include Me! QUALITY OF LIFE INITIATIVE
TECHNICAL REPORT

Prepared for:
Community Living British Columbia

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Table of Contents

APPENDICES:

A. My Life: Personal Outcomes Index™
B. Master List Requirements
C. Templates of Letters and Consent Forms
D. Training Manual for Service Providers
E. Training Manual for Self-Advocate Interviewers
F. Suggested Alternative Questions and Phrasing
G. Decision Rules to Evaluate the Reliability and Validity of Responses to the *My Life Personal Outcome Index*™

SECTION 1: PROJECT BACKGROUND

1.1   *include Me!* Quality of Life Initiative

The *include Me!* Quality of Life Initiative is a project of Community Living BC (CLBC) to gather the opinions of persons with developmental disabilities about how they perceive their quality of life. Over time, these opinions are anticipated to help guide decision making for everyone involved in community living. For CLBC and the service providers they support, this initiative is seen to be most helpful in identifying key areas of support where they can make the most positive impact in the lives of persons with developmental disabilities.

At the end of 2011, CLBC engaged R.A. Malatest and Associates Ltd. *(the Contractor)* to implement the *include Me!* Quality of Life Initiative on behalf of CLBC and, subsequently, to analyze the survey data collected.

1.2   *My Life Personal Outcomes Index*™

The *My Life: Personal Outcomes Index™* is the instrument used to measure the quality of life of persons with developmental disabilities (see Appendix A). The index was developed with international quality of life expert, Dr. Robert Schalock, and was piloted in the jurisdiction of Edmonton's Persons with Developmental Disabilities (PDD). [1]

Following Dr. Shalock's framework, the *My Life* survey has 48 questions that measure quality of life in eight domains, grouped in three broad areas (see Table 1.1). Two additional questions are also included in the survey to get information about employment and accessibility.

Table 1.1 – *My Life: Personal Outcomes Index™*: Domains and Associated Indicators

INDEPENDENCE	SOCIAL PARTICIPATION	WELL-BEING
Personal Development	Interpersonal Relations	Emotional Well-Being
Self-Determination	Social Inclusion	Physical Well-Being
	Rights	Material Well-Being

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[1] Government of Alberta – Human Services (2012). My Life Survey: the Personal Outcomes Initiative. URL http://humanservices.alberta.ca/disability-services/pdd-poi.html

The information gathered through the *My Life* survey are then analyzed to generate insights for CLBC and service providers on how the supports and services that are currently offered may be enhanced or modified to further improve the quality of life of supported individuals.

1.3   Scope of the *include Me!* Quality of Life Initiative

The *include Me!* Initiative in 2012/13 engaged individuals who are supported by 15 accredited service providers operating in two CLBC operational regions: Fraser Region and Vancouver Coastal. However, for the purpose of reporting, service providers are segmented in three regional groups: Fraser Region, Vancouver Coastal, and both Fraser and Vancouver Coastal regions when service providers had offices in both regions.

For the 2013/14 round, the initiative will still include service providers in the Fraser and Vancouver Coastal regions, but it will also expand to cover the interior region of BC, specifically South Central Okanagan and North Okanagan Shuswap. In Vancouver Coastal and Fraser regions, the initiative is expected to extend beyond the accredited service providers and also include other types, namely the unaccredited, direct home share providers, person-centred societies, and agents.

Over the long-term, the *include Me!* Initiative is expected to be implemented annually in all five CLBC regions: Fraser, Vancouver Coastal, Vancouver Island, Interior and Northern BC. As a result, it is anticipated that through the initiative, the opinions of approximately 4,500 persons with developmental disabilities will be gathered each year.

1.4   Structure of the Technical Report

This technical report summarizes the project background, the lessons learned during the 2012/13 round of the *include Me!* Initiative, and the processes that could be improved in subsequent years. It also details the methodology in the survey planning and administration process, data handling and analysis, and report production.

Although key survey results are discussed in the summary report and individual reports, information from specific analyses concerning the psychometric properties of the *My Life Personal Outcomes Index*^{TM}, additional correlation and regression analyses, and data specific issues are provided in this technical report.

SECTION 2: SURVEY ADMINISTRATION

2.1 Overview of Survey Administration

In terms of survey administration, the Contractor completed the following key activities:

- Engaged CLBC-accredited service providers throughout the survey process;
- Hired and trained self-advocate interviewers to conduct in-person peer-to-peer interviews; and
- Conducted proxy interviews over the phone when a CLBC-supported individual was unable or unwilling to self-report.

Throughout the survey administration process, the Contractor worked towards adhering to general principles that were deemed important by the CLBC Personal Outcomes Initiative Team. These guiding principles, which have shaped and influenced the survey administration process, include the following:

- In-person interviews with CLBC-supported individuals are preferably conducted by self-advocate interviewers (and recorders, if necessary);
- Self-reporting among CLBC-supported individuals is preferred over letting proxies speak on their behalf;
- When proxies are identified for individuals who are unable or unwilling to self-report:
  - Two proxies who know the respondent for at least one year have to be identified to complete the survey; and
  - Family members or friends are preferred over paid staff to be engaged as proxies.

To facilitate the smooth implementation of the survey administration activities, the Contractor provided on-going support to service providers and self-advocate interviewers. The supports provided by the Contractor are discussed in detail in subsequent sections of this report. Highlights of the support provided by the Contractor are outlined here:

- Creation of a sampling plan with the participating service providers;
- Development of an online tool for interview scheduling;
- Training of service providers and provision of on-going support to ensure effective scheduling and completion of surveys;
- Training of self-advocate interviewers and recorders, and provision of on-going support on the conduct of the *include Me!* interviews;
- Tracking and monitoring of interview scheduling and survey completions; and

- Development of an integrated database for information collected from service providers and from in-person and phone interviews.

2.2 Engagement of CLBC-Accredited Service Providers

Fifteen service providers that are operating in two CLBC operational regions (Fraser and Vancouver Coastal regions) participated in the 2012/13 round of the *include Me!* Initiative (see Table 2.1)

Table 2.1 – Participating Service Providers by Operational Region

FRASER REGION	VANCOUVER COASTAL	BOTH VANCOVER COASTAL & FRASER
Chilliwack Society for Community Living [CSCL]	Greater Vancouver Community Services Society [GVCSS]	
Community Ventures Society [CVS]	NS ConneXions Society	Pacific Coast Community Resources Inc. [PCCRI]
Ridge Meadows Association for Community Living [RMACL]	North Shore Disability Resource Centre [NSDRC]	posAbilities
Simon Fraser Society for Community Living [SFSCL]	Powell River Association for Community Living [PRACL]	Spectrum Society for Community Living
Surrey Association for Community Living [SACL]	Sunshine Coast Association for Community Living [SCACL]	Thompson Community Services [TCS]
	Vancouver Resource Society [VRS]	

Each of the above service providers were engaged in identifying and obtaining the consent of the CLBC-supported individuals to be interviewed as well as in scheduling the interviews themselves. Service providers were also instrumental in identifying and obtaining the consent of proxies on behalf of individuals who are unable or unwilling to be personally surveyed.

2.2.1 Support to Service Providers

To assist service providers in their key role in implementing the *include Me!* Initiative, the Contractor developed and provided the service providers with the following tools:

- A comprehensive manual (see Appendix D) covering the following topics:
  - An overview of Dr. Schalock's framework and the purpose of the *include Me!* Initiative;
  - The process for providing Malatest with a list of CLBC-supported individuals served by the organization (including how to safely transmit information);
  - Additional information required for those who are selected to participate;
  - Requirements for consent;
  - A guide to booking interviews online using CallWeb; and
  - Procedures and protocols for conducting interviews (e.g., check-in and check-out of self-advocate interviewers, cancellations, and challenging situations that may arise during an interview, etc.).
- A communication tool kit with the following materials:
  - Cover letter templates for self-reporting individuals, committees, and proxies;
  - Consent form templates for self-reporting individuals, committees, and proxies;
  - *include Me!* posters;
  - *include Me!* Frequently Asked Questions (FAQ) for CLBC-supported individuals and their family members; and
  - A PowerPoint presentation to introduce *include Me!*

Along with the tools, the Contractor also provided the following training sessions to service providers:

- In-person group training session on May 11, 2012 in Vancouver;
- Group refresher session via teleconference on September 5, 2012;
- Various in-person training sessions for service providers outside of Metro Vancouver; and
- Other ad-hoc training or assistance and follow-up sessions (in-person and by phone) as needed by service providers.

In addition to the tools and training offered to service providers, the Contractor helped build service providers' capacity to introduce the *include Me!* Initiative to the individuals they support, the individuals' families, and the staff within their ranks. Service providers were supported in terms of having established processes to gather consent and schedule interviews.

2.3 Engagement of Self-Advocate Interviewers and Recorders

In previous studies that used the *My Life: Personal Outcomes Index™*, participants with developmental disabilities cited that they felt more comfortable being asked questions by an interviewer who also had a developmental disability. As such, the Contractor committed to engage self-advocate interviewers (wherever possible) in the *include Me!* Initiative and pay these self-advocates competitive wages for all work completed for the project.

2.3.1 Recruitment and Hiring of Self-Advocate Interviewers and Recorders

To recruit and hire self-advocate interviewers, the Contractor engaged service providers as well as CLBC's *include Me!* team to refer potential individuals who could be considered for the role. Posters and print advertisements were also strategically utilized to disseminate information among self-advocates and within institutions where staff may be in a position to make referrals.

Upon receipt of referrals, the Contractor conducted interviews with self-advocates based on a standardized interview questionnaire. The purpose of the interview was to gain information about availability and access to transportation as well as relevant work experience (including involvement in the 2010-2011 Demonstration project) and other pertinent information that may help determine what role the individual would be best suited for (interviewer vs. recorder).

Self-advocates who successfully complete the interviews were then invited to attend an in-person training session, which was a pre-requisite for hiring. For the 2012-13 round of the *include Me!* Initiative, 22 self-advocates in Metro Vancouver, Chilliwack, Powell River, and Sechelt were recruited, trained, and hired to serve as interviewers or recorders.

2.3.2 Support to Self-Advocate Interviewers and Recorders

To assist self-advocate interviewers and recorders in their key roles, the Contractor developed and provided them with the following tools:

- A comprehensive manual (see Appendix E) covering the following topics:
  - An overview of Dr. Schalock's framework and the purpose of the *include Me!* Initiative;
  - A guide to accessing the online schedule of interviews in CallWeb;
  - Materials needed to conduct interviews (e.g., symbol sheets, questionnaires, postage paid envelopes to mail back the surveys to Malatest, etc.)

  o Procedures and protocols for conducting interviews (e.g., check-in and check-out with service providers, dealing with unexpected issues and challenging situations during an interview, etc.); and

  o General suggestions about professionalism when communicating with service providers, respondents, etc.

Beyond providing a manual for self-advocates' reference, the Contractor also offered a number of training sessions to interviewers and recorders:

- Group in-person training sessions (see Figure 2.1);
- Individual on-site coaching and quality assurance checks on their first few interviews; and
- Other ad-hoc training and follow-up sessions (in-person and by phone) as needed by self-advocates.

