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Quality of Life of Persons with Severe or Profound Intellectual and Developmental Disabilities Transitioning Into Community From a Complex Care Residence in Canada

La qualité de vie des personnes ayant une déficience intellectuelle ou un trouble du développement sévère ou profonde qui effectuent une transition communautaire à partir d'un milieu de vie spécialisé au Canada.

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Abstract

Over the last three decades, the construct of Quality of Life (QoL) has been advocated as an important indicator of the quality and effectiveness of social care practice and policy for persons with intellectual and developmental disabilities. As part of a larger multi-year evaluation study, this cross-sectional investigation describes the QoL of 59 persons with severe or profound intellectual and developmental disabilities who were living in the complex care residence, Health and Transition Services of St.Amant, in the City of Winnipeg, Canada, and were in transition to community homes. QoL data on the 59 individuals prior to their transition were collected mostly retrospectively by proxy administering the standardized tool San Martin Scale to St.Amant staff who were most knowledgeable of the life of the persons being assessed while residing in the complex care residence. Results are presented in a descriptive fashion by reporting on the QoL of our study population in the eight QoL dimensions assessed in the San Martin Scale. Importantly, an accurate assessment of the QoL of the 59 participants before their transition to community living serves as the baseline for their evaluation post-transition. Overall, our study population scored at the same level as, or above scores *for the San Martin reference sample with intellectual and developmental disabilities in the QoL dimensions of Self-determination, Emotional Well-being, Physical Well-being, and Social Inclusion. Conversely, overall, our study population scored lower than the reference sample in the dimensions of Rights, Personal Development, Inter-personal Relations, and Material Well-being. We provide some recommendations for social care practice for persons with intellectual and developmental disabilities grounded in our findings.*

Résumé

Au cours des trois dernières décennies, le concept de la qualité de vie (QdV) a été reconnu comme un indicateur de la qualité et de l’efficacité des politiques et des pratiques dans le secteur des services sociaux pour les personnes ayant une déficience intellectuelle ou un trouble du développement. Cette enquête transversale, qui fait partie d’une plus grande étude longitudinale, décrit la QdV de 59 personnes ayant une déficience intellectuelle et développementale sévère ou profonde. Ces personnes vivaient dans un milieu de vie spécialisé des services de santé et de transition de St.Amant dans la ville de Winnipeg au Canada et étaient en transition vers un milieu de vie en communauté. Les données concernant la QdV avant leur transition ont principalement été récoltées de façon rétrospective au moyen d’un outil standardisé, l’échelle San Martin, complété par un membre du personnel de St.Amant qui connaissaient bien la personne lorsqu’elle résidait en milieu de vie spécialisé. Les résultats sont présentés de manière descriptive en rapportant la QdV de la population étudiée selon les huit dimensions de la QdV évaluées par l’échelle San Martin. Cette évaluation précise de la QdV des 59 participants avant leur transition vers un milieu de vie en communauté permet également d’établir un niveau de base pour l’évaluation suivant cette transition. Dans l’ensemble, la population étudiée a obtenu des résultats égaux ou supérieurs à ceux de l’échantillon de référence ayant une déficience intellectuelle ou un trouble du développement au niveau de dimensions suivantes de la QdV : l’autodétermination, le bien-être émotionnel, le bien-être physique et l’inclusion sociale. Cependant, de façon globale la population étudiée a obtenu un résultat moindre au niveau des dimensions suivantes : les droits, le développement personnel, les relations interpersonnelles et le bien-être matériel. À travers nos constats, nous proposons quelques recommandations en matière de pratiques des services sociaux pour les personnes ayant une déficience intellectuelle ou un trouble du développement.

Mots-clés : désinstitutionalisation, transition communautaire, déficience intellectuelle, trouble du développement, qualité de vie, échelle San Martin, services sociaux

Introduction

The World Health Organization (WHO) defines Quality of Life (QoL) as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (WHO, 1997). Over the last three decades, the construct of QoL has been advocated as an important indicator of the quality and effectiveness of social care practice and policy for persons with intellectual and developmental disabilities (Rand & Malley, 2017; Schalock, 2004; Schalock, Bonham, &

Verdugo, 2008; Verdugo & Schalock, 2009). Furthermore, since the publication of the Convention on the Rights of Persons with Disabilities in 2006 (United Nations, 2006), the QoL construct has been proposed as a useful link between the social rights and the personal lives of persons with disabilities (Shippers, Zuna, & Brown, 2015), as well as a key construct to drive progress towards empowerment, equity, and self-determination (Navas, Gómez, Verdugo, & Schalock, 2012).

