Title: Factors Predicting Quality of Life for People with Intellectual Disabilities: Results from the ANFFAS-study in Italy.

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Abstract

Background: This study describes the socio-demographic, clinical and functional characteristics of a representative sample of services users in Italy. The supports provided by formal agencies, natural networks and actual levels of quality of life (QoL) were assessed. Methods: 1,285 individuals with intellectual and developmental disabilities (IDD) served by 23 different services participated to the study. The influence of availability of support strategies, environmental factors, client characteristics, personal desires and goals, and support needs on the current QoL status was investigated using multiple regression. Results: QoL outcomes were significantly explained by support needs, client characteristics, personal goals and desires, and marginally by the presence of support strategies and environmental factors. Further, only a minor effect was found from support activities for general QoL outcomes. Conclusions: the results confirmed that the personal outcomes could be predicted providing support activities aligned to the specific personal needs and goals, confirming the importance of Personal Centered Planning process.

Introduction

The concept of quality of life (QoL) and its application has been thoroughly investigated in the field of intellectual disabilities (ID) (Felce & Perry, 1995; Schalock et al., 2002). A model has been developed that considers QoL as a multidimensional phenomenon, composed of central domains and indicators influenced by personal characteristics and environmental and contextual variables (Schalock et al., 2005). The domains and specific indicators have been identified and critically assessed (Brown, Schalock, & Brown, 2009) fulfilling the requirement of cross-cultural validation (Jenaro et al, 2005) showing emic and ethic characteristics, with features common to everyone, and other characteristics that are culturally sensitive and specific to the individual (Lyons, 2005; Schalock et al., 2005). In particular, the eight domains model, developed by Shalock and Verdugo (2002), has been widely used, consisting of emotional physical, and material wellbeing; personal development; social inclusion; interpersonal relationships; self-determination; rights; and incorporating three major factors of independence, social participation and wellbeing. The model structure has been empirically validated, and hierarchical domain empirically confirmed (Wang, Schalock, Verdugo, & Jenaro, 2010). The present study investigated personal outcomes using a QoL oriented perspective as emphasized by Shogren et al. (2009, p. 312) "*on the base of recent work in the field of individual-referenced quality of life that focuses on the identification of domain-referenced quality indicators, the measurement of these respective indicators results in personal outcomes (Gardner & Carran, 2005; Schalock, Gardner, & Bradley, 2007)*". Consequently, the question of how to practically measure QoL has become a prominent issue (Bernheim, 1999; Nota, Soresi, & Perry, 2006), as the increasing demand for the application of the concept in health care, social services, and schools has urged the development of personal outcome measurement. Furthermore, Claes et al. (2010) stated that standardized QoL outcome measurements should be grounded on eight principles, based on their literature review of psychological measurement in scale development (Anastasi, 1961; Cronbach, 1955; Murphy, 1998) and on QoL assessment literature in

the field of ID (Brown, Keith, & Schalock, 2004; Cummins, 1997; Schalock, Bonham, & Verdugo, 2008; Schalock et al., 2007). Only a few instruments have been developed that incorporate these 8 principals, including the Personal Outcomes Scale (POS) (Van Loon, Hove, Schalock, & Claes, 2008) and Gencat (Verdugo, Arias, Gómez, & Schalock, 2010).

QoL instruments have developed into a research track focused on which variables predict QoL. Recent studies have shown the influence of different sets of variables related to personal characteristics and environmental factors (Claes, Van Hove, Vandevelde, van Loon, & Schalock, 2012; Felce et al., 2008; Gómez, Peña, Arias, & Verdugo, 2014; Ticha, Hewitt, Nord, & Larson, 2013; Wehmeyer & Garner, 2003).

Following the recommendation by Ticha et al. (2013) to use a common framework, the present study included variables related to the process of person-centered planning (PCP). In the last decades, "*the support paradigm brought together the related practices of person-centered planning, personal development and growth opportunities, community inclusion and self-determination and empowerment*" (Robert L. Schalock & Verdugo, 2012, p. 79). The application of this concept in daily practice was central to QoL. Thompson et al. (2002, p. 390) showed that QoL could be promoted by the delivery of specific supports, but understanding the influence of personal support and support needs on QoL has been more theoretically investigated (Schalock and Verdugo, 2012) than empirically (Claes et al., 2012).

