Assessing the Quality of Life of Individuals with Intellectual Disabilities in a Small Care Living Facility

by

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DEDICATION

For my family and all your ongoing love and support

*Everything happens for a reason.*
ABSTRACT

Some individuals with intellectual disabilities require assistance in different areas of life such as completing everyday tasks, money management, or perhaps living arrangements. Individuals have their own strengths and limitations. It is important that each individual can express his or her strengths and that the individual is provided with opportunities to work on the weakness or have assistance, if required. In other words, it is important for all individuals to have a life they value enriched by their expectations and wants. The current study evaluates the quality of life of two females who were diagnosed with an intellectual disability. This study used the methods from a previous quality of life evaluation that was conducted by Brown and colleagues in 1997, which evaluated the quality of life of individuals with an intellectual disability living in Ontario. The current study used the same quality of life package as Brown et al. (1997). After consent was obtained, the participant was asked to complete a questionnaire with the student assessor. As well, the package required a significant other to complete a similar questionnaire as the participant questionnaire. Finally, the assessor completed a questionnaire that was different from the participant and significant other questionnaires. The study found that the two participants who lived in a small care facility had an overall good quality of life based upon the three domains: Being, Belonging, and Becoming. The discussion section of the thesis provides further explanation regarding the participants’ good quality of life. Furthermore, additional strengths, limitations, and multilevel challenges to the thesis, as well recommendations for future research are discussed.
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Chapter I: Introduction

Quality of life (QOL) is a very important aspect of everyday living. What one does on a daily basis, such as what you eat, where you live, and how one decides to spend their money are some things in a person’s life that can help make it better. The environment in which one resides or visits can influence the happiness of an individual. An enriched environment filled with valued situations, events, or people that make the individual happy can help increase QOL. QOL is an individualized concept which means it is different for everyone based on their needs, wants, or wishes. Community events and programs are based upon the needs and wants of people but also help make the lives of those who live in that community more fulfilling by perhaps providing a sense of belonging. QOL has moved from a theoretical concept to both a measureable construct and now an influence for change in the community. The hypothesis of this study was that individuals with intellectual disabilities would have an overall below adequate QOL score, similar to the findings of Brown et al. (1997).

Two important terms to understand are quality of life and developmental disabilities. QOL can be difficult to define and measure. It has previously been described as “general requirements for happiness” (Prescott-Allen, 2001) or “positive life experiences” (Campbell et al., 1976). A more general definition of QOL is the overall happiness that one has with their own life or how good life is for them. QOL is a very individualized term which means it varies for everyone. Many things can influence the QOL for an individual such as culture, health issues, individual beliefs, or the community in which one resides in. Although QOL is an individualized concept and theoretically can be assessed the same way for everyone, models have been created for specific populations to ensure the assessment can be completed regardless of any deficits the
participant may have. Many different instruments have been designed to fit the needs of different populations being assessed. This study will be assessing the QOL of an individual with a developmental disability.

The second key term is developmental disability, also referred to as intellectual disability or intellectual development disorder. Both terms, intellectual disability and intellectual development disorder, are used in the DSM-5 to replace the term mental retardation (American Psychiatric Association, 2013). The three criteria outlined by the DSM-5 include: deficits in intellectual functions (e.g., reasoning, problem solving, planning, or abstract thinking), deficits in adaptive functioning which result in failure to meet developmental and sociocultural standards, and onset of deficits occurring during the developmental period. Similar to the DSM-5, the American Association on Intellectual and Developmental Disabilities (AAIDD; 2010) defines developmental disabilities as impairments in both intellectual functioning and adaptive behaviour that occurs before the age of 18. When determining an assessment tool to be used for QOL, it is important to have a clear understanding of the population one is working with. Individuals with developmental disabilities may not have the abilities to understand the requirements of a complex assessment, therefore, an assessment tool that an individual with a developmental disability is capable of completing is required.

QOL is not a new term but has been a main focus in many studies and played a role in the closing of institutions in Ontario. QOL has helped identify and plan support needs for individuals, activities presented by organizations, and services that should be provided in the community. The closure of the institutions was to promote integration in the community and promote independent living for individuals with developmental
disabilities. Although the original plan was to have all institutions closed by 2012, the Ontario government was three years ahead of schedule and closed the final three institutions in March of 2009 (Ministry of Community and Social Services, 2009). People with developmental disabilities have been living in the community for many years now, with deinstitutionalization beginning in the mid-80s and QOL continues to be an ongoing concern. From the completion of a functional assessment interview, direct observations, to having discussions with an agency’s consulting psychologist, QOL continues to be an issue with this population. Everyone deserves to have a high QOL even if they do have a disability. It is important to remember that individuals with developmental disabilities receive individual funding for their individual support and services. If one resides in a group home, he/she is essentially paying room and board at that home. Therefore, the services provided by the home should fit the individual’s wants and needs. This study is being done to address the concerns around QOL, promote positive programing and staffing, discuss ethical concerns, and address the relationship between problems behaviours and QOL.

In this study, the quality of life of an individual with a developmental disability is discussed. The assessment results are being compared to the previous study completed by Brown, Raphael, and Renwick (1997). With the support of the literature, quality of life is important to consider when determining if people with developmental disabilities are living a satisfying life to the best of their abilities. QOL should be a main factor when determining living settings, life plans, day planning, and behaviour programming because it plays a large role in one’s overall happiness as well as influencing behaviour. A comparison of the results found by Brown et al. and the findings of this study will
examine the current QOL for two individuals with intellectual disabilities as compared to institution living in the late 1990s.

This study will discuss a method of assessing QOL for an individual with a developmental disability who lives in Ontario. The hypothesis of this study was that individuals with intellectual disabilities would have an overall below adequate QOL score, similar to the findings of Brown et al. (1997). Results will be provided based upon the assessment methods and will be compared to the findings of previous studies. The focus of this study is on the QOL scoring for individuals who lived in small care living facilities during the period when Brown et al. (1997) completed their study. This study will provide a discussion to provide feedback and suggestions for QOL and developmental disabilities. This thesis will discuss empirical literature that provides an overview of what intellectual disabilities are and relevant research to QOL. Following the literature review, the method developed for this thesis, results from the method, and a discussion section are included.
Chapter II: Literature Review

There has been much research done about QOL, intellectual disabilities, and assessment tools. This literature review will provide an overview of QOL and why is it important. An overview of intellectual disabilities and the history of intellectual disabilities in Ontario will also be highlighted. As well, a brief summary of a province wide QOL study in Ontario will be discussed.

Quality of life – What is it and why is it important

How happy one is with their life, the choices they have made, and the place in which they live are a few of the important factors when determining if one has a satisfying life. Quality of life is a concept that applies to everyone and is difficult to define. Although it is difficult to define, general concepts are now understood. A general definition or concept of QOL examines how happy or satisfied one is with their own life. Ways to measure an individual’s QOL have also been a challenge over the years but the importance of QOL has been a topic of discussion in many fields. According to Reed, KÖSslet, and Hawthor (2012), interventions that involve the use of therapeutic drugs evaluate the QOL to determine judgments about their cost effectiveness for the patients. QOL is a multifactorial measure that assesses emotional, social and physical wellbeing, and the ability to complete everyday tasks of daily living. QOL is a term that can also be defined on an individual level. Factors such as culture, personal beliefs, and personal values all play a role in QOL. QOL is a general term that can be helpful with different populations. Everyone has a right to live a high QOL if they desire, although opportunities for attaining a high QOL may be limited.
Gerontology is a field that has also taken an interest in assessing QOL. Shrestha and Zarit (2012) state that QOL is an indicator of how well society meets the needs of the elderly. As people age, different resources and programs are required. When determining if one has a high QOL, it is important to consider goals, expectations, standards, and concerns important to that individual. QOL has moved from a theoretical concept to both a measurable construct and now an influence for change in the community. Resources available in the community are based upon the wants and needs of individuals who live in that community.

Martin, Schneider, Eicher, and Moor (2012) state that if a community has low levels of resources that alone does not necessarily motivate individuals to use those resources (p. 34). In other words, just because there is only a golf course in the community, people are not necessarily going to start golfing. Resources should be based upon what the people living in the community want and need. By having resources available to the community, higher QOL scores are more attainable. Not only is having greater resources important to determine QOL but, when looking at low QOL scores, one can determine which resources are missing or which resources may be beneficial to the individual and perhaps suggestions for improving the resources may be presented.

