study, also because their children were not bothered at all. The problem was rather to include in the study a population as homogeneous as possible, avoiding to include individuals with a too high level, sometimes even if we had the agreement of the guardians.

When targeting the most intellectually challenged individuals, who constitute the subject of the present study, it is difficult to understand what their real needs are. The present research is intended to provide information on the type of structure that positively correlates with the QoL and decreased behavior problems. Adapting to the individual needs by customizing the care system would be the ideal strategy, but this is very hard to do for the most cognitively disadvantaged population.

**Table I** Age and sex distribution of residents

Residence	Sex		Age (years)			CARS			VABS		
	Male	Female	Median	Q1	Q3	Median	Q1	Q3	Median	Q1	Q3
A	4	2	29.0	27.3	35.3	46.5	44.4	47.9	18.0	16.3	20.5
B	1	1	21.0	20.0	22.0	42.8	41.9	43.6	19.0	16.5	21.5
C	7	1	45.5	42.5	49.3	46.0	41.3	52.1	15.5	12.8	22.5
D	5	0	27.0	23.0	38.0	50.0	49.0	50.0	25.0	22.0	29.0
E	10	6	30.5	23.5	37.5	47.8	41.8	49.1	14.0	9.3	17.8
F	6	5	33.0	31.0	38.5	44.0	35.0	46.8	7.0	5.0	9.0
G	5	1	33.5	29.8	38.8	37.3	34.3	41.0	26.5	20.8	27.0
H	8	4	38.0	33.8	39.3	49.3	45.0	54.1	14.0	10.5	15.5
I	4	3	37.0	27.5	41.5	50.0	47.3	52.3	10.0	9.5	13.0
J	4	0	42.0	40.0	44.3	42.8	40.3	44.1	23.5	21.0	27.8
K	1	2	36.0	34.5	39.0	44.5	42.5	47.0	23.0	21.5	24.0
L	2	1	35.0	30.0	42.0	45.0	42.3	50.3	33.0	20.5	33.0
M	7	0	34.0	30.0	35.5	45.0	43.8	46.0	20.0	16.5	21.0
N	4	2	31.5	31.0	35.8	44.5	42.3	47.5	18.5	14.8	20.8
O	3	2	26.0	24.0	27.0	52.5	47.0	52.5	12.0	11.0	18.0
Total	71	30	34.0	27.0	40.0	46.0	42.0	49.5	16.0	10.0	21.0

**Note:** Q1, first quartile; Q3, third quartile; CARS, Childhood Autism Rating Scale; VABS, Vineland Adaptive Behavior Scales

## RP

The RP was established with the aid of two questionnaires developed from the literature. WMS: this 47-item scale evaluates the internal organization of the residence. It assesses the presence of individual planning (13 items), behavioral assessment and teaching (9 items), planning of daily or weekly activities (9 items), staff support for residents' activities (3 items), staff training (13 items), and a total score.

### *Assessment procedures*

The psychologists of each institution have collected the consent forms from the guardians. The VABS, CARS, aberrant behavior checklist (ABC), Visual Analogue Scale (VAS) (EVA) et Inventaire de la Qualité de Vie en Milieu Résidentiel (IQVMR) rating scales have been assessed by one of the authors who has filled the questionnaire with the aid of the referent educator for each of the individuals participating to the study. The questionnaire on residential parameters (QRP) has been completed by the responsible of each institution.

*QRP.* This questionnaire follows an exploratory approach and is composed of the following questions: How many residents live in the residence? How many bedrooms are there in the residence? What is the total number of fulltime equivalent (FTE) educational staff (e.g. educators, socio-educational staff, and monitors), non-educational staff, and therapeutic staff (e.g. medical doctors, nurses, psychologists, speech therapists, occupational therapists, and physiotherapists)? From these questions, six parameters were derived by dividing the following by the total number of residents: the number of FTE educational staff, non-educational staff, therapeutic staff (including medical doctors), and medical doctors; the number of bedrooms; and the number of participants in the study.

The six scores of the WMS (including the total score) and the 12 parameters derived from the QRP constituted the RP.

*RP.* We assessed the level of autism via the CARS and age equivalent with the VABS. CARS: the CARS is a 15-item structured diagnostic hetero evaluation (the questionnaire is answered by a proxy and not by the patient) created to assess and quantify the presence of ASD. A rating is made on a scale from 1 (normal behavior) to 4 (severely disturbed behavior). The total score allows for classification of the adult into three diagnostic categories: no autism (15-26.5), mild autism (27-33), or severe autism (33.5-60). We used the French version of the CARS, which was validated for use with adults (Mesibov *et al.*, 1989).

