My Life: Personal Outcomes Index™: Summary Report

Persons with Developmental Disabilities
Alberta Human Services

**Provincial Aggregate
Final Report**

October 16, 2012

Highlights of Key Findings

Introduction

- ➢ Beginning October 2011, surveying using the My Life: Personal Outcomes Index™ – a survey tool designed to measure quality of life of adults with developmental disabilities – was expanded from the Edmonton region to include all PDD regions across the province: Calgary, Central, Edmonton, Northeast, Northwest, and South.

- ➢ Surveying is intended to gather quality of life results for participating service providers and provide PDD with an overall look at the quality of life of individuals receiving funded supports, including examination of differences across groups.

Survey Administration and Reliability

- ➢ Surveys were completed by (or by proxies on behalf of) a total of 671 individuals across 13 participating service providers[1] in all PDD regions across the province as well as individuals supported through Family Managed Supports (FMS). The overall survey response rate was 66%.

- ➢ Surveys for 196 individuals were completed by proxies (29% of the total sample). This proxy rate represents a continued decrease from previous iterations of the survey conducted in the Edmonton region (from 39% in the pilot, 38% in Phase II validation administration, and 35% in the 2010-11 survey administration).The proportion of individuals represented by proxies ranged from 0% to 75% across participating service providers.

- ➢ Analysis demonstrates that the My Life: Personal Outcomes Index™ is reliable for the population of individuals receiving supports through the PDD Program, producing reliability scores in the acceptable or good ranges for all domains.

- ➢ Overall, analysis indicates that the My Life instrument is reliable for the two primary respondent groups (self-report respondents and individuals represented by proxies), although reliability scores obtained for self-report respondents tend to be more consistent with aggregate results when compared to those obtained for individuals represented by proxies.

Quality of Life Results

- ➢ As measured on a scale from 0 to 10, where 0 represents low quality of life and 10 represents high quality of life, respondents' average domain scores were highest in the three domains related to well-being: emotional well-being (8.12), material well-being (7.70), and physical well-being (7.63). The lowest domain score was observed in social inclusion (5.67).

- ➢ When comparing <u>service provider types</u> to aggregate domain scores:
    - o No statistically significant differences between large service provider and aggregate results were observed.

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[1] Small agency aggregate results are not available in this report due to a very small sample size as of March 31, 2012.

- The average score for individuals supported through FMS was higher than the aggregate score in the areas of emotional, physical, and material well-being.

➤ When comparing average domain scores by respondent <u>service code</u> (home living supports (code 1000), employment supports (2000), and community access supports (code 3000)) to the aggregate, on average those receiving employment supports scored higher than the aggregate in the domains of self-determination and rights and lower than the aggregate in the domain of emotional well-being.

➤ When comparing average domain scores by <u>type of area of residence</u> (large urban, small urban, and rural), the following trends were observed:

- On average respondents residing in large urban areas scored higher than the aggregate in the domains of emotional and physical well-being.

- Respondents residing in small urban areas tended to score lower than the aggregate in the domain of physical well-being.

➤ When comparing the domain scores of <u>individual service providers</u> with the aggregate domain scores:

- Statistically significant differences were the most common in the domains of emotional and physical well-being.

- Where significant differences between a provider's domain scores and the aggregate scores were observed, these differences tended to be in the same direction (e.g., all differences for that provider were either above or below the aggregate), with only one exception.

➤ When average domain scores for respondents supported by large service providers were compared with those for individuals supported through FMS, the scores for FMS were significantly higher (p ≤ .05) in the three domains related to well-being (emotional, physical, and material well-being).

➤ In the investigation of relationships between quality of life scores and respondent demographic characteristics some significant trends emerged, the most notable related to transportation. Specifically, better mobility within one's community was related to higher quality of life in all domains.

➤ Statistical analyses indicate that respondent type (self-report or proxy) has an impact on average domain scores in at least seven of the eight quality of life domains. It is currently unclear whether differences are due to real differences in the individuals represented or due to a respondent effect (i.e., a result of whom is reporting for an individual). Nonetheless, when controlling for other demographic variables:

- Individuals represented by proxy respondents were more likely than self-report respondents to have higher average domain scores for the three domains related to well-being (emotional, physical, and material).

- Self-report respondents were more likely than individuals represented by proxies to have higher average domain scores in the areas of self-determination, interpersonal relations, social inclusion, and rights.

Moving Forward

➤ <u>Need for and selection of proxies.</u> It is recommended that the process used to determine need for and selection of proxies be reviewed. Given the evidence for

significant differences in response between self-respondents and proxies, the minimization of proxy rates (to the degree possible) is desirable.

➢ Revisions/improvements to surveying processes. Various other revisions/improvements to surveying processes are suggested, including: (a) minimizing missing data (i.e., unanswered survey questions), (b) reviewing and streamlining the process for FMS surveying prior to expanding surveying of this group from the Edmonton region to all other PDD regions, (c) reviewing the electronic data collection pilot using iPad tablets prior to broader roll-out, and (d) once the survey sample includes adequate representation from all regions, examining testing processes/results to determine the state of affairs at that time.

➢ Information on support levels and/or level/nature of disability. Consideration of the collection of information on required support levels and/or level/nature of disability of survey respondents is recommended as this may be an important variable for examining relationships between demographic characteristics and quality of life scores.

➢ Review of survey questionnaire. Although data analysis results have shown all eight domains included in the current questionnaire to produce reliability scores at the acceptable level or higher, it is recommended that the survey questionnaire be reviewed for possible revisions as part of a continuous quality improvement process.

➢ Review of sampling plan. A review of the sampling plan for provincial surveying is recommended to ensure the plan will adequately meet the information needs of the PDD Program.

➢ Consideration of most useful information required. Current reporting processes provide a wealth of information generated through statistical analyses that is useful to senior planners, agencies, and clients. It is recommended that the most useful pieces of information required for moving forward be considered in order to direct future analyses accordingly.

Introduction and Approach

Operating within the Ministry of Alberta Human Services, the Persons with Developmental Disabilities (PDD) Program works with others to support adults with developmental disabilities to be included in community life and to be as independent as possible.[2] PDD operates in accordance with the *Government Accountability Act* and, as such, is accountable and obligated to demonstrate and be responsible for performance achieved in light of previously agreed upon expectations. These expectations are set out in the Business Plan submitted by PDD to the Minister of Human Services as expected outcomes. An expected outcome consists of clear communication of what individuals and/or groups hope to achieve. They are often expressed as goals and/or objectives. Performance measurement is a method for assessing progress toward stated goals. PDD is focused on improving the quality of life (QoL) of individuals with developmental disabilities.

Beginning October 2011, surveying using the My Life: Personal Outcomes Index™ – a survey tool designed to measure quality of life of adults with developmental disabilities – was expanded from the Edmonton region to include all other PDD regions across the province: Calgary, Central, Edmonton, Northeast, Northwest, and South. The current report provides a summary of the results of the 2011-12 provincial surveying.

What is Quality of Life?