Goncher, Sherman, Barnett, and Haskins (2013) discuss QOL from a different perspective. Their study focused on graduate trainees in clinical psychology and the emphasis of self-care and quality of life. Self-care can be defined as the actions one does to maintain the well-being of personal health and promote development. With the use of the *Perceived Self-Care Emphasis Questionnaire* (PSEQ), Goncher et al., assessed 262 graduate trainees ages 21 to 57. Along with the completion of the PSEQ, participants
completed the Quality of Life Index (QLI) – Generic Version III (Ferrans, & Powers, 1985). The QLI consist of two sections; how satisfied individuals are with their life and how important each aspect of their life is to them. The two sections are made up of 33 questions which are rated on a 6-point likert-type scale “1” representing very dissatisfied or unimportant and “6” representing very satisfied or important. All the participants were trainees in doctoral clinical psychology programs. Two main hypotheses were proven through the study; there would be a relation between students’ perceptions of self-care emphasis in their doctoral clinical psychology program and quality of life and there would be a relationship between graduate student self-care utilization and quality of life. In other words, students who scored high on self-care emphasis would also score higher on a measure of QOL. Tasks such as brushing your teeth, eating a balanced diet, and exercising regularly can influence an individual’s self-care. QOL can be influenced by what some people take as a simple task although if an individual does not have the opportunity, resources or choice to complete the tasks, QOL can be lowered. Goncher et al.’s study concluded that quality of life and self-care are directly related.

The American Association on Intellectual and Developmental Disabilities (AAIDD, 2010) outlines what is necessary for a meaningful QOL for individuals with developmental disabilities. The opportunity to receive support, encouragement, opportunity, and resources at all stages of life should be provided for a meaningful quality of life. As mentioned earlier, an aging population may need more resources than a young population. Although individuals with developmental disabilities may already need more resources than those who do not have a disability, different or more resources, more support, more encouragement, and more chances for opportunity may need to be
considered for different ages. This may also apply the opposite way; one may need less support, encouragement, opportunity or resources as they age, although the individual should be responsible for determining if they do need more or less support.

A meaningful QOL should provide opportunities for decision-making including where the individual wants to live and who is in their lives. The opportunity to live a life enriched by friends and family and have opportunities to build meaningful and intimate relationships should also be provided. The AAID also suggests that a meaningful QOL should include the opportunity to select services and supports necessary for individual living needs and one should not have to wait for an uncertain and extended length of time. Although the AAIDD’s main focus for QOL is around individuals with developmental disabilities, these suggestions can be important to individuals who do not have a developmental disability. Support, encouragement, opportunity, resources, friends, family, and living are important to everyone, not just individuals with a disability.

Similar to what the AAIDD outlines for what is necessary for a meaningful QOL, Brown et al. (1997) discuss general principles for QOL. These principles state that every person with a developmental disability has the right to live a quality life similar to those who do not have a disability. Assessing QOL can be completed the same way for all people with the scores reflecting each individual in their own way. For some, religion is not going to be as important as other things. Scoring of a QOL assessment represents that individual and their individual wants and needs. Brown et al. also state that people live in environments and QOL reflects people’s perceptions of themselves, their environment, and how they fit with their environment. For people who do not have an enriching
environment with friends, family, support, or services required, they most likely have a lower QOL.

Quality of life can be a difficult term to define and understand because there are many things that influence an individual’s QOL. However, it is important to recognize that although it reflects individual needs, QOL can be assessed in the same way for everyone. When assessing QOL, it is essential to understand the population you are dealing with to ensure correct instruments and procedures can be followed. Although QOL can be assessed the same for everyone, prompts, rewording, or visual aids may be required to assist the individual who is completing the assessment. Understanding the population being assessed is important with QOL as for any assessment tool.

**Intellectual Disabilities – Overview and History**

Previously, mental retardation was the term used to describe an individual with a developmental disability (American Psychiatric Association, 2013). Today, both intellectual disability and intellectual development disorder are used in the DSM-5 to replace the term mental retardation (American Psychiatric Association, 2013).

The AAIDD (2010) used the term developmental disability to replace mental retardation. The AAIDD defines a developmental disability as impairments in both intellectual functioning and adaptive behaviour that are present before the age of 18. Intellectual function, or intelligence, refers to the general mental capacity such as the ability for one to reason, problem solve, or learn new things. Adaptive behaviour consists of conceptual, social, and practical skills. These skills are learned and performed in everyday life. Conceptual skills include language, money, time, and self-direction. Being able to understand conversation, the value of money, the use of time and time-
management, and being able to self-direct are not skills that people with intellectual disabilities typically demonstrate. Social skills include social problem solving, interpersonal skills, social responsibility, and self-esteem. Individuals with intellectual disabilities may also lack social skills. This can influence their relationships with peers at school, work, or in the community. This is important because relationships do influence quality of life for some individuals. Practical skills include the activities of daily living, which includes personal care, health care, transportation, and safety. Practical skills can be difficult for an individual with a developmental disability because the understanding of why practical skills are important or the ability to learn the skills may not be easily attainable for the individual. This can influence QOL because being able to live a happy life safely is a right for any individual. Intellectual function and adaptive behaviour are limitations in individuals with a developmental disability with different severities for each individual depending on their diagnoses.

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association, 2013) also outlines the criteria for developmental disabilities. The DSM-5 states that this population usually has an IQ score of about 70 or below. The diagnosis of a developmental disability involves impairments of general abilities that impact adaptive functioning in three domains: conceptual, social, and practical. The conceptual domain includes impairments in language, reading, writing, math, reasoning, knowledge, and memory. The social domain refers to impairments to social judgments, empathy, interpersonal communication skills, and the ability to make and keep friendships. The final domain is the practical domain which focuses on self-management in areas such as personal care, job responsibilities, money management,
recreation, and organization school and work tasks. These domains determine how well an individual copes with everyday tasks. Developmental disabilities include impairments in multiple domains but an individual with a developmental disability may also have problem behaviours.

According to Neidert, Doizer, Iwata, and Hafen (2010), tantrums, noncompliance, and aggressive behaviours are a few of the common problem behaviours presented by individuals with intellectual disabilities. Researchers have found that increasing the QOL can be effective in decreasing the problematic behaviours and promoting overall happiness. West and Patton (2010) state that, with the use of positive approaches or positive behavioral support, an individual’s quality of life can be increased through education and environmental redesign. Not only should QOL be a main focus with this population because it is their right to live an independent life, have personal control, and be integrated into mainstream society but improvements to QOL can also promote positive behaviour. Integration into mainstream society has recently become more important with this population by parents, advocates, and perhaps researchers.

**Transition from Institutional to Community Living**

Throughout history, people who do not have a disability have typically live in the community without many issues. This, however, is not true for those individuals who have had any form of a disability throughout history.

In the 1790s, society did not differentiate between people with developmental disabilities and those with mental health issues (MCSS, 2012). During this time, families would attempt to look after their loved one who had a developmental disability as best as they could. When families could no longer care for the individual they would be placed in
a common jail. This changed in 1839 when legislation built the first provincial “asylum” (MCSS, 2012). This act made the provincial government responsible to care for people with developmental disabilities.

Services were provided within the institutions for each individual and their needs. By 1987, society began to see that people who had a developmental disability did not need to be separated from society by living in an institution. By closing the institutions, people believed that individuals with a developmental disability would integrate better with society. The Ontario government planned to have all institutions closed by 2012. The movement went ahead and the final three institutions closed in 2009, three years ahead of schedule.