*VABS.* The VABS (Sparrow *et al.*, 1984) is a semi-structured interview carried out with the referent educator, which measures adaptive behaviors, including the ability to cope with environmental changes, learn new everyday skills, and demonstrate autonomy. The rating scale measures five domains: communication (67 items), autonomy (92 items), socialization (66 items), motor skills (36 items), and maladaptive behavior. The first four domains are key components of the VABS, and the last domain is optional and used to measure obviously undesirable behaviors. Ratings are made on a scale from 0 (activity is never completed) to 2 (activity is completed in a satisfactory way). The total scores are subsequently converted into developmental ages in each domain and sub-domain. We used the validated French version (Fombonne *et al.*, 1995).

*ABC.* The ABC (Aman *et al.*, 1985a, b) is a 58-item hetero evaluation administered by the referent educator to quantify and qualify behavioral disorders. Each item is rated from 0 (not a problem at all) to 3 (a very significant problem). The scale is composed of five factors: irritability, agitation, crying (F1), lethargy, social withdrawal (F2), stereotypic behavior (F3), hyperactivity, non-compliance (F4), and inappropriate language (F5). The frequency of behavioral episodes was also recorded. We used the French version of the ABC, translated from English by the authors (Aman, 2010).

*Analogic visual scale for satisfaction with care.* A VAS (Huskisson, 1974; Scott and Huskisson, 1979) was used to measure the subjective perception of satisfaction with the care provided and of its efficacy by educators (EVA), measured at the same time as the ABC. This scale is composed of two questions rated from 0 (no satisfaction or efficacy) to 10 (very high satisfaction or efficacy).



*QoL inventory in residential environments*. This rating scale (validated in French as IQVMR; Tremblay and Martin-Laval, 1997) is designed to assess QoL basing on a proxy-patient model. This inventory is composed of 80 items covering eight areas (individuality, self-control, environment, health and safety, social integration, leisure and recreational activities, special needs, staff training, and supervision). These areas do not match those included in anyone of the most common tools for the assessment of G-QoL, but they are more oriented to the aspects specifically linked to the living environment. Furthermore, the IQVMR has not been conceived to inquire the relationship between importance and satisfaction.

Answers are given on a three point scale (0 = objective not reached, 1 = objective partially reached, 2 = objective reached).

During data collection, the residential psychologist served as the link between the research team and the residence's educational team and between the research team and families. The VABS, CARS, ABC, EVA, and IQVMR were completed with the help of the referent educator. The WMS and QRP were completed with the help of senior members of each residence. This questionnaire considers different items: individuality, self-control, environment, health and safety, social integration, recreational activities, special needs, and personnel training and supervision.

## Data analysis

To evaluate our hypothesis, we conducted the following analyses:

1. Using the 18 parameters of the RP of the 15 residences, we identified clusters of residences via the *fpc* package (Hennig, 2014) of the R program (R Core Team, 2015).
2. We investigated the direct relationship between the RP-defined cluster to which residents belonged and their QoL (evaluated by the IQVMR), using a one-way analysis of variance (ANOVA).
3. We investigated the relationship between the RP-defined cluster to which residents belonged and their QoL (IQVMR) using the following as covariates: first, the presence of behavioral disorders (ABC); second, the presence of adaptive behaviors (VABS); and because of the importance of the attitude of educational teams, third, the perception of satisfaction with the care provided and of its EVA. These analyses were performed with analyses of covariance (ANCOVA).
4. We investigated the relationship between the RP-defined clusters to which residents belonged and the following: first, the presence of behavioral disorders (ABC); second, the presence of adaptive behaviors (VABS); and because of the importance of the attitude of educational teams, third, the perception of satisfaction with the care provided and of its EVA. These analyses were performed with ANOVAs using Welch's correction for non-uniform variance.

## Ethics

Informed written consent was obtained from residents' representatives (parents or legal tutors). Residents who did not provide consent were excluded from the study. The evaluation was performed without the resident being present, and it was based on observations collected during private consultations with educators. Participant data were made anonymous through coding. The protocol adhered to the ethical guidelines of each country's national regulations, and it was submitted to the relevant authorities in the different countries, who approved it. No incidents occurred in any phase of the study.