Quality of life (QoL) is a complex, multidimensional concept. Its origins are in the very beginnings of western philosophy, and it continues to be a popular notion in modern health and social science literature. There are many definitions of quality of life in the academic literature. However, two major perspectives on indicators of QoL are offered:

1) Quality of life describes the environment where people live. QoL is indicated through statistics such as average income, air quality, and crime rates. This understanding of QoL is closely related to the concept of *standard of living*.

2) Quality of life describes how people experience where and how they live. QoL is indicated through statements and statistics that capture perception such as: How would you rate your personal health? How safe do you feel walking in your neighbourhood? Do you feel you have enough resources to meet your basic needs? Do you trust your neighbours? Do you have enough friends? Do you experience enough personal privacy?

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[2] Source: http://www.seniors.alberta.ca/pdd/.

The approach to quality of life adopted by the PDD Program focuses on measuring well-being, rather than standard of living, of individuals receiving services and supports. To do so, a theoretical framework consisting of eight domains of quality of life, as put forth in the quality of life literature, was adopted and serves as the basis for the My Life: Personal Outcomes Index™.[3] The eight domains include:

- ✓ Emotional well-being
- ✓ Interpersonal relations
- ✓ Material well-being
- ✓ Personal development
- ✓ Physical well-being
- ✓ Self-determination
- ✓ Social inclusion
- ✓ Rights

Based on the theoretical framework adopted, each of the eight domains is connected to one of three overarching factors:[4]

- ➢ Independence (personal development, self-determination)
- ➢ Social participation (interpersonal relations, social inclusion, rights)
- ➢ Well-being (emotional well-being, physical well-being, material well-being)

Data Collection and Analysis

Survey Administration

The My Life survey was developed to be peer-administered. Therefore adults with developmental disabilities are hired and trained as surveyors. The survey is then administered by peer teams consisting of one interviewer (individual who read the survey questions) and one recorder (individual who recorded the respondent's answers).[5]

Surveys were administered at a time and place convenient for the respondent. Across the 890 surveys administered (494 self-report and 396 proxies), just over two thirds (68%) were administered at a centralized location, such as an office or day program, 15% were administered at the individual's home, 5% were administered by telephone, 2% were administered in an "other" location, and data were missing for 10% of surveys (further detail is provided on page 27). In all cases attempts were made to administer the survey in a private location free from the presence of other individuals or staff, unless otherwise

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[3] See Schalock, R.L., Gardner, J.F. & Bradley, V.J. (2007) *Quality of Life for People with Intellectual and Other Developmental Disabilities: Applications Across Individuals, Organizations, Communities, and Systems.* American Association on Intellectual and Developmental Disabilities, Washington, DC.

[4] Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008). The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning, 31,* 181-190.

[5] Survey responses were primarily recorded with a pen and paper. However, during 2011-12 the use of iPads for electronic data collection was investigated for possible broader roll-out in the future.

requested by the respondent. Securing a private location was most challenging in the case of group homes.

Sample Selection and Response Rate

Individuals across the province were invited to participate in the 2011-12 administration of the My Life survey through random sampling procedures. The survey sample was selected from 14 service providers falling into three categories: small providers (serving under 10 individuals), large providers (serving 10 or more individuals), and those providing Family Managed Supports (FMS). Table 1 provides further details on the participating agencies in each PDD region, including the number of individuals surveyed from each service provider and the corresponding response rates.

Table 1. Proportion of individuals served by each service provider and survey sample sizes

Service Provider	PDD Region	Total number of eligible[6] individuals served	Proportion of total population	Sample size	Response rate
Large Providers					
Adaptabilities	Edmonton	15	1.3%	10	66.7%
Cosmos	Central	87	7.8%	73	83.9%
Excel	Edmonton	149	13.3%	64	43.0%
LCLA	Edmonton	15	1.3%	12	80.0%
MirkaCare	Edmonton	37	3.3%	34	91.9%
Newell	South	20	1.8%	15	75.0%
PClass	Central	120	10.7%	92	77.3%
Rehoboth-Calgary	Calgary	38	3.4%	32	84.2%
Rehoboth-Grande Prairie	Northwest	25	2.2%	19	76.0%
Rehoboth-Lethbridge	South	69	6.1%	51	73.9%
Robin Hood	Edmonton	268	23.9%	139	63.5%
VALID	Northeast	41	3.6%	38	92.7%
Subtotal: Large providers	*n/a*	*884*	*78.7%*	*579*	*n/a*
Small Providers					
K-Bri	Edmonton	4	0.4%	4	100.0%
Family Managed Supports					
Family Managed Supports	Edmonton	234	20.9%	114[7]	62.0%
Total	*n/a*	*1122*	*100.0%*	*671**	*65.7%*

* NOTE: Some individuals were included in the random sample for more than one participating service provider. Thus, the total number of individuals represented is *less* than the sum of the sample size for each service provider, as each individual is counted in the aggregate sample only once.

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[6] Some individuals were considered to be ineligible for the My Life survey sample including: (a) those individuals who participated (or were asked to participate) in the My Life survey in the last 12 months and (b) individuals who had completed the Supports Intensity Scale (SIS) within the past six months.
[7] Note: The 114 individuals receiving supports through Family Managed Services (FMS) included in the survey sample included 44 individuals surveyed during 2011-12 combined with an additional 70 individuals previously surveyed in 2010-11.

Based on the total number of individuals represented in the survey sample (n=671) and the total eligible population size (N=1122), the margin of error for the aggregate sample at a 95% level of confidence is ±2.4%. That is, we are 95% confident that the results reported here for the <u>aggregate</u> sample are accurate ±2.4%. Note that this margin of error applies <u>only</u> to percentages. See Appendix A for the domain score confidence intervals.)

<u>Use of Proxies</u>

In some instances an individual was willing to participate in the My Life survey but was unable to complete it on his/her own due either to an inability to understand the questions appropriately or to communicate his/her responses. Proxy need was determined either by the key contact from the service provider or the individual's guardian (if one was in place). In such instances the individual's guardian, or in some cases a representative from the service provider if the guardian was unsure, was asked to provide the names of two people who had: (a) known the individual well for at least the past three months, (b) an understanding of the individual's current life experiences and circumstances, and (c) directly observed the individual in one or more environments within the past three months or longer. These people were then contacted and asked to complete the My Life survey <u>on behalf</u> of the individual (as proxies for that individual). The responses of the two proxies were then averaged for all survey questions.[8] Proxy interviews were conducted either in person by QoL surveyor teams or over the telephone by team leaders or the project data collection manager.

Surveys for 196 individuals were completed by proxies (29% of the total sample). Note that this proxy rate represents a continued decline from earlier iterations of the survey conducted in the Edmonton region (from 39% in the pilot, 38% in Phase II validation administration, and 35% in the 2010-11 survey administration). The proportion of individuals represented by proxy respondents for each service provider is outlined in Table 2.

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[8] In 10 instances only one proxy interview could be completed. Data from these interviews were still included in all analyses.