The Ontario government developed a long-term plan that was to reflect how people would live in communities. *The Services and Supports to Promote the Social and Inclusion of Persons with Developmental Disabilities Act* was passed in 2008 (MCSS, 2012). This act was dedicated to promoting better services, more choice, and fairness to help people with developmental disabilities get services easier, receive support for the change, and ensure everyone in Ontario would be treated fairly. The president of Community Living Ontario stated, “many people with an intellectual disability now have a better quality of life because they are active members of their communities and are more connected with friends and family” (MCSS, 2012). It has been four years since the final three institutions were closed and questions as to the truth in this statement still arise. With long waiting lists to receive many of the services provided in the community and also to receive assessments for funding, QOL is questionable for some individuals.
Quality of Life Project – Summary of Project

The Quality of Life Project (Brown et al., 1997) evaluated the overall goals of improving the QOL of people with developmental disabilities in Ontario. The purpose of this program was to evaluate policy objectives that were outlined by the MCSS, acquire descriptive and demographic information about people with developmental disabilities who live in Ontario, and develop a QOL instrument package. The view of the study assessed the policy objectives of the MCSS and discussed their important role in ensuring QOL is being considered when planning for the individuals. The study discussed QOL of five areas, with Southeastern Ontario with the highest number of participants still residing in large care living.

The Quality of Life Project was completed in three phases. Between 1991 and 1992, the first phase focused on the development of a conceptual framework and determined a method with which QOL could be measured with developmental disabilities. QOL was defined as the degree to which a person enjoys the important possibilities in his/her life (Brown et al., 1997). The framework was based upon three main domains: being, belonging, and becoming. From those three domains, nine sub-domains were developed. Those were physical being, psychological being, spiritual being, physical belonging, social belonging, community belonging, practical becoming, leisure becoming, and growth becoming. The second phase was completed in 1993 and included validation of the measures and testing the methodology in the field. The third and final phase was between 1994 and 1999. This phase was the assessment process of QOL by using the QOL Package designed by Brown et al. (1997). The goal of this phase was to assess the QOL of people with developmental disabilities. Over the four and a half
years, a random sample of 504 adults with developmental disabilities who lived in Ontario was assessed to complete the third phase.

The 504 participants were selected randomly across Ontario based upon the five regions. The different living options included: large care (any home that provided long-term living arrangements for ten or more individuals), small care, independent living, and living with families. These individual’s were asked to complete a questionnaire that was composed of 54 questions based upon the three domains: being, belong, and becoming. Similar to Martin et al. (2012), Brown et al. (1997) used a scale to answer each question. The scale ranged from “one”, which represented very little to “five”, which represented a lot. Both studies by Martin et al. (2012) and Brown et al. used a rating scale of importance and satisfaction. They both argued that importance and satisfaction together make QOL. This meant that importance of item and satisfaction of an item determine the rating for that items. For example, an individual may not find going to church important and therefore they never go. For this item, the importance of going to church would be score low and the satisfaction of their church going would potentially be scored high due to their minimal attendance to church.

Brown et al. (1997) concluded that three main factors affect QOL: the family in which an individual lives, quality of community life, and quality of cultural life of the more general society in which the individual lives. The overall impression discovered by Brown et al. was that QOL was tolerable, but not good for people with an intellectual disability living in Ontario. Lifestyle is a factor later discussed by Brown and Percy (2011) that also influences an individual’s quality of life.
Brown’s study played a significant role in Ontario’s quality of life and developmental disabilities. Not only did the *Quality of Life Project* make Ontario an international leader in both the fields of developmental disabilities and quality of life, it established QOL as a key service principle in Ontario’s developmental services. The study also emphasized the importance of improving the lives of people with developmental disabilities and gathered valuable information about adults with intellectual disabilities who received funding services from the MCSS. However, since the study, QOL has not been assessed to this extent again. Individuals with intellectual disabilities are no longer played in institutions in Ontario and QOL continues to be a concern in the field of Developmental Disabilities.

**Ministry of Community and Social Services**

The MCSS is a government ministry that can help people with developmental disabilities to receive financial assistance. The MCSS provides a variety of services in Ontario with many different goals. When it comes to developmental disabilities in Ontario, the goal of the MCSS is to help people with intellectual disabilities to live, work, and participate in activities in the community. QOL was established as a priority for the MCSS multi-year plan and is a significant factor when evaluating the success of specific policy objectives. The latter includes promoting and supporting personal independence, community living, personal control, and integration into mainstream society (Brown et al., 1999). The four key MCSS principles examined in the *Quality of Life Project* include: personal control, independence, integration, and personal support. These principles, which were established by the MCSS, all play an important role in QOL.
Lifestyle and Quality of Life

The lifestyle a person chooses to live can largely affect QOL. There are a total of nine different aspects of lifestyle that Brown and Percy (2011) discuss. The aspects examined include basic living (e.g., where do people live, what are people’s homes like, and what people are able to do), financial support, services required, and leisure activities. Helping people with developmental disabilities pursue a lifestyle that involves more independent living in and among the community and to use stronger community living skills can increase quality of life scores.

In 1995, 10% of individuals with developmental disabilities who lived in Ontario lived in large care facilities (Brown & Percy, 2011). Large care facilities included any facility that cared for ten or more individuals. For individuals who lived in large care facilities, two thirds participated in their communities less than once a week. They proposed that this occurred because there was limited funding for traveling between the institutions and the community. Involvement in the community was clearly an issue for individuals who lived in large care facilities in 1995 and, for some, it may still continue to be this way today.

Important factors to consider for the future of QOL for people with a intellectual disability living in Ontario include examining the level of happiness, how to increase their happiness, and determining the available material resources so they are able to lead a full and dignified life. Brown et al. (1997) determined that the overall QOL for people with intellectual disabilities living in Ontario are living only adequate lives. For everyone else, an “adequate” QOL would not be satisfying according to Brown et al. Adequate is defined as an acceptable or sufficient satisfaction with something. Every individual with
an intellectual disability has the right to live a quality life. For everyone, QOL represents how satisfied people are with the aspects of their life that is important to them.

**Higher Quality of Life**

The literature suggests that QOL can be influenced by many factors for both people with a developmental disability and without an intellectual disability. Martin et al. (2012) state that higher quality of life can be obtained with the availability of more resources, higher levels of resources, activities combined with more resources, and activities congruent with central life domains. In other words, simply because there are more or higher levels of resource does not mean that it is useful to a particular individual or the majority of individuals. More resources need to be available to attain a high QOL. Day programs, community events, or opportunity to participate in community by volunteering are resources outside of the home that can help build friendships and social involvement.

According to Verdugo, Schalock, Keith, and Stancliffe (2005), quality of life is the degree to which people have life experiences that they value. QOL reflects domains that contribute to a full and interconnected life, considers the context of physical, social, and cultural environments that are important to people, and includes experiences both common to all humans and those unique individuals. Quality of life is a multidimensional construct that should be a main focus in everyone’s life. Although QOL has previously been studied in Ontario before institutions were closed, no recent studies have been completed to determine the QOL for individuals with intellectual disabilities living in Ontario today. Literature suggests that many factors influence QOL but it is an individualized term. Determining if QOL has improved for an individual who previously
lived in an institution but now lives in the community may help determine if the goals of society have been achieved. Any factors that are currently successful with maintaining a high QOL and factors that have room for improvements will be a main focus of this study.
Chapter III: Method

Participants

The study required a total of four participants. The study’s focus was on the QOL of two primary participants but required a significant other for each of the participants in order to complete the QOL package. Both primary participants were clients of a community agency and previously received behavioural services from the agency’s consulting psychologist and behaviour therapist. These participants were selected based on recommendations from the agency’s consulting psychologist. Both primary participants currently reside at the community agency’s Short-Term Behaviour Home (STBH).

Participant 1. The first participant was a 30-year-old female. Participant 1 was referred to the agency’s behavioural team due to demanding behaviours, noncompliance, need for routine and structure, swearing, temper tantrums, and aggression. As a result of ongoing and increasing behaviours, this client was admitted to the STBH to address the behaviours. The participant has remained at the STBH for 4 years as a result of legal issues. However, in the near future, the participant hopes to be living in the apartment program offered by the agency.

Participant 2. A significant other, that is, someone who knows Participant 1 well, was required to complete an interview with the student assessor. Due to distant family connections, the significant other was a full-time staff at the STBH. This staff was someone who has worked with Participant 1 since her arrival at the STBH. Participant 2 is a full-time staff at the home and has worked with participant 1 for four years. Participant 2 and was selected through conversations with the consulting psychologist, behavioural therapist, and participant 1.
**Participant 3.** Participant 3 was another client of the agency who also resided in the STBH. This participant was an 18-year-old female who was referred due to ongoing verbal and physical conflict in the family home. She hopes to graduate high school this year with a diploma and continue her education by attending post-secondary schools.