## Results

The RP of the 15 residences is shown in Table II. The cluster method known as partitioning around medoids (Kaufman and Rousseeuw, 1987) provided us with three clusters of residences. The optimal number of clusters was also confirmed with the Calinski and Harabasz's (1974)

**Table II** Residential parameters

Residence	Cases	Res	Cases/Res	Rooms	Ed	N-Ed	Ther	MD	Rooms/Res	Ed/Res
A (1)	6	36	0.17	36	64	12	0	0	1	1.78
B (1)	2	94	0.02	94	96	22	0	0	1	1.02
C (2)	8	246	0.03	109	61.45	146.6	20.85	0.6	0.44	0.25
D (1)	5	119	0.04	122	79.55	44.5	1.9	0	1.03	0.67
E (3)	16	30	0.53	32	25	11	6.12	1	1.07	0.83
F (3)	11	80	0.14	83	74	15	9.26	1	1.04	0.93
G (3)	6	75	0.08	65	37	0	12	0.5	0.87	0.49
H (3)	12	50	0.24	50	33	9	6	0.25	1	0.66
I (3)	7	40	0.18	20	16	8	6	0.25	0.5	0.4
J (3)	4	8	0.50	8	16.3	3.45	0.3	0.05	1	2.04
K (1)	3	26	0.12	26	28.85	11.6	0.76	0	1	1.11
L (1)	3	49	0.06	49	36.1	14.25	0.5	0	1	0.74
M (2)	7	300	0.02	216	202.01	79.68	15.83	0	0.72	0.67
N (1)	6	32	0.19	22	31	10	4.01	0.35	0.69	0.97
O (2)	5	217	0.02	200	240	50	4	0.5	0.92	1.11
Residence	N-Ed/Res	Ther/Res	MD/Res	I-Plan	B-Ass	DW Plan	Staff Supp	Staff Train	WMS Tot	
A (1)	0.33	0	0	12	10	12	2	14	50	
B (1)	0.23	0	0	14	11	13	2	14	54	
C (2)	0.6	0.08	0	11	10	11	3	8	43	
D (1)	0.37	0.02	0	13	11	7	3	10	44	
E (3)	0.37	0.2	0.03	7	3	9	4	10	33	
F (3)	0.19	0.12	0.01	8	6	9	2	7	32	
G (3)	0	0.16	0.01	9	3	6	3	7	28	
H (3)	0.18	0.12	0.01	6	1	5	2	7	21	
I (3)	0.2	0.15	0.01	5	0	6	1	3	15	
J (3)	0.43	0.04	0.01	8	1	10	4	7	30	
K (1)	0.45	0.03	0	15	9	12	4	11	51	
L (1)	0.29	0.01	0	14	8	12	4	11	49	
M (2)	0.27	0.05	0	12	7	7	1	12	39	
N (1)	0.31	0.13	0.01	13	8	10	3	12	46	
O (2)	0.23	0.02	0	14	10	12	2	10	48	

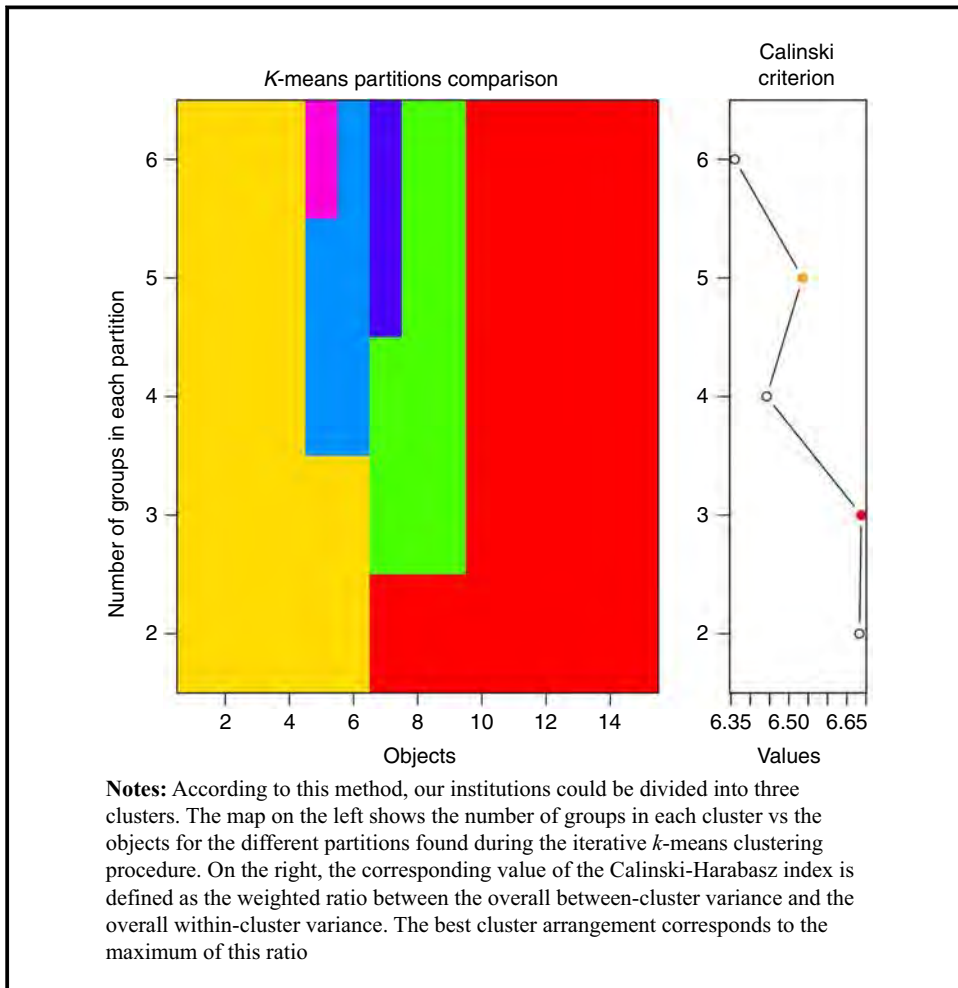
**Notes:** The number in bracket next to the residence identifier is the cluster to which the residence belongs. Cases, number of cases retained for our study in the residence; Res, number of residents; Cases/Res, ratio of the number of cases to the number of residents; Rooms, number of bedrooms; Ed, number of fulltime equivalent (FTE) educative staff; N-Ed, number of FTE non-educative staff; Ther, number of FTE therapeutic staff; MD, number of FTE medical doctors; Rooms/Res, ratio of the number of bedrooms to the number of residents; Ed/Res, Ratio of the number of FTE educative staff to the number of residents; N-Ed/Res, ratio of the number of FTE non-educational staff to the number of residents; Ther/Res, ratio of the number of FTE therapeutic staff to the number of residents; MD/Res, ratio of the number of FTE medical doctors to the number of residents; I-Plan, Working Method Scale (WMS) score for the presence of methods for individual planning; B-Ass, WMS score for behavioral assessment and teaching; DW Plan, WMS score for the planning of daily and weekly activities; Staff Supp, WMS score for staff support of residents' activities; Staff Train; WMS score for staff training; WMS Tot, WMS total score. Note that the number of cases was not used directly in the clustering procedure