Figure 2.1 – Interviewer Training
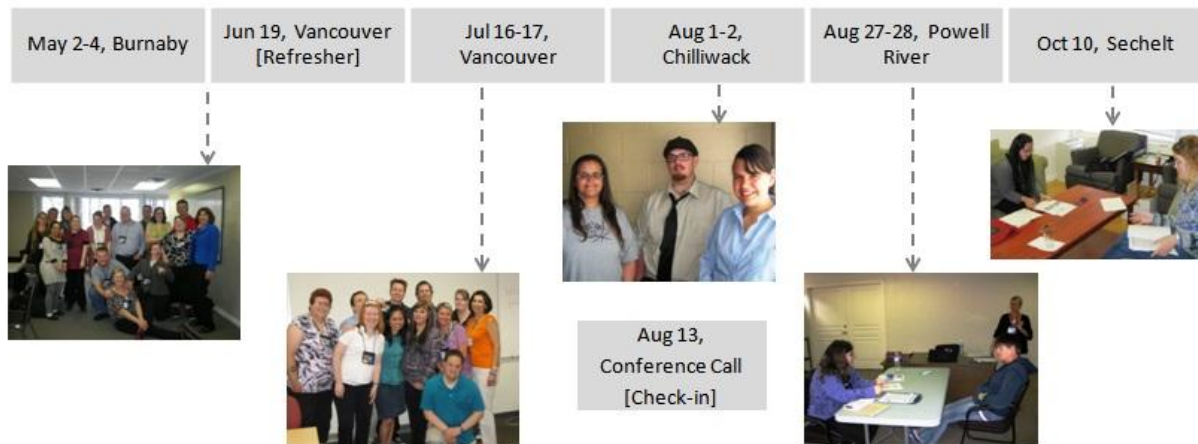
To ensure the integrity of the survey process, the successful completion of in-person training sessions was a pre-requisite for hiring interviewers and recorders. Through the training sessions, it was possible to provide identical instruction to interviewers and recorders, as well as to establish a common understanding within the group about concepts and interpretations of questions. Furthermore, because these sessions involved a lot of role playing, they also served as a venue for the Contractor to be able to assess each self-advocate's abilities and readiness to independently conduct interviews as an interviewer or to be involved as a recorder. More customized training was offered to those who needed further support.

2.4   *My Life* Survey Scheduler Using CallWeb

The Contractor developed the *My Life* Survey Scheduler using the CallWeb online data collection system in order to facilitate the real-time coordination of schedules, especially among self-advocate interviewers and the respondents that the service providers scheduled for interviews. Through the online scheduler, service providers had access to real-time information about the availability of self-advocate interviewers. Meanwhile, on the part of self-advocate interviewers, the tool was helpful in providing them with as much advanced notice as possible about their upcoming interviews.

Overall, the online scheduler was instrumental in reducing the administrative burden associated with interview scheduling. Only in exceptional circumstances was the online scheduler circumvented, and most of the reasons to do so were to accommodate special requests like off-site interviews, last-minute changes, etc. In those cases, the Contractor liaised with the service providers and interviewers by phone and email to facilitate scheduling.

Beyond scheduling, the *My Life* Survey Scheduler also provided a platform for ensuring that service providers fully recorded the supported individuals' information before it was submitted to the Contractor. This check was possible with the online scheduler because, by default, service providers could not schedule interviews unless they had first completed the respondent profile.

Furthermore, the *My Life* Survey Scheduler also allowed the Contractor to monitor service providers' progress in gathering consent forms. Especially in the case of proxies, updates on their consent for the Contractor to contact them for phone interviews were primarily relayed through the online scheduler.

2.5   2012/13 *include Me!* Survey Process

When service providers were engaged for the 2012/13 round of the *include Me!* Initiative, the Contractor first worked with them to determine the sample of supported individuals who would be interviewed. This process led to the creation of a respondent list that served as a reference for subsequent tasks in data collection, such as gathering consent forms and scheduling interviews.

2.5.1 Sampling and Respondent List Composition

The Contractor worked with CLBC's *include Me!* team to develop guidelines for the sampling plan by service provider. The guidelines that were developed called for random sampling by organization. However, in the 2012/13 round, only one service provider (posAbilities) decided to incorporate this approach as most did not have a sufficient number of individuals they support to warrant random sampling or in a few other cases, the service provider decided to use a census approach to minimize sampling error. For all the service providers, other than posAbilities, a census approach was used where all CLBC-supported individuals in their lists were invited to participate in order to ensure a sufficient number of survey completions that would yield statistically reliable results.

Individuals who were receiving support from multiple service providers (and therefore, were identified in multiple lists) were randomly assigned to only one service provider so that they would be contacted and interviewed only once. Overall, the 15 participating service providers were expected to reach out to a sample of 1,542 CLBC-supported individuals for the 2012/13 round of the *include Me!* Initiative.

2.5.2 Master List of CLBC-Supported Individuals

Once the respondent lists of all participating service providers were finalized, the service providers were then requested to provide additional information on each individual in the list. In summary, the information that was required per individual included the following (see Appendix B for more detailed information):

- Demographic profile: address, birth date, gender, Aboriginal identity;
- Types of services accessed: residential, community inclusion, respite, support for individuals and families;
- Interview-relevant information: legal status, need for proxies, preferred language of communication, etc.

2.5.3 Consent of Individuals, Committees, and Proxies

The Contractor worked with service providers to gather the required consent for each individual in their master lists. Templates for letters and consent forms (see Appendix C) were provided by the Contractor, but service providers mailed them and followed-up their receipt.

Table 2.2 summarizes the process for determining who would sign the consent forms based on the circumstances of the supported individuals and the type of consent form used for each.

Table 2.2 – Required Consent Forms

Individuals WITH Committees, *i.e.,* public trustees, court-appointment legal guardians	Consenting Authority	Required Consent Form
(a) If the individual can **self-report**	Committee	Committee Consent Form
(b) If the individual requires **proxies**	Committee *[Step 1]*	Committee Consent Form
	2 Proxies *[Step 2]*	Proxy Consent Form or Verbal Consent *[from each proxy]*
Individuals WITHOUT Committees, *i.e.,* all who do not have another individual making legal decision on his/her behalf	Consenting Authority	Required Consent Form
(a) If the individual can **self-report**	CLBC-Supported Individual	Participant Consent Form
(b) If the individual requires **proxies**	2 Proxies	Proxy Consent Form or Verbal Consent *[from each proxy]*

The identification of proxies was left to the discretion of service providers after they were provided guidelines that the proxies should have known the supported individual for at least one year, and that paid staff were to be engaged only as proxies if there were no family members or friends who could be interviewed. For the most part, service providers indicated that they attempted to have the supported individuals identify proxies whom they felt would best represent them in the survey.

2.5.4 Survey Administration

Interviews that involved individuals who could self-report were scheduled by service providers and were conducted in-person by self-advocate interviewers either at the service providers' program sites or at alternative locations that respondents preferred (e.g., home, coffee shop, etc.). Meanwhile, proxy interviews were conducted by Malatest surveyors over the phone once notice was provided by service providers that the proxies' consent were obtained.

In the 2012/13 round of the *include Me!* Initiative, the process of scheduling and completing interviews occurred from July 2012 to February 2013. However, within that period, there were notable differences in the duration of survey administration across service providers (see Figure 2.2).

Figure 2.2 – Survey Administration Summary across Service Providers between July 2012 and February 2013

Valid Universe or Sample[a] & Participation Rate[b] (✓) by Service Provider[c]		Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb
Self-Report Interviews	**TCS**	n=28			✓ 64%				
	RMACL	n=96				✓ 80%			
	PRACL		n=81			✓ 44%			
	posAbilities		n=201				✓ 41%		
	CSCL		n=149						✓ 70%
	PCCRI			n=19 ✓ 63%					
	SACL			n=110		✓ 44%			
	CVS				n=43 ✓ 49%				
	SCACL				n=35 ✓ 80%				
	SFSCL				n=121 ✓ 75%				
	Spectrum				n=82			✓ 33%	
	GVCSS					n=3 ✓ 67%			
	NS ConneXions					n=84 ✓ 46%			
	VRS					n=42 ✓ 74%			
	NSDRC					n=24		✓ 4%	
Proxy Interviews	**Malatest**	n=301 x 2							✓ 82%

[a] *Valid universe or sample of the self-report interviews are based on the number identified in the service providers' master lists Meanwhile, the valid sample among the proxy interviews are based on the number of individuals whose proxies were provided by service providers to the Contractor.*
[b] *Participation rate is the ratio of valid completed surveys over the valid total sample.*
[c] *Refer to Table 2.1 for the full names of service providers. Service providers are color-coded according to their CLBC operational region: red=Both Vancouver Coastal and Fraser, blue=Fraser Region, and green=Vancouver Coastal.*

Also noted in Figure 2.2, the variation in experiences across service providers was not only in terms of the duration of survey administration but also in terms of the participation rate among the individuals that they were trying to engage.

2.5.5   Survey Participation and Response Rates

When the 2012/13 round of the *include Me!* Initiative wrapped up, survey results were collected from (and on behalf of) 864 CLBC-supported individuals. Over 7 of 10 surveys were completed by the CLBC-supported individuals themselves, instead of by proxies. This outcome strongly adheres to the objective of giving people with developmental disabilities an opportunity to speak for themselves about their quality of life. Furthermore, this is an empowering outcome, especially for self-advocate interviewers who conducted the vast majority of self-reported interviews.

Overall, the 864 completed surveys represent 56% of the expected total sample of 1,542 (see Overall *Participation Rate* in Figure 2.3). Moreover, it also represents 90% of those individuals who gave service providers their consent to participate (see Overall *Response Rate* in Figure 2.3). This finding suggests that the primary hurdle in survey completion is the initial buy-in on the part of supported individuals, as well as their committees or proxies.

Figure 2.3 – Overall Participation and Response Rates

Service Providers[a]	Participation Rate: Valid Completes / Valid Universe or Sample	Response Rate: Valid Completes / Number Who Consented
RMACL	81% of 135	93% of 117
GVCSS	77% of 26	80% of 25
SFSCL	77% of 143	94% of 117
SCACL	71% of 42	94% of 32
PCCRI	69% of 71	92% of 53
TCS	64% of 53	79% of 43
CSCL	62% of 196	95% of 129
VRS	61% of 59	84% of 43
NS ConneXions	52% of 131	76% of 89
CVS	51% of 63	100% of 32
PRACL	48% of 93	92% of 49
posAbilities	43% of 250	91% of 119
SACL	43% of 141	97% of 63
Spectrum	33% of 94	97% of 32
NSDRC	20% of 45	75% of 12
OVERALL	56% of 1,542	90% of 955

[a] *Refer to Table 2.1 for the full names of service providers.*

2.6 Strategies to Improve Response Rates

Upon recognition that getting the consent of supported individuals, their committees, and proxies was a key challenge in survey administration, the Contractor and CLBC's *include Me!* team explored various strategies to work with service providers to respond to this challenge. The following strategies were implemented: information sessions with individuals and their families, including those sessions that were immediately followed by the actual conduct of interviews; a prize draw; follow-up letters and calls to encourage survey completions directly from the Contractor; and the offer to do phone interviews as an option for self-advocates.

2.6.1 Information Sessions with Supported Individuals and their Families

All participating service providers were offered the option for CLBC's *include Me!* team to conduct information sessions that introduced the *include Me!* Initiative and its interview process to supported individuals and their families. These sessions typically involved a presentation about the initiative, a brief mock interview involving a self-advocate interviewer and a volunteer from the audience, with some time allocated for questions and answers.

In some cases, the Contractor also offered to assist in organizing *include Me!* event days in service providers' program sites that were frequented by respondents (e.g., day program centres). During the *include Me!* event days, the service providers gathered as many supported individuals in their master list who were onsite to participate in an information session conducted by the Contractor. Following the information sessions, the Contractor collects the consent forms, while multiple interviewers are also available onsite to complete interviews immediately after.

2.6.2 Prize Draw

The Contractor announced on November 2012 a draw that would award the following prizes:

- One (1) grand prize of an iPad,
- Two (2) runner-up prizes of iPods, and
- Ten (10) consolation prizes of $25 Tim Horton's gift cards.

The prize draw was held on February 2012 after all the 2012/13 interviews were completed. The winners were chosen among self-reporting individuals who completed the survey and indicated their interest to participate in the draw.

2.6.3 Follow-up Letters and Calls Directly from the Contractor

In an effort to complete more interviews after service providers had completed their scheduling efforts, the Contractor solicited consent from service providers to mail letters and subsequently make phone calls to the individuals who had explicitly refused to participate or who had not responded to follow-up efforts.