Services are developing and providing support activities for their clients based on the national and international legislation (UN, 2006) and on the mission and vision of the single support provider. Furthermore, the outcomes of an individual supports plan for a person should result an enhanced quality of life, as Van Loon et al. (2013, p. 84) suggested. However little is known about the influencing factors leading to QoL-outcomes (Keith & Bonham, 2005). Consequently, a research need emerged to understand which services (Gómez et al., 2014) are better aligned to produce QoL outcomes for specific populations (Gomez, Verdugo, Arias, Navas, & Schalock, 2013). Moreover, a wider comprehension of which variables relate to an improvement of QoL and which variables are

mostly influencing the QoL was required (Schalock & Luckasson, 2014), as the study of Claes et al. (2012) exploratory investigated. The present study aimed to comprehensively investigate the inter-relations between the process of service provision and the achievement of QoL outcomes. A better understanding of the supports leading to QoL outcomes is meaningful to implement evidence-based services and outcomes, especially in times for clients and organization in a time of budgets revision. The components of supports studied included all variables with regard to planning, monitoring, and evaluation of individualized intervention, as described by the American Association on Intellectual and Developmental Disabilities (Schalock et al., 2010; Thompson et al., 2009). Planning is described as a process starting from two specific components: identification of desired life experiences and goals of the client, and assessed support needs, and consists of developing and implementing an individualized support plan (ISP) prioritizing preferences and identifying personal outcomes and support. Implementation of the support strategies and monitoring the process provide the final evaluation of personal outcomes. Based on the individual and environmental variables involved in the ISP definition, the following predictors were added to the study: personal goals, assessed support needs, and support provided.

Personal Goals

The inclusion of personal goals and wishes is a starting point for PCP (Schalock et al., 2010; Thompson et al., 2009). The process incorporates the individual's dreams, personal preferences, and interests (Thompson et al., 2009) and operationalizes this information to achieve the personal subjective QoL (Schalock et al., 2005).

Support need

The concept of support leads to understanding how every individual could have a valued and personally meaningful life in society, on the condition that support strategies are provided to overcome the gap between personal competencies and environmental requirements (Thompson et

al., 2009). Support needs can be qualitatively investigated in a conversational format, querying the client about required support and quantified using the Support Intensity Scale (SIS), the most widely acknowledged reliable instrument (Thompson et al., 2004).

Support provided

Support is intended to overcome the gap between person competencies and the environmental requirements. A support system is defined as the planned and integrated use of individualized support strategies and resources that encompass the multiple aspects of human performance in multiple settings (Schalock et al., 2010). Thus, a support system provides a framework for support delivery and enhancement of human functioning and achievement of personal outcomes (Thompson et al., 2009). The components of support systems evaluated in this study are summarized in Table 1. The support model provides an organized system through which individualized support can be programmed and implemented (Robert L. Schalock & Verdugo, 2012). The system use provides a framework for coordinating the procurement and the application of specific supports.

Table1: Classification for coordinating and evaluating specific supports provided

Aims

This study determines the influence of five classes of predictors for QoL (as shown in Table 4) using multiple regression. The socio-ecological variables and supports provided to clients are investigated to better explain actual QoL outcomes of services for people with intellectual and developmental disabilities (IDD) in Italy, as previously investigated, at user level, by Claes et al. (2012) in Holland and, at organization level, by Gómez et al. (2014), in Catalunia. The present

study further investigated the predictors' influence of all the listed variables. The present study further investigated the predictors' influence of all the listed variables, including all the necessary components in the development of Support Plan leading to evidence-based outcomes on QoL.

Regression analysis

The hierarchical multiple regression analysis incorporated five predictor clusters for QoL outcomes, based on previous studies by Claes et al. (2012), Schalock et al. (2007), and Schalock and Verdugo (2012). The specific clusters employed are shown in Table 2 and briefly described below.