criteria, defined as the weighted ratio between the overall between-cluster variance and the overall within-cluster variance. The best cluster arrangement corresponds to the maximum of this ratio, which in our case was three clusters (see Figure 1).

To better understand the nature of the clusters, we performed a principal components analysis on the RP using the `prcomp` function of the R package, and plotted the clusters on a biplot (see Figure 2). The first cluster (red) was characterized by high ratios of educators and non-educators to residents and by high values of the WMS. These components were highly correlated. The second cluster (green) was characterized by the absolute size of the residence, number of rooms, number of residents, and number of educational and non-educational staff. The third cluster (blue) was characterized by the high relative and absolute values of the medical and therapeutic component. We note that these are negatively correlated with the WMS score.

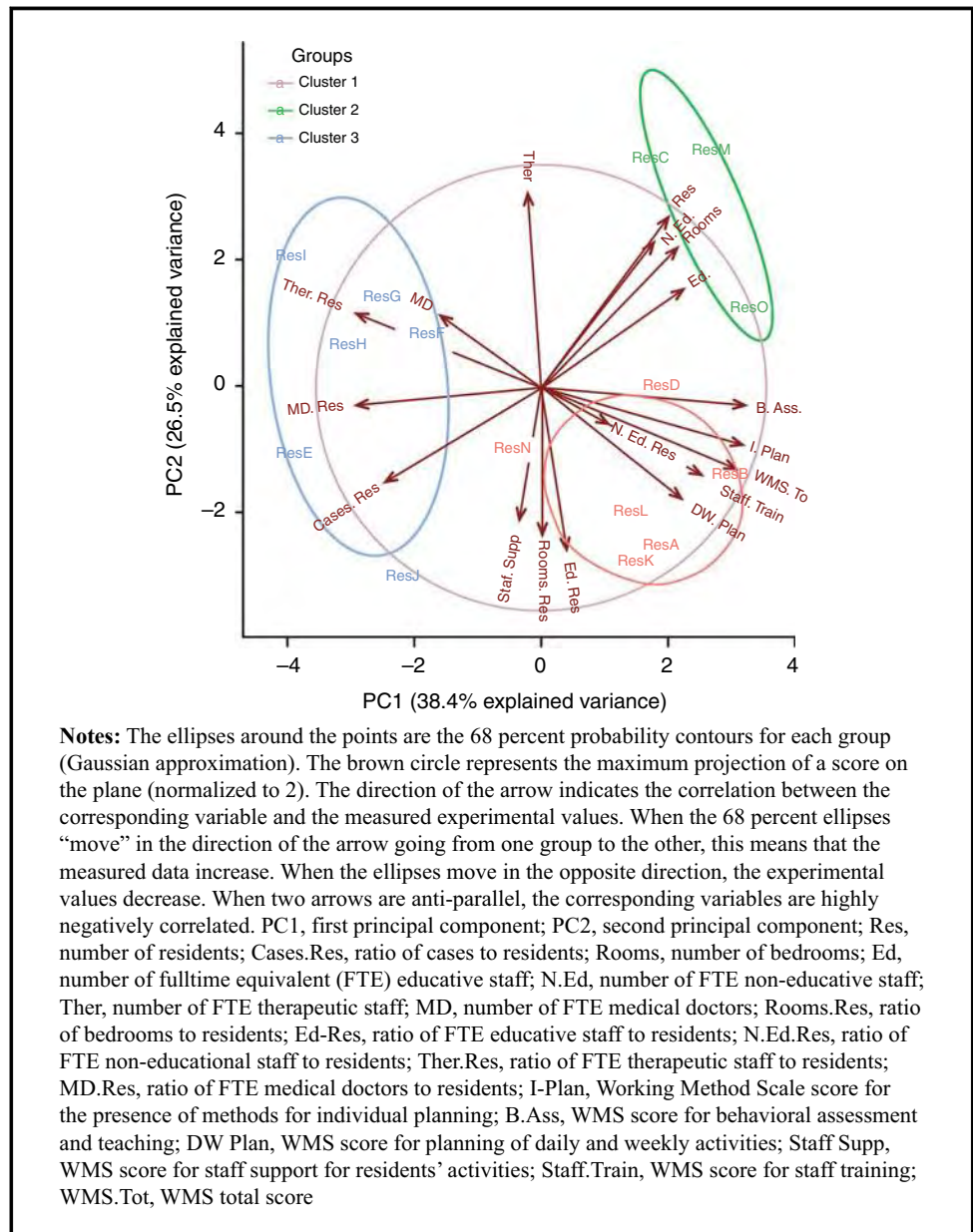
In Table III, we report the distributions of age, CARS, ABC, EVA, VABS age equivalent (months), and IQVMR scores in the three clusters (median, first, and third quartiles). We compared the QoL values in the three clusters with one-way ANOVA, without finding any significant differences. To control the possible effect of the other variables, we repeated this exercise using the EVA, ABC, and VABS scores as covariates using ANCOVA, again without finding any significant differences