Table 2. Proportion of surveys completed by proxies by service provider[†]

Service Provider	Number of respondents	Number of individuals self-reporting	Number of individuals represented by proxy	Proportion of individuals represented by proxy
Large Providers				
Adaptabilities	10	4	6	60.0%
Cosmos	73	67	6	8.2%
Excel	64	51	13	20.3%
LCLA	12	12	0	0.0%
MirkaCare	34	16	18	52.9%
Newell	15	13	2	13.3%
PClass	92	40	52	56.5%
Rehoboth-Calgary	32	22	10	31.3%
Rehoboth-Grande Prairie	19	9	10	52.6%
Rehoboth-Lethbridge	51	49	2	3.9%
Robin Hood	139	124	15	10.8%
VALID	38	31	7	18.4%
Small Providers				
K-Bri	4	1	3	75.0%
Family Managed Supports				
Family Managed Supports	114	55	59	51.8%
*Total**	*671*	*475*	*196*	*29.2%*

* NOTE: Some individuals were included in the random sample for more than one participating service provider. Thus, the total number of individuals represented is *less* than the sum of the sample size for each service provider, as each individual is counted in the aggregate sample only once.
[†]The numbers provided in this table are unweighted.[9]

Data Analysis

Survey data were entered in a database and subsequently analyzed. There were five key components to the analysis, the results of which are reported in this document:

1. To examine reliability of each of the QoL indices (i.e., eight domains) measured through the My Life Index, the internal consistency reliability of the items included within each domain was tested (by calculating Cronbach's Alpha).[10]

2. An overall average domain score was calculated for each of the eight domains. Average domain scores were calculated for the aggregate sample and for the following sub-groups:

   a. Individual service providers
   b. Aggregate of large service providers
   c. Respondent type sub-samples (self-report and proxy)

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[9] That is, the numbers provided represent the actual number of surveys completed for each service provider.
[10] Internal consistency reliability was also investigated separately for self-report and proxy respondents.

d. Aggregate sample by primary service code (e.g., 1000, 2000, or 3000 level services) and service sub-code (1010, 1020, 1030, 1040, 1050, 2010, and 2020)

e. Aggregate sample by type of area of residence (urban, small urban, rural)

f. Large service provider aggregate by service code

3. Average domain scores for sub-groups (a) through (f) (with the exception of (c) – self-report versus proxy) were compared with average domain scores for the aggregate sample. Statistically significant differences ($p \leq .05$) between each service provider's domain scores and the aggregate scores were calculated using independent samples two-tailed t-tests.[11]

4. Average domain scores by respondent type (self-report or proxy) were compared. Statistically significant differences ($p \leq .05$) between domain scores by respondent type were calculated using independent samples two-tailed t-tests.

5. Ordinary Least Squares multiple regression was used to examine relationships between quality of life scores and demographic variables as well as the impact of respondent type (self-report or proxy). Statistical significance was considered at the $p \leq .05$ level. These analyses enabled examination of which demographic and respondent type variables were significantly related to quality of life scores.

Weighting factors to account for service provider proportion and duplicate records (i.e., respondents who were surveyed through more than one provider) were applied for all analyses other than internal consistency reliability and the calculation and comparison of average service provider domain scores (for individual service providers and FMS results). Application of weighting factors ensured the proportion of individuals served by each service provider represented in the sample corresponded with population proportions as indicated in Table 1 and that each respondent was counted only once in the aggregate sample. Internal consistency reliability analyses were weighted by the duplicate record weighting factor only.

Presentation of Results

Results are presented in seven parts:

1. Aggregate results of overall quality of life scores
2. Comparison of aggregate and sub-group quality of life results
3. Comparison of large service provider aggregate and subgroup quality of life results
4. Relationships between respondent demographic characteristics and quality of life scores
5. Impact of proxy reporting
6. Survey reliability of quality of life domains (internal consistency reliability results)
7. Discussion of results

Note about statistically significant differences: Throughout this report the concept of "statistical significance" is referred to, particularly when comparing the results for two groups. When a difference between groups is statistically significant, it is unlikely to have occurred by chance. The possibility that the difference could have occurred by chance is referred to as the level of probability, typically denoted by the letter "p" (referred to as the p-

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[11] A difference is considered statistically significant if it is unlikely to have occurred by chance.

value). Probability in this report is considered at the level of 5% or less (≤ .05), meaning that when a result is indicated as being statistically significant there is no more than a 5% probability that it occurred due to chance alone (hence the notation "p ≤ .05"). It is important to note that the determination of whether a difference is statistically significant takes into account not only the scores observed but also the sample size and the standard deviation (the spread of the scores). Thus, even though the difference between two scores may seem to be large, in some cases this difference may not be statistically significant (unlikely to have occurred by chance) due to other properties of the sample.

Aggregate Quality of Life Results

Domain scores were calculated for all respondents on a scale from 0 to 10, where 0 represents low quality of life and 10 represents high quality of life. Overall domain averages were then calculated across all respondents (n=676[12]) and results are presented in Figure 1.[13] As the figure demonstrates, the lowest average score across all domains was 5.67 for social inclusion, followed by 6.24 for self-determination. The highest average score was observed for emotional well-being at 8.12, followed by material well-being (7.70) and physical well-being (7.63).

Figure 1. Average quality of life domain scores across all respondents (n=676)
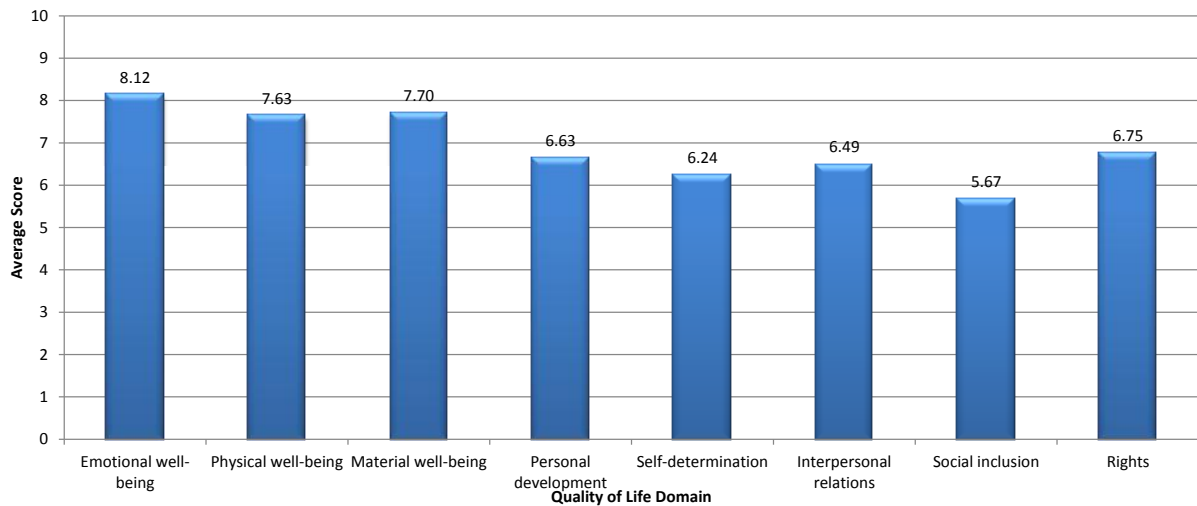
Confidence intervals for each mean domain score are presented in Appendix A.