Table 2

QoL predictors were examined, and differences among subgroups, as determined by personal (e.g. intellectual functioning) and environmental (e.g. geographical location) characteristics, were considered for further analyses.

Methods

Participants

The participants of this study were users of the various services provided by the National Association for Families of people with Intellectual and/or Developmental Disabilities (ANFFAS), the largest association supporting people with IDD in Italy, present in 16 different regions, including over 30.000 service users. ANFFAS is a no profit organization, operating to promote the application of solidarity and social inclusion. The participants were selected by a case manager, the person responsible for the implementation of the study in each service, based on a written informed consent and voluntary participation of the participant or the participant's legal representatives. All

information has been anonymized for participant privacy. The authors have anonymized all the collected information, for privacy reasons, on the basis of the Italian legislation for privacy (law 193, 30 June 2003). The study ethical standards of the study were approved by ANFFAS scientific committee and the research was conducted in accordance with the principles of the Declaration of Helsinki (Assocociation, 2013).

Table 3 summarizes the participant details. There were 1,285 participants, including 776 males (60%) and 509 females (40%) with ages 16–80 years (mean=41.69, standard deviation (SD)=14.03). Intellectual functioning levels were Mild (n=101, 8%), Moderate (n=342, 27%), Severe (n=400, 34%) and Not Specified (n=442, 31%), retrieved from data assessed by a commission for disability or handicap certification, taken from the client files. The most common diagnoses of the clients involved in the research were: Trisomy 21 (n=165, 12.84%), Autism Spectrum Disorder (n=82, 6.38%), and Epilepsy (n=85, 6.62%), as was previously reported in Italian service users samples (Croce, Lombardi, Nolani, & Cavagnola, 2011). The majority of the participants lived in a city (n=525, 50%), or town (505, 48%), with a limited number in remote areas (n=16, 2%). The majority were living with their original family (n=700, 67%), followed by living in a large residential context, more than 10 people, (n=178, 17%), smaller residential facilities, between 5 and 10 people, inclusive, (n=157, 15%), and a small group living independently (n=11, 1%). No participants were living in a small residential facility (maximum of 4 people). The majority of activities were provided within the services: day care activities (n=761, 72%), followed by volunteer (unpaid) activities provided in the service (n=137, 14%), and volunteer activities provided in the community (n=126, 12%). A small group of participants had a paid job (n=21, 2%). The classification of the activities was based on the most common activities provided during a classical week of service attendance.

Table 3

Procedure

The selection of ANFFAS affiliated centers commenced in June and closed in September 2014. The first 23 centers that expressed their willingness to participate were included in the study. Each selected center identified a case-manager responsible for the data input, and the case managers were trained by the researchers to administer the instruments. The assessment process required

- Personal Outcome Scale (POS) for the client and a proxy

- SIS for the operator responsible for support provision to the client and evaluation of the client's personal file and ISP to retrieve:

    o Environmental factors

    o Personal characteristics

    o Personal and family desires and goals

The data were collected over a six months span in electronic format using the "Matrici Ecologiche" program, designed to support the creation of a PCP, with QoL oriented ISP as output (ANFFAS, 2015). Incentives were used for all of the centers in the form of free trainings and supervision on the use of the instruments, as well as a fee of 1,000 Euro which was paid to the case managers for data collection and input.

Instruments

Personal outcome scale

The POS (Van Loon et al., 2008) was used to measure the current levels of QoL related personal outcomes, as adapted to the Italian population by Balboni & Coscarelli (in press). The scale is based on the eight domains QoL model (Shalock & Verdugo, 2002) and was translated into several languages: English, Spanish, Catalan, German and Portuguese. The instrument is composed of 48 items over 8 QoL domains and 3 factors, in accordance with the Schalock and Verdugo model. The instrument requires a conversational administration with the user or a proxy, where each item

evaluates the specific QoL indicator on the scale: 1 (seldom or never), 2 (often), and 3 (always). The final score is composed of the personal and proxy report. The POS was administered by the case manager in a session with the participant and/or proxy (family member or care giver or professional) who understood and knew the recent life experiences of the individual (last 3-6 months) well. The outcome was a profile composed of domain scores for the 3 factors (independence, social participation and wellbeing) and a total score. The Italian version of the instrument showed good to adequate psychometric properties: internal consistency, test/retest reliability, and convergent and divergent validity Balboni, Coscarelli, Giunti, and Schalock (2013). The QoL profiles of the participants is summarized in Table 4.