**Participant 4.** Participant 4 was a full-time staff member from the STBH who knew Participant 3 very well. Participant 4 has worked with participant 3 since her arrival at the STBH 3 years ago. This staff was also selected for the good client-staff rapport they display. This staff was selected through conversations with the consulting psychologist, behavioural therapist, and participant 3. Because participant 3 does not have family contacts, she felt as though a staff member would be a relevant significant other for the purpose of the study.

**Setting**

The primary setting for the study was the agency’s Short-Term Behaviour Home in which both participants resided. The STBH is located within the same community as the agency. The STBH was previously outside the town in a rural area and had recently relocated into the town. This move is important due to the significant change in both the participant’s lives. According to staff, the move increased the participant’s accessibility to more activities in town. The STBH consists of a full basement with a developing sensory room, game room, and gym. The main floor has four bedrooms, two bathrooms, a kitchen, main dining area, and two living areas. The third floor, which is an apartment style room, consists of a walk-in closet, full bathroom, and basic kitchen (sitting area, microwave, toaster oven, and small fridge). Since this is a new location for the STBH, the two participants were the only residents at the time of this study. The house is staffed 24
hours each day. The number of staff on shift each day is dependent on the schedules of the residents. During the day, there can be two to three staff working. Throughout the night, there is typically one staff scheduled.

In addition to the STBH, the agency’s main office was a setting used by the student assessor to calculate the QOL scores and finalize the reports.

**Informed Consent**

Consent was required for all the participants. The file on record at the community agency stated that both primary participants 1 and 3 were able to provide their own consent. In addition to the signed consent, the student assessor and the agency’s Behavioural Therapist explained the purpose of the study and questionnaire to both participants verbally. An example of the written consent forms used for the primary participants is provided in Appendix A. The consent form for the significant others, participant 2 and 4, is outlined in Appendix B. All four participants were informed they could withdraw at any time and that, should they wish to withdraw, all of their data relevant to the study will be destroyed. Consent will be kept in a locked cabinet for ten years at the community agency’s main office.

**Design**

The independent variables in this study were scores for each domain and subdomain. The dependent variables of this study were the nine sub-domains. This study is a cross-sectional study design. The data for this study was presented using a table displaying the raw scores on the measurements. An analysis of correlations will be calculated using the manual, which will be used to interpret the scores, assess the current QOL, and provide personal support planning for the case studies. The data was displayed
in a line graph, which represented the QOL scored for each questionnaire completed by the student assessor, significant other, and primary participant. The line graph was designed with trend lines to clearly identify patterns in the scores as well as a line identifying an “adequate” QOL. The line graph also had a break between each of the three domains to help separate the different domains and their scores.

**Measures**

The *Quality of Life for People with Intellectual/Developmental Disabilities – Full Version Instrument Package (Revised Edition)* (Raphael, Brown, & Rootman, 2012) was used to determine QOL. Three questionnaires were used to complete the QOL package; participant questionnaire, significant other questionnaire, and an assessor questionnaire.

The QOL package manual reported having an internal consistency of .91 for the participant interview, .94 for other person questionnaire, and .63 for the assessor questionnaire. The assessor questionnaire is believed to have a lower internal consistency because it does not have specific questions compared to the other two questionnaires and has a different scoring manual. Due to this, the assessor questionnaire is designed for discussion and comparison purposes only. A good quality of life is defined as having an overall QOL score ranging from 3.0 to 5.0.

**Questionnaire Domains.** The framework for the questionnaires is based upon three main domains: *being*, *belonging*, and *becoming*. Each of the three domains has three sub-domains for a total of nine sub-domains, which are explained in detail below. According to Brown et al. (1997), these domains determine quality of life and form the basis of an individual’s QOL score. An average score is calculated for each of the three
domains based upon the sub-domains. From that, an overall QOL score is obtained for the three domains. Recommendations are typically based upon the scores of each domain.

**Being Domain.** This domain’s framework examines factors related to the individual as a person. The three sub-domains that contribute to the being domain are *physical, psychological,* and *spiritual being.* *Physical being* explores the physical lifestyle of an individual. Foods consumed, daily exercises, hygiene, and overall appearance are examples of this sub-domain.

*Psychological being* reflects an individual’s mental health or the relationship with oneself. This sub-domain produces a score of confidence or satisfaction with oneself.

The *spiritual being* sub-domain assesses the personal values held by an individual. While these values are not necessarily based upon religious beliefs, what a person considers right and wrong or good and bad can influence the individual’s spiritual being.

**Belonging Domain.** This second domain assesses how one integrates with the places and people in his or her life. The first sub-domain, *physical belonging* examines factors associated with the individual's physical environment; for example, location, safety, and privacy.

*Social belonging* discusses the relationships with the people the individual interacts with on a regular basis.

Finally, *community belonging* considers the resources available in the community such as education, work, or social resources.

**Becoming Domain.** The third and final domain, *becoming* assesses the characteristics one has to achieve hopes, dreams, or goals. The first sub-domain, *practical*
becoming, examines the activities that a person does day-to-day. These activities include any volunteer work, paid work, school, or self-care.

Leisure becoming assesses the activities that a person does for fun. This also includes what an individual does on holidays or vacation activities.

The final of the nine sub-domains is growth becoming. This sub-domain scores personal growth through adaptation and the way an individual improves oneself. The three domains and nine sub-domains are the foundation for the questionnaires described below.

Participant Questionnaire. The participant questionnaire was completed by the participant and the student assessor. The participant questionnaire was completed in a semi-structured interview to engage conversation with the participant and to provide more information to rate each question. The conversation approach is important to elicit more responses to the questions. Each of the 54 items is rated on a 5-point Likert scale: 1 representing “not at all”, 2 representing “a little”, 3 representing “some”, 4 representing “quite a bit” and 5 representing “a lot”. For each item or sub-domain of QOL importance and satisfaction were rated. Each item is assessed for its degree of importance, or relevance to the individual’s life, as well as its degree of enjoyment or satisfaction experienced by the individual. For example, physical being is one of the sub-domains of the being domain. The question may ask ‘how important to you is looking after your physical health’ followed by a question asking ‘how satisfied are you with your physical health’. Brown determined in his earlier study that importance and satisfaction determine QOL.
**Significant Other Questionnaire.** The significant other questionnaire is similar to the participant questionnaire. The questionnaire consists of 54 items designed from the three domains and nine sub-domains. This questionnaire used the same 5-point likert scale used in the participant questionnaire (1 representing “not at all” and 5 representing “a lot”). An individual who knows the participant well completes this questionnaire. Similar to the participant questionnaires, the significant other questionnaire was a semi-structured interview to allow conversation. The purpose of the conversation during the interview is to provide qualitative data to provide a more in-depth and descriptive approach to each question. This questionnaire is designed for the significant other to complete independently.

**Assessor Questionnaire.** The questionnaire is made up of 27 items and provided a more descriptive account of the participant’s QOL. This questionnaire begins by asking questions about the participant’s *being*, beginning with physical being such as ‘is the person dressed appropriately’. The following two domains, *belonging* and *becoming* then have questions to determine a QOL score for each. The assessor questionnaire will provide back-up information and comparison for the discussion and evaluation of the QOL score. It is important to note that the assessor questionnaire scoring method is different from the previous questionnaires. The scoring method for the assessor questionnaire is calculated using a different manual provided in the QOL package. The scoring method ranges from 0 to 3 for the Being and Belonging Domains. The Becoming Domain is scored from 0 to 8 using the manual. These scores represent the rating for each item in the assessor questionnaire. This will affect the results by not having as precise scoring as the participant and significant other questionnaires.
**Procedures**

Prior to the data collection, consent was obtained both verbally and in writing for both primary participants and significant others. Both primary participants were aware of the procedure, risk, and the involvement of a significant other. The initial interviews and follow-up interviews were conducted in a private room at the STBH. The participant, the student assessor and her agency supervisor, a behaviour therapist, were present for the initial interview. The room had limited distractions to help the participants complete the questionnaires. Both the student assessor and agency supervisor had a copy of the participant questionnaire. In addition to the questionnaires, visual aids were provided for the participants to help them rate each item on the questionnaire (Appendix C).