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[12] Weighted figure.

[13] In the case that a respondent answered less than two thirds of items within a domain, an overall domain score was not calculated for that individual.

Comparison of Aggregate and Sub-group Quality of Life Results

Quality of life results for the aggregate sample were compared with various subgroups, including:[14]

- Type of service provider (large providers and individuals supported through FMS)[15]
- Service code subgroups (respondents receiving service codes falling into three primary categories)
- Subgroups based on type of area of residence (urban, small urban, or rural)
- Individual service providers participating in the provincial surveying

Comparison by Type of Service Provider

Average domain scores for the aggregate sample, large service providers, and individuals supported through FMS are presented in Figure 2 (next page). Where the difference between the aggregate score and a subgroup score is statistically significant ($p ≤ .05$), the subgroup's score is marked with an asterisk (*) and highlighted in pink.

As illustrated in the figure, there were no domains in which the difference between the aggregate score and the large service provider aggregate score was statistically significant. However, in comparing the aggregate to FMS scores, three statistically significant differences were observed (in all three cases the FMS scores were higher):

- **Emotional well-being** – The average score for individuals supported through <u>FMS</u> (8.89) was <u>higher</u> than the aggregate score (8.12).

- **Physical well-being** – The average score for individuals supported through <u>FMS</u> (8.23) was <u>higher</u> than the aggregate score (7.63).

- **Material well-being** – The average score for individuals supported through <u>FMS</u> (8.20) was <u>higher</u> than the aggregate score (7.70).
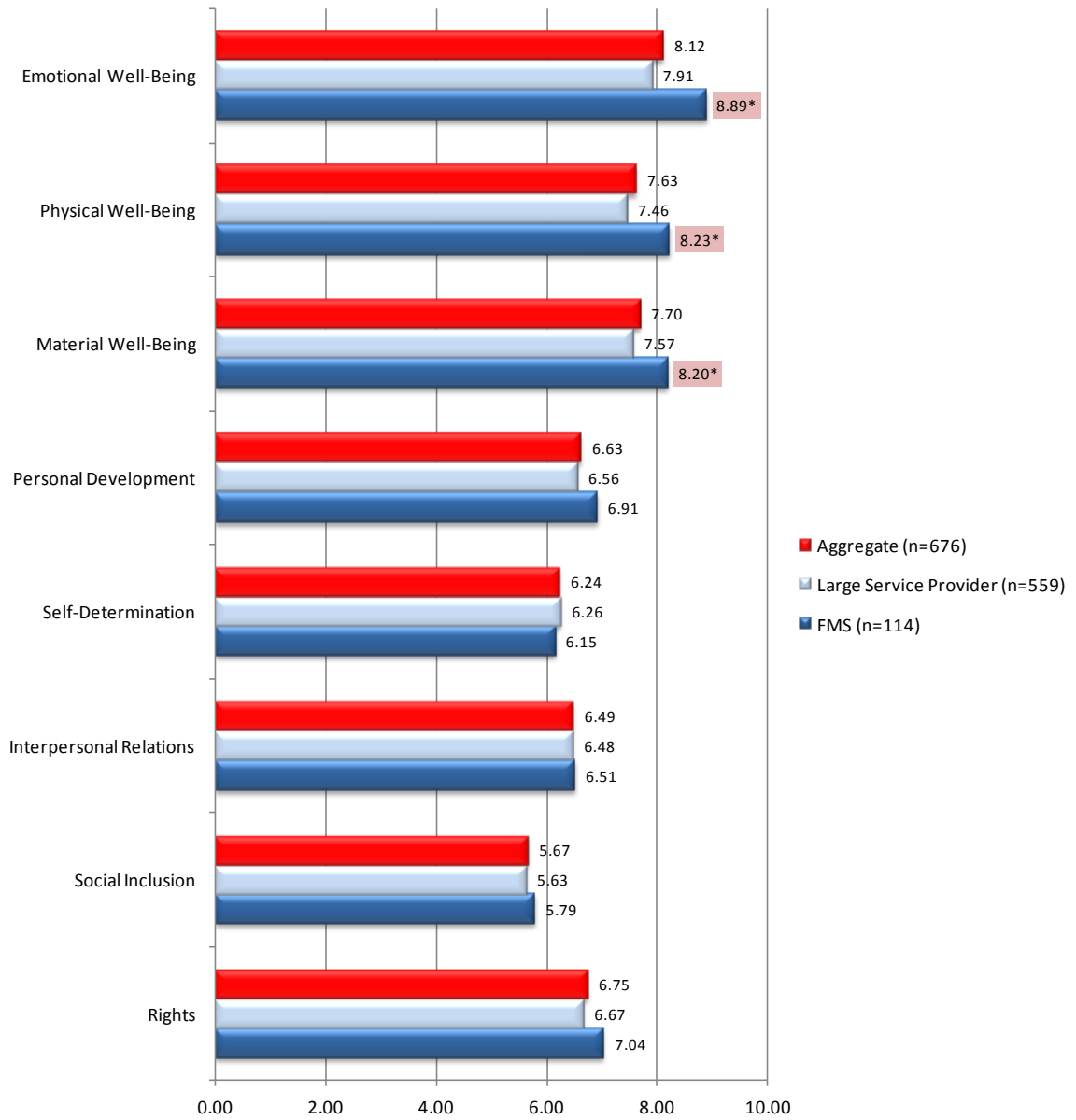
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[14] The figures in this section represent weighted figures.
[15] For confidentiality purposes, the small service provider results (four respondents) were not compared.

Figure 2. Comparison of aggregate quality of life results by type of provider

Emotional Well-Being
- 8.12 (Aggregate)
- 7.91 (Large Service Provider)
- 8.89* (FMS)

Physical Well-Being
- 7.63 (Aggregate)
- 7.46 (Large Service Provider)
- 8.23* (FMS)

Material Well-Being
- 7.70 (Aggregate)
- 7.57 (Large Service Provider)
- 8.20* (FMS)

Personal Development
- 6.63 (Aggregate)
- 6.56 (Large Service Provider)
- 6.91 (FMS)

Self-Determination
- 6.24 (Aggregate)
- 6.26 (Large Service Provider)
- 6.15 (FMS)

Interpersonal Relations
- 6.49 (Aggregate)
- 6.48 (Large Service Provider)
- 6.51 (FMS)

Social Inclusion
- 5.67 (Aggregate)
- 5.63 (Large Service Provider)
- 5.79 (FMS)

Rights
- 6.75 (Aggregate)
- 6.67 (Large Service Provider)
- 7.04 (FMS)

Legend:
- Aggregate (n=676)
- Large Service Provider (n=559)
- FMS (n=114)

* Difference between aggregate and sub-group is statistically significant ($p \leq .05$).