Definitions of the QoL construct have significantly evolved over the past 30 years, especially in the field of intellectual and developmental disabilities (Gómez, Arias, Verdugo, Tasse, & Brown, 2015). Currently, QoL is characterized as a multidimensional construct involving domains and indicators, having methodological pluralism that encompasses subjective and objective measures, and incorporating multiple levels of the environment including the microsystem (individual), the mesosystem (agency and program), and the macrosystem (culture and society; Gómez, Arias, Verdugo, & Navas, 2012; Schalock et. al, 2002; Schalock et al., 2005; Verdugo, Schalock, Keith, & Stancliffe, 2005).

When persons with intellectual and developmental disabilities move from large institutions into smaller community-based living arrangements, there is an assumption of improvement in overall QoL and standard of living (Young et al., 1998). Many studies report that deinstitutionalization is associated with positive impacts across most QoL outcomes, including competence and personal growth (Cooper & Picton, 2000), challenging and adaptive behaviour (Golding, Emerson, & Thornton, 2005; Young, 2006), community participation (Young, 2006; Young & Ashman, 2004a, 2004b), autonomy and freedom in choice (Ager, Myers, Kerr, Myles, & Green, 2001), engagement in meaningful activities (Cooper & Picton, 2000), and quality of interactions with staff, family and friends (Emerson & Hatton, 1994; McCarron et al., 2018; Young et al., 1998). For example, Young (2006) conducted a prospective study in Australia investigating changes in QoL of 60 persons (aged 27-81 years) with moderate and severe intellectual and developmental disabilities who were transitioning from an institutional setting to a variety of community-based living arrangements. Findings showed that participants had significantly higher quality-of-life scores at both 12- and 24-months post-transition compared to pre-transition (baseline).

However, within reviews that find overall improvements in QoL following deinstitutionalization, there were studies reporting significant deterioration or limited day-to-day differences (Chowdhury & Benson, 2011; Heller & Miller, 1998; Verdonschot et al., 2009), as well as mixed or worse comparative outcomes for challenging behaviour, psychotropic medication use, health, and mortality (Kozma, Mansell, & Beadle-Brown, 2009). For example, Bigby (2008) conducted a mixed methods study to examine changes in the nature of informal relationships of 24 persons (aged 39-68 years) with moderate and severe intellectual and developmental disabilities transitioning from an institution in Australia to small group homes in the community. She found a decrease in the contacts that the study participants had with their family members from pre-transition to five years post-transition.

Therefore, the question of if and how community transition affects the QoL of persons with intellectual and developmental disabilities still remains unanswered. The study presented in this paper aimed at addressing this critical question as part of a larger multi-year evaluation study. In this paper, we describe the QoL of 59 persons with severe or profound intellectual and developmental disabilities who were living in the complex care residence Health and Transition Services (former River Road Place) of St.Amant in the City of Winnipeg (Canada) and were in transition to community homes. Additionally, we provide some recommendations for social care practice for persons with intellectual and developmental disabilities grounded in our pre-transition results.

Here, severe or profound intellectual and developmental disabilities are defined based on the definitions of intellectual disability provided by the American Association on Intellectual and Developmental Disabilities (AAIDD, 2010) and by the American Psychiatric Association in the Diagnostic and Statistical Manual of Mental Disorder (DSM-5) (APA, 2013). According to the DSM-5, intellectual disabilities are neurodevelopmental disorders that begin in childhood and are characterized by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living (APA, 2013). Both, the AAIDD and the APA classify severity of intellectual disability according to the levels of support needed to achieve an individual's optimal personal functioning (AAIDD, 2010; APA, 2013). Persons are diagnosed as having severe or profound intellectual disability if they receive an IQ score of 35 or lower and if they require extensive or pervasive support to perform daily activities in every aspect of daily routines. Some persons may require daily assistance with self-care activities and safety supervision, while others may require 24-hour care.