**Figure 1** Determination of the best number of clusters via the Calinski-Harabasz method



(see Table IV). We discarded the result for VABS health and safety because we considered this to be an artifact as the data were essentially constant with some large outliers, which reduces the reliability of ANCOVA. The values in brackets indicate that the cases for which the ANCOVA assumption of homogeneity of regression slopes was not satisfied, and therefore the ANCOVA result was not reliable. This was tested by fitting a linear regression for the dependent variable versus the covariate and then adding an interaction between the dependent variable and the covariate. If the interaction between the two is not statistically significant, the assumption of homogeneity of the regression slopes is considered verified (Tabachnick and Fidell, 2001, p. 292).

Given that we found no difference in the QoL, we turned our attention to the other dependent variables, we measured to see whether any of those showed any correlation with the cluster assignment taken as categorical independent variable. We therefore compared the ABC, EVA, and VABS in the three clusters via ANOVA with Welch's correction using the standard one-way test provided by the R package. Although this test does not assume the distributions to be homoscedastic, for completeness, we performed a variance test on the three distributions via the Fligner-Killeen (Conover *et al.*, 1981) test of homogeneity of variances (see Table V). If the Fligner-Killeen test is significant, then the variances are different, which may introduce bias in the ANOVA. In our case, in all instances in which the ANOVA was significant, the Fligner-Killeen test was negative (i.e. the variances of the corresponding variable in the three clusters were compatible). As seen in Table V, we found significant differences among the residents of the three clusters for ABC F1 (irritability, agitation, crying) and F2 (lethargy/social withdrawal), VABS living, social, and motor skills, and VABS global age. The individual differences can be seen in Table III.

**Figure 2** Biplot of the principal component analysis of the institutional clusters

Given that the Vineland global age score is simply the average of the other VABS variables, it does not provide any additional information and we will ignore it.

To determine where differences existed for ABC F1, ABC F2 and VABS living, social, and motor skills, we performed a series of *post hoc* Mann-Whitney *U* tests, the results of which can be seen in Table VI. In particular, we can see that ABC F1 is higher in the first cluster, and ABC F2 is lower in the third one. VABS living skills are wide spaced apart in the three clusters, while social and motor skills appear to be lower in the third cluster. These results are discussed in the next section.