Comparisons within the Aggregate Sample by Service Code

Average domain scores for the aggregate sample were compared with average domain scores for respondents receiving supports falling under particular service codes. Service codes were classified into three primary categories and seven sub-categories[16]:

1. Home living supports (code 1000)

    - 1010: Overnight staffed residence
    - 1020: Support homes
    - 1030: Supported independent living
    - 1040: In-home respite
    - 1050: Out of home respite

2. Employment supports (code 2000)

    - 2010: Employment prep
    - 2020: Employment placement

3. Community access supports (code 3000)

    - 3000: Community access

Results of Comparisons by Primary Service Code

Results indicate that there were three domains where statistically significant differences between aggregate and primary service code subgroup scores were observed (code 2000, employment supports, in all three cases):

- **Emotional well-being** – The average domain score for respondents receiving supports in the service code 2000 category (7.73) was lower than the aggregate (8.12).

- **Self-determination** – The average domain score for respondents receiving supports in the service code 2000 category (6.80) was higher than the aggregate (6.24).

- **Rights** – The average domain score for respondents receiving supports in the service code 2000 category (7.38) was higher than the aggregate (6.75).

Results of Comparisons by Service Sub-codes

Results indicate that a statistically significant difference ($p \leq .05$) between at least one service sub-code and the aggregate domain score was observed for five out of the eight domains (excluding material well-being, personal development, and social inclusion). The following trends were observed:

- Where statistically significant differences were observed, in all but two instances the average service sub-code domain score was higher than the average aggregate domain score.

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[16] Note: The support code 3000 (community access supports) is not included in the sub-code comparison as there are no sub-codes under this category. The service code 3000 is considered a primary service code.

- Significantly <u>higher</u> domain scores in the areas of self-determination and rights were observed for individuals receiving supports in both the <u>1030</u> (supported independent living) and <u>2010</u> (employment prep) categories when compared to the aggregate sample. In addition, when compared to the aggregate, individuals receiving supports in the <u>2010</u> category obtained a <u>higher</u> average domain score in the area of interpersonal relations.

- Compared to the aggregate sample, individuals receiving supports in the <u>1040</u> (in-home respite) category obtained <u>higher</u> average scores in the areas of emotional and physical well-being.

- Compared to the aggregate sample, individuals receiving supports in the <u>2020</u> (employment placement) category obtained a <u>higher</u> score in the domain of rights and a <u>lower</u> score in the domain of emotional well-being.

- A significantly <u>lower</u> domain score was observed for individuals in the <u>1010</u> (overnight staffed residence) category as compared to the aggregate domain score in the area of rights.

- No significant differences from the aggregate scores were observed for individuals receiving supports in the <u>1020</u> (support homes) or <u>1050</u> (out of home respite) categories.

Comparisons within the Aggregate Sample by Type of Area of Residence

Average domain scores for the aggregate sample were compared with average domain scores by type of area of residence of respondents. Area of residence was classified into one of three categories:

1. Large urban (cities with a population greater than 100,000 – Edmonton and Calgary)
2. Small urban (towns/cities/urban service areas with a population greater than 20,000 and less than 100,000)
3. Rural (all areas of the province not categorized as large urban or small urban centres)

Type of area of residence was assigned based on the respondent's postal code.

Three statistically significant differences between groups were observed in two domain areas:

- **Emotional well-being** – The average score for respondents residing in a <u>large urban</u> area (8.47) was <u>higher</u> than the aggregate score (8.12).

- **Physical well-being** – The average score for respondents residing in a <u>large urban</u> area (7.99) was <u>higher</u> than the aggregate score (7.63) while the average score for respondents residing in a <u>small urban</u> area (7.34) was <u>lower</u> than the aggregate score.

Comparison of Large Service Provider and Subgroup Quality of Life Results

Average domain scores for the 12 large service providers included in the survey sample (Adaptabilities, Cosmos, Excel, LCLA, MirkaCare, Newell, PClass, Rehoboth-Calgary, Rehoboth-Grande Prairie, Rehoboth-Lethbridge, Robin Hood, and VALID) were compared with two subgroups, including subgroups by service code and individual service provider scores, as well as with individuals supported through Family Managed Supports.

Note: Aggregate data for large service providers were weighted by a large service provider weighting factor to ensure the proportion of individuals served by each large provider included in the sample corresponded with population proportions.

Comparison within the Large Service Provider Sample by Service Code

Average domain scores for the large service provider sample were compared with average domain scores for respondents, within the large provider samples, receiving supports falling under particular service codes. Service codes were classified into three categories.
1. Code 1000 supports – Home living supports (includes codes 1010, 1020, 1030, 1040, and 1050)

2. Code 2000 supports – Employment supports (includes codes 2010 and 2020)

3. Code 3000 supports – Community access supports (includes code 3000)

There were two domains where statistically significant differences (p ≤ .05) between large service provider aggregate and service code subgroup (the 2000 category, employment supports, in both cases) scores were observed:

- **Self-determination** – The average domain score for respondents receiving supports in the service code 2000 category (6.77) was higher than the large service provider aggregate (6.26).

- **Rights** – The average domain score for respondents receiving supports in the service code 2000 category (7.38) was higher than the large service provider aggregate (6.67).

Comparison between Large Service Provider Aggregate and Family Managed Supports Quality of Life Results

Average domain scores for respondents supported by large service providers were compared with those for individuals supported through Family Managed Supports.

Results are presented in Figure 3, which illustrates that significant differences were observed in the three domains related to well-being (emotional, physical, and material). In all three domains the score for individuals supported through FMS was higher than the score for individuals supported by a large service provider.

Figure 3. Comparison of large service provider and FMS quality of life results
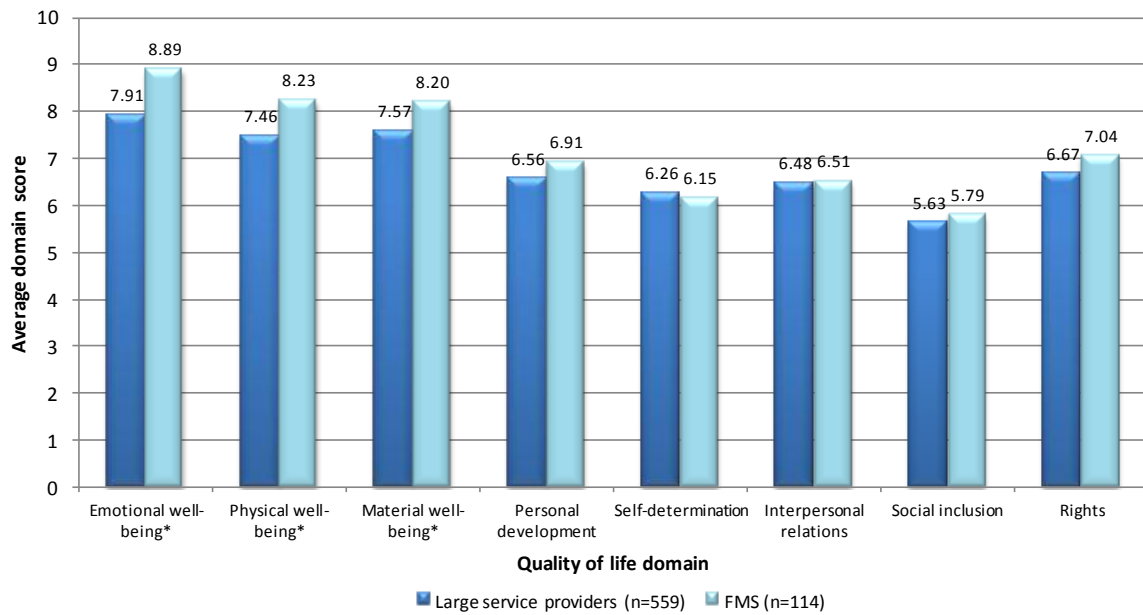
* Difference between groups is statistically significant (p ≤.05).