St.Amant is one of the largest not-for-profit organizations in Winnipeg that offer a wide range of programs and services to support Manitobans with intellectual and developmental disabilities and their families. Health and Transition Services of St.Amant is a complex care residence that provides quality residential care and developmental services to children and adults with intellectual and developmental disabilities.

Conceptual Framework

For the purpose of this study we used the QoL framework proposed by Schalock and Verdugo (2002), which is a widely accepted conceptual framework of QoL. According to this framework, QoL encompasses eight domains that are operationalized by a number of indicators (Schalock, et. al., 2002; Schalock et al., 2005). This QoL framework is currently identified as the gold standard in the social care field because: 1) it is referenced widely in the scholarly literature, 2) it includes cross-cultural universal characteristics (Schalock et. al, 2002; Schalock et al., 2005; Gómez et al., 2015; Verdugo, Navas, Gómez, & Schalock, 2012), 3) it has demonstrated validity (Gómez, Verdugo, Arias, & Arias, 2010; Wang, Schalock, Verdugo, & Jenaro, 2010), and 4) it has been used with a variety of populations such as persons with sensory and physical disabilities, as well as with mental health problems (Gómez, 2014; De Maeyer, Vanderplasschen, & Broekaert, 2009). The eight domains of this QoL framework include: 1) Self-determination, 2) Emotional Well-being, 3) Physical Well-being, 4) Material Well-being, 5) Rights, 6) Personal Development, 7) Social Inclusion, and 8) Interpersonal Relations.

Methods

Setting

Manitoba is the 5th largest province in Canada with a population of 1,278,365 (Statistics Canada, 2017). It is estimated that about 9,000 persons with intellectual and developmental disabilities aged 18+ years live in this province (Shooshtari et al., 2017).

The present study was part of a larger multi-year evaluation study examining the process and outcomes of community transitions for persons with intellectual and developmental disabilities who are moving from the complex care residence, Health and Transition Services of St.Amant, located in the province of Manitoba (Canada) into community homes. The larger longitudinal study started in 2016, and it is ongoing. Every year a number of residents of Health and Transition Services transition from the complex care residence into community homes. For this larger study, we are collecting data on those persons who are scheduled to be transitioned to community living in the near future and are simultaneously also collecting post-transition data for those persons who have already been transitioned to the community.

One of the main objectives of the larger longitudinal study is to measure the impact of community transitions on the QoL of the persons transitioned from Health and Transition Services of St.Amant into community-based residences. This will involve comparison of pre- and post-transition data on the people who transitioned. As a first step in this investigation, we measured the QoL pre-transition of 59 persons with severe or profound intellectual disabilities. At the time of data collection 86% of our study population had already been moved to a community residence, so most of the pre-transition data were collected retrospectively. The study was approved by the Research Ethics Board of the University of Manitoba.

Study Design

This was a cross-sectional study based on data that were collected on study participants' QoL prior to their transition from a complex care residence to community homes.

Study Population

Our study population consisted of 59 persons with severe or profound intellectual and developmental disabilities (AAIDD, 2010; APA, 2013) residing in the complex care facility Health and Transition Services of St.Amant. These 59 persons represent those who were transitioned from St.Amant in the first 4 years of implementation of the community transition process (2014-2018). At the time of data collection, the majority of the study participants had already been transitioned to the community (*n* = 51), while others were still residing in the complex care residence Health and Transition Services and were scheduled to be transitioned to the community in the near future (*n* = 8).

Study Measures

Quality of life. To measure the QoL of the study participants, we used the standardized assessment tool, San Martin Scale (Verdugo et al., 2013). The San Martin Scale (Verdugo et al., 2013; Verdugo, Gómez, Arias, Santamaría et al., 2014) is based on the eight-domain QoL framework proposed by Schalock and Verdugo (2002); it includes the domains of Self-determination, Emotional Well-being, Physical Well-being, Material Well-being, Rights, Personal Development, Social Inclusion, and Interpersonal Relations. The scale is a 95-item questionnaire that is completed by proxy, by a family member or support staff, who is most knowledgeable about the person being assessed.