## Discussion

Our results indicate that RP does not seem to be correlated with the QoL either directly or indirectly via aberrant behaviors (ABC), adaptive behaviors (i.e. the ability to cope with

**Table III** Gender, age, CARS, ABC, EVA, VABS age equivalent (months), and IQVMR scores in the three residential clusters

CL	Males	Females	Age (years)			CARS			F2	F3	F4	F5	EVA			Global				
			Med	Q1	Q3	Med	Q1	Q3					Med	Q1	Q3		Med	Q1	Q3	
1	17	8	31.0	25.0	37.0	46.0	43.0	49.0												
2	17	3	34.0	26.8	45.0	46.0	42.9	52.1												
3	37	19	35.0	29.0	40.0	46.0	38.4	49.5												
CL	ABC																			
F1	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3		
1	1.2	0.9	1.7	1.2	0.6	1.6	1.4	1.0	1.0	2.1	1.3	1.8	1.0	0.3	2.0	7.0	6.0	9.0		
2	0.6	0.3	1.4	1.1	0.7	1.4	0.9	0.7	0.7	1.6	1.0	1.1	0.1	0.0	1.5	8.0	7.0	8.0		
3	0.9	0.4	1.5	0.6	0.3	0.9	1.1	0.3	1.7	0.9	0.5	1.3	0.8	0.0	1.6	7.0	6.0	8.0		
CL	Vineland age (months)																			
	Communication																			
Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3
1	15.0	12.0	17.0	35.0	28.0	40.0	11.0	6.0	21.0	31.0	23.0	39.0	21.0	17.0	25.0	17.0	17.0	15.0	12.0	16.0
2	12.0	9.8	14.3	28.0	22.5	32.0	10.0	3.3	16.0	25.5	19.0	35.3	17.0	12.8	20.5	17.0	16.0	13.5	10.0	17.0
3	13.0	6.5	16.0	20.0	14.0	28.3	7.0	0.9	11.0	17.0	11.8	29.0	13.0	8.8	17.3	17.0	16.8	13.0	11.0	15.0
CL	IQVMR																			
	Environment																			
Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3
1	17.0	17.0	18.0	20.0	19.0	20.0	14.0	9.0	15.0	16.0	14.0	18.0	20.0	20.0	20.0	17.0	14.0	134.0	126.0	141.0
2	16.0	14.8	19.0	20.0	20.0	20.0	14.0	12.0	16.0	16.0	13.8	18.0	20.0	20.0	20.0	16.0	14.0	134.0	126.5	139.3
3	17.0	16.0	18.0	20.0	20.0	20.0	13.0	12.0	16.0	15.5	13.0	18.0	20.0	19.0	20.0	16.0	13.8	130.5	124.0	138.3
CL	Health and safety																			
Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3
1	17.0	18.0	20.0	19.0	20.0	20.0	14.0	9.0	15.0	16.0	14.0	18.0	20.0	20.0	20.0	17.0	14.0	134.0	126.0	141.0
2	16.0	14.8	19.0	20.0	20.0	20.0	14.0	12.0	16.0	16.0	13.8	18.0	20.0	20.0	20.0	16.0	14.0	134.0	126.5	139.3
3	17.0	16.0	18.0	20.0	20.0	20.0	13.0	12.0	16.0	15.5	13.0	18.0	20.0	19.0	20.0	16.0	13.8	130.5	124.0	138.3
CL	Special needs																			
Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3	Med	Q1	Q3
1	17.0	18.0	20.0	19.0	20.0	20.0	14.0	9.0	15.0	16.0	14.0	18.0	20.0	20.0	20.0	17.0	14.0	134.0	126.0	141.0
2	16.0	14.8	19.0	20.0	20.0	20.0	14.0	12.0	16.0	16.0	13.8	18.0	20.0	20.0	20.0	16.0	14.0	134.0	126.5	139.3
3	17.0	16.0	18.0	20.0	20.0	20.0	13.0	12.0	16.0	15.5	13.0	18.0	20.0	19.0	20.0	16.0	13.8	130.5	124.0	138.3

**Notes:** CL, cluster; Med, median; Q1, first quartile; Q3, third quartile; CARS, Children Autism Rating Scale; ABC, aberrant behavior checklist; EVA, Analogic Visual Scale; IQVMR, Quality of Life Inventory in Residential Environments