Confidence intervals for each mean domain score are presented in Appendix A.

Relationships between Demographic Characteristics and Quality of Life Scores

Multiple regression analyses were used to determine which demographic variables had a significant relationship ($p \leq .05$) with quality of life scores for each domain. The overall domain score served as the dependent variable, while the independent variables included in the regression models were as follows:

- Respondent age
- Respondent gender
- Guardianship (whether respondent was an independent adult or had a guardian through the Office of the Public Guardian, using individuals with private guardians as the reference/comparison category)
- Total direct client costs[17]
- Employment status (whether respondent had paid employment or not)
- Transportation (survey question: Are you able to get around your community easily?)

Note: Regression analyses were used to determine where significant relationships exist between demographic variables and quality of life scores, while controlling for other demographic variables. These relationships do not necessarily imply causation (e.g., having better access to transportation does not necessarily cause quality of life scores to increase). Thus, results should be interpreted as exploring relationships rather than as exploring causation.

As Table 3 illustrates, all seven demographic variables investigated were significantly associated with at least one quality of life domain.

Table 3. Summary of significant relationships* of demographic variables with QoL domains

	Emotional well-being	Physical well-being	Material well-being	Personal development	Self-determination	Interpersonal relations	Social inclusion	Rights	*Total # of significant relationships*
Age				✓					*1*
Gender					✓				*1*
Independent adult			✓		✓		✓	✓	*4*
Office of the Public Guardian	✓								*1*
Total direct client cost					✓			✓	*2*
Employed	✓	✓		✓	✓	✓	✓	✓	*7*
Able to get around community easily	✓	✓	✓	✓	✓	✓	✓	✓	*8*
Adjusted R^2 score[†]	*.14*	*.13*	*.13*	*.14*	*.20*	*.08*	*.15*	*.23*	*-*

* $p \leq .05$
[†] Proportion of the total variance explained by the model, adjusted for the number of regressors.

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[17] The "total direct client cost" variable includes those costs accrued by the primary service provider under which the respondent was sampled as well as by any other service providers providing supports to the individual.

Specifically, the following relationships were observed:

- **Respondent age:** As respondent age increased, respondents were more likely to have <u>lower</u> overall scores in the domain of personal development.

- **Respondent gender:** Males were more likely than females to have <u>lower</u> overall scores in the self-determination domain.

- **Independent adult status:** Independent adults were more likely than those with a private guardian to have <u>lower</u> overall scores in the domains of material well-being and social inclusion but <u>higher</u> overall scores in the areas of self-determination and rights.

- **Office of the Public Guardian:** Individuals represented by the OPG were more likely than those with a private guardian to have <u>lower</u> overall scores in the domain of emotional well-being.

- **Total direct costs:** As total direct costs increased, respondents were more likely to have <u>lower</u> overall scores in the domains of self-determination and rights.

- **Employment status:** Having paid employment was related to <u>lower</u> quality of life scores in the domains of emotional and physical well-being but <u>higher</u> quality of life scores in the domains of personal development, self-determination, interpersonal relations, social inclusion, and rights.

- **Ability to get around community easily:** As their ease of getting around the community increased, respondents became more likely to have <u>higher</u> overall scores in all eight domains.

In conclusion, among the eight quality of life domains:

- ✓ Being older is negatively related to personal development.
- ✓ Being male is negatively related to self-determination.
- ✓ Being an independent adult (compared to having a private guardian) is negatively related to material well-being and social inclusion but positively related to self-determination and rights.
- ✓ Representation through the OPG (as opposed to having a private guardian) is negatively related to emotional well-being.
- ✓ Being associated with higher direct costs is negatively related to self-determination and rights.
- ✓ Having paid employment is related to higher quality of life in five domains (personal development, self-determination, interpersonal relations, social inclusion, and rights) but lower quality of life in two (emotional and physical well-being).
- ✓ Better mobility within one's community is related to higher quality of life in all domains.

Impact of Proxy Reporting

To assess the degree to which the use of proxies has an impact on average domain scores the following analyses were conducted:

- T-tests for independent samples were used to determine whether differences between average domain scores for self-report respondents and individuals represented by proxies were statistically significant (p ≤ .05).

- Regression analyses were conducted to explore the effect of having proxies complete the survey on an individual's behalf while controlling for other demographic variables.

Significant Differences between Average Domain Scores by Respondent Type

Statistical analyses were used to determine whether there were significant differences in average domain scores for self-report respondents compared to individuals represented by proxy respondents. As illustrated in Figure 4, differences between average domain scores were statistically significant (p ≤ .05) for seven out of the eight domains (all except personal development).

Proxies tended to produce higher scores for the three domains related to well-being (emotional, physical, and material well-being), while self-report respondents tended to produce higher scores in the domains of self-determination, interpersonal relations, social inclusion, and rights.