Table 4

Support intensity scale

The SIS (Thompson et al., 2004) is an internationally used and standardized instrument to assess the current status of personal support needs of a person to participate in regular human activities (home and community living, lifelong learning, employment, health and social activities, health and safety, protection and advocacy). The Italian version, adapted by Leoni and Croce (2008), scores each support need area and provides a total score. Two additional subscales were considered for exceptional support needs: medical and behavioral. Cottini, Fedeli, Leoni, and Croce (2008) reported that the Italian version of the SIS showed good psychometric properties and could be considered a reliable instrument for assessment purposes, displaying internal consistency, test–retest reliability, and convergent and divergent validity. The case manager's assessed client support needs by interviewing personal assistants. Table 5 shows a summary of the Support Needs profile for the participants.

Table 5

Support provision

A checklist was created to measure the availability of support for each participant at the time of the study. Each support and activity area was assessed in a specific QoL oriented framework (Schalock et al., 2007). Each interview retrieved the information from the personal assistant of the client registering the availability of support for the client. Supports were classified using the Robert L. Schalock and Verdugo (2012) classification, shown in Table 1, and descriptions of support availability are given in Table 6.

Environmental factors.

The material regarding the environmental location of living was retrieved from the filed information of the users. The data was operationalized in categories: geographical location (City; Village; Country-side), living arrangement (independently; family of origin apartment; small residential service, less than 10 people; large residential context, with more than 10 users) and employment status (paid job, volunteer extern, volunteer intern, day care center activities).

Client characteristics.

Information regarding the client characteristics included in the regression analysis was collected through a self-developed checklist. The variables considered were: Age; Gender; Mobility; Level of Intellectual Functioning. The information was collected from the files of the clients.

Wishes and goals

Each personal assistant retrieved if the wishes and expectations of the subject (what is important to the person) were described in the Individual Support Plan of the client and consequently identified the nature and the number of these personal wishes. All the information was classified according to the QoL domains. The same classification format was used to collect the information expressed by the family members, caregivers or guardians regarding what they wished and which were the expectations regarding the client (what was important for the person). The reliability and validity of the information was checked by the first author by random selection of assessed information and by offering a supervision in the data assessment to the case managers.

Table 6

Data analysis

STATISTICA (StatSoft, 2010) was used to provide preliminary analyses and descriptive statistics for all variables. The influences of assessed support needs, support strategies, environmental factors, client characteristics, and QoL outcomes were calculated using hierarchical multiple regression (Table 7). The level of intellectual functioning was used as a control for the influence of living arrangement and working status/activities provisions for QoL personal outcomes. Pearson correlations were used to explore the relationship between the availability of support strategies and personal outcomes, and to understand the influences of variables included in the model on QoL outcomes for the clients.

Results

The 15 variables explained 57% of the variance, $R^2 = 0.569$, $F(5,1092) = 215.33$, $p < 0.001$, as summarized in Table 7. Personal characteristics explained 23% ($R^2 = 0.228$, $F(4,215) = 52,744$, $p < 0.001$). Including support needs explained 27% of the variance, $R^2 = 0.267$, $F(16,179) = 12.564$, $p < 0.001$. Adding personal and family goals explained an additional 5% of the variance, $R^2 = 0.051$, $F(1,1158) = 52.956$, $p < 0.001$.

Present support strategies explain an additional 1%, $R^2 = 0.092$, $F(4,1273) = 3.1637$, $p < 0.05$), and environmental factors explain a further 1%, $R^2 = 0.104$, ($F(3,381) = 14.771$, $p < 0.05$) of the variance.