Respondents are asked to indicate how often each item/statement occurs in the everyday life of the person being assessed on a 4-point Likert scale from Never (1) to Always (4) – with Sometimes (2) and Often (3) as the two additional response options (Verdugo, Gómez, Arias, Santamaría et al., 2014). As previously explained, the 95 items included in the scale are divided into the eight QoL domains defined by Schalock and Verdugo (2002), with 11-12 items included in each QoL domain. Administration time varies from 20 to 40 minutes (Verdugo, Gómez, Arias, Santamaría et al., 2014). To score respondents' answers, the responses to each item are scored by assigning them a value from 1 (Never) to 4 (Always). Then, raw item scores or "direct scores" on each QoL domain are added together to form eight direct total scores (one per each QoL domain), which are then transformed into eight standard scores (mean = 10; standard deviation = 3) using a conversion table developed by Verdugo and colleagues at the time of validating the scale. Additionally, summing the eight standard scores, it is possible to obtain a "Standard Compound Score" or Quality of Life Index (mean = 100; standard deviation = 15), which provides a summary of the QoL of the person being assessed that takes into account the scores he/she obtained to all eight QoL domains. Therefore, the results obtained on the San Martin Scale provide a measure of QoL for each person, or an entire sample relative to the norms developed for persons with intellectual and developmental disabilities and extensive support needs. The characteristics of this reference population are described below.

The San Martin Scale was validated by administering the instrument to a sample of 1,770 people (age range = 16-77 years old) with significant intellectual and developmental disabilities living in Spain who had extensive or pervasive support needs and were residing in a variety of settings (Verdugo, Gómez, Arias, Navas et al., 2014). The persons included in this validity study had an intellectual disability and presented the need for extensive and general support (e.g., persons with severe and profound intellectual disabilities or persons with problems relating to the development of serious health issues and related disabilities). The entire reference population required extensive support (45%) or generalized support (55%) and most of them had a high level of "great dependency" (62%). Besides from intellectual disabilities, 92% of this population presented other related conditions such as epilepsy (27,8%), limitations in lower limbs (27,4%), behavioural problems (26%), Down Syndrome (17,2%), autism (17,2%), cerebral palsy (19,9%), mental health problems (16,4%) limitations in upper limbs (15, 3%), visual disability (14,9%), hearing disability (6,4%) or serious health problems (4,7%). The results of this validity study suggested that the eight QoL domains assessed in the scale are reliable (Cronbach's alpha = .82-.93). Further, Confirmatory Factor Analysis provided construct validity evidence related to the internal structure of the scale.

The original version of the San Martin Scale was developed in the Spanish language to specifically assess QoL of persons with intellectual and developmental disabilities and living in a residential setting and presenting co-occurring medical conditions (Verdugo, Gómez, Arias, Navas et al., 2014). This standardized tool was recently adapted in the English language and its use was validated in a sample of 236 persons with concurrent diagnoses of intellectual and developmental disabilities and autism (age range = 17-52 years) who required full-time residential care (Stone et al., 2020). The results of this validation study suggested that the English version of the San Martin Scale provides a reliable and valid assessment of the QoL of persons with intellectual and developmental disabilities who have low functioning and extensive support needs. Given the existing evidence on validity of San Martin Scale, we decided to use this standardized tool to assess QoL in our study population, which included persons with severe or profound intellectual and developmental disabilities and extensive support needs. There is evidence of more negative QoL outcomes for persons with severe intellectual and developmental disabilities and extensive support needs, whose ability to live and perform everyday activities and tasks independently is profoundly impacted in a negative way. Therefore, it is important to use standardized instruments that are specifically developed to assess QoL in this population, such as the San Martin Scale that we adopted in our study.

Socio-demographic characteristics. A number of measures were used to describe the study population's socio-demographic characteristics including sex (male or female), age (in years), length of residency (in years), and Indigenous status (yes/no). We used these measures to describe our study population and tested their associations with participants' QoL.

Data Collection

Data were collected between May and September of 2018. A total of 59 QoL assessments were conducted. The assessments were completed by 50 St.Amant staff (46 resident assistants, 2 social workers, and 2 health care aids), who were the most knowledgeable persons about the study participants. We chose the staff on the basis of two criteria: 1) the frequency of contact with the person to be assessed, which in most cases was every day, and 2) the total length of time that the person to be assessed had been in the care of the respondent. Most of the respondents had provided care to the study participants at St.Amant for several years.