Among the 15 service providers, only two service providers agreed for the Contractor to send out follow-up letters; and between these two, only one agreed for the Contractor to subsequently make phone calls. The sentiment of the majority was to respect the initial decision of supported individuals and for the Contractor to not make follow-up contact.

Overall, there were very survey completions among those who were followed-up to reconsider their initial decision to not participate in the survey.

2.6.4 Phone Interviews as an Option for Self-Reporting Individuals

The Contractor conducted phone interviews with some self-reporting individuals, upon the request of service providers. This option was particularly requested for self-advocates who were working during the day, and could not come to the interview locations. The uptake for this offer was limited, but self-advocates who managed to complete the survey over the phone appreciated their inclusion in the initiative.

SECTION 3: DATA HANDLING

3.1   Overview of Data Handling

In the 2012/13 round of the *include Me!* Initiative, the interviews employed the following tools for data collection:

- Paper-based questionnaires, which self-advocate interviewers completed with self-reporting respondents during in-person interviews, and
- Computer-Assisted Telephone Interview (CATI) system, which was employed by Malatest surveyors when conducting proxy and some self-report interviews.

The mixed methodology in data collection called for the Contractor to develop an integrated database, which not only merged the survey data from various sources but also linked the master list data from service providers (see Section 2.5.2 Master List of CLBC-Supported Individuals). For this purpose, a web-based collection system was established using CallWeb, so that data from different sources could be stored in an integrated manner and easily extracted in the required formats for analysis.

Overall, the Contractor has ensured that data handling processes met all internal and external privacy and security standards.

3.2   Data Entry and Quality Assurance Checks

The Contractor developed an integrated database using the CallWeb online data collection system in order to streamline the information collected through paper-based questionnaires, telephone interviews, and master lists submitted by service providers.

3.2.1   Data Collected through Phone Interviews

With the CATI system, all information collected through telephone interviews were entered real time into CallWeb. To ensure quality in this data entry process, the Contractor put in place a system of checks, which included the periodic review (conducted by the research team) of the data entered by the phone surveyors. Furthermore, some phone interviews were also recorded for use in survey administration quality assurance checks and interviewer training.

3.2.2 Data Collected through Paper-Based Questionnaires

During in-person interviews, self-advocates collected the survey responses through paper-based questionnaires that had pre-coded respondent IDs. These respondent IDs, which were unique per individual, were assigned at the beginning of the survey process to everyone in the service providers' master lists.

In terms of data security and privacy, the respondent IDs were useful and secure identifiers for the paper-based questionnaires, especially since these were mailed back by self-advocate interviewers to the Contractor. Because of the limitations of Canada Post to guarantee mail delivery, only pre-coded respondent IDs were included on the questionnaires to ensure that CLBC-supported individuals' personally identifiable information was protected in case of loss.

As the Contractor received the survey questionnaires, the respondent IDs then served as a reference for the data entry team to identify respondents and record their answers in CallWeb. To ensure the quality of this data entry process, the Contractor's research team periodically reviewed the data entered for completeness and accuracy. Following conventional research practices, this process was conducted with more than 5% of the paper-based questionnaires that were collected. Furthermore, all original copies were retained by the Contractor in a secure location should there be a need for additional data verification.

3.2.3 Data Submitted by Service Providers

The master list information from service providers (see Section 2.5.2 Master List of CLBC-Supported Individuals) was entered in the integrated database through batch uploads because the information was provided to the Contractor in Excel spreadsheets.

After the batch upload, a checking mechanism was put in place to verify the completeness of the information about each supported individual. By linking the master list information to the online scheduler, it became mandatory for service providers to review and complete all the relevant information before interviews could be scheduled (see Section 2.4 My Life Survey Scheduler Using CallWeb).

3.3 Data Extraction and Cleaning

Because the Contractor decided to primarily use the SPSS statistical software for data analysis, the CallWeb data had to be extracted into the format that the software required. In data extraction, three SPSS files were created:

- Survey responses of self-reporting individuals,
- Survey responses of proxies, and
- Master list information from service providers.

Upon extraction, the data was cleaned in SPSS to prepare it for analysis.

3.3.1 Partial Completions Among Self-Reporting Individuals

Survey respondents can indicate that they want to skip questions or even opt out of the survey part-way through the interview. When these situations occur, the interviewers were trained to respect the respondent's decision. Given this policy, surveys had to be closely reviewed for completeness.

Partially completed surveys were only included if the respondent answered *four out of six questions* in *at least one of the eight quality of life domains* (see Section 1.2 *My Life Personal Outcomes Index*^{TM}). Cases that did not meet the minimum criteria had to be excluded from the dataset used for analysis.

3.3.2 Partial Completions Among Proxies

As mentioned earlier in the report, the survey administration for the *include Me!* Initiative required having two proxies who could answer on behalf of one supported individual (see Section 2.1 Overview of Survey Administration). As proxies completed the survey, they were given the same options as self-reporting individuals to skip questions or opt out of the survey part-way through the interview. For this reason, partial completions were also expected in the file with the survey responses of proxies.

The minimum criteria for inclusion in the final dataset also applied to proxy survey data. However, if one proxy did not respond to a question, but the second proxy did, the one response was considered the average, and the data was included. Those cases where only one proxy completed the survey for an individual had to be excluded from the dataset used for

analysis. In the 2012/13 round of the *include Me!* Initiative, 49 cases were excluded for this reason.

3.4 Data Linking and Output

After the files containing the survey responses were cleaned, a combined data file containing the aggregated information from the three SPSS files was created. The key components of the final data output included the following:

- Survey responses of self-reporting individuals,
- Average responses of two proxies who completed the survey, and
- Selected master list information per supported individual (e.g., service provider, CLBC operational region, age, and services accessed).

This final data output was then used in data analysis. It was also shared with the CLBC *include Me!* team after the supported individuals' personally identifiable information had been removed.

3.5 Privacy and Security Standards

The Contractor's full compliance with federal and provincial privacy legislation is especially relevant in terms of data handling. From experience with conducting projects contracted by government departments and agencies, universities, and colleges, the Contractor is well aware of and has demonstrated capacity working within the ethical and legal bounds of the FOIPPA and PIPA (e.g., unauthorized use or disclosure of information). Furthermore, the Contractor adheres to professional standards through its membership associations (Canadian Evaluation Society and Marketing Research and Intelligence Association).

The Contractor's Victoria office (from which all data handling activities for this project were centralized) has been granted a Top Secret Facility Security Clearance by the Canadian Industrial Security Directorate (CISD), which includes the authority to hold PROTECTED information or assets up to and including the PROTECTED "B" level (file number 5410-02 – federal government security clearance). Furthermore, all project team members meet or exceeded the minimum security level of the Federal Enhanced Reliability clearance, with most members holding Secret or Top Secret clearance.

SECTION 4: DATA ANALYSIS

4.1   Overview of Analytical Approach

The planned analyses involved a number of analytical techniques, from psychometric analysis of the *My Life: Personal Outcome Index*^{TM} to priority area analysis that examined the interrelationships among the various indicators of quality of life. The primary analysis focused on the average and percent positive domain scores computed for each of the eight quality of life domains. Statistical significance of group differences was evaluated by conducting mean and proportion comparison tests (e.g., t-test for independent samples or z-test for independent proportion). Responses obtained between self-reporters and proxies were compared to explore if any bias was introduced through proxy interviewing. Where feasible, bias was controlled statistically by including the mode of administration as a covariate in the analysis.

4.2   Scoring – Mean Scores and Percent Positive Scores

Domain scores were calculated in accordance to the scoring method used in previous studies and initiatives that used the *My Life Personal Outcomes Index*™. This included the calculation of a mean domain score and percent positive scores at the various levels of reporting—service providers, operational region, and overall.

4.2.1   Rounding and Averaging of Survey Responses

For the purpose of this report, most scores (e.g., mean and percent positive scores) have a level of precision of up to one decimal place and are stored internally up to the precision allowed by the software. Extra decimal places were rounded in the computation processes in accordance to the default of each program. For example, for certain procedures in SPSS, real numbers are rounded to the nearest integer, except where the decimal places are exactly 5. In these cases, it rounds to the even integer by default (e.g., 82.65% is rounded to 82.6%). In WinCross, the *round half up* rule was selected, where decimal places of exactly 5 are always rounded up to the next highest integer. Finally, un-biased rounding (*round half to even*) was used in R (a statistical computing programming language), which was used to produce the graphics and perform internal calculations.

The scores of individuals who participated via proxy (rather than self-report), are represented by the average of the two proxies' answers. Responses were rounded up to the next most

positive response category if the two proxies rated the questions differently. This approach simplified the interpretation of survey responses by trading off a small to medium amount of variation.

4.2.2   Domain Scoring

To calculate a domain score for each of the eight quality of life domains, responses to each question were first re-scaled to have a score of 0, 5, and 10 before computing the mean scores across questions that comprise that domain. For example, for the question "Do you feel good about yourself?" (Q3), a response of "most of the time" would be assigned a score of 10, "sometimes" a score of 5, and "rarely or never" a score of 0. Therefore, a higher score represents a more positive answer for that question. The individual-level domain score was then computed based on the average across six questions that comprise a domain. If a respondent skipped more than two questions per domain, the responses were not included in the computation. The domain scores that are referred to in the report are the average of the individual-level domain scores. The average domain score is the arithmetic mean of the sum of the re-scaled survey responses (0, 5, and 10) divided by the count of all valid responses. Higher scores represent a more positive outcome for that domain.

4.2.3   Percent Positive Scores

To facilitate interpretation of survey results, survey responses are standardized as a percentage of the "positive" answers to survey questions. "Positive" answers are defined as the most positive response category to a survey question (i.e., Top-box) regardless of the response categories. Results are easier to compare when they are all scored the same way, such as when reporting a percent positive score, since there is less variation in interpretation of what constitutes a "good score."

The domain percent positive scores were calculated in two steps. First, two total scores were calculated for each individual. The first total score consisted of the sum of all positive values for questions corresponding to each domain. The second total score consisted of the sum of all valid responses for questions corresponding to the same domain. Depending on the particular grouping or aggregation that was required, the two individual total scores were aggregated as a ratio using a custom SPSS macro to obtain a summary domain scores. Computationally, the domain scores can be represented as follows, where subscript i represents an individual and subscript j equals to the level of aggregation, such as the service provider or the operational region.

Include Me! Quality of Life Survey Initiative Methodology Report
Community Living British Columbia

R.A. Malatest & Associates Ltd.
May 2013

$$Domain\ Percent\ Positive\ Scores = \frac{\sum_{i,j}(Positive\ Value)}{\sum_{i,j}(Valid\ Response\ Item)} \times 100$$

4.3   Descriptive Summary about Accessibility (Q49) and Employment (Q50)

In addition to the 48 survey questions designed to measure the eight domains of quality of life, a percent positive score was also calculated for the accessibility (Q49) and employment (Q50) questions and reported in the full service provider and operational region reports. These results were presented along with the frequency counts and percentage responses summarized in the Appendix tables. The contractor also conducted additional analyses to examine the relationship of accessibility and employment with Q3 (i.e., sense of wellness) and the eight quality of life domains (see Section 4.7 for details).

4.4   Margin of Error

The target survey completions and sampling methodology were designed to achieve a good to acceptable margin of error at the service provider level. The margin of error indicates the imprecision inherent in survey data. A smaller margin of error indicates the survey results were more precisely measured. A margin of error of ±5% or ±8% is considered good and acceptable respectively.