Table 7

Table 8 shows the significant predictive variables for personal outcomes were: Age (B -.27 Std. Err. 0,07 T -3.52 p<.001); Level of intellectual functioning (B. 35 Std. Err. 43,24T 8,557p<.001); Mobility status (B .10 Std. Err. 0,05 T -2,00 p<.05); SIS total score (B -.57 Std. Err. 0,05 T -11.42 p<.001); Wishes and goals expressed by the subject (B .21 Std. Err. 0,03 T 7,27 p<.001); Availability of staff directed support (B .18 Std. Err. 0,07 T 2.27 p<.05); and Employment status (B .22 Std. Err. 0,65 T 4. 67 p<.001).

Table 8

The QoL personal outcome score was investigated over the different QoL domains, as summarized in Table 9. The following variables were significant predictors of the QoL score result in the 8 domains (Table 9): personal development, R²=.68, support need (B -.58 Std. Err. 0,07 t-test -11.40 p<.001), age (B -.26 Std. Err. 0,04 t-test -5.96 p<.05), mobility (B -.11 Std. Err. 0,05 t-test -4.48 p<.001), availability of staff directed support (B .24 Std. Err. 0,07 t-test 3.73 p<.05), and technology (B .11 Std. Err. 0,07 t-test 2.26 p<.05); self-determination, R²=.43, support need (B -.55 Std. Err. 0,07 t-test -7.76 p<.001), availability of staff directed support (B .30 Std. Err. 0,07 t-test 4.06 p<.001); interpersonal relationships, R²=.34, support need (B -.55 Std. Err. 0,07 t-test -8.18 p<.001), age (B -.18 Std. Err. 0,06, t-test -2.95 p<.005), availability of staff directed support (B .21 Std. Err. 0,1 t-test 2.28 p<.005); social inclusion, R²=.31, support need (B -.49 Std. Err. 0,05 t-test -8.18 p<.001), age (B -.15 Std. Err. 0,06 t-test -2.06 p<.005), availability of staff directed support (B .21 Std. Err. 0,1 t-test 2.28 p<.005); rights and empowerment, R²=.53, support need (B -.49 Std. Err. 0,07 t-test -7.02 p<.001), availability of staff directed support (B .34 Std. Err. 0,08 t-test 3.94 p<.001), level of intellectual functioning (B .14 Std. Err. 0,64 t-test 2.21 p<.005); emotional wellbeing, R²=.23, support need (B -.49 Std. Err. 0,07 t-test -8.18 p<.001), employment status (B -.19 Std. Err. 0,7 t-test -2.24 p<.05), natural support (B .17 Std. Err. 0,7 t-test 2.20 p<.05); physical wellbeing, R²=.26, support need (B -.23 Std. Err. 0,07 t-test -3.92 p<.001), age (B -.19 Std. Err. 0,06

t-test -2.66 p<.05) availability of staff directed support (B .44 Std. Err. 0,08 t-test 3.04 p<.05);

material wellbeing, R²=.36, level of intellectual functioning (B .26 Std. Err. 0,7 t-test 3.46 p<.005), age (B -.16 Std. Err. 0,06 t-test -2.57 p<.005), employment status (B .21 Std. Err. 0,7 t-test 3.11 p<.005), availability of staff directed support (B .30 Std. Err. 0,1 t-test 2.92 p<.05), support need (B -.19 Std. Err. 0,08 t-test -2.39 p<.05).

Table 9

To probe differences among the participant groups and the effects of the living environment on QoL, a one way ANOVA was performed, controlling for levels of intellectual functioning. Clients with mild intellectual disability experience better QoL outcomes than other groups $(F(2,53) = 28.80, p < 0.01)$. Gender differences were not significant, which conforms with previous research (Van Loon et al., 2008; Verdugo et al., 2010). Participants living in larger residential settings (more than 10 people) experience significantly lower QoL than the others $(F(3, 977) = 28.739, p < 0.001)$. Employment status has a significant impact on QoL, $(F(3, 362) = 16.670, p < 0.001)$, Participants with a paid job and those engaging in voluntary activities in the community have significant superiors $(p < 0.001)$ QoL as measured by the Post Hoc Tukey HSD compared to the other participants. Geographical location of participant's homes was not significant for QoL.

Using Pearson's correlation, specific support categories showed a modest relationship $(r < .30)$ with QoL personal outcomes. However, only the availability of staff directed support showed a statistically significant correlation $r = .10$, significance at $p < 0.05$ level (two-tailed).

