Collaborative Research Grant Initiative:
Mental Wellness in Seniors and Persons with Disabilities

Ideas Fund Final Report

Quality of Life as a Guiding Construct in Disability Services

December, 2013 - Debbie Reid
EXECUTIVE SUMMARY
Over the course of the last year we were successful in researching, developing, delivering and evaluating a training course on supporting Quality of Life (QOL) in disability services at SKILLS Society. This project examined what is needed to teach Disability Service Workers to better understand QOL and what improves QOL outcomes for people with disabilities. We found that the course developed was relevant to SKILLS Society and support workers striving to support better quality of life. As a result of our research, the training course is mandatory for all SKILLS Society employees.

RESEARCH OVERVIEW
Objective(s)
To develop, deliver, and evaluate the learning outcomes of a two day *Train the Trainer* course on Quality of Life as a guiding construct. This will be achieved by:
1. Developing course materials to teach workers in disability services about the kinds of practices that improve quality of life outcomes for persons supported through disability services.
2. Searching for evidence to support course development
3. Obtaining data regarding learning outcomes.
4. To find relevant knowledge in the area of supporting persons with disabilities to achieve quality of life indicators.
5. To develop useable course materials that will be understandable to a wide range of workers in disability services.
6. To gather qualitative and quantitative data regarding learning outcomes of course participants via questionnaires and focus groups. Data will inform areas for future research around how to best teach workers in Disability services to support individuals to achieve better life quality.

Background
Quality of Life (QOL) is emerging as a central, guiding construct in the evaluation of outcomes of community supports to people with developmental disabilities. It has been shown in practice and the literature that individuals with developmental disabilities experience severe challenges achieving the kinds of lives that the average citizen would expect for him or herself. The over-arching goal of supports to people with disabilities should be to work in ways that enhance life quality for service recipients.

One of the most serious problems in our sector is that there is a conspicuous absence of training protocols and courses for staff that focus clearly on QOL as a guiding construct. The workforce in our sector is extremely diverse in terms of cultural, generational, and experiential demographics. The QOL construct unites an incredibly diverse workforce by guiding both their understanding of the people they support and by providing a framework for evaluation of their own support work.

Approach and Methods
Using powerful images that illuminate both the underlying theory and the practice approaches that roll out from that theory, the training was delivered to a group of key leaders within the host organization SKILLS Society. We employed conversational approaches that acknowledged varying literacy levels and the oral tradition of many cultures, and engaged the individual and collective wisdom that exists in our diverse workforce.
The Training Course

The majority of our time was spent researching literature on QOL and disability and creating the course content. We drew heavily from the *Quality of Life Model* (Centre for Health Promotion, 2012) to understand what makes up QOL. This model defines Quality of Life as “The degree to which a person enjoys the important possibilities of his or her life”, and constructs QOL out of three broad domains: Being, Belonging, and Becoming. This model was chosen for its holistic and broad perspective, and the intuitive understanding of it that people from many walks of life seem to demonstrate when exposed to it. (i.e., our experience while conducting the training was that these concepts made intuitive sense to people and were words that they naturally used to describe life quality in their own lives).

A power point presentation with abundant visual imagery and links to videos related to Quality of Life was developed. This formed the basis of examining how support staff can plan their support of people in such a manner that enhanced outcomes in the quality of life of the individuals being served are enhanced.

Links were also made to the *Persons with Developmental Disabilities My Life Survey: The Personal Outcomes Initiative* (Government of Alberta, 2012). This survey is being used in Alberta to gather aggregate data about how well disability organizations are doing in assisting their clientele to achieve positive QOL outcomes. This survey is based on a model of Quality of Life developed by Dr. Robert Schalock and breaks Quality of Life into 8 domains:

- Personal Development
- Self Determination
- Interpersonal Relationships
- Social Inclusion
- Rights
- Emotional Well-Being
- Physical Well-Being
- Material Well-Being

Training Session

On May 18th, 2012, 60 key leaders from SKILLS Society attended the full day training session on Quality of Life. The training presented a model of Quality of Life based on the University of Toronto Quality of Life Research Unit. The training involved PowerPoint, video, and small group discussion.