Data Analysis

Data were analyzed using the software SPSS version 21.0. Frequency distributions were examined to describe the study population's socio-demographic characteristics following the standardized procedures for scoring and reporting QoL data described by Verdugo and colleagues in the Manual of the San Martín Scale (Verdugo et al., 2013). First we computed the raw scores in each QoL dimension, and then transformed them into standardized scores (M = 10 and SD = 3), which allow for a more meaningful and comparable interpretation of the mean scores obtained by our study population in the eight QoL domains. Next, for each study participant and for the entire study population, we created a Quality of Life Index with a mean of 100 and standard deviation of 15. The Index summarizes the overall QoL of the person assessed based on the scores he/she obtained in the eight QoL dimensions assessed by proxy. We also tested the bi-variate association between our study population's socio-demographic characteristics and their QoL by conducting correlation analyses and chi-squared tests.

Results

Study Population

The study population's socio-demographic characteristics are summarized in Table 1. As shown in Table 1, our study population was almost evenly divided between sexes, including 32 men and 27 women. The cause of intellectual and developmental disabilities was not known for 42% of the study population. Of those with a known cause, 18% had Down syndrome, 44% had cerebral palsy, and 38% had other genetic disorders. On average, participants were 40 years old (*SD* = 11, range = 13-62 years). The study participants' length of stay in the complex care residence ranged from 2.4 years to 47.9 years (*M* = 26.5 years, *SD* = 14.3). Only a small proportion of our study population had a known Indigenous ethno-cultural background (26%).

In accordance with professional assessments provided by St.Amant clinicians, our study population was characterized by severe or profound levels of intellectual and developmental disabilities and presented with a variety of co-occurring medical conditions involving physical and/or mental health problems. Some of the most common co-occurring conditions included physical and sensory disabilities, seizure disorders or epilepsy, and mental health problems such as anxiety and mood disorders. Consequently, our study population was characterized by very low functioning that greatly impacted their ability to live and perform everyday activity and tasks independently, which was at the root of their extensive care needs.

Table 1 - *Description of the Study Population*

		Mean	SD	Min-Max	Median
Age*		40	11	13-62	42
Length of Stay in the Complex Care Residence*		26.5	14.3	2.4-47.9	31.2
			N	%	
Causes of Intellectual and Developmental Disability	Down Syndrome		6	18	
	Cerebral Palsy		15	44	
	Other Etiology		13	38	
	Missing		25		
Sex	Male		32	55	
	Female		27	45	
Indigenous Status	Yes		9	26	
	No		25	74	
	Missing		25		

* Age and length of residency at St.Amant is reported in years.

As we expected, there was a statistically significant positive correlation between the study participants' age and their length of stay in the complex care residence ($r = .58$, $p = .000$). In order to perform chi-squared testing, after analyzing the distribution of our study participants' age and length of residence at St.Amant, we divided our study population into four age groups (group 1 = 13-29 years, group 2 = 30-40 years, group 3 = 41-50 years, group 4 = 51-62 years) and four lengths of stay in the complex care residence Health and Transition Services (group 1=2.4-10 years, group 2 = 11-29 years, group 3 = 30-39 years, group 4 = 40-47.9 years). Chi-squared test results showed no differences in the proportions of male and female participants across the four age groups ($X^2_{(3)} = 3.9$, $p = .269$), suggesting that males and females were evenly divided across these four age groups. Significant chi-squared test results ($X^2_{(3)} = 9.1$, $p = .028$) indicated that there were significant differences between the distributions of male and female participants across the four categories of lengths of stay in the complex care residence, with a greater number of women who resided in the facility only for up to 10 years compared to men and a greater number of men who stayed in the residence for 11-29 years compared to women.

Quality of Life

The descriptive statistics of the standardized scores in the eight QoL dimensions for the entire study population are presented in Table 2. As shown in this table, on average our study population scored at the same level of, or above what expected for persons with severe intellectual and developmental disabilities in the Self-Determination ($M = 11.4$, $SD = 2.7$), Emotional Well-being ($M = 10.2$, $SD = 3.1$), Physical Well-being ($M = 10.1$, $SD = 2.3$), and Social Inclusion ($M = 10.1$, $SD = 2.5$) dimensions. The four dimensions in which on average our study population obtained scores lower than the mean standard scores were Rights ($M = 8.2$), Personal Development ($M = 8.6$), Inter-personal Relations ($M = 9.1$), and Material Well-being ($M = 9.0$).