Discussion

This study provides an overview of the most significant predictive variables, confirming that QoL is a multicomponent concept (Wang et al., 2010). Overall, support needs seem to be the best

predicting factor and its influence is strong and well represented in all the QoL domains. The result shows the importance of support needs assessment and the predictive usefulness of integrating the data using ISP to obtain personal QoL outcomes.

The prediction capacity of support needs was more outspoken compared to personal characteristics, even if level of ID and age were still significant predictors. Moreover, support needs were the only variable that were significant predictor in each QoL domain, reinforcing the influence and the importance of the concept in the explanation of the client's actual QoL. The results show the importance of a support need assessment and the predictive usefulness of integrating the data in an ISP to achieve QoL personal outcomes. The results underscore the importance of grounding support strategies on actual support needs of the person, rather than on personal characteristics. This relates to the necessity of each person participating in meaningful activities in his/her life community rather than "simply" focusing on the deficits. Furthermore, the supports paradigm addresses support needs beyond the basic care needs, and points towards enhancement of: personal development, empowerment, social inclusion and desired social roles (Thompson et al., 2002). The support paradigm implies a person- centered approach, rather than a professional-driven or system-centered planning (Thompson, Schalock, Agosta, Teninty, & Fortune, 2014), focusing on the person's personal perspectives and goals (Schalock et al., 2010).

The personal desires and goals explained approximately 5% of the variance and was a significant predictor of QoL outcomes. Furthermore, only the personal-reported desire was predictive in terms of QoL outcomes (21%), confirming the predictive value of self-respondency (Keith & Bonham, 2005). The present finding supports the relevance of a PCP-approach and the importance of involving the service user in the process of outcome definition and support provision, as suggested in other research (Buntinx & Schalock, 2010; Thompson et al., 2009). The focus on self-determination and inclusion of the client in the process of the ISP definition, confirms what is a right defined by UNCRPD (UN, 2006). Additionally, these data challenge the present and

institutional way of delivering supports to find a new dimension in which the subject is an active participant in the determination of his/her own QoL.

Employment status and activities undertaken was a significant predictor of QoL outcomes, as found in Claes et al. (2012). In the emotional and material wellbeing domains, the environmental factor of employment was a significant predictor and the presence of external activities (volunteering in the community and paid job) was a discriminant for better QoL outcomes, the analysis between groups furthermore confirmed the difference in terms of QoL profile for the two mentioned subgroups. Employment opportunities are considered as a challenge, as Thompson et al. (2014, p. 3) highlighted that lack of involvement in the labor market "deprived people with ID/DD to make a contribution to their world. The results from the present study stressed that persons with ID who participated in volunteer activities outside the center where they live, experienced higher levels of QoL. Furthermore, results showed that interventions related to the provision of supports for occupational activities promoted material and emotional well-being of clients.

Staff directed support was a significant predictor in the individual QoL domains except emotional wellbeing. Natural support was a significant predictor in emotional wellbeing and technology was significant in personal development, showing the importance of specific support categories for specific QoL domains. However, this study found only a minor effect from support activities for general QoL outcomes. The central role and relevance of support activities was not directly investigated, and further analysis is required.

The predictors analysis highlighted that clients with lower intellectual functioning and higher support need have significantly lower levels of QoL. The marginal influence of support activities contrasts with the Claes et al. (2012), where natural support, technology, and staff directed support were the principal predictors for QoL outcomes. However, these previous results were derived from a study within a single organization devoted to QoL outcomes in the Netherlands, as compared to the current study, that includes 23 different organizations that were not familiar with the concepts of

QoL or support. The current study outcomes stress the requirement for alignment of support activities to outcomes. The lack of alignment could result in waste of resources and outcomes different from personal desires and/or not QoL related (Schalock, Verdugo, Bonham, Fantova, & Van Loon, 2008).

To further improve QoL based outcomes, emphasis should be on providing support activities aligned to the specific QoL domain, on the basis of the support need of the individual. The inclusion of personal variables and characteristic in the support planning process is important, and the process must start from a PCP and include the personal desired goals. In addition, future achievement of personal outcomes should consider that people living in smaller settings and engaging in community activities will experience better QoL Outcomes.