The margin of error of the percent positive score at the 95% confidence level is obtained by multiplying the standard error of the estimate by the critical value, 1.96. For example, if the reported percent positive score is 50%, with a margin of error of ±5%, the true score is captured within the range of 45% and 55% 19 out of 20 times. The standard error of a reported percentage, such as the percent positive score, measures its variability and is calculated as follows:

$$SE = \sqrt{\frac{P_0(1 - P_0)}{n}}$$

$$Margin\ of\ Error = 1.96 \times SE$$

OR

$$Margin\ of\ Error = 1.96 \times \sqrt{\frac{P_0(1 - P_0)}{n}}$$

The margin of error cited in the reports is a conservative estimate (or the maximum sample error) because it assumes a distribution with a 50% positive score and 50% non-positive score. For this study, the sample size (n) is defined by the number of completions (i.e., survey with at least one valid response), not the number of respondents who answered each question or a set of questions (e.g., domain scores).

Of note, the finite population correction factor was only applied to margin of error calculations at the unit level (i.e., service provider level). Due to uncertainty around estimates of population size, this correction factor was not applied to higher-level reporting (i.e., Operational Region Reports or Executive Summary Report). In general, as the sampling proportion increases, the correction factors will reduce the margin of error because more of the population is included in the sample.

4.5   Psychometric Properties of the *My Life Personal Outcomes Index*^TM

The psychometric properties of the *My Life Personal Outcome Index* ^TM were assessed via item level analysis and confirmatory factor analysis. The distribution of item responses among self-report and proxy ratings were examined separately given known differences in responses between the two information sources. This entailed examination of the mean, standard deviation, corrected item-total correlation (ITC), and square multiple correlation (SMC) values for each item according to *a priori* criteria. The Contractor also estimated the reliability and consistency of responses of each of the eight quality of life domains by calculating Cronbach's Alpha (α). This was followed by a series of confirmatory factor analyses to determine the scale dimensionality and examine the patterns of relationships between survey items using responses from self-advocates only (see Section 4.5.1 Confirmatory Factory Analysis for detailed explanation). Results from these analyses were used to gauge whether valid and reliable inference can be drawn from the index and corresponding subscales. The findings also helped determine whether the interpretation of sub-scale scores is appropriate.

4.5.1   Confirmatory Factor Analysis

Confirmatory factor analysis (CFA) was used to replicate the theoretical factor structure specified by the quality of life framework and select factor structure previously tested in the demonstration project. Given an existing body of knowledge about the theoretical and empirical structure of the index, a confirmatory approach (i.e., CFA) was used instead of an exploratory approach (i.e., exploratory factor analysis; EFA). According to the quality of life framework, individuals' quality of life can be conceptualized as eight distinct but inter-related

facets. The framework further theorizes that each domain represents a subscale or facet of three higher-level constructs labelled as well-being, social participation, and independence (see Table 1.1). Second order models might be suitable when the lower order factors are inter-correlated (as assumed here), and higher order factors are hypothesized to explain these associations.[2] Conceptually, it has also been argued that the three factors of quality of life are subsumed by an overall quality of life construct.

Prior to factor analyses, several steps were taken to ensure that assumptions of the techniques are met.[3] During this stage, it was determined that the factor structure of proxy ratings cannot be tested due to extremely positive responses on certain items (i.e., ceiling effect). Therefore, factor analysis was carried out using responses from self-advocates only. Given that the responses to the index were not on an interval scale, the model was estimated using the diagonally weighted least square estimator with robust standard errors and mean and variance adjusted test statistics (WLSMV), which is appropriate for ordinal responses.[4] Missing responses were listwise deleted, resulting in a total effective sample size of 442. In total, three competing models were fitted and tested using the *lavaan* package (version 0.512) in R:[5]

- Model 1 – a first order model that specifies the eight quality of life domains are interrelated, with each domain defined by six indicators (i.e. six survey questions; see Figure 4.1);
- Model 2 – a second order model with three correlated specific quality of life factors that define the measurement of the eight quality of life domains (see Figure 4.2); and
- Model 3 – a third order model with each of the three specific quality of life factors hypothesized to contribute significantly to the measurement of an overall quality of life construct (see Figure 4.3).

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[2] Chen, F. F., Sousa, K. H., & West, S. G. (2005). Testing measurement invariance of second-order factor models. *Structural Equation Modeling, 12*, 471-492.
[3] Tabachnick, B. G., & Fidell, L. S. (2006). *Using multivariate statistics (5th ed.)*. Boston: Allyn and Bacon.
[4] Brown, T. A. (2006). *Confirmatory factor analysis for applied research*. New York: Guilford Press.
[5] Yves Rosseel (2012). lavaan: An R Package for Structural Equation Modeling. Journal of Statistical Software, 48(2), 1-36. URL http://www.jstatsoft.org/v48/i02/.

Figure 4.1 – Conceptual Path Diagram of the First Order Correlated Factor Model (Model 1)
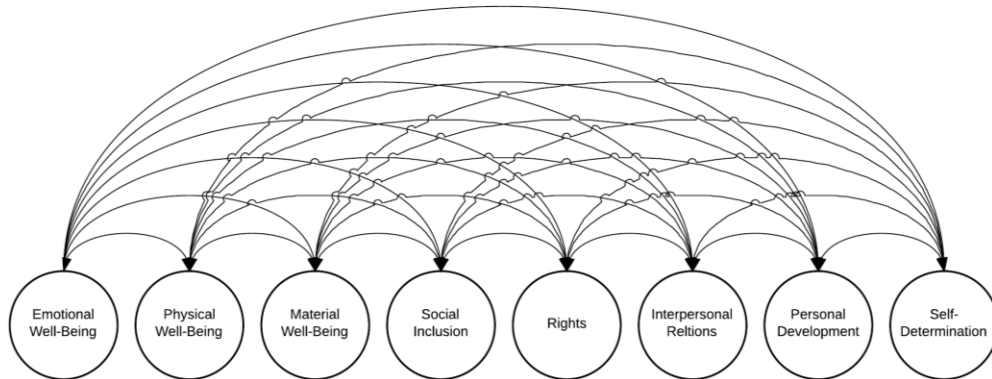
Figure 4.2 – Conceptual Path Diagram of the Second Order Correlated Factor Model (Model 2)
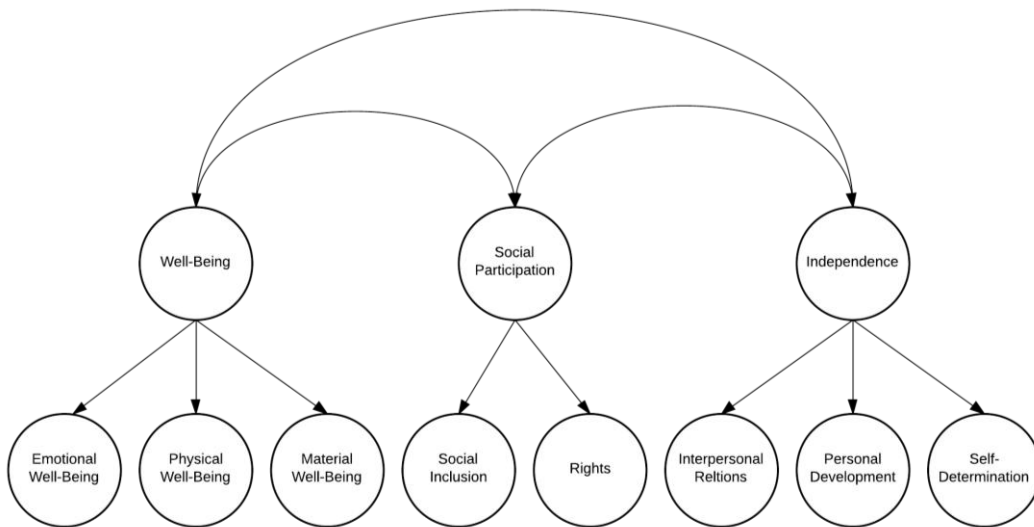
Figure 4.3 – Conceptual Path Diagram of the Third Order Correlated Factor Model (Model 3)
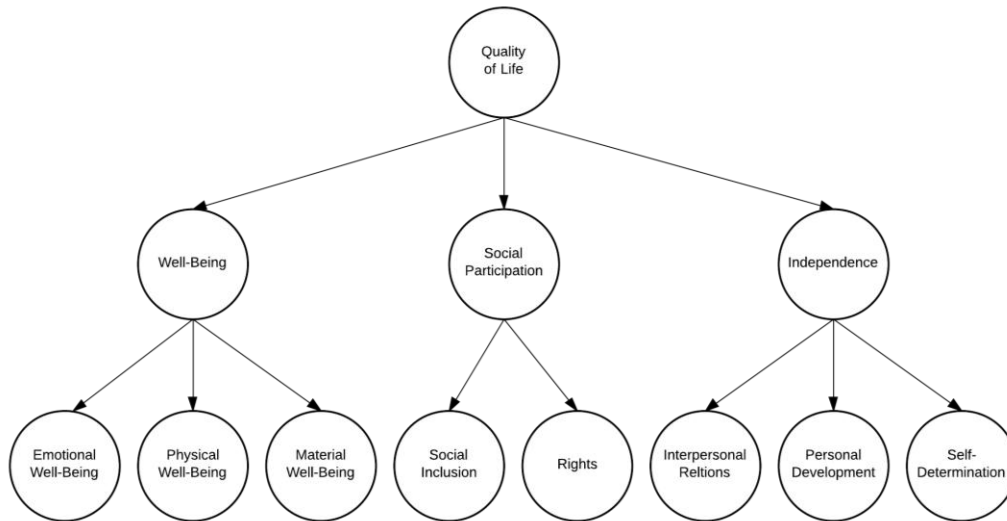
In addition to a scaled Chi-square statistic to determine whether the model has good fit with the data, two other recommended goodness of fit indices, the Comparative Fit Index (CFI) and Root Mean Squared Error of Approximations (RMSEA), were consulted. A conventional cut-off of CFI value greater than .95 and RMSEA value less than .5 were used to assess global fit (see Appendix G for an explanation of these criteria).[6,7]

All three models were estimated using WLSMV. Although all models converged, each ran into computational issues, such as having an estimated correlation greater than one or having a negative variance (i.e., Heywood case). This suggests, among other possibilities, that the model may be mis-specified or there is multicollinearity among subsets of items; therefore, interpretation of model fit and parameter estimates should proceed with caution.

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[6] Hu, L. T., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis. Conventional criteria versus new alternatives. *Structural Equation Modeling, 6*, 1-55.

[7] McDonald, R. P., & Ho, M. R. (2002). Principles and practice in reporting structural equation analyses. *Psychological Methods, 7*, 64-82.

Table 4.1 - Goodness of Fit Indices for Tested Factor Models of the *MyLife Personal Outcome Index* ™ (Self-Report only; n = 442)

Model #	Model	Model Comparison	Scaled χ^2	df	CFI	RMSEA	90% CI	Δ Scaled χ^2	Δ df
-	Null Model	-	1851.289***	57	.000	.267	(.264-.269)	-	-
1	1st Order Correlated Model	-	390.386***	205	.897	.045	(.017-.049)	-	-
2	2nd Order Model	vs. Model 1	432.820***	203	.872	.051	(.025-.054)	20.8*	9.82
3	3rd Order Model	vs. Model 1	605.303***	200	.774	.068	(.044-.071)	90.0***	9.82

Note: CFI = Comparative Fit Index, RMSEA = Root Mean Square Error of Approximation, Δχ^2 difference test is based on the corrected scaled Chi-square difference test.
* *p* <.05, ** *p* < .01, *** *p* < .001

As shown in Table 4.1, a number of fit indices indicated that the initial first order correlated model (Model 1) had a less than ideal fit, χ^2 (df = 205) = 390.386, *p* <.001. Although the comparative fit index (CFI = .897) was below the cut-off of .95, the obtained value was respectable for an unmodified CFA model. Of further note, the Root Mean Square Error of Approximation was within the acceptable range (RMSEA = .045, CI_{90} = .017-.049). These initial results are very encouraging for an unmodified model, suggesting that the correlated first order factor model is an accurate specification of the pattern of relationships among items on the index.