**Table IV** Analysis of the dependence of the IQVMR parameters on the IP clusters

Covariate	IQVMR								
	Indiv	Self-cont	Env	H and S	Soc int	Leisure	Spec needs	Staff tr	Supervision
No covariate	0.28	0.13	0.46	0.00	0.53	0.53	0.81	0.32	0.47
<i>EVA</i>									
Satisfaction	0.28	0.13	0.46	0.00	(0.53)	(0.54)	(0.80)	0.33	0.48
Global	0.28	0.13	0.46	0.00	0.53	0.53	0.81	0.33	0.48
<i>ABC</i>									
F1	0.28	0.13	0.46	0.00	0.53	0.53	0.81	0.33	0.48
F2	0.28	0.13	0.46	(0.00)	0.53	0.53	0.81	0.31	0.48
F3	0.28	0.13	0.46	0.00	0.53	0.53	0.81	0.33	0.47
F4	0.28	0.13	0.46	0.00	0.53	0.53	(0.81)	0.33	0.47
F5	0.28	0.13	0.46	0.00	0.53	0.54	0.81	0.32	0.48
<i>VABS</i>									
Communication	0.28	0.13	0.46	0.00	0.53	0.53	0.81	0.33	0.47
Autonomy	0.28	0.13	0.46	0.00	0.53	0.53	0.81	0.33	0.47
Socialization	0.27	0.13	0.46	0.00	0.52	0.53	0.81	0.32	0.47
Motility	0.28	(0.13)	0.46	0.00	0.53	0.53	0.81	0.33	0.47
Age	0.27	0.13	0.46	0.00	0.52	0.53	0.81	0.32	0.47

**Notes:** The first row shows the ANOVA results using the IQVMR parameters as dependent variables. The other rows are the results of ANCOVA analysis using the EVA, ABC, and VABS parameters. No statistically significant result was found. The values in brackets indicate that the ANCOVA assumption of linearity between the covariate and the dependent variable was not satisfied, and therefore the ANCOVA result was not reliable. The health and safety column has been reported for completeness; however, it has to be discarded since the recorded values were constant across the institutions, apart from a few outliers (see text). EVA, Analogic Visual Scale; ABC, aberrant behavior checklist; VABS, Vineland Adaptive Behavior Scales; IQVMR, Quality of Life Inventory in Residential Environments; Indiv, individuality; Self Cont, self-control; Env, environment; H & S, health and safety; Soc Int, social interaction; Staff Tr, staff training

**Table V** Comparison of the measures of ABC, EVA, VABS age equivalent (months), and IQVMR in the three clusters via an ANOVA with Welch's correction using the R standard one-way test

	Age	EVA			ABC					Vineland age (months)				
		CARS	Sat	Glob	F1	F2	F3	F4	F5	Comm	Living Sk	Social	Motor Sk	Global
p ANOVA	0.50	0.45	0.08	0.44	0.03*	0.04*	0.11	0.09	0.38	0.32	0.00**	0.01**	0.00**	0.00**
p Fligner	0.19	0.12	0.50	0.42	0.13	0.33	0.92	0.06	0.87	0.08	0.55	0.07	0.35	0.74

**Notes:** Although the ANOVA with Welch's correction does not assume the distributions to be homoscedastic, for completeness we performed a variance test on the three distributions via a Fligner-Killeen test of homogeneity of variances. EVA, Analogic Visual Scale; Sat, EVA caretaker satisfaction score; Glob, EVA global score; ABC, aberrant behavior checklist; CARS, Childhood Autism Rating Scale; VABS, Vineland Adaptive Behavior Scales; IQVMR, Quality of Life Inventory in Residential Environments; Comm, communication; Living Sk, living skills; Social, socialization skills; Motor Sk, motor skills; Global, global skills; p Fligner, probability that the variances are not homogeneous, according to the Fligner-Killeen test of homogeneity of variances. \* $p < 0.05$ ; \*\* $p < 0.01$

**Table VI** Post hoc Mann-Whitney U tests on the combinations of clusters for variables with significant ANOVA results (see text)

Clusters	ABC		Living	VABS skills	
	F1	F2		Social	Motor
1 vs 2	0.03*	0.95	0.01*	0.72	0.24
2 vs 3	0.49	0.02*	0.04*	0.09	0.03*
3 vs 1	0.03*	0.04*	0.00**	0.02*	0.00**

**Notes:** ABC, aberrant behavior checklist; VABS, Vineland Adaptive Behavior Scales. \* $p < 0.05$ ; \*\* $p < 0.01$

environmental changes, to learn new everyday skills, and to demonstrate autonomy; VABS), or educator satisfaction (EVA). Our starting hypothesis that QoL is correlated with the residence parameters does not seem to be supported by our data.

On the other hand, we found significant relationships between the cluster assignment of the participants and some of the other variables. Communication skills do not show a particular correlation with RP cluster, but living, social, and motor skills seem to be correlated to it. The *post hoc* test (Table VI) indicates that the third cluster is different from the other two, being characterized by lower VABS skills, whereas the first cluster has the highest VABS values. The ABC data show a significantly lower value of F2 (lethargy, withdrawal) for the third cluster, characterized by a larger medical and therapeutic presence. This low value could be seen to be in conflict with the low VABS scores for living, socialization, and motor skills (see Table III) in this cluster. ABC F1 (irritability, agitation, crying) is significantly greater in residences belonging to the first cluster, which are characterized by higher WMS scores regarding activity planning.