Limitations

One particular limitation of the current study is that candidate selection was driven by the willingness of the association to participate. This could have produced bias and excluded organizations less motivated in measuring and understanding their outcomes. Furthermore, the fact that the case managers selected the participants is a limiting factor for external validity and to some extent internal validity. The second one generates from selection of organizations that are not familiar with the concept of supports and QoL. As we can see in table 6 the majority of the support were based on the staff rather than on a more ecological framework, where the operators are fully aware of the informal supports present. This could be a limitation in the inclusion of supports, although it reflects much of the actual vision of service providers, focusing on staff who take care of the person rather than focus on the inclusion of the person (McConkey & Collins, 2010). As most of the findings of the current and present studies rest upon correlational data analyses, the design of future research would benefit from experimental longitudinal studies where specific variables could be manipulated and examined, comparing the effectiveness of different sets of supports in determining QoL outcomes.

Conclusions

Historical practices have been focused on adaptive behavior weaknesses as a mean of improving a person's competencies (Shogren, 2013). The use of instruments linked to the traditional concept of functioning, looking at the damaged components and limitations in participation or at list to neutral and not problematic states (Buntinx, 2013) is part of the medical practice to diagnose ID and to plan supports. Future research should understand the importance of instruments to assess participant functioning and support needs in relation to preferences and desires of specific functioning components of the subject, creating a better balance between *what is important to* and *what is important for* the person (Schalock & Luckasson, 2014). Furthermore the use of instruments to assess individual functioning could benefit of inclusion of an assessment of strengths and not only limitation encountered by the subject in the relevant life ecology, as suggested by the AAIDD model (Schalock et al., 2010) or by Wemeiher in 2013, including assessment instruments, like the VIA (Shogren, Wehmeyer, Forber-Pratt, & Palmer, 2015) to evaluate users strengths and virtues. The use of these practices could promote a role change of the person from a secondary role, as object of assessment, to a primary role, as participant (Schalock & Alonso, 2013).

Future investigation should focus on the role and relevance of support activities to analyze further the predicting value of single support strategies. A review of the classification of supports and strategies could contribute to extend the results of the current study, investigating not only the role of the support categories, but linking the individual support received to QoL prediction. In particular, the association of a functioning profile could be related to personal supports data retrieved, to understand which functional components and specific supports are better predictors of QoL outcomes. As suggested by Shogren (2013), the process could change the practice of the services delivery to the person, from an evidence based perspective, moving from the promotion of

typical human functioning to meaningful and personally defined quality of life outcomes in the

individually valued environments.

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Table1	
Components of a support system	
Element	Specific Support Strategies
Natural Support	Family Friends Colleagues Community involvement
Technology	Assisting technology Information technology
Prosthetics	Sensory motor devices
Staff directed	Incentives Skills/knowledge Positive behavioral support
Professional services	Physical Occupational Speech Medical Psychiatric Psychological therapy

Table 2

Framework for hierarchical multiple regression analyses

Predictor	Dataset	Indicators
Client characteristics	Age	Years
	Gender	M / F
	Level of intellectual functioning	Mild, moderate, severe, profound
	Mobility status	Able to walk independently
Desires and goals	Person	N° of wishes and goals included in the ISP
	Family	
Support Needs	Assessed Support Needs	Total Support Intensity Scale Index
Support strategies	Assistive and information Technology	
	Prosthetics (sensory aids and mobility devices)	Presence and Number of support strategies included in the ISP
	Staff directed support	
	Professional services	
	Natural support	
Environmental factors	Geographical location	Town, village, country-side
	Living environment	Family, large residential, small residential, independently
	Employment status	Paid job, volunteer extern, volunteer intern, day care center activities

Table 3

Study participant details (N=1285)