The revised second order factor model (Model 2) achieved poorer overall goodness of fit when compared to the first order correlated factors model, $\Delta \chi^2$ (df = 9.82) = 20.8, *p* < .05. The model Chi-square value is χ^2 (df = 203) = 432.820, *p* <.001. Similarly, the CFI (.872) and the RMSEA (.051, CI_{90} = .025-.054) values reflect poorer model fit. The fitted third order factor model also exhibited poor global fit with a model Chi-square value of χ^2 (df = 200) = 605.503, *p* <.001. Both the CFI (.774) and the RMSEA (.068, CI_{90} = .044-.071) also corroborate that the model fit the data poorly. The scaled Chi-square difference test further indicated that the third order factor model fit significantly worse than the first order correlated factors model, $\Delta \chi^2$ (df = 9.82) = 90.0, *p* < .001.

In summary, results from the confirmatory factor analysis indicate that the factor structure of the index remains equivocal and that certain questions may benefit from revision. Although post-hoc modifications and residual statistics can be consulted to arrive at a better fitting model, in the absence of strong theoretical guidance at this stage, it was decided that the model will not be revised based on statistical criteria alone. Furthermore, the presence of

estimation problems for some models cast doubt on the stability of parameter estimates and the evaluation of global model fit. Model comparisons using the scaled Chi-square difference test indicated that both the 2nd order and 3rd order model had significantly worse fit than the first order correlated model (see Table 4.1). Taken together, this suggested that the factorial structure of the *My Life Personal Outcome Index* [TM] was best represented as eight inter-related domains for self-report, and the current data do not support the presence of higher order factors. Additional research on an independent sample of self-advocates and proxy is needed to confirm the dimensionality of the index.

Table 4.2 summarizes the inter-factor correlations from the first order correlated model (Model 1) along with the Spearman rank-order correlation coefficients among the average domain scores for the eight quality of life domains. All eight factors are highly correlated with each other ($r > .5$). As expected, after accounting for specific factor variance and measurement errors, the correlations among domains for self-report as calculated from the CFA were in general higher than the correlations estimated using the average domain scores.

Table 4.2 – Inter-Correlations between Domain Scores and Factors of the *MyLife Personal Outcome Index* ™ Self-Report (Proxy Ratings)

	Emotional Well-Being	Physical Well-Being	Material Well-Being	Social Inclusions	Rights	Interpersonal Relations	Personal Development	Self-Determination	Mean	SD
Emotional Well-Being	—	.344 (.185)	.435 (.161)	.328 (.288)	.413 (.156)	.425 (.344)	.455 (.316)	.444 (.211)	7.9 (9.7)	2.0 (.5)
Physical Well-Being	.694	—	.582 (.087)	.419 (.249)	.527 (.250)	.460 (.203)	.477 (.257)	.564 (.265)	7.2 (8.4)	2.3 (1.7)
Material Well-Being	.596	.894	—	.470 (.319)	.506 (.321)	.446 (.192)	.581 (.421)	.552 (.304)	7.5 (8.9)	2.1 (1.1)
Social Inclusions	.587	.821	.781	—	.348 (.313)	.578 (.521)	.607 (.567)	.405 (.549)	6.7 (5.9)	2.2 (2.0)
Rights	.687	.892	.874	.715	—	.357 (.160)	.496 (.409)	.575 (.539)	7.4 (6.8)	2.2 (1.9)
Interpersonal Relations	.827	.769	.782	1.013†	.753	—	.491 (.331)	.435 (.327)	7.0 (7.2)	2.0 (1.8)
Personal Development	.705	.874	.785	.954	.833	.823	—	.539 (.502)	7.2 (7.2)	2.4 (1.8)
Self-Determination	.748	.861	.889	.716	.958	.752	.874	—	7.2 (5.8)	2.4 (2.2)

Note: Spearman Rank Order correlation between the domain scores are presented above the diagonal for self-report (n = 594) and proxy ratings (n = 240) in parenthesis; Mean of the domain score on the diagonal for self-report and proxy ratings in parenthesis; Factor correlation from the confirmatory factor analysis model 1 is presented below the diagonal for self-report only (n = 442). All analysis conducted with listwise deletion.
† Heywood case (i.e., correlation greater than 1).

4.5.2 Item-Level Analysis

Table 4.3 summarizes the estimated reliability of responses for the *My Life Personal Outcome Index*[TM]. Reliability of responses was evaluated using Cronbach's alpha, which is a commonly used lower-bound estimate of internal consistency. In addition to reliability estimates calculated for the overall index, Cronbach's alphas were calculated separately for each of the eight quality of life domains and presented by respondent types (self-report vs. proxy ratings).

Table 4.3 – Reliability of Responses of the *My Life Personal Outcome Index*[TM]

| | Cronbach's Alpha | | | |
| | n = 857* | n = 610* | n= 247* | |
	Combined	Self-Report Only	Proxy Rating Only	N of Items
Emotional Well-Being	**.754**	**.712**	.208	6
Interpersonal Relations	.596	.579	.677	6
Social Inclusion	.638	.624	**.701**	6
Personal Development	**.737**	**.759**	.699	6
Self-Determination	**.735**	**.727**	**.743**	6
Physical Well-Being	**.710**	**.710**	.424	6
Material Well-Being	**.716**	**.715**	.653	6
Rights	.592	.646	.587	6
Overall	**.919**	**.929**	**.883**	48

* Up to this number of cases due to listwise deletion. Bolded values indicated it met the conventional cut-off of .7

As seen in Table 4.3, overall, the index has excellent reliability of responses, both when survey responses were combined or when self-report and proxy ratings were assessed separately. However, a wider range of estimates were obtained when examining each domain individually. In general, the internal consistency of self-report ratings was higher than those obtained from proxy ratings. Of note, reliability estimates were below the acceptable threshold of .7 for the Interpersonal Relations, Social Inclusion, and Rights domains. The reliability estimates for proxy ratings on questions related to emotional well-being were extremely poor, likely due to ceiling effect and restricted variances resulting from a high percentage of proxy who rated very positively on these questions.

The next set of tables (Table 4.4 to 4.11) provides a detailed summary of the results from the item-level analyses on the full sample and confirmatory factor analysis conducted with self-report completions only. As noted in the previous section, factor analysis results were not

available for proxy ratings due to computational issues. In addition to presenting the means, standard deviations, and percent positive responses by self-report and proxy ratings, the statistically significant differences between self-report and proxy ratings were also noted. Each subscale or domain was also evaluated in accordance to six criteria to determine whether it has good psychometrics properties (see Appendix G for an explanation of these criteria):

- Whether the entire range of response categories were used, or conversely, whether certain response options were chosen disproportionably than others (creating a ceiling effect as indicated by a mean score of 9.5 or higher);
- Whether the corrected item-total correlations (ITC) for both self-report and proxy ratings were greater than .3. The ITC estimates the correlation between the survey question with the rest of the questions in that domain;
- Whether the squared multiple correlation coefficient (SMC) for both self-report and proxy ratings were greater than .3. The SMC measures the proportion of variance explained by a common factor (i.e., domain);
- Whether the change in Cronbach's alpha if the item was excluded from the subscale remain above the recommended cut-off of .7;
- Whether the standardized factor loadings from the confirmatory factor analysis (Model 1) on self-report respondents only were greater than .4.
- Whether the error variances, or the item unreliability, obtained from the same confirmatory factor analysis (Model 1) on self-report respondents only were less than .5.

Cut-off of these criteria was based on recommended practices in the psychometric literature.[8] In Tables 4.4 to 4.11, items that met the criteria are shaded green and red if they did not. Implications of the reliability and unreliability of responses for each subscale are briefly discussed in the remainder of this section.

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[8] DeVellis, R. F. (2003). *Scale development: Theory and applications (2nd ed.)*. Thousand Oaks, CA: Sage Publications.

Table 4.4 – Psychometric Proprieties of the Emotional Well-Being Domain Subscale – Self-Report (Proxy Ratings)

	n	Mean	SD	% Pos	Significant Difference	Item-Total Correlation	Squared Multiple Correlation	Alpha (α) if Item Deleted	Factor Loading (λ)	Error Variance	Criteria					
											C	ITC	SMC	α	λ	ε
Emotional Well-Being	608 (247)	7.9 (9.7)	2.1 (0.5)	66.2% (94.4%)	Yes											
Q1	601 (245)	8.3 (9.9)	3.1 (.7)	74.3% (99.2%)	Yes	.444 (-.047)	.201 (.002)	.674 (.251)	0.694	0.518						
Q2	601 (245)	8.3 (9.9)	3.0 (.6)	42.1% (98.4%)	Yes	.408 (.092)	.168 (.041)	.684 (.186)	0.581	0.662						
Q3	601 (245)	7.8 (9.4)	3.2 (1.6)	73.1% (88.7%)	Yes	.416 (.092)	.177 (.015)	.682 (.183)	0.657	0.568						
Q4	601 (245)	7.6 (9.3)	3.3 (1.8)	64.3% (85.4%)	Yes	.427 (.123)	.185 (.028)	.679 (.148)	0.713	0.491						
Q5	601 (245)	7.5 (9.9)	3.3 (.8)	59.9% (97.6%)	Yes	.487 (.142)	.242 (.057)	.660 (.153)	0.644	0.585						
Q6	601 (245)	7.8 (9.9)	3.4 (.8)	58.9% (97.2%)	Yes	.480 (.164)	.236 (.043)	.662 (.135)	0.648	0.58						

* Green denotes item that met the criterion and red denotes item that failed the criterion. C = Ceiling (*M* < 9.5); ITC = Corrected Item-Total Correlation > .3; SMC = Squared Multiple Correlation >. 3; α = Alpha >. 7; λ = Loadings > .4; ε = Error Variance <.5.

Despite good overall reliability of responses (α > .7), the emotional well-being subscale lacks good psychometric properties at the item level, in particular for proxy ratings. Across the six criteria, only the factor loadings (λ > .4) met the *a priori* cut-off. As seen in the means, standard deviations, and percent positive scores, proxies were much more likely to pick the most positive response category than self-advocates. These extremely positive responses restricted response variation, which led to attenuated correlations among survey items (ITC < .3). Both the squared multiple correlations and error variances indicated that a substantial amount of variations were unique to the item and were not explained by a common factor.

Table 4.5 – Psychometric Proprieties of the Interpersonal Relations Domain Subscale – Self-Report (Proxy Ratings)

	n	Mean	SD	% Pos	Significant Difference	Item-Total Correlation	Squared Multiple Correlation	Alpha (α) if Item Deleted	Factor Loading (λ)	Error Variance	Criteria					
											C	ITC	SMC	α	λ	ε
Interpersonal Relations	606 (246)	6.9 (7.2)	2.1 (1.8)	54.9% (53.4%)	No											
Q7	565 (227)	8.1 (7.6)	3.2 (2.9)	66.6% (55.9%)	Yes	.424 (.501)	.191 (.272)	.492 (.602)	0.568	0.677						
Q8	565 (227)	8.0 (9.5)	3.1 (1.6)	70.8% (91.9%)	Yes	.241 (.224)	.068 (.066)	.564 (.684)	0.696	0.515						
Q9	565 (227)	8.4 (9.0)	3.0 (2.3)	66.0% (82.3%)	Yes	.324 (.216)	.129 (.071)	.533 (.689)	0.511	0.738						
Q10	565 (227)	5.9 (4.9)	4.0 (3.3)	74.1% (20.3%)	Yes	.247 (.561)	.067 (.334)	.570 (.574)	0.304	0.908						
Q11	565 (227)	6.2 (6.7)	3.9 (3.4)	43.5% (47.0%)	No	.350 (.464)	.141 (.234)	.519 (.616)	0.515	0.735						
Q12	565 (227)	5.3 (5.3)	3.8 (3.2)	32.9% (24.8%)	Yes	.338 (.462)	.131 (.254)	.525 (.615)	0.468	0.781						

* Green denotes item that met the criterion and red denotes item that failed the criterion. C = Ceiling ($M < 9.5$); ITC = Corrected Item-Total Correlation > .3; SMC = Squared Multiple Correlation >. 3; α = Alpha >. 7; λ = Loadings > .4; ε = Error Variance <.5.