Table 2 - *Descriptive Statistics of the Standardized Scores of the 59 Study Participants in the Eight Quality of Life Dimensions*

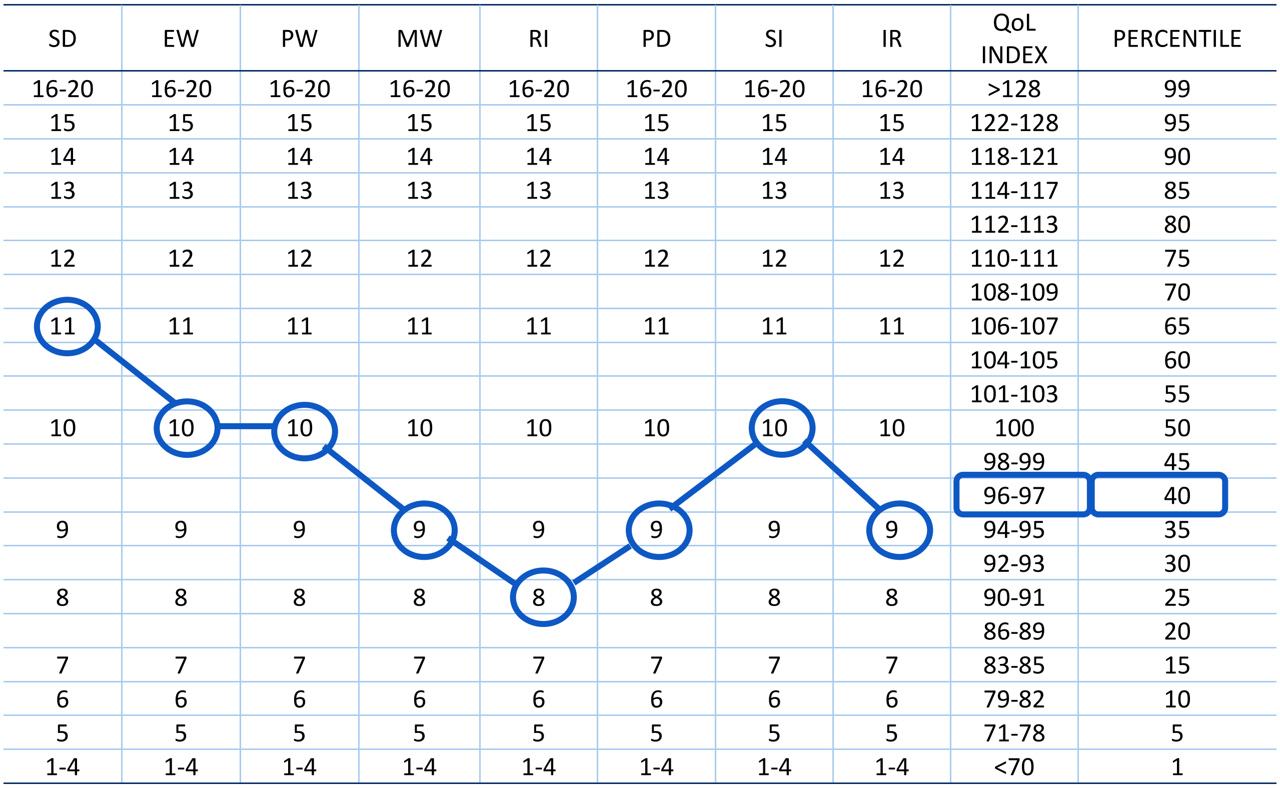
Dimension	Standard Scores			
	Mean	SD	Min-Max	Median
1. SELF-DETERMINATION	11.4	2.7	5-16	11
2. EMOTIONAL WELL-BEING	10.2	3.1	3-15	11
3. PHYSICAL WELL-BEING	10.1	2.3	3-15	11
4. MATERIAL WELL-BEING	9	3.8	1-14	10
5. RIGHTS	8.2	5.2	1-15	10
6. PERSONAL DEVELOPMENT	8.6	3.2	1-15	9
7. SOCIAL INCLUSION	10.1	2.5	5-15	10
8. INTERPERSONAL RELATIONS	9.1	4.1	3-15	9

NOTE: No missing values.
Overall, our study participants scored at the same level of, or above what expected for persons with severe or profound intellectual and developmental disabilities in the QoL dimensions of self-determination, emotional well-being, physical well-being, and social inclusion. Conversely, overall, our study participants scored lower than what observed in similar populations in the dimensions of rights, personal development, inter-personal relations, and material well-being.