Participants

Participants were a mix of Team Leaders, Managers and Senior Managers from across the organization. All 60 were identified as leaders who provide guidance to staff regarding supporting practices that lead to enhanced quality of life for people SKILLS supports.

Method

To assess the attitudes, opinions, and perceived learning regarding QOL by staff that attended the training we conducted focus groups and sent out a questionnaire to all participants.

Questionnaire

A questionnaire (See Appendix 1) was sent out June 5th, 2012 to all training participants. They were asked to complete the survey and return it in an unmarked envelope by June 15th, 2012. The questionnaire gathered both qualitative and quantitative data on learning outcomes.

Focus Groups

Five focus groups were conducted with 5 to 7 participants each and began with the question, “What did you learn from the Quality of Life training session?”. Open discussion followed. Notes were taken and later themes were identified.
Findings

**Questionnaire Findings**
Thirty-three participants completed the questionnaire, a response rate of 55%. The survey measured whether a participant felt a shift in their ideas about quality of life by asking: "On a scale of 1 to 5, how much do you think your ideas about quality of life have shifted? (where 1 is least and 5 is most)." The responses ranged from 2 to 5. The average response was 3, however many commented that the training affirmed that they were already focusing on Quality of Life, however they learned new ideas and strategies to support it.

**Qualitative Themes from the Questionnaire**
1. The training reminded staff to focus on QOL as a guiding construct in providing and evaluating supports to individuals.
2. The three areas of Being, Belonging and Becoming helped make QOL more understandable.
3. The training helped clarify for staff what the overall construct is for quality of life.
4. More staff should take the training.
5. Participants felt they would need more training in order to be able to train others in QOL.

**Focus Group Findings**
The following themes arose from the Focus groups:

**Being, Belonging, and Becoming**
- Participants generally felt that this way of conceptualizing and talking about the components of QOL was quite helpful and gave them some concrete ways of helping front-line staff to plan their support of individuals.
- It would be important to build this language into any planning and/or evaluative tools that we use.
- The day to day managing of problems, logistics, crises and other issues that arise can get in the way of providing leadership around supporting staff to “do the right things” to assist people achieve improved life quality. The Being, Belonging, and Becoming construct helps re-focus.
- Helps with the language barriers that exist within our workforce. Three words that unite us in our thinking about our work.

**Need for Asynchronous Training & Self-Study**
- Given the rate of turnover of frontline staff, along with the cultural diversity and the different shifts that people work, there is a need to translate this training into something that people can watch individually or in small groups.
- Some participants spoke about a kind of apathy that exists in our workforce, where staff just “show up” to work their shift. Some Leaders expressed that they see a kind of skepticism about this kind of “lens” during a time of diminishing resources in our field.
- People have intuitive sense that they understand QOL. A kind of “Ya, that was good, cause it reaffirms what I’ve always thought”. But the question back is “Do you understand it well enough to guide the work of others?” Our sense is that Leaders need more immersion in, and practice with, these ideas in order to deepen their understanding and to sustain successful action.

**The Demands of the Day Often Get in the Way of Us Thinking Holistically About People**
- Quality of Life as a guiding construct is, in a sense, an antidote to relativist thinking about people, i.e., “Oh well, this is the best we can do given the circumstances”. Good Enough vs Good Lives
- We need to take time to reflect, plan, and evaluate. We will not serve people well if we are always just acting in “management” mode (e.g., especially managing crises).

**Forums for Fortifying Reflection and Accountability**
- Need for regular “meetings” or “gatherings” of Team Leaders with the Manager to whom they report where the discussion is focused on QOL:
  » what people are learning,
  » where are the successes?,
  » how can we do more as individuals, as a leadership team, as an organization.
The work itself can be isolating and these kinds of gatherings can help leaders re-fuel and re-focus. Mentoring one another is essential. So is holding one another accountable for outcomes.

The Importance of Reporting
Many participants expressed concerns regarding the link between regular reporting and sustained action. They suggested that quarterly progress reports that include QOL as a lens would motivate front-line and leadership staff to stay focused on this important matter.