Interpersonal relations was one of three domains with poor overall internal consistency of responses (α < .7). A ceiling effect was evident in responses for Q8, where the majority of proxies selected the most positive response option. The item-total correlations showed that some questions (Q8, Q9, and Q10) correlated weakly (ITC <.3) with other items for either proxy or self-report. This suggested the subscale is comprised of items that measure different concepts. Except for Q10, all remaining items contributed to the measurement of this domain (λ > .4). Although the mean domain scores between self-report and proxy ratings did not differ statistically, some questions were rated higher by proxies (Q8, Q9 and Q10) and others were rated higher by self-advocates (Q7 and 10). Both the squared multiple correlations and error variances indicated that a substantial amount of variations were unique to the item.

Table 4.6 – Psychometric Proprieties of the Social Inclusion Domain Subscale – Self-Report (Proxy Ratings)

	n	Mean	SD	% Pos	Significant Difference	Item-Total Correlation	Squared Multiple Correlation	Alpha (α) if Item Deleted	Factor Loading (λ)	Error Variance	Criteria					
											C	ITC	SMC	α	λ	ε
Social Inclusion	604 (246)	6.7 (5.8)	2.2 (2.0)	52.4% (37.4%)	Yes											
Q13	590 (234)	6.7 (6.7)	4.2 (3.3)	57.1% (44.1%)	Yes	.339 (.453)	.118 (.210)	.589 (.655)	0.438	0.808						
Q14	590 (234)	7.7 (5.3)	3.2 (3.6)	61.5% (29.0%)	Yes	.330 (.434)	.118 (.230)	.591 (.663)	0.610	0.628						
Q15	590 (234)	5.2 (3.3)	4.0 (3.2)	34.0% (8.7%)	Yes	.386 (.389)	.159 (.178)	.568 (.675)	0.527	0.723						
Q16	590 (234)	5.6 (3.1)	4.2 (3.3)	40.7% (9.9%)	Yes	.362 (.515)	.139 (.279)	.579 (.633)	0.446	0.801						
Q17	590 (234)	7.4 (7.9)	3.7 (2.7)	62.5% (59.8%)	No	.409 (.434)	.173 (.206)	.560 (.663)	0.553	0.694						
Q18	590 (234)	7.5 (8.5)	3.2 (2.5)	58.3% (72.2%)	Yes	.317 (.385)	.109 (.152)	.595 (.677)	0.594	0.647						

* Green denotes item that met the criterion and red denotes item that failed the criterion. C = Ceiling ($M <$ 9.5); ITC = Corrected Item-Total Correlation > .3; SMC = Squared Multiple Correlation >. 3; α = Alpha >. 7; λ = Loadings > .4; ε = Error Variance <.5.

Although the internal consistency of the social inclusion subscale was poor (α < .7), at the item level, questions related to social inclusion performed reasonably well. None of the questions exhibited a ceiling effect, suggesting that all response categories were utilized. All six items also had good item-total correlation (ITC >. 3) for both self-report and proxy ratings. The domain is well measured by the six indicators (λ > .4). For this domain, self-advocates consistently responded more positively than proxies on most items (except for Q18). Both the squared multiple correlations and error variances indicate that a substantial amount of variation was unique to the item.

Table 4.7 – Psychometric Proprieties of the Personal Development Domain Subscale – Self-Report (Proxy Ratings)

	n	Mean	SD	% Pos	Significant Difference	Item-Total Correlation	Squared Multiple Correlation	Alpha (α) if Item Deleted	Factor Loading (λ)	Error Variance	Criteria					
											C	ITC	SMC	α	λ	ε
Personal Development	601 (246)	7.2 (7.2)	2.4 (1.8)	57.0% (51.4%)	No											
Q19	591 (233)	7.4 (5.3)	3.5 (3.1)	59.7% (22.1%)	Yes	.510 (.443)	.273 (.215)	.721 (.656)	0.664	0.559						
Q20	591 (233)	6.9 (6.5)	3.8 (3.1)	54.9% (38.8%)	Yes	.453 (.410)	.211 (.180)	.737 (.667)	0.668	0.553						
Q21	591 (233)	7.4 (8.6)	3.5 (2.4)	59.9% (73.2%)	Yes	.567 (.412)	.345 (.208)	.705 (.666)	0.716	0.488						
Q22	591 (233)	7.5 (8.5)	3.4 (2.4)	59.4% (71.0%)	Yes	.519 (.426)	.293 (.188)	.719 (.663)	0.692	0.522						
Q23	591 (233)	6.5 (6.1)	3.8 (3.2)	48.8% (33.3%)	Yes	.451 (.442)	.217 (.211)	.738 (.657)	0.618	0.618						
Q24	591 (233)	7.5 (8.4)	3.3 (2.5)	59.0% (69.3%)	Yes	.508 (.471)	.270 (.252)	.722 (.649)	0.708	0.498						

* Green denotes item that met the criterion and red denotes item that failed the criterion. C = Ceiling ($M < 9.5$); ITC = Corrected Item-Total Correlation > .3; SMC = Squared Multiple Correlation >. 3; α = Alpha >. 7; λ = Loadings > .4; ε = Error Variance <.5.

The personal development subscale has good psychometric properties. There was no evidence of ceiling effects, and items were moderately related to each other (ITC > .3). Factor analysis indicated that this domain is well defined by the six survey items (λ range from 618 to .716). Like most subscales of the index, the psychometric properties for proxy ratings were lower than their self-reported counterparts. Both the squared multiple correlations and error variances also indicated that a substantial amount of variation was unique to the item and was not explained by a common factor.

Table 4.8 – Psychometric Proprieties of the Self-Determination Domain Subscale – Self-Report (Proxy Ratings)

	n	Mean	SD	% Pos	Significant Difference	Item-Total Correlation	Squared Multiple Correlation	Alpha (α) if Item Deleted	Factor Loading (λ)	Error Variance	Criteria					
											C	ITC	SMC	α	λ	ε
Self-Determination	601 (247)	7.2 (5.8)	2.4 (2.2)	58.9% (38.0%)	Yes											
Q25	585 (234)	7.0 (4.2)	3.9 (3.5)	58.5% (17.6%)	Yes	.498 (.500)	.287 (.480)	.678 (.701)	0.585	0.657						
Q26	585 (234)	6.9 (3.6)	3.8 (3.5)	55.9% (13.4%)	Yes	.512 (.535)	.295 (.487)	.674 (.690)	0.601	0.639						
Q27	585 (234)	7.2 (7.7)	3.6 (2.8)	57.4% (58.5%)	No	.446 (.385)	.216 (.215)	.694 (.731)	0.668	0.554						
Q28	585 (234)	7.4 (7.2)	3.4 (3.1)	59.0% (51.4%)	Yes	.473 (.518)	.246 (.297)	.687 (.697)	0.75	0.437						
Q29	585 (234)	8.1 (7.9)	3.3 (3.3)	72.5% (68.7%)	No	.434 (.398)	.203 (.227)	.698 (.729)	0.742	0.449						
Q30	585 (234)	6.5 (3.9)	3.9 (3.6)	49.8% (17.6%)	Yes	.410 (.546)	.172 (.314)	.706 (.687)	0.499	0.751						

* Green denotes item that met the criterion and red denotes item that failed the criterion. C = Ceiling ($M < 9.5$); ITC = Corrected Item-Total Correlation > .3; SMC = Squared Multiple Correlation >. 3; α = Alpha >. 7; λ = Loadings > .4; ε = Error Variance <.5.

Among all eight subscales, self-determination demonstrates the best psychometric properties. Moderate item-total correlations indicated that the items were related, suggestive of a self-determination construct. This was corroborated by factor analytic results, where all six indicators loaded highly onto the factor (λ >.67). Except for Q27 and Q29, responses from self-advocates were statistically higher than ratings by proxies. The means, standard deviations, and percent positive scores indicated that the full range of response categories was used. Both the squared multiple correlations and error variances indicated that a substantial amount of variation was not explained by a common factor.

Table 4.9 – Psychometric Proprieties of the Physical Well-Being Domain Subscale – Self-Report (Proxy Ratings)

	n	Mean	SD	% Pos	Significant Difference	Item-Total Correlation	Squared Multiple Correlation	Alpha (α) if Item Deleted	Factor Loading (λ)	Error Variance	Criteria					
											C	ITC	SMC	α	λ	ε
Physical Well-Being	596 (242)	7.5 (8.9)	2.1 (1.1)	58.6% (80.0%)	Yes											
Q31	593 (243)	8.1 (9.9)	3.0 (.6)	68.0% (98.4%)	Yes	.395 (.046)	.185 (.012)	.685 (.439)	0.723	0.477						
Q32	593 (243)	7.0 (8.0)	3.3 (2.7)	50.8% (61.8%)	Yes	.516 (.440)	.284 (.220)	.647 (.175)	0.688	0.527						
Q33	593 (243)	7.4 (8.6)	3.4 (2.3)	57.5% (71.4%)	Yes	.402 (.191)	.184 (.076)	.683 (.390)	0.555	0.692						
Q34	593 (243)	7.3 (7.3)	3.5 (3.2)	57.7% (53.5%)	No	.332 (.305)	.116 (.168)	.707 (.315)	0.486	0.764						
Q35	593 (243)	7.8 (9.7)	3.1 (1.4)	62.4% (95.5%)	Yes	.492 (.176)	.246 (.062)	.656 (.399)	0.665	0.558						
Q36	593 (243)	7.3 (10.0)	3.3 (.5)	54.9% (99.2%)	Yes	.525 (.013)	.303 (.058)	.644 (.442)	0.734	0.462						

* Green denotes item that met the criterion and red denotes item that failed the criterion. C = Ceiling (*M* < 9.5); ITC = Corrected Item-Total Correlation > .3; SMC = Squared Multiple Correlation >. 3; α = Alpha >. 7; λ = Loadings > .4; ε = Error Variance <.5.

Similar to the emotional well-being subscale, the reliability of responses for proxy ratings were much lower compared to self-report ratings (see Table 4.3). Item-total correlations indicated that the items were moderately correlated among self-report ratings but less so for proxy ratings. The means, standard deviations, and percent positives also showed a ceiling effect for Q31, Q35, and Q36. This restriction of range may have resulted in the low correlations among item and the poor internal consistency for proxy ratings. Looking only at self-report ratings, all six indicators loaded highly onto the hypothesized factor (λ >.67). Except for Q34, proxy ratings were consistently more positive than responses from self-advocates; these differences were statistically significant. Both the squared multiple correlations and error variances indicated that a substantial amount of variation was not explained by a common factor.