The mean Quality of Life Index for our study population was 98 (*SD* =15) with a median of 97, indicating that 50% of the persons in our study population scored above 97. This indicates that approximately half of our study population had good overall QoL compared to what was observed for a similar population (Verdugo, Gómez, Arias, Navas et al., 2014; Verdugo, Gómez, Arias, Santamaría et al., 2014). Twenty-five percent or one-fourth of our study population obtained very high Quality of Life Index scores that followed beyond one standard deviation above the mean (Quality of Life Index scores = 115-129).

The QoL data obtained administering the San Martin Scale can be graphically presented as a Quality of Life Profile that includes the total standardized scores in the eight dimensions, as well as the corresponding Quality of Life Index and its percentile. Figure 1 presents our study population's Quality of Life Profile. The average QoL Index for our study population at 40th percentile, was very close to the average observed for a similar population (Verdugo, Gómez, Arias, Navas et al., 2014; Verdugo, Gómez, Arias, Santamaría et al., 2014).

Figure 1 - *Quality of Life Profile for the Study Population*



SD	EW	PW	MW	RI	PD	SI	IR	QoL INDEX	PERCENTILE
16-20	16-20	16-20	16-20	16-20	16-20	16-20	16-20	>128	99
15	15	15	15	15	15	15	15	122-128	95
14	14	14	14	14	14	14	14	118-121	90
13	13	13	13	13	13	13	13	114-117	85
								112-113	80
12	12	12	12	12	12	12	12	110-111	75
								108-109	70
11	11	11	11	11	11	11	11	106-107	65
								104-105	60
								101-103	55
10	10	10	10	10	10	10	10	100	50
								98-99	45
								96-97	40
9	9	9	9	9	9	9	9	94-95	35
								92-93	30
8	8	8	8	8	8	8	8	90-91	25
								86-89	20
7	7	7	7	7	7	7	7	83-85	15
6	6	6	6	6	6	6	6	79-82	10
5	5	5	5	5	5	5	5	71-78	5
1-4	1-4	1-4	1-4	1-4	1-4	1-4	1-4	<70	1

NOTE: SD = Self-determination, EW = Emotional Well-being, PW = Physical Well-being, MW = Material Wellbeing, RI = Rights, PD = Personal Development, SI = Social Inclusion, and IR = Interpersonal Relations. The Quality of Life Index and corresponding Percentile are calculated by using the conversion tables provided in the San Martín Scale Manual (Verdugo, Gómez, Arias, Navas et al., 2014).
The entries in this matrix are taken from the San Martin Manual. They represent the distribution of standardized scores for the reference population. The circled scores are those for our study population. The latter are close to the mean scores of 10 at the 50th percentile of the reference population.

Discussion

In this paper, we describe the QoL of 59 persons with severe intellectual and developmental disabilities residing in a complex care residence prior to their transition into community. Given the limited and inconsistent evidence available from the literature regarding the impact of community transitions on QoL of persons with intellectual and developmental disabilities, we conducted this study to further investigate this important topic. In this paper we summarize the baseline (pre-transition) QoL data but planning to conduct post-transition assessments to measure the community transitions impact, the information that could be used by service providers and policy makers to provide the best community-based living options for persons with intellectual and developmental disabilities.

The study findings provided a general picture of the overall QoL of our study population and also offered insight on the QoL experienced in each of the eight specific QoL domains. We found that on average, the overall QoL of our study population was comparable to what was expected for persons with severe intellectual and developmental disabilities (Quality of Life Index: $M = 97$). The domain-specific data showed that our study population scored average or above average in the following four QoL dimensions: Self-determination, Emotional Well-being, Physical Well-being and Social Inclusion. However, our study participants scored below average in the Material Well-being, Rights, Personal Development, and Interpersonal Relations.