**Questionnaire Sessions.** Both questionnaires for Participant 1 and Participant 3 were completed in two, two-hour sessions. The sessions were separated to allow breaks for the participant and allow sufficient time for discussion during the sessions. The first session was focused on building rapport with Participant 1 and Participant 3. This session took place at the STBH where the student assessor and participants discussed the purpose of the study and the participation in the study. The second session began with a review of the purpose, the questionnaire, and the scoring aid.

The significant other questionnaires were completed with the student assessor at the STBH. This questionnaire is designed to have the significant other complete it independently. Both of the significant other questionnaires were completed in the same format as the participant questionnaire, conversation followed by rating. This was to allow conversation between the significant other and student assessor as well as to ensure the significant other was able to ask for clarification, if necessary.
The assessor questionnaires were completed at the STBH to ensure that the student assessor could accurately complete the questionnaire. For example, some questions required information about the participant’s environment (e.g., personal space in the home). The student assessor completed these questionnaires independently.

**Scoring.** Each of the 54 items on the participant and significant other questionnaires are rated on a 5-point likert scale for both importance and satisfaction. The scoring is calculated using the scoring manual provided in the QOL package. Scores are determined based on the individual’s selection on the 5-point likert scale. Those scores are then added and an average is calculated to determine a QOL score for the domain.

There are five ranges of QOL scores with the first range representing an excellent QOL ranging from 6.0 to 10.00. If an individual scores within this range, there is not a need for recommendations. A good QOL score is 3.0 to 5.99, indicating a good QOL with no major concerns. An adequate QOL score is a range from -1.0 to 2.99 indicating there are areas in need of improvement. Scores -1.1 to -5.99 indicate a problematic QOL and needs improvement, and -6.0 to -10.00 score indicates a very problematic QOL and need for assistance or intervention. Scoring for the questionnaires were completed after the questionnaire sessions at the agency’s main office.
Chapter IV: Results

The hypothesis of this study was that individuals with intellectual disabilities would have an overall below adequate QOL score, similar to the findings of Brown et al. (1997). The scoring manual included in the QOL full version instrument package (Myersough & Renwick, 2012) was used to correlate the scores for the QOL questionnaires. The scoring manual is a chart that has importance and satisfaction in two different columns and a final score in the third column. For each of the three domains Being, Belonging, and Becoming, the average of each subdomain was calculated to determine the total QOL score for both Participant 1 and Participant 3. The QOL score was compared to the QOL indicator (Table 1) to determine the final QOL category for each primary participant. The level of criterion that was used for this study focused on a QOL score equal to or less than 2.99, which falls into a category of an adequate QOL.

Table 1

<table>
<thead>
<tr>
<th>QOL score indicator for questionnaires</th>
<th>QOL Indication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range of QOL scores</td>
<td></td>
</tr>
<tr>
<td>6.0 to 10.00</td>
<td>The ideal range indicating an excellent QOL</td>
</tr>
<tr>
<td>3.0 to 5.99</td>
<td>A ‘good’ QOL with no major concerns</td>
</tr>
<tr>
<td>-1.0 to 2.99</td>
<td>Adequate QOL but some areas might need improvement</td>
</tr>
<tr>
<td>-1.1 to -5.99</td>
<td>Problematic and needs improvement</td>
</tr>
<tr>
<td>-6.0 to -10.00</td>
<td>Very problematic and may indicate a need for assistance/intervention</td>
</tr>
</tbody>
</table>
QOL Scores for Participant 1

The average of all three questionnaires; the participant questionnaire, significant other questionnaire, and assessor questionnaire, was 3.5. This means that on average, Participant 1 has an overall good QOL. However, when examining the domains and subdomains of each the questionnaires, there are areas that have a below adequate score. The mean scores of the questionnaires for Participant 1 are displayed in Figure 1. The raw data for Participant 1 is outlined in Appendix D.

![Figure 1: Mean scores of the Assessor questionnaire, Significant Other questionnaire, and the Participant Questionnaire for each subdomain and domain.](image)

**Participant Questionnaire**

The results for Participant 1 indicated an overall QOL score of 4.1. This score falls within the good QOL range.
**Being Domain.** The Being Domain resulted in a total score of 5.6, a good QOL. With regard to the sub-domains, the Physical Being score of 5.6 and the Psychological Being score of 4 were both considered in the good range. The Spiritual Being sub-domain resulted in a score of 7.4, considered in the ideal range.

**Belonging Domain.** The Belonging Domain resulted in a total score of 5.4, a good QOL. The Physical Belonging had a final overall score of 8.4 and Community Belonging scored 6, both falling within the ideal range. The Social Belonging sub-domain resulted in a score of 2, representing an adequate QOL score.

**Becoming Domain.** Within this domain, results from the sub-domains of Practical, Leisure, and Growth were 1.6, 1.4, and 1, respectively. These scores all fell within the adequate range.

Based on the results, Participant 1 scored herself as having an overall good QOL.

**Significant Other Questionnaire**

The significant other questionnaire completed by Participant 2 assessed Participant 1’s QOL. This questionnaire resulted in Participant 1 having an overall QOL score of 2.8. This score falls within the adequate QOL range.

**Being Domain.** Within this domain, results from the sub-domains of Physical and Psychological Being were 2.5 and 0. Both scores fall within the adequate range. Spiritual Being score was 4, falling within the good range.

**Belonging Domain.** Within this domain, results from the sub-domains of Physical and Social were 5 and 4.1, falling within the adequate range. Results from the sub-domain, Community Belonging scored 2.5, falling within the adequate range.
**Becoming Domain.** Within this Domain, results from the sub-domains of Practical and Growth were 2.6 and 2, falling within the adequate range. Results from Leisure Becoming scored 3.5, falling within the good range.

**Assessor Questionnaire**

The assessor questionnaire resulted in Participant 1 having an overall score of 3.7, falling within the good range.

**Being Domain.** Within this domain, results from the sub-domain of spiritual was 2, falling within the adequate range. Results from the Physical and Psychological sub-domains resulted in 5 and 4, falling within the good range.

**Belonging Domain.** The Belonging Domain resulted in an overall score of 5, falling within the good range. Within this domain, results from the sub-domains of Social and Physical were 5 and 4, falling within the good range. Community Belonging scored 6, falling within the ideal range.

**Becoming Domain.** The Becoming Domain resulted in an overall score of 2.6, representing an adequate score. Within this domain, results from the sub-domains of Growth and Practical scored 0 and 2, falling within the adequate range. Leisure Becoming scored 6, falling within the ideal range.

**QOL Scores for Participant 3**

The average of all three questionnaires, the participant questionnaire, significant other questionnaire, and assessor questionnaire, was 3.1. This means that, on average, the three questionnaires indicate that Participant 1 has an overall good QOL. However, when examining the domains and sub-domains of each of the questionnaires, there are areas of
concern. The questionnaires for Participant 3 are displayed in Figure 2. The raw data for Participant 3 is outlined in Appendix E.

![Figure 2: Mean scores of the Assessor questionnaire, Significant Other questionnaire, and the Participant Questionnaire for each subdomain and domain.](image)

**Participant Questionnaire**

The participant questionnaire resulted in Participant 3 having an overall QOL score of 3.0. This score falls within the good QOL range. Participant 3 completed this questionnaire.

**Being Domain.** The Being Domain had an overall score of 1.7 resulting in the adequate range. Physical Being scored -0.2 and the Psychological Being score -1.0, both
falling within the adequate range. The Spiritual Being scored 6.4, falling within the ideal range.

**Belonging Domain.** The Belonging Domain scored 3.8, falling within the good range. Within this domain, results from the sub-domains of Social and Community were 4.2 and 5, both falling within the good range. Physical Belonging scored 2.4, falling within the adequate range.

**Becoming Domain.** The Becoming Domain resulted in a score of 3.6, representing an overall good score. Within this domain, results from the sub-domains of Practical, Leisure, and Growth were 3.2, 4.4, and 3.2, all falling within the good range.

**Significant Other Questionnaire**

The scores of the significant other questionnaire for Participant 3 displayed a final score of 2.3 score, representing an adequate QOL. Participant 4 completed this questionnaire.