Table 4.10 – Psychometric Proprieties of the Material Well-Being Domain Subscale – Self-Report (Proxy Ratings)

	n	Mean	SD	% Pos	Significant Difference	Item-Total Correlation	Squared Multiple Correlation	Alpha (α) if Item Deleted	Factor Loading (λ)	Error Variance	Criteria					
											C	ITC	SMC	α	λ	ε
Material Well-Being	599 (247)	7.2 (8.4)	2.3 (1.7)	56.6% (74.2%)	Yes						C	ITC	SMC	α	λ	ε
Q37	503 (201)	7.3 (8.4)	3.3 (2.8)	55.0% (74.2%)	Yes	.498 (.455)	.258 (.408)	.663 (.583)	0.735	0.46						
Q38	503 (201)	7.3 (7.8)	3.4 (3.3)	56.2% (65.4%)	Yes	.505 (.594)	.260 (.499)	.660 (.515)	0.674	0.546						
Q39	503 (201)	7.6 (8.4)	3.2 (2.4)	60.4% (69.7%)	Yes	.395 (.385)	.176 (.181)	.692 (.611)	0.670	0.551						
Q40	503 (201)	6.7 (9.4)	4.0 (2.1)	54.7% (89.4%)	Yes	.428 (.369)	.219 (.252)	.684 (.619)	0.517	0.732						
Q41	503 (201)	7.4 (9.7)	3.5 (1.4)	59.8% (96.4%)	Yes	.539 (.214)	.297 (.190)	.648 (.659)	0.674	0.545						
Q42	503 (201)	6.6 (6.7)	3.9 (3.8)	53.5% (52.5%)	No	.346 (.341)	.137 (.140)	.711 (.648)	0.451	0.797						

* Green denotes item that met the criterion and red denotes item that failed the criterion. C = Ceiling ($M < 9.5$); ITC = Corrected Item-Total Correlation > .3; SMC = Squared Multiple Correlation >. 3; α = Alpha >. 7; λ = Loadings > .4; ε = Error Variance <.5.

The overall reliability of responses for the material well-being subscale was good. Item-total correlations indicated that, except for proxy ratings of Q41, items were moderately correlated with each other, suggestive of an underlying construct. The means, standard deviations, and percent positive scores indicated that the full range of response categories was used. Aside from Q42, when compared to self-advocates, proxies consistently answered questions related to material well-being more positively, and these differences were statistically significant. Factor analysis provided support that the domain is well measured by the six indicators (λ >.4). Both the squared multiple correlations and error variances indicated that a substantial amount of variation was unique to the item and was not explained by a common factor.

Table 4.11 – Psychometric Proprieties of the Rights Domain Subscale – Self-Report (Proxy Ratings)

	n	Mean	SD	% Pos	Significant Difference	Item-Total Correlation	Squared Multiple Correlation	Alpha (α) if Item Deleted	Factor Loading (λ)	Error Variance	Criteria					
											C	ITC	SMC	α	λ	ε
Rights	594 (240)	7.4 (6.8)	2.2 (1.9)	62.5% (53.9%)	Yes											
Q43	580 (223)	7.8 (6.1)	3.6 (4.0)	69.5% (45.0%)	Yes	.349 (.437)	.143 (.222)	.612 (.483)	0.553	0.694						
Q44	580 (223)	7.9 (7.6)	3.1 (2.9)	63.4% (55.1%)	Yes	.489 (.438)	.280 (.298)	.568 (.497)	0.725	0.474						
Q45	580 (223)	7.4 (8.0)	3.5 (3.1)	58.3% (66.0%)	Yes	.496 (.444)	.302 (.255)	.558 (.489)	0.778	0.395						
Q46	580 (223)	7.1 (7.4)	3.7 (3.3)	56.6% (56.9%)	No	.425 (.315)	.198 (.138)	.583 (.545)	0.644	0.585						
Q47	580 (223)	7.1 (9.1)	3.5 (2.0)	54.0% (84.5%)	Yes	.454 (.273)	.280 (.168)	.573 (.566)	0.725	0.474						
Q48	580 (223)	7.5 (2.3)	4.2 (3.7)	72.8% (14.2%)	Yes	.126 (.109)	.021 (.036)	.707 (.642)	0.216	0.953						

* Green denotes item that met the criterion and red denotes item that failed the criterion. C = Ceiling ($M <$ 9.5); ITC = Corrected Item-Total Correlation > .3; SMC = Squared Multiple Correlation >. 3; α = Alpha >. 7; λ = Loadings > .4; ε = Error Variance <.5.

Rights was one of three domains with poor overall internal consistency of responses ($\alpha < .7$). At the item level, though the full range of response categories were utilized, Q48 appeared to be unrelated to the other items (ITC < .3). The same question also failed to load onto a common factor when factor analyzed (λ <.4). Although most percent positive scores were significantly higher for self-advocates compared to proxies, Q45 and Q47 were rated higher by proxies. Self-advocates and proxies also have very different views when it comes to Q48, with proxies providing a much lower percent positive and mean score. Both the squared multiple correlations and error variances indicated that a substantial amount of variation was unique to the item.

4.6   Priority Area Analysis

Priority areas for improvement were determined based on the relationship between two criteria:

- Importance of each question to the overall sense of well-being as determined by their Spearman rank order correlations to Q3 "Do you feel good about yourself?", and
- Performance based on the percentage of respondents who selected the most positive answer, e.g., "most of the time."

The question "Do you feel good about yourself?" was selected as an indicator for individuals' perceived sense of wellness because of its face validity—it is a question that is simple for individuals to understand and easy to explain to others. The higher the correlation between the sense of well-being and performance, the more important this aspect of quality of life is to the individual's perceived sense of wellness. Survey questions with a correlation greater than .2 and the lowest percentage of positive responses (below the median responses) were deemed to be the aspects of quality of life where efforts can be targeted.[9] The two survey questions about accessibility (Q49) and employment (Q50) were excluded from the priority area analysis because they are not part of the eight quality of life domains. Survey questions are ranked to highlight aspects of quality of life that are most actionable and can be targeted to drive efforts to improve the individual's quality of life. Survey questions with the lowest performing scores and the highest correlations to the individual's perceived sense of wellness are listed. These questions were important to the perceived sense of wellness and were rated as low-performing by respondents. In this context, rather than just focussing on low performing scores, the service provider and regional reports highlighted the quality of life attributes that would be helpful for service providers and CLBC to focus on since they have a high correlation with an individual's perceived sense of wellness. Improving scores in these areas would most likely have the greatest impact in terms of improving the quality of life measure for self advocates served by the service providers.

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[9] Of note, for the PosAbilities service provider report, it was decided that survey questions with a positive correlation that is significantly different from zero (i.e. >.16) and the lowest percentage of positive responses were deemed to be the aspects of quality of life where efforts can be targeted. Please note that these correlations, though significantly different from zero, are lower than the 0.2 cut-off applied to the other service providers. A lower correlation indicates a weaker relationship with Q3.

4.7   Correlation Analysis

As detailed in Section 4.6 (Priority Area Analysis), key driver analysis was conducted to examine the relative importance of the quality of life domains at the item levels based on the strength of their relationship with a measure of perceived sense of wellness. The magnitude and direction of these correlations were examined using the Spearman rank order correlation coefficient, which is more appropriate than the Pearson product moment correlation for data that is ordinal in nature. The Contractor approached individual outcome measurement as an ongoing study of dynamic outcomes rather than a static state of mind. As such, the analysis identifies quality of life indicators and areas of priority for service delivery improvement.

In addition, the Contractor also examined the relationships between quality of life scores and demographic variables using correlation, regression, and related methods (i.e., OLS estimator or maximum likelihood estimator). These findings are reported in the executive summary report, along with separate analyses that examine the relationships between accessibility (Q49) and employment (Q50) with Q3 (i.e., sense of wellness). To account for measurement error and unreliability of measurement, a structural equation modeling (SEM) approach was fitted to simultaneously determine the relative importance of key demographic factors and correlates, including age, gender, whether residential services were offered, whether the interviews were proxy interviews, the operational regions, accessibility (Q49), and employment (Q50) on the eight individual quality of life domains. Unlike separate multiple linear regressions, SEM reduces the likelihood of chance findings and Type I error, while adjusting for measurement unreliability.[10] This adjustment was important given the wide range of reliability estimates obtained for the index and corresponding subscales. The un-attenuated estimates provide a less biased relationship between demographic factors and individuals' facets of quality of life.

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[10] Iacobucci, D. (2009). Everything you always wanted to know about SEM (structural equations modeling) but were afraid to ask. *Journal of Consumer Psychology, 19*, 673-680.

SECTION 5: REPORTING

5.1   Summary of Report Production

To share survey administration updates and findings from the surveys, the Contractor committed to produce reports for CLBC and the service providers that were engaged in the 2012/13 round of the *include Me!* Initiative (see Table 5.1).

Table 5.1 – Summary of Number and Type of Reports

Report	Specifications/Description	# for 2012/13
Quarterly Status Reports		
Status Reports [For CLBC]	Summarized the progress in survey administration, deliverables achieved, and deliverables remaining (including progress and expected delivery).	Monthly from Jul 2012 to Feb 2013
Final Reports		
Service Provider Reports [For CLBC and each service provider]	Summarized the survey results in graphical and tabular format. In these reports, the service provider's results were compared to the aggregate results at the operational region and overall levels.	14*
Service Provider Storyboard [For CLBC and each service provider]	Summarized the key survey metrics in graphical and tabular format.	14*
Regional Reports [For CLBC and each service provider]	Summarized the survey results in graphical and tabular format. In these reports, the operational region's results (Vancouver Coastal, Fraser, and Both in 2012/13) were compared to the overall survey results.	3
Technical Report / Methodology Report [For CLBC]	Summarized the project background, survey administration, data handling, data analysis, report production, and lesson learned and limitations.	1
Executive Summary Report [For CLBC]	This high level report presented key findings from the different analyses and discussed best practices.	1

* Service provider reports are only generated if surveys were completed by (or on behalf of) at least 20 supported individuals.

Especially for the production of the service provider reports, the service provider storyboards, and the regional reports, the Contractor employed R Studio and WinCross to develop customized templates and partially automated processes to improve the efficiency and accuracy of report generation. Checklists and processes for manual quality assurance checks were also put in place to supplement the customization and automation efforts.

Overall, it is anticipated that developing these processes will benefit not only the current round but also reporting for subsequent implementations of the *include Me!* Initiative.

5.2   Quality Assurance Checks in Report Production

Each draft of the produced reports went through a full quality assurance check that involved multiple staff in the research team. The processes to conduct quality assurance checks are outlined here:

- *Number Checks*. Verifying that the numbers reported in each section of the report are correct and in the right location. Additional checks were done to ensure that the different scores (e.g., the original raw responses and percent positive scores) for each question were consistently represented within and across reports.
- *Graph Checks*. Verifying that the question in each graph is ordered appropriately and that the content of the graph is correct.
- *Format Checks*. Verifying that the format of the graph (e.g., the legend and colour) and table (e.g., the header and order of cells), page margins, and page break are correct.
- *Narrative Checks*. Verifying that the correct customized text has been used in the reports for the different levels of report and that each sentence is grammatically sound and free of spelling errors.

To guide the process of conducting quality assurance checks, lists that outlined the verification requirements were developed for each report type.

5.3   Presentation and Workshops

Beyond report production, the Contractor also committed to deliver presentations to the CLBC leadership and staff as well as the service providers who were engaged in the 2012/13 round of the *include Me!* Initiative. These presentations are intended to cover the following topics:

- Project and survey administration overview,

- Survey results and their implications, and
- Successes, challenges, and recommendations for quality improvement.

The presentation to the CLBC leadership and staff took place on March 14, 2013. Meanwhile, the presentation to the service providers is scheduled for the end of April. The presentation to service providers has two components: (a) group session to discuss the overall findings, and (b) individualized workshops for the Contractor to provide additional information on how to interpret and act on the survey results. Individual workshops will only be organized with service providers that have at least 20 supported individuals in their final sample.

SECTION 6: CHALLENGES AND LESSONS LEARNED

6.1 Overview of the Challenges and Lessons Learned

The challenges and lessons learned from the 2012/13 implementation of the *include Me!* Initiative were related to survey administration and data analysis. These challenges and lessons learned are especially relevant for consideration when improving the future rounds of the initiative.

6.2 Survey Administration

The importance of service provider engagement and buy-in for the *include Me!* Initiative was a key factor related to the success of survey administration. This finding highlights the importance of addressing survey administration challenges identified by service providers around collecting consent forms and scheduling interviews.