As we said before, the conditions of our study prevent us from drawing any definitive causal conclusion. However, we could suggest the hypothesis that a strong medical and therapeutic component would reduce the need for psychotropic medication and hence reduce side effects as a result of more finely tuned prescriptions. These treatments often involve the use of sedatives, which could explain the reduced lethargy (F2 score) in the third cluster, assuming reduced utilization. This result is consistent with the presence of medical doctors and therapists introducing a more “personalized” administration of treatments to residents. VABS living, socialization, and motor skill scores were strongly correlated with the cluster assignment. Their significantly higher values in the first cluster suggest a positive correlation with the presence and activity of educational staff, particularly in the first cluster. The residents’ skills measured by the VABS appeared to be correlated with good organization of their activities as measured by WMS, and the presence of an important and well-structured educational component. Communication skills did not seem to be affected. However, residents were non-verbal with an age equivalent of less than three years, so this result is hardly surprising.

It is important to underline that we could not identify a relationship between QoL and RP. QoL seemed to be more of a relative indicator than an absolute one, in accordance with recent observations of Beadle-Brown *et al.* (2015) that the existing literature fails to identify a clear relationship between the nature and quality of care interventions and the resulting QoL, although this might depend on the lack of appropriateness or reliability of the QoL model, assessment tool and procedures used in research.

Well-organized patterns of activities are correlated with higher residents’ skill levels, but the demands of the educators regarding their activities probably increase as well, as might the expectations of both educators and residents. This parallel increase does not correlate with the “perceived” QoL possibly in connection with the fact that more able residents are expected to do more. This increase in stimuli seems, however, to be accompanied by an increase in irritability and agitation as measured by ABC F1 (irritability, agitation, crying). Conversely, a lower presence of educators seems to be accompanied by a lower amount of stimuli received by the residents.

It is also interesting to note that the absolute size of the residence does not seem to be correlated with the residents’ status in any significant way.

Living accommodation which are part of interventions based on the improvement of QoL have significant rehabilitative implications related to the development of adaptive skills. Furthermore, when applied to living arrangements, QoL approach encourages a rehabilitative intervention intended to the optimization of relationship between importance attributed to different aspects of the way in which people live and the satisfaction perceived in the same areas. The level of satisfaction perceived depend also on the interest in a particular living accommodation.

Our findings indicate that some residential solutions can work better than others, albeit with regard to some specific parameters and some population subgroups. New conceptual models of inclusive residential care support the convenience of a wide range of accommodation alternatives that may fit the individual needs of a highly heterogeneous population group. A unique residential alternative, albeit optimal from a community care perspective, may not be adequate for all persons with ID.

## Conclusions

Once we identified the residential clusters via their RP, we examined whether a specific RP cluster was related to the QoL (IQVMR score), via the presence/absence of behavioral disorders (ABC) and social and personal abilities (VABS), and in relation to the efficacy and satisfaction of educators (EVA). Our objective was to understand which residential parameters were correlated with the QoL of persons who could not express themselves verbally.

In our analysis, we could not determine the correlation between the RP values and the corresponding QoL directly or via the presence or absence of aberrant behavior, level of autonomy, or the perceptions of efficacy of, and satisfaction with the educational team. Our data show that the ABC F2 (lethargy) is lower in the third cluster with more doctors and therapists, even if the VABS autonomy skills are lower. ABC F1 (irritability, agitation, crying) is higher in the first cluster, which had a high educator presence. In the same cluster, we note a positive correlation between WMS scores and residents' autonomy. Our data indicate that better organization of daily and weekly activities is positively correlated with an increase in residents' autonomy and ability to make choices; however, this is accompanied by an increase in aberrant behaviors such as agitation and irritability. In this context, QoL seems to be a relative more than an absolute measure. A possible interpretation is that the greater the resident's skills, the higher the expectations and needs to be fulfilled become. In some sense, QoL is a measure of the ratio of these factors, and hence it does not appear to be a very sensitive measure. This last observation, supported by the literature, does not allow us to identify a synthetic rating tool that could help professionals relate RP with the effectiveness of the care provided.

In conclusion, we can say that the present study, although not allowing us to characterize QoL as an indicator of the effect of RP on residents, does give indications of relationships between RP and specific aspects of residents' conditions. As we already mentioned above, the assignment of participants to residences is influenced by socioeconomic and cultural factors we cannot control and that can introduce a bias in the results. Moreover, although the residential clusters appeared well defined, the limited number of residences, and the corresponding limited number of residents, represent a limitation of the present work.

Notwithstanding this fact, the results presented could have potential implications for the care given to this population and could aid the understanding of the beneficial profile of residences dedicated to the care of adults with severe ASD and severe-to-profound ID. The present study of RP also provides indications on a more practical level, namely in the orientation of training programs for educational teams, to better meet the needs of persons with severe ASD and severe-to-profound ID living in residences.

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