**Being Domain.** The Being Domain had an overall score of 2.4, falling within the adequate range. Physical scored 3.2, falling within the good range. Psychological had a final score of -2.0 falling within the problematic range. Spiritual scored 6.2, falling within the ideal range.

**Belonging Domain.** The Belonging Domain had an overall score of 2.4, falling within the adequate range. Within this domain, results from the sub-domains Social and Community were 0 and 2.2, falling within the adequate range. Physical Belonging scored 5, falling within the good range.

**Becoming Domain.** The Becoming Domain had an overall score of 2.3, resulting in the adequate range. Within this domain, results from the sub-domains Growth and
Practical were 0.4 and 2, falling within the adequate range. Leisure Becoming scored 4.6, falling within the good range.

Assessor Questionnaire

The assessor questionnaire resulted in Participant 3 having an overall score of 4.1, falling within the good QOL range.

**Being Domain.** The Being Domain had an overall score of 4.0, falling within the good range. Physical Being scored 6, falling within the ideal range. Psychological Being scored 5, falling within the good range. Spiritual Being scored 1, falling within the adequate range.

**Belonging Domain.** The Belonging Domain resulted in an overall score of 4.3, falling within the good range. Within this domain, results from the sub-domains Social and Physical were both 3, falling within the good range. Community Belonging scored 7, falling within the ideal range.

**Becoming Domain.** The Becoming Domain resulted in an overall score of 4, falling within the good range. Practical Becoming scored 6, falling within the ideal range. Leisure Becoming scored 4, falling within the good range. Growth Becoming scored 2, falling within the adequate range.
Chapter V: Discussion

The current study was completed to assess the quality of life of two individuals with intellectual disabilities. The participants both resided in a small care living facility that was staffed full-time. The hypothesis of the study was similar to the hypothesis of Brown et al. (1997) that the participants would have an overall below adequate QOL. However, unlike Brown’s study, the current study concluded that the two individuals have an overall good QOL score.

Brown et al. (1997) found that individuals residing within small care living facilities tended to obtain a level of QOL within the adequate range. Within the current study, from the perspective of individuals with intellectual disabilities, the average QOL also fell within the adequate range. From the perspective of the participant’s significant other, the participant’s QOL was assessed as good while living within a small care facility. The perspective of the assessor was similar to that of the significant other. For individuals who were able to participate in life activities more independently, a higher level of QOL was obtained. Conversely, lower QOL scores were found for participants with behaviour problems.

QOL Scores for Participant 1

Participant 1 and the assessor both scored the participant as having a good QOL. The significant other to Participant 1, known as Participant 2, scored Participant 1 as having an overall adequate QOL. The participant believed that her Physical Being, Psychological Being, and Spiritual Being were all enriched to a level in which the Participant was pleased with the domains. While the assessor questionnaire found similar results, the significant other to Participant 1 believed that the Being Domain could benefit
from further enrichment. In spite of improvements from when the participant entered the small living facility, physical health, personal hygiene, limited self-control, and low self-esteem were identified as areas that would benefit from further intervention. Similar to the findings of Goncher, Sherman, Barnett, and Haskins (2013), the significant other suggested that Participant 1’s self-care is low which affects her overall QOL.

The participant questionnaire, assessor questionnaire, and significant other questionnaire indicate that Participant 1 fits within her current environment, her social group, and her community extremely well. The place of residence was scored the highest for Participant 1 among the three questionnaires. Participant 1 displays what the AAID (2010) suggest as requirements for an enrichment environment for a high QOL. She receives encouragement, support, and, to the best of the staff’s abilities, they provide Participant 1 with chances for opportunities. However, this will be something to consider when Participant 1 moves from the STBH because this is only a storm-term care facility and Participant 1 has a goal of living independently in the future.

The average of the Belonging Domain for all three domains indicate that Participant 1 has an adequate QOL in the Becoming Domain. The three sub-domains, Practical Becoming, Leisure Becoming, and Growth Becoming, scores indicate the need for enrichment. The Becoming Domain specifically looks at what opportunities the individual has for major daily activity, visiting/socializing, and to learn new things. Participant 1, Participant 2, and the student assessor believe that there are limited opportunities within the community for the Participant to enrich her Becoming Domain. Martin, Schneider, Eicher, and Moor (2012) suggest that, if the community has low levels or resources for individuals, their QOL can be negatively impacted. The community
should try to provide resources for different populations. For the purpose of this study, opportunities for different or preferred living arrangements should be encouraged within the community, daily programs, and resources for learning new things.

**QOL Scores for Participant 3**

The overall QOL score for Participant 3 was a score of 3.1, a good QOL based upon the scores on all three questionnaires. Participant 3 and the assessor both score the participant as having a good QOL. The significant other to Participant 1, known as Participant 4, scored Participant 1 as having an overall adequate QOL. These scores are extremely similar to the findings for Participant 1.

Similar to the findings of Brown, et al (1997), the Participant also scored herself as having an adequate QOL score in the Being Domain. These two questionnaires scored Participant 3 as having an ideal Spiritual Being but adequate or problematic Physical and Psychological Being. Both Participant 3 and the significant other felt that physical health was extremely important and neither was satisfied with her physical health or the opportunities for her to improve her physical health. The opportunities were limited by the few programs offered to individuals with disabilities and funding available for her to participate in the limited programs that are offered. This strongly supports Shrestha and Zarit’s (2012) idea that just because programs are offered in the community does not mean everyone will benefit from them. Participant 3 should not have to participate in something that she dislikes only because it is the only resource offered.

Participant 3 and the Student Assessor believed that Participant 3 had a good Belonging Domain. Participant 3 fits within her home very well and she also fits in with her friends she associates with. Participant 4 scored Participant 3 as having an adequate
Belong Domain. Participant 4 felt that Participant 3 did not have enriching Social or Community Belonging. It was stated by Participant 4 that Participant 3 does not have the opportunities to be enriched by her society or community, limiting her belonging within them. The difference in scoring in the Belonging Domain may be due to the personal beliefs among the participants. Participant 3 enjoys her current home. She is also aware that the enrichment in her life can be transferred from this home to her next home. The significant other to Participant 3 felt as though all opportunities for Participant 3 were limited within the Belonging Domain. There was not anywhere else for Participant 3 to move when she was removed form the family home. Also, Participant 4 believed that Participant 3 did have friends. She felt as though there was limited opportunities for Participant 3 to make friends.

Similar to the Belonging Domain, the significant other scored Participant 3 as having an adequate Becoming Domain. Both Participant 3 and the Student Assessor scored Participant 3 as having a good Becoming Domain. They felt as though the participant was able to improve herself in the ways she wanted to with the opportunities within the community. Participant 3 was still in high school, which provided her with opportunities to continue growing in the subjects and areas of life she wishes to. With the assistance to her social worker at the community agency, Participant 3 hopes to further her growth and development by going to post-secondary school. The significant other to Participant 3 stated that those opportunities for Participant 3 to attend different schools are limited. Programs for Participant 3 to attend outside of school that would help her with her becoming are limited. This is due to both her age and funding.
Overall, the results for both participants were similar. It was mentioned frequently, especially by the significant others, that there are opportunities for individuals with intellectual disabilities in the community however, funding is extremely limited. Not only is there only a limited number of agency’s that run programs for this population, but funding for each individual is limited. For both of the participants, their opportunities within the STBH are limited and largely depend on staffing. Because the participants live in a home that is owned by an agency, they are unable to stay home alone. In same cases, if one of the girls wanted to do something they would both have to agree to do it if there was only one staff working that day. That would also mean that even if the one girl did not necessarily want to do it but was going to join along, it would be at her expense. This was not always the case and it would usually work out but this was a possibility.

**Limitations**

There were a few limitations in this study. Previous QOL studies involved large sample sizes, which was not achievable for the current study. If time allowed, more participants could have potentially been recruited which would have been beneficial to the overall results. Because the participant questionnaire and significant other questionnaire are both lengthy and need to be completed with the student assessor present, it can be a time consuming process. It was also difficult to find a time that was suitable for both the staff and participant.