Figure 4. Average domain scores by respondent type
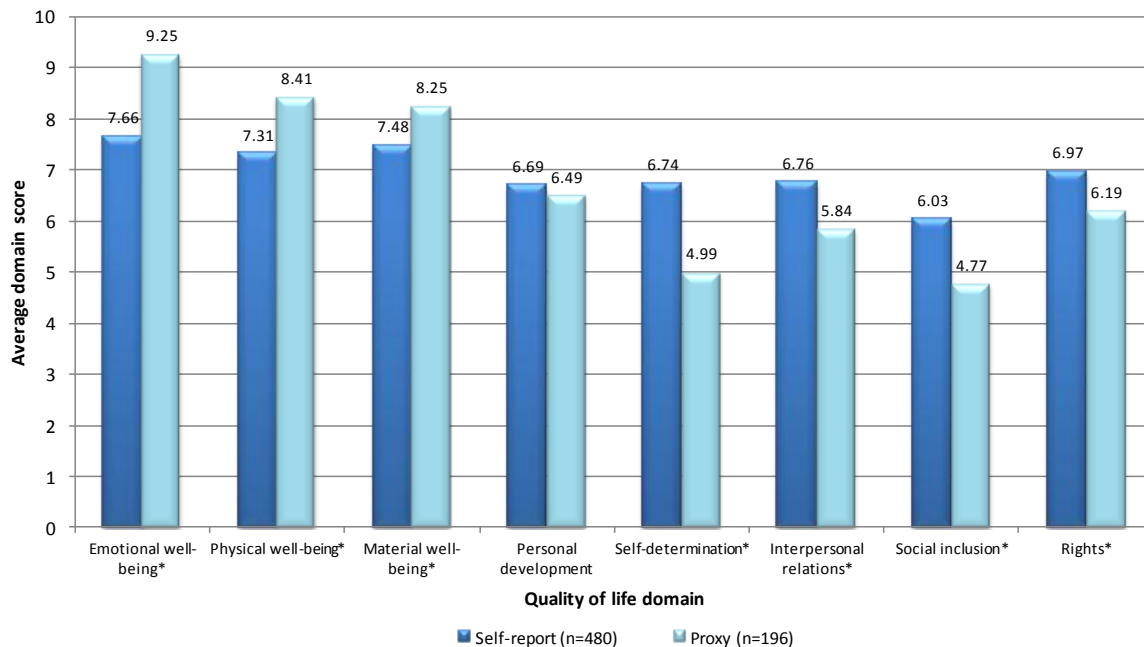
* Difference between groups is statistically significant (p ≤.05).

Relationships between Domain Scores and Response Type (multiple regression results)

It is difficult to determine whether the observed differences between average domain scores are due to: (a) different characteristics of the individual (i.e., real individual differences) or (b) differences in respondent type (e.g., a respondent effect). In an attempt to account for differences in individual characteristics, respondent type (self-report or proxy) was added to the regression equation for each domain.[18] Note, however, that these analyses are <u>limited</u> by the fact that there are no data directly available for level or type of disability, which should be directly related to use of proxy respondents. Rather, it was hoped that total direct client costs would provide some *indication* of level of disability, although it is recognized that it is certainly an imperfect indicator.

Results suggest that whether the survey was completed via self-report or proxy was significantly related (p ≤ .05) to average domain scores for seven of the eight domains (all but personal development). Specific findings suggest that, when controlling for other demographic variables:

- Individuals represented by proxy respondents were more likely than self-report respondents to have <u>higher</u> average domain scores for the three domains related to well-being (emotional, physical, and material).

- Self-report respondents were more likely than individuals represented by proxies to have <u>higher</u> average domain scores for the domains self-determination, interpersonal relations, social inclusion, and rights.

Conclusion: Impact of Proxy Reporting

Results suggest that respondent type (self-report or proxy) does have an impact on average domain score in at least seven of the eight quality of life domains (all except personal development). In domains related to well-being proxies tend to produce higher domain scores while higher scores were observed for self-report respondents in the domains of self-determination, interpersonal relations, social inclusion, and rights. At this point it is unclear whether differences are due to real differences in the individuals represented or due to a respondent effect (i.e., a result of whom is reporting for an individual). Further data on level or nature of disability may help to untangle this question, although it is likely that a targeted research study would be necessary to more fully understand the reason for the differences in domain scores by respondent type.

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[18] See section: "Relationships between Demographic Characteristics and Quality of Life Scores" for further discussion of the regression equations.

Internal Consistency Reliability

Testing the psychometrics of a survey instrument essentially enables one to determine how "good" a survey is – that is, whether the survey will produce data that are reliable (can be reproduced and are stable) and valid (measure what the instrument intends to measure).[19] The items that comprised each domain (n=6) were subjected to internal consistency reliability analysis (calculating Cronbach's Alpha) to test the degree to which survey items in a given domain measured the same construct.

Index reliability scores can be interpreted as follows:

- less than 0.60 = needs work
- 0.60 – 0.69   = acceptable
- 0.70 – 0.79   = good
- 0.80 or higher = very good

Of the eight indices subjected to internal consistency reliability analysis:

- Three produced good reliability scores (emotional well-being, personal development, self-determination); and

- Five produced acceptable reliability scores (interpersonal relations, material well-being, physical well-being, rights, social inclusion).

The internal consistency reliability of each domain was also compared by respondent group (self-report or proxy). Results indicate that:

- Reliability scores for self-report respondents (n=475) were very close to those for the aggregate sample (n=671), typically slightly lower than the aggregate score (but within .05 points).
- Reliability scores for individuals represented by proxy respondents (n=196) had slightly more variation from the aggregate with one domain (emotional well-being) producing a substantially lower reliability score and one domain (social inclusion) producing a substantially higher score. Other domains varied to smaller degrees either above or below the aggregate scores.

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[19] Litwin. M. 2003. *How to Assess and Interpret Survey Psychometrics*. 2nd edition. Thousand Oaks, California: Sage Publications.

Discussion of Results

The 2011-12 administration of the My Life: Personal Outcomes Index™ initiated the expansion of My Life: Personal Outcomes Index™ surveying from the Edmonton region to all other PDD regions across the province: Calgary, Central, Edmonton, Northeast, Northwest, and South. Surveying was intended to gather quality of life results for the participating service providers and to provide PDD with an overall look at the quality of life of individuals receiving funded supports, including an examination of differences across groups.

Conclusions

Based on the results obtained through the provincial testing phase of the My Life tool, the following conclusions can be drawn:

> ➤ Reliability analysis demonstrates that the My Life instrument in its current form is reliable in all eight domains for the PDD Program population.

> ➤ Average domain scores for the aggregate sample were highest in the three domains related to well-being: emotional well-being, physical well-being, and material well-being.

> ➤ Item nonresponse tends to be highest for survey questions related to material well-being.

> ➤ Across all group differences in average domain scores investigated, the most variability (i.e., the largest number of significant differences between sub-group and aggregate scores) was observed for the domain emotional well-being being with the least variability across groups observed for personal development.

> ➤ Transportation, conceptualized as ease of getting around one's community, was significantly related to all eight domains in a positive direction.

> ➤ Respondent type (self-report or proxy) appears to have an impact on average domain scores in at least seven of the eight domains, with proxies producing higher scores in the three domains related to well-being (emotional, physical, and material), and self-report respondents producing higher scores in the areas of self-determination, interpersonal relations, social inclusion, and rights.

> ➤ Overall, the provincial testing phase appears to compare favourably to previous work conducted during pilot testing in the Edmonton region.

Recommendations for Moving Forward

It is recommended that the following items be considered when moving forward:

Process

1. **Review the process used to determine need for proxies.**
   Since pilot administration of the quality of life survey (ending in Spring 2009) the proxy rate has declined a full 10% (from 39% to 29%). However, across agencies included in the 2011-12 provincial survey administration, the rate of proxy use ranged from 0% to 60%. Given the evidence for significant differences in response

between self-respondents and proxies, the minimization of proxy rates (to the degree possible) is desirable. The degree to which proxy need is currently determined through an objective process (as opposed to a subjective assessment) remains unclear. As such, it is recommended that the process used to determine need for a proxy be reviewed for both objectivity and consistency. It may be helpful to include in this review a discussion with service providers related to how proxy need was typically determined. Such a review may help to further reduce the proxy rate in the future.