As mentioned in the survey administration section of this report, the success rate of interviewers was affected by service providers' ability to get consent from supported individuals, their proxies, and Committees to (subsequently) schedule interviews (see Section 2.5.5 Survey Participation and Response Rates). The diversity in the experiences of the 15 service providers that were engaged in the 2012/13 round of the initiative provided a good illustration of both the challenges around collecting consent forms and some best practices to adopt in the future.

6.2.1 Collecting Consent Forms

The following are keys challenges and lessons learned from the 2012/13 round, which were specifically relevant to obtaining consent to participate in the initiative:

- *Administrative constraints:* Some service providers underestimated the level of effort and resources needed to meet the administrative requirements of the initiative. For this reason, some of them opted to assign only one person to handle the coordination for completing the master list, mailing out letters, collecting forms, and scheduling interviews. Because the process proved to be tedious for only one person to handle (especially on top of their other responsibilities), it was not uncommon for the Contractor to find periods of inactivity among service providers as well as to hear grievances about a lack of support or

funding from CLBC, given the required tasks. In some instances, service providers have opted to engage part-time or temporary staff whose effectiveness was limited because they were unfamiliar with and unknown to the supported individuals. For this reason, the Contractor recognizes the need to better communicate to service providers the requirements of the initiative and the supports available to service providers from CLBC and the Contractor. Learning from the more successful experiences, service providers should be encouraged to appoint lead coordinators whose role would not be to personally complete all of the required tasks for the initiative, but to champion the initiative within their organizations and engage other staff to be involved in encouraging the supported individuals to participate.

- *Lack of awareness about the initiative among supported individuals and families:* CLBC's *include Me!* team offered to conduct information sessions about the initiative, but uptake among service providers was low. In some cases, the offer came after service providers had already begun scheduling; but in other cases, there was simply a lack of interest among individuals and families. However, it was noted in the 2012/13 round that the information sessions helped drive participation among respondents of service providers who agreed to host them and used them as a venue to collect consent forms. In the future, the value of hosting information sessions prior to scheduling needs to be further emphasized to service providers. Furthermore, based on lessons learned from successful service providers in the 2012/13 round, it could also be suggested that these information sessions serve as venues to collect consent forms, as well as to immediately conduct interviews as it was done on *include Me!* event days (see Section 2.6.1 Information Sessions with Supported Individuals and their Families). Overall, generating participant interest and buy-in as early as possible in the project cycle was proven to be crucial, especially because it was also noted in the 2012/13 round that any follow-up efforts after a self-advocate or a proxy had already refused were not effective in recovering interest.

- *Need for timely communication about the prize draw:* Although there was notable interest in the prize draw, the impact on the 2012/13 response rates were challenging to determine because of the delayed announcement—the prizes were announced on November 2012, while some service providers were scheduling interviews as early as July. Because of the potential confusion among those who had already completed the survey and those who had not yet done so, some service providers opted not to advertise the prize draw. Due to limited information on the impact of this strategy, it is recommended that a prize is again conducted, but details on the prizes should be announced earlier and be included in the invitation letters to supported individuals.

- *Lack of clarity on public guardians/trustees' mandate to consent to surveys*: Some service providers have indicated that they experienced difficulties when trying to get public guardians/trustees' consent for supported individuals to be interviewed. Limitations in their mandate were cited to be the public guardians/trustees' rationale for not signing consent forms. However, the rationale of public guardians/trustees needs to be further explored, and a mitigation strategy to help service providers obtain their consent should be developed. Perhaps putting an emphasis on encouraging public guardians/trustees' to consent for proxies to complete on behalf of supported individuals.

- *Trade-offs with the proxy requirement that preferred family members and friends over staff*: The preference for family members or friends to act as proxies rather than support staff was communicated to service providers (see Section 2.1 Overview of Survey Administration), but its implementation proved to be challenging. As it turned out, some family members and friends preferred to designate support staff as proxies because the latter see supported individuals more frequently. Furthermore, most of the supported individuals' friends also have a developmental disability, which may limit their ability to complete the survey on behalf of another person. In some cases, the person with disabilities did not have family or friends, so staff were the only ones available to act as proxies.

6.2.2   Scheduling Interviews

In terms of scheduling interviews, the key challenge and lesson learned from the 2012/13 round was the *frequency of missed appointments*. The challenge was noted to be linked to respondents' lack of familiarity with some interview locations (e.g., the service provider's head office). Moving forward, service providers should be advised to select interview locations that are frequented by their supported individuals (e.g., day program sites). This will not only reduce missed appointments but also allow service providers to easily identify replacements when missed appointments occur.

Furthermore, the experiences of participating service providers in the 2012/13 round suggest that a longer period allocated for survey administration did not always result in a higher participation rates. Knowing that there may be higher administration costs associated with prolonged implementation, this finding supports the value of encouraging service providers in future rounds to work towards organizing as many interviews as possible in a compressed period of time.

6.3   Data Analysis

The types of conclusions and inferences one can draw from population surveys are often limited by a number of factors, including logistical and methodological issues. Some of these issues could be inherent in the evaluation design and were therefore acknowledged during the survey process. Others could also arise during the reporting phase or after the results are viewed by service providers and data users.

Surveying a target population group, such as this one, often faces a number of limitations, including logistical issues (e.g., administration of survey in a uniform and standardized manner across diverse areas and populations) and privacy concerns (e.g., satisfying the consent requirement). The following section provides a summary of data-related lessons and limitations concerning the survey process.

This sub-section briefly outlines some of the data-related lessons learned.

- *Challenges with the reliability of some of the collected data:* Data analyses and interviewer feedback pointed to a need to revise the survey items to improve the psychometric properties of the *My Life Personal Outcome Index^{TM}*. The following were the challenges noted in the 2012/13 round of the initiative:

  - Concerns about the clarity of questions were raised by interviewers after they were asked by respondents to further explain questions. With CLBC inputs, the Contractor successfully developed alternative question phrasings to facilitate the interview process to obtain more reliable answers from individuals.
  - Lack of reliable data on services provided to individuals limits the ability to link *My Life* survey results with types of services (i.e., residential services, community inclusion, respite services, and support for individuals and families).
  - Consistent with other research in Alberta and Maryland, the reliability of the Index was deemed acceptable for self-report but not for proxy ratings, particularly on the emotional and physical well-being domains. Factors that may have contributed to poor reliability include differences in how self-advocates and proxies interpreted and answered the questions, reduced correlation among survey questions as a result of extremely positive responses (i.e., ceiling effect), choice of scoring, averaging, and rounding methods.
  - The presence of the ceiling effect and the resulting restricted scale responses, in particular for proxy ratings, limited the kind of analyses on proxy data that could be

performed to understand the inter-relationship among the eight quality of life domains.

- o The impact of ceiling effect and restricted variance on the inter-relationship among the items can be minimized by changing how scores are averaged between two proxy ratings for the same individual. Allowing mid-point score when averaged (i.e., 2.5 or 7.5 on a 10-point scale) or using un-biased rounding (e.g., *round half to even* rule) would disattenuate the correlations. The extra variation could permit better discrimination between individuals' level of quality of life and provide a more accurate depiction of the true relationship among items that can be used to further refine the psychometric properties of the index (analysis is currently underway to ascertain if re-scoring how proxy ratings are combined will reduce the impact of ceiling effect).

- o The factorial structure of the *My Life Personal Outcome Index*^{TM} remains to be determined and evaluated for different populations and respondent groups (self-report vs. proxy). When the survey data was used to test a model representing the *Quality of Life Framework*, results suggest that the patterns of correlations among questions are complex. This means that domain scores should be interpreted and used with caution, as item and factor analytic results suggested that some domains have complex structure and therefore may consist of measures of distinct areas of quality of life. For example, some questions (e.g., Q10 and Q48) were found to be weak indicators for their domain and other questions (e.g., Q8 and Q14) contributed to the measurement of multiple domains (i.e., cross-loadings). These results suggest that the Index may be measuring aspects of quality of life differently from what is conceptualized in the *Quality of Life Framework* - both in terms of the number of domains the tool measures as well as the type of questions contributing to their measurement.

- *Potential bias introduced by missing responses:* Not everyone who completed the survey answered all the questions. Item level non-responses were more prevalent on a few questions, namely Q38, Q40, and Q41, which were related to having control over their finances (i.e., money), which a number of respondents deemed to be not applicable in their context. Additional analysis may be carried out in the future to examine the impact of missing data on the inferences drawn from survey findings.

- *Issues related to internal validity (e.g., confounding variables):* The correlation and priority area analysis looks at the relationship among survey items, perceived sense of wellness, and aspects of quality of life at the bivariate level without controlling for all relevant

factors. The absence of a control (i.e., covariate) means the direction and magnitude of these correlations could change if the effects of context variables are adjusted. Additional analysis may be carried out to investigate the sensitivity of the correlation coefficients to these contextual factors.

6.4   Recommendation to Improve the *My Life Personal Outcome Index*[TM]

Valid and reliable conclusions can only be drawn if the tool accurately and consistently captures individuals' quality of life. Lessons learned from survey administration and in-depth analysis has identified areas where the Index can be improved that could lead to better informed evidence in enhancing self-advocates quality of life. Based on these findings, the Contractor proposes three options to improve the Index reliability. Table 6.1 provides a summary of the questions we proposed to change and our rationales for changing them.

Table 6.1 – Proposed Questions for Revisions and Their Rationales

Survey Question	Recommendation (rephrase/remove/replace)	Rationale
Q8. Is there someone you can ask for help if you need it?	Remove or Replace	• Contribute to the measurement of multiple domains (i.e., cross-loadings)
Q10. How many friends do you have that are not paid staff?	Rephrase	• Ambiguous interpretation for respondents • Significant and large difference between self-report and proxy ratings
Q14. Do you help others when they need your help?	Remove or Replace	• Contribute to the measurement of multiple domains (i.e., cross-loadings)
Q20. Do you have the chance to become what you want?	Rephrase	• Ambiguous interpretation for respondents
Q35. Do you eat foods that are good for you?	Rephrase	• Ambiguous interpretation for respondents
Q36. Do you have enough rest and relaxation in your life?	Rephrase	• Significant and large difference between self-report and proxy ratings
Q40. Do you usually have enough money to pay your bills?	Rephrase	• Ambiguous interpretation for respondents • High percentage of non-response
Q41. Do you have enough money for food each week?	Rephrase	• High percentage of non-response
Q48. Do you have your own key to your home?	Rephrase or Replace	• Significant and large difference between self-report and proxy ratings

First, ambiguous questions can be rephrased, removed, or replaced with new questions. In particular, we would propose eliminating or replacing Q8 and Q14 because they contribute to the measurement of more than one domain (i.e., cross-loadings). Other questions, such as Q10, Q20, Q35, and Q40 should be re-worded to make the questions more clear (see Appendix F for suggested questions phrasing). The implementation of standardized probes or alternative phrasing could also help respondents understand the intent of the questions and enable them to provide answer that better reflect their quality of life.

Second, changes in survey administration can improve the reliability of responses. One possibility is to develop clearer decision rules to identify when proxies are required and who is best to fill that role. For example, staff members may hold different views when ask to rate self-advocates' quality of life compared to family members and therefore may not be the best candidates when proxies are required.

Third, changes to how the index is scored can improve the sensitivity of the measurement to differences in quality of life. As mentioned in the previous section, further analysis would indicate whether allowing mid-point score when averaging two proxy responses (i.e., 2.5 or 7.5 on a 10-point scale) could permit better discrimination between individuals' level of quality of life. Furthermore, significant difference observed between self-advocates and proxies percent positive scores on specific questions (e.g., Q10, Q36, Q48) as well as between their mean domain scores on six of the eight quality of life domains (emotional well-being, physical well-being, material well-being, self-determination, social inclusion, and rights) suggest that where possible, results obtained from self-advocates and proxies should not be combined in the analysis as their ratings may not be inter-changeable.