Variable	Count	Percentage
Gender		
Males	776	60%
Female	509	40%
Age		
Mean	42	
Standard Deviation	14	
Intellectual Functioning		
Mild	101	8%
Moderate	342	27%
Severe	400	34%
Not Specified	442	31%
Most prevalent Diagnosis		
Trisomy 21	165	12.84%
Autism Spectrum Disorder	82	6.38%
Epilepsy	85	6.62%
Geographical location		
City	525	50%
Town	505	48%
Remote Area	16	2%
Living environment		
Family	700	67%
Large residential context	178	17%

(> 10 clients)		
Small residential context	157	15%
(> 4, < 10 clients)		
Living independently	11	1%
Activities		
Day care activities	761	72%
Volunteer Internal	137	14%
Volunteer external	126	12%
Paid job	21	2%

Table 4

Personal Outcome Scale profile of the population

POS	Mean	Standard Deviation
Personal development	10.94	3.27
Self determination	11.91	2.98
Interpersonal relationships	12.76	3.03
Social inclusion	9.18	2.72
Rights and empowerment	11.95	2.11
Emotional wellbeing:	14.34	2.42
Physical wellbeing	14.40	2.02
Material Well-being	11.46	2.34
POS total score	97.66	14.89

Note POS scores: domain minimum score=6 and maximum score=18, total minimum score=48 and maximum score=144. Lower scores signify lower levels of experienced QoL outcomes.

Table 5

Support Intensity Scale indices for the participants

SIS	Mean	Standard Deviation
Home living	53.50	19.39
Community living	56.35	19.94
Lifelong learning	68.90	23.89
Employment	63.67	20.86
Health and security	58.43	21.46
Social activities	54.09	22.14
SIS global index	63.53	16.03

Note SIS subscales and global index: minimum score=0 and maximum score=100. Lower scores signify lower levels of support needs.

Table 6

Number of support system components provided to participants

Support system components	Mean	Standard Deviation
Technology	1.76	1.62
Prosthetics	0.2	0.51
Staff-directed support	5.32	3.78
Professional services	0.68	0.98
Natural support	1.29	1.55

Table 7

Regression coefficients for overall QoL outcomes

Block and components	Regression coefficient (R^2)	R^2 change	F statistic
1 Client Characteristics	0.228	–	74.353**
Age			
Gender			
Level of intellectual functioning			
Mobility status			
2 Supports need	0.495	0.267	52.744**
Assessed Support Needs			
3 Desires and Goals	0.545	0.051	52.96**
Person			
Family			
4 Support strategies	0.559	0.014	14.771*
Technology			
Prosthetics			
Staff directed support			
Professional services			
Natural support			
5 Environmental factors	0.569	0.01	3.163*
Geographical location			
Living environment			
Employment status			

(*p value < .05; ** p value < .001)

Table 8

Significant predicting variables for personal outcomes

Predictor variable	Beta
SIS index	-0.57**
Level of intellectual functioning	0.35**
Age	-0.27**
Employment status	0.22**
Desires and goals expressed by the subject	0.21**
Staff directed support	0.18*
Mobility status	-0.10*

(*p value < .05; ** p value < .001)

Table 9

Regression coefficients for single domain QoL outcomes

QoL Domain	R²	Predictor	Beta
Personal development	0.68	Support Needs	-0.58**
		Age	-0.26*
		Staff directed support	0.24*
		Technology	0.11*
		Mobility	-0.11**
Self determination	0.43	Support Needs	-0.55**
		Staff directed support	0.30**
Interpersonal relationships	0.34	Support Needs	-0.55**
		Staff directed support	0.21*
		Age	-0.18*
Social inclusion	0.31	Support Needs	-0.49**
		Staff directed support	0.21*
		Age	-0.15*
Rights and empowerment	0.53	Support Needs	-0.49**
		Staff directed support	0.34**
		Level of intellectual functioning	0.14*
Emotional wellbeing:	0.23	Support Needs	-0.49**
		Employment status	-0.19*
		Natural support	0.17*
Physical wellbeing	0.26	Staff directed support	0.44*
		Support Needs	-0.23**

		Age	-0.19*
Material wellbeing	0.36	Staff directed support	0.30*
		Level of intellectual functioning	0.26*
		Employment status	0.21*
		Support Needs	-0.19*
		Age	-0.16*

(*p value < .05; ** p value < .001)