The San Martin Scale items used to measure Material Well-being assessed the conditions and safety of the residence, the appropriateness of the technical aids used by the individuals for their daily functioning, and care of personal belongings. Items used to measure the respect of Rights focused on staff knowledge of rights of persons with intellectual and developmental disabilities as well as respect of intimacy, privacy, and confidentiality. Personal Development was measures with items related to self-improvement, learning of new skills, and motivational abilities. The items used to measure Interpersonal Relationships focused on relationships with family, social networking, and communication.

Our study findings highlight the areas of priority for St.Amant to act on to improve the QoL of their clients as they are transitioning into community homes. Some of the recommended strategies include staff training on respect of the rights of persons with disabilities, providing the clients with more opportunities for personal development and interpersonal relationships as well as provision of a safe physical environment based on the wishes and preferences of persons with disability that is also accommodating of their special needs, and prevents injuries. Educating persons with disabilities themselves about their rights and educating the healthcare professionals and the public about the rights of persons with disabilities are highly recommended.

Some limitations of our study should be noted. The QoL data in this study were collected by proxy, and for most part retrospectively. Proxy reporting might have negatively affected the accuracy of the information obtained (Cummins, 2002). There is conflicting evidence regarding the concordance between self-report and proxy-report in the evaluation of QoL of persons with intellectual and developmental disabilities (e.g., Schmidt et al., 2010; Verdugo et al., 2005; Zimmermann & Endermann, 2008). Regardless of this controversy, many researchers believe that data collection by proxy is useful in certain situations, specifically when people are unable to respond for themselves (Baldoni, Coscarelli, Giunti, & Schalock, 2013; Chowdhury & Benson, 2011; Verdugo at al., 2005), which was the case in our study.

Proxy reporting also increases the chance of desirability bias. In this study the data were gathered by proxy by interviewing St.Amant staff. Due to their employment status, the St.Amant staff might have responded to the questions with the desire to please their supervisors and the higher management of the organization.

Data that were collected retrospectively is susceptible to recall bias. Furthermore, because some of the staff we interviewed maintained professional contact with the persons assessed after they were transitioned to the community, their retrospective evaluation of the persons' QoL pre-transition may have been affected by their knowledge of the persons' current QoL in the community. Therefore, caution needs to be used in interpreting the results here presented, as well as in generalizing the results to other populations.

Despite these limitations, the QoL data we collected by proxy are very valuable as they provide support staff and program managers with a detailed information on individuals' QoL that they could potentially use in their routine practice in provision of health and social services, guiding the development of person-centred care plans that are tailored to meet the specific needs of persons with intellectual and developmental disabilities. We recommend the routine use of standardized tools to measure QoL as part of the standard of care for persons with intellectual and developmental disabilities regardless of their living arrangements.

The research described in this paper is part of a larger longitudinal study, where the same group of individuals will be followed over time to assess changes in their health and quality of life post- transition. Data collected in the study will set the foundation to better understand the experience of individuals with severe intellectual and developmental disabilities as they transition from large congregate settings into small community homes.

Key Messages From This Article

People with disabilities. You deserve to live in a comfortable home where the people who care for you provide you with services that promote your quality of life in all domains.

Professionals. It is of paramount importance that you possess the knowledge and professional skills needed to provide services that improve the quality of life of the persons with intellectual and developmental disabilities you care for.

Policymakers. Professionals need to be educated about the importance of routinely assessing and promoting the quality of life of the persons with intellectual and developmental disabilities they care for.

Messages clés de cet article

Personnes ayant une incapacité. Vous méritez de vivre dans une résidence confortable où les personnes qui vous offrent des soins utilisent des services qui promeuvent votre qualité de vie dans tous les domaines.

Professionnels. Il est de la plus haute importance que vous possédiez les connaissances et les compétences professionnelles nécessaires pour fournir des services qui améliorent la qualité de vie des personnes ayant une déficience intellectuelle ou un trouble du développement dont vous vous occupez.

Décideurs. Les professionnels doivent être sensibilisés à l’importance de régulièrement évaluer et promouvoir la qualité de vie des personnes ayant une déficience intellectuelle ou un trouble du développement dont ils s’occupent.

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