Along with having a larger sample size, it may have been beneficial to have more or different significant other’s for both participants. Due to limited family contact, staff members at the participant’s homes were recruited for significant others. Bias towards a higher QOL score could have potentially resulted from this.
It was also stated in the study by Brown et al. (1997) that the severity of the disability did not affect their study. However, for the purpose of the current study, individuals who were diagnosed between the mild or moderate intellectual disability ranges had to be selected due to limited time. It was suggested that having two significant other questionnaires could be completed for those individuals who fell within the severe range, however, limited time prevented contact and completion of the questionnaires with any individuals who met the severe criteria.

**Program Changes**

The original research project was initially going to involve a single participant to complete the QOL package. This participant lived in a large care living facility during Brown and colleagues province wide study. However, the participant changed when it was decided by both the agency supervisor and student assessor that this participant would not fit the requirements for the questionnaire. This was due to both her intellectual disability and physical health. This resulted in changing the participants and two individuals were selected who the agency had contact with.

**Multilevel Challenge to Service Implementation**

Throughout the timeframe of this thesis completion, multiple challenges were encountered on several different levels. The quality of life assessment had an influence on a client level, program level, organizational, and society level. However, with this being a new assessment tool to the agency, it is predicted that more challenges will be encountered in the future.

**Client Level.** For this particular study, both clients had never participated in any previous studies similar to this QOL assessment. For these clients, the multilevel
challenge to service implementation was almost the opposite. Both participants had an overall good QOL score. As a result of this study, strengths to the individual’s current lives were concluded and will be essential elements when both individuals move on and further intergrade into the community.

**Program Level.** The current report examines the QOL of two individuals with intellectual disabilities with an assessment tool that is new to the agency. Due to time restrictions, the report only touched on the QOL questionnaire and results. However, on a program level this assessment tool can help many different teams within the community agency, specifically the behavioural services. Behaviour programs are individualized and should have an overall goal of enriching an individual’s life. This assessment tool could potentially help enrich individual programs by focusing on certain domains.

**Organization Level.** The community agency that the student was placed at did not have an assessment tool that could be used to assess the quality of life of individuals with intellectual disabilities. However, the agency was willing to purchase one for not only the purpose of this thesis but also for the agency to later use. As a result of this, the student was unable to seek much assistance about the use of the scale. Having people to brainstorm ideas with and discuss the scale would have been beneficial. However, it was a great learning experience for the student. It was also an opportunity to show the staff how to use a new package. As a result of this study, the community agency now has a new assessment tool that the agency had interest in purchasing.

**Societal Level.** Similar to the previous levels, this research project brought a new assessment tool an agency but also to the society. From this assessment tool, individuals among society can discover what strengths are in place, what areas need enrichments, or
areas that could use modifications. This assessment tool assesses three domains, and 9 sub-domains. A large part of the assessment tool looks at resources that are provided within society. For example, community belonging is a sub-domain that is assessed within the questionnaire. By assessing a large population, an average score for this domain can be calculated and then determined if it is enriched enough for the population being assessed.

This assessment tool provides many opportunities on an individual or client level, program, organizational, and societal level.

**Contributions to the Field of Behavioural Psychology**

This study further assesses QOL for individuals with intellectual disabilities. Previous studies have been conducted in this topic, however, recent studies lack in the area. In 1997, Brown and colleagues conducted the most recent study that is relevant to the field of intellectual disabilities and also the most relevant study to the geographical location were this research study was conducted. Quality of life is an area that has been studied for many years, however, this particular questionnaire is not used to the extent it could be. The QOL package used in this study has been used in several countries around the world and is known within many community agencies. However, some agencies may not have the funding to purchase the package or the time to train employees to use the package. This current study was beneficial to the participants who took part but it was also extremely beneficial to the community agency in which the QOL Package was purchased. There is now an opportunity for not only the community agency’s staff to continue using the package but there is now an opportunity for future placement students
to use the package and continue assessing QOL in hopes to enrich the lives of more individuals with intellectual disabilities.

**Recommendations for Future Research**

It would be recommended for researchers to have a larger sample size for the study. In order to ensure more reliable results when comparing this study to previous research, larger sample sizes should be considered. Also, having a variety of participants, both verbal and non-verbal, from a variety of living arrangements, such as independent living, family, or large care living would be recommended for future research. A major delay in the current research study was the purchase and training of the QOL package. It would be recommended for future research to have a QOL package selected if there is only a specific time frame for the study to be conducted. Future research could not only assess the QOL of individuals with intellectual disabilities but also the lives of those who do not have a dual diagnosis, diagnosis of Autism Spectrum Disorder, or no diagnosis. Quality of life is important to all individuals. It can be assessed for all individuals, which makes this QOL package beneficial for the field. There are many opportunities with this assessment tool and research in this field should continue.
References


Myerscough, T., & Renwich R. (2012). *Quality of life for people with intellectual/developmental disabilities full version instrument package (revised edition).* Quality of Life Research Unit: Toronto, ON


Participant Consent

**Project title:** Evaluating the Quality of Life of Individuals with Intellectual Disabilities

**Principal Investigator:** Kierstin Fox

**Name of supervisor:** Lana Di Fazio

**Name of Institution:** St. Lawrence College

**Name of part partnering institution/agency:** Community Agency

**Invitation**

You are being invited to take part in a research study. I am a student in my 4th year of the Behavioural Psychology program at St. Lawrence College. I am currently on placement at the community agency. As a part of this placement, I am completing a research project (called an applied thesis). I would like to ask you for your help to complete this project. The information in this form will help you understand my project. Please read the information carefully and ask all the questions you might have before you decide if you want to take part.

**Why is this study being done?**

This study is being done to understand generally how happy you are with your life. The term being used to describe your happiness with your life is quality of life. This study is going to determine how good your quality of life is and the reasons for it. Suggestions for improvements will also be considered and potentially implemented.

**What will you need to do if you take part?**

If you choose to take part you will be asked to spend a full day with a student assessor, who is supervised by the agency’s behaviour therapist. The day will involve you completing a questionnaire with the help of the student assessor. The questionnaire has a total of 54 items. The assessor will score the items based on your answer to each question using a 5-point rating scale. The items are scored both on importance and enjoyment. In addition to you completing a questionnaire, a person who knows you well will be asked to complete a different questionnaire that is based on your quality of life. The significant other will be a staff member at your group home who works with you for the majority of the time.

**What are the potential benefits of taking part?**

Benefits of taking part in this research study include learning more about yourself, what makes you happy, and your quality of life. The study may also
help your overall quality of life improve by looking at the results and determining which areas you are not happy with. In addition to potentially improving your own quality of life, this study may also help address issues among the quality of life of individuals with developmental disabilities.

**What are the potential disadvantages or risks of taking part?**
Risks from taking part in this research study are minimal but may include emotional stress from the questionnaire/survey, boredom or tiredness from the questionnaire/surveys, jeopardy to social or free time (i.e., interview will need to take place at home and without anyone else).

**What happens if something goes wrong?**
Everybody is different and if you do have any strong reactions to the questions, you may talk to me, or your counsellor at the agency at any time.

**Will my information you collect from me in this project be kept private?**
We will make every attempt to keep any information that identified you strictly confidential unless required by law. You will be assigned a code number to enter on the questionnaires. All materials will be kept in the locked cabinet for ten years. The consent forms and completed questionnaires will be kept in a locked filing cabinet at the agency’s main office. Any information on the computer will be password protected. You will not be identified by name in any report, publications, or presentations resulting from this project.

**Do you have to take part?**
Taking part is voluntary. It is up to you to decide whether or not to take part in this research project. If you do decide to take part, you will be asked to sign this consent form. If you do decide to take part in this research project, you are still free to withdraw at any time, without giving any reason, and without incurring any penalty, or negative effects.

**Contact for further information**
This project has been approved by the Research Ethics Board at St. Lawrence College. The project will be developed under the supervision of Lana Di Fazio, my supervisor from St. Lawrence College and Dr. Joe Molino and Tom Turner, my agency supervisors. I really appreciate your cooperation and if you have any additional questions or concerns, feel free to ask me, Kierstin Fox (kfox10@sl.on.ca). You can also contact my College Supervisor Lana Di Fazio at Lana.Difazio@csc-scc.gc.ca or you may also contact the Research Ethics Board at reb@sl.on.ca.