2. **Review the process used to determine the selection of proxies.**
   The proxy selection process aims to identify two individuals to serve as proxies for every individual in need of proxy response. According to established proxy selection criteria, individuals serving as proxies must have: (a) known the individual well for the past three months, (b) an understanding of the individual's current life experiences and circumstance, and (c) directly observed the individual in one or more environments within the past three months or longer. However, there is an indication that some proxies involved in the 2011-12 surveying have not been sufficiently familiar with enough aspects of the individual's life in order to respond to the survey fully and completely. As a result, there has been an increased number of missing responses, particularly for material well-being questions. In addition, in some cases, only one proxy has been surveyed, meaning that the individual's results rely solely on the responses of a single proxy rather than a more desirable average of the two proxies. It is recommended that the process for selecting proxies be reviewed for adherence to the three criteria above and that all efforts be undertaken to connect to the recommended two proxies for each individual represented by proxy.

3. **Minimize missing data.**
   During the 2011-12 survey administration, completed questionnaires for some agencies were found to have fairly high numbers of missing responses. Recognizing that in some cases an individual or proxy for that individual may be unsure of how to respond to a question, it is important that steps be taken to minimize missing responses (e.g., by rephrasing questions or providing additional explanation). Staff training is a key component, and staff refreshers have been conducted with surveyors in this area. Moving ahead, it will be important that regular refreshers take place as needed. As well, it is recommended that those in key data collection/supervision roles review all completed questionnaires prior to forwarding them for data entry/analysis in order to address any unnecessarily missing data in a timely fashion.

4. **Streamline the process for FMS surveying.**
   To date, FMS surveying has taken place in the Edmonton region only and is scheduled to occur in the region over a three-year interval (2011-12 marked the second year of surveying with all remaining FMS surveying scheduled for completion in 2012-13). The process has experienced some challenges in terms of, for example, completion (FMS surveying is often fit in around other agency surveying) and accurately tracking the number of non-responses and refusals of survey invitations. It is recommended that the process for surveying individuals served through FMS be reviewed and streamlined prior to FMS surveying in other regions.

5. **Review the electronic data collection pilot.**
   Since the inception of the My Life surveying process, individuals' responses have typically been recorded via pen and paper. However, during 2011-12, electronic data collection was piloted for a portion of the survey sample whereby responses were entered on the spot using iPad tablets. Although initial feedback on the use of tablets has been positive, a more thorough understanding of the process is required, particularly before consideration of broader roll-out. As such, it is recommended that the process for electronic data collection and the associated benefits and drawbacks be examined and documented.

6. **Examine testing processes/results.**
   Although the quality of life surveying has been broadened from the Edmonton region to encompass PDD-funded individuals across the province, to date provincial test data are comprised primarily of Edmonton-based results. However, as surveying continues in the coming years, the results will become more representative of the province as a whole. It is recommended that once the survey sample includes adequate representation from all regions (e.g., following the 2013-14 cycle), all processes and results be reviewed to determine the state of affairs at that time.

<u>Respondent Demographics</u>

7. **Consider collecting information on the level of supports required and/or level/nature of disability.**
   Consider collecting information on the level of supports required and/or level/nature of disability as this may be an important variable to include in future regression models to examine relationships between demographic characteristics and quality of life scores.

<u>Questionnaire</u>

8. **Review questionnaire for possible revision.**
   Across the various phases of the My Life surveying process, considerable efforts have been targeted towards ensuring the validity and reliability of the survey instrument. Data analysis results have shown that all eight domains included in the current questionnaire produce reliability scores at the acceptable level or higher. However, as the My Life surveying process strives for continuous quality improvement, there may be room for further refinement. It is recommended that the survey questions be reviewed and revised where needed. Survey questions with higher proportions of missing responses (e.g., in the material well-being domain) may provide a useful starting point for consideration of any changes.

<u>Regional Sampling Strategy</u>

9. **Review the sampling plan.**
   It is recommended that the sampling strategy established for provincial surveying be reviewed regularly (e.g., annually) to determine appropriateness in moving forward. Adjustments can be made as needed.

10. Consider the most useful pieces of information required for moving forward.
The current report provides a wealth of information generated through a range of statistical analyses. The results reported are useful not only to senior planners but to agencies and, thus, their clientele. However, as the data set continues to grow as additional service providers are surveyed across the province, there may be new opportunities for analysis available. For example, survey location (individual's home, centralized, telephone or other location) and , where proxies are used, type of proxy relationship (parent/guardian, other family member, friend, staff, or other) represent data already collected that may warrant further examination for their roles in relation to quality of life scores. The most useful pieces of information required for moving forward should be considered so that future analyses are directed accordingly.

Appendix A: Quality of Life Scores Confidence Intervals

At a confidence level of 95%, confidence intervals for each of the mean domain scores for the aggregate, large service provider aggregate, and FMS are presented in Tables 6 to 8 below.[20] Using the domain of emotional well-being for the aggregate sample as an example (see Table 6), we can say that we are 95% confident that the aggregate score for emotional well-being is between 7.97 and 8.26 for the population of interest.

Table 3. PDD aggregate sample 95% confidence intervals (n=676)

PDD aggregate sample	Mean	Lower limit	Upper limit
Emotional well-being	8.12	7.97	8.26
Interpersonal relations	6.49	6.34	6.64
Material well-being	7.70	7.55	7.84
Personal development	6.63	6.46	6.80
Physical well-being	7.63	7.49	7.77
Rights	6.75	6.59	6.91
Self-determination	6.24	6.06	6.41
Social inclusion	5.67	5.49	5.84

Table 4. Large service provider aggregate sample 95% confidence intervals (n=559)

Large service provider aggregate sample	Mean	Lower limit	Upper limit
Emotional well-being	7.91	7.74	8.08
Interpersonal relations	6.48	6.31	6.65
Material well-being	7.57	7.40	7.73
Personal development	6.56	6.37	6.75
Physical well-being	7.46	7.30	7.62
Rights	6.67	6.49	6.85
Self-determination	6.26	6.07	6.46
Social inclusion	5.63	5.45	5.82

Table 5. Family Managed Supports sample 95% confidence intervals (n=114)

Family Managed Supports sample	Mean	Lower limit	Upper limit
Emotional well-being	8.89	8.63	9.15
Interpersonal relations	6.51	6.18	6.84
Material well-being	8.20	7.88	8.52
Personal development	6.91	6.54	7.28
Physical well-being	8.23	7.97	8.50
Rights	7.04	6.68	7.41
Self-determination	6.15	5.71	6.59
Social inclusion	5.79	5.36	6.22

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[20] Small agency aggregate results are not available in this report due to a very small sample size as of March 31, 2012.