**Consent**
If you agree to take part in this research project, please complete the following form and return it to me as soon as possible. A copy of this signed document will be given to you for your own records. An additional copy of your consent will be retained at the agency for ten years.

By signing this form, I agree that:
✓ The study has been explained to me.
✓ All my questions were answered.
✓ Possible harm and discomforts and possible benefits (if any) of this study have been explained to me.
✓ I understand that I have the right not to participate and the right to stop at any time.
✓ I am free now, and in the future, to ask any questions I have about the study.
✓ I have been told that my personal information will be kept confidential.
✓ I understand that no information that would identify me will be released or printed without asking me first.
✓ I understand that I will receive a signed copy of this consent form.

I hereby consent to take part.
Appendix B: Significant Other Consent

100 Portsmouth Ave.
Kingston, Ontario K7L 5A6

Significant Other Consent

**Project title:** Evaluating the Quality of Life of Individuals with Intellectual Disabilities

**Principal Investigator:** Kierstin Fox  
**Name of supervisor:** Lana Di Fazio  
**Name of Institution:** St. Lawrence College  
**Name of part partnering institution/agency:** Developmental Services of Leeds and Grenville

**Invitation**
You are being invited to take part in a research study. I am a student in my 4th year of the Behavioural Psychology program at St. Lawrence College. I am currently on placement at the Developmental Services of Leeds and Grenville. As a part of this placement, I am completing a research project (called an applied thesis). I would like to ask you for your help to complete this project. The information in this form will help you understand my project. Please read the information carefully and ask all the questions you might have before you decide if you want to take part.

**Why is this study being done?**
This study is being done to look at the factors that affect the quality of life of individuals with developmental disabilities. It is being done to determine factors that influence quality of life, what factors are currently successful and what factors need to be improved. This study is also being done to compare previous quality of life studies to the results of this quality of life study.

**What will you need to do if you take part?**
If you chose to take part in this study you will be asked to spend 90 minutes with the student assessor. You will be asked to complete a questionnaire that has a total of 54 items. You will be asked to score each item based on importance and satisfaction using a five point rating scale with one representing not at all, three representing some and five representing a lot.

**What are the potential benefits of taking part?**
Benefits of taking part in this research study may include learning more about what factors contribute to quality of life, what factors are already good and what factors could use improvement. This will help you understand the quality of life your significant other has but also may help you understand your own quality of life. The results from this study may also benefit others who live in the community with a developmental disability.
What are the potential disadvantages or risks of taking part?
Risks from taking part in this research study are minimal but may include emotional stress from the questionnaire/survey, or boredom or tiredness from the questionnaire/surveys).

Will my information you collect from me in this project be kept private?
We will make every attempt to keep any information that identified you strictly confidential unless required by law. You will be assigned a code number to enter on the questionnaires. All materials will be kept in the locked cabinet for ten years. The consent forms and completed questionnaires will be kept in a lock filing cabinet at the agency’s main office. Any information on the computer will be password protected. You will not be identified by name in any report, publications, or presentations resulting from this project.

Do you have to take part?
Taking part is voluntary. It is up to you to decide whether or not to take part in this research project. If you do decide to take part, you will be asked to sign this consent form. If you do decide to take part in this research project, you are still free to withdraw at any time, without giving any reason, and without incurring any penalty, or negative effects.

Contact for further information
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Consent
If you agree to take part in this research project, please complete the following form and return it to me as soon as possible. A copy of this signed document will be given to you for your own records. An additional copy of your consent will be retained at the agency for ten years.

By signing this form, I agree that:

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- All my questions were answered.
- Possible harm and discomforts and possible benefits (if any) of this study have been explained to me.
- I understand that I have the right not to participate and the right to stop at any time.
- I am free now, and in the future, to ask any questions I have about the
study.
✓ I have been told that my personal information will be kept confidential.
✓ I understand that no information that would identify me will be released or printed without asking me first.
✓ I understand that I will receive a signed copy of this consent form.

I hereby consent to take part.
Appendix C: Visual Scoring Aid
Appendix D: Results For Participant 1 Questionnaires: Participant Questionnaire, Significant Other Questionnaire, and Assessor Questionnaire

**Raw scores for Being Domain for Participant 1**

<table>
<thead>
<tr>
<th></th>
<th>Physical Being</th>
<th>Psychological Being</th>
<th>Spiritual Being</th>
<th>Total Being Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessor</td>
<td>5</td>
<td>4</td>
<td>2</td>
<td>3.6</td>
</tr>
<tr>
<td>Other</td>
<td>2.5</td>
<td>0</td>
<td>4</td>
<td>2.1</td>
</tr>
<tr>
<td>Participant</td>
<td>5.6</td>
<td>4</td>
<td>7.4</td>
<td>5.6</td>
</tr>
</tbody>
</table>

**Raw Scores for Belonging Domain for Participant 1**

<table>
<thead>
<tr>
<th></th>
<th>Social Belonging</th>
<th>Community Belonging</th>
<th>Physical Belonging</th>
<th>Total Belonging Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessor</td>
<td>5</td>
<td>6</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>4.1</td>
<td>2.5</td>
<td>5</td>
<td>3.8</td>
</tr>
<tr>
<td>Participant</td>
<td>2</td>
<td>6</td>
<td>8.4</td>
<td>5.4</td>
</tr>
</tbody>
</table>

**Raw scores for Becoming Domain for Participant 1**

<table>
<thead>
<tr>
<th></th>
<th>Practical Becoming</th>
<th>Leisure Becoming</th>
<th>Growth Becoming</th>
<th>Total Becoming Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessor</td>
<td>2</td>
<td>6</td>
<td>0</td>
<td>2.6</td>
</tr>
<tr>
<td>Other</td>
<td>2.6</td>
<td>3.5</td>
<td>2</td>
<td>2.7</td>
</tr>
<tr>
<td>Participant</td>
<td>1.6</td>
<td>1.4</td>
<td>1</td>
<td>1.3</td>
</tr>
</tbody>
</table>

Total QOL score for all three Domains, Participant = 4.1

Total QOL score for all three Domains, Other = 2.8

Total QOL score for all three Domains, Assessor = 3.7

*Total QOL score calculation

Total Being Score + Total Belonging Score + Total Becoming Score/3 = Total QOL score
Appendix E: Results For Participant 3 Questionnaires: Participant Questionnaire, Significant Other Questionnaire, and Assessor Questionnaire

**Raw scores for Being Domain for Participant 3**

<table>
<thead>
<tr>
<th></th>
<th>Physical Being</th>
<th>Psychological Being</th>
<th>Spiritual Being</th>
<th>Total Being Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessor</td>
<td>6</td>
<td>5</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>3.2</td>
<td>-2</td>
<td>6.2</td>
<td>2.4</td>
</tr>
<tr>
<td>Participant</td>
<td>-0.2</td>
<td>-1</td>
<td>6.4</td>
<td>1.7</td>
</tr>
</tbody>
</table>

**Raw scores for Belonging Domain for Participant 3**

<table>
<thead>
<tr>
<th></th>
<th>Social Belonging</th>
<th>Community Belonging</th>
<th>Physical Belonging</th>
<th>Total Belonging Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessor</td>
<td>3</td>
<td>7</td>
<td>4</td>
<td>4.3</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>2.2</td>
<td>10</td>
<td>2.4</td>
</tr>
<tr>
<td>Participant</td>
<td>4.2</td>
<td>5</td>
<td>2.4</td>
<td>3.8</td>
</tr>
</tbody>
</table>

**Raw scores for Becoming Domain for Participant 3**

<table>
<thead>
<tr>
<th></th>
<th>Practical Becoming</th>
<th>Leisure Becoming</th>
<th>Growth Becoming</th>
<th>Total Becoming Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessor</td>
<td>6</td>
<td>4</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>4.6</td>
<td>0.4</td>
<td>2.3</td>
</tr>
<tr>
<td>Participant</td>
<td>3.2</td>
<td>4.4</td>
<td>3.2</td>
<td>3.6</td>
</tr>
</tbody>
</table>

Total QOL score for all three Domains, Participant = 3.0

Total QOL score for all three Domains, Other = 2.3

Total QOL score for all three Domains, Assessor = 4.1

*Total QOL score calculation

Total Being Score + Total Belonging Score + Total Becoming Score/3 = Total QOL score