Need to Make Links Explicit Between Quality of Life and other Organizational Initiatives
One of the dangers in an organization like SKILLS that places high value on innovation is that people may fail to “connect the dots” across various initiatives. There was much discussion about the social change initiative that SKILLS Society leads called Project Citizenship: People with disabilities and their stories of engaged citizenship and the powerful ways in which story is used to convey culture shifting ideas (see www.projectcitizenship.com). As leaders in this QOL training, there are plans to integrate training that shows how powerful a vehicle story can be for conveying meaning and ideas related to QOL and practices that support it.

Conclusions
Quality of Life is perhaps the most important and powerful construct in guiding and evaluating the effects of good supports to people with developmental disabilities. Training is imperative and must be engaging and address wide cultural and literacy differences that exist in our workforce.

IMPLICATIONS FOR POLICY OR PRACTICE
Implications for Policy Makers
Allocation of Resources
The main implication of our findings is that allocation of resources for training around QOL is important especially with Alberta Human Services assessing QOL outcomes of people with disabilities who receive services. Without sufficient training, it will be unlikely that service organizations will properly support enhancement of quality of life of the people they serve.

Collaborative Training Opportunity
Given that resources (fiscal and people) are limited, it may be fruitful to look across sectors where there are opportunities for collaborative training in this area.

Implications for service providers like the host agency SKILLS Society
Quality of Life Training has become Mandatory Training
The training was seen as useful to staff orientation and training and therefore made mandatory for all staff at SKILLS Society. To date, the Quality of Life training has been offered five additional times since the initial training day.

Integrating Quality of Life as a construct into Abuse Prevention Training
One of the managers who participated in the training took the training further by integrating the Quality of Life Model (Centre for Health Promotion, 2012) into the mandatory abuse prevention raining. In this way, more staff exposed to the importance of supporting quality of life as a means to also protect vulnerable populations from abuse.

Integrating Quality of Life in a New Service Planning Tool
The Quality of Life training has also been integrated into a service planning tool as a means to ensure that plans for supporting people with disabilities focus on actions that lead towards better quality of life. In the tool there are questions that encourage the staff to engage in discussion and planning to achieve better quality of life outcomes for the individuals supported. This planning tool is going to be used by the whole organization and was implemented January 2013.
DIRECTIONS FOR FURTHER RESEARCH
As this is a first step, there are plans to apply for future grants in order to enhance our capacity for developing rich, balanced, relevant and effective training modules for Community Disability Service workers and the broader human services sector.

Given the rate of turnover of frontline staff, along with the cultural diversity and the different shifts that people work, there is a need to translate this training into something that people can watch on their own or in small groups. This will require some personnel and financial resources to create videos, webinars, and other on-line materials. We would anticipate a much more rapid knowledge mobilization in our large organization as a result of this kind of packaging of the QOL material.

KNOWLEDGE DISSEMINATION AND TRANSLATION ACTIVITIES
Presentations will be made at conferences when possible. Possible collaboration with:
- Post-secondary institutions
- Alberta Council of Disability Service Providers (in their on-line Foundations training)
- Potential exploration of developing a local Community of Practice that focuses on QOL

PRINCIPAL APPLICANT (TEAM LEADER)

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<thead>
<tr>
<th>Name</th>
<th>Position Title</th>
<th>Topics of interest</th>
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<tbody>
<tr>
<td>Debbie Reid, M.Ed.</td>
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<td>Quality of Life, citizenship, health and safety, community development, human rights.</td>
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PROJECT PARTNERS (TEAM MEMBERS)

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<tr>
<td>Ben Weinlick, M.A.</td>
<td>Senior Manager of Research and Organizational Learning</td>
<td>Research, writing, teaching, data collection, data analysis</td>
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PUBLICATIONS AND PRESENTATIONS
We presented research findings at Found in Translation in March 2013 and at the Alberta Council of Disability Services conference in April 2013.

REFERENCES
ABOUT THE ALBERTA ADDICTION AND MENTAL HEALTH RESEARCH PARTNERSHIP PROGRAM

The Alberta Addiction and Mental Health Research Partnership Program is comprised of a broad-based multi-sectoral group, representing service providers, academic researchers, policy-makers and consumer groups, working together to improve the coordination and implementation of practice-based addiction and mental health research in Alberta.

The mission of the Research Partnership Program is to improve addiction and mental health outcomes for Albertans along identified research priority themes, by generating evidence and expediting its transfer into addiction and mental health promotion, prevention of mental illness, and innovative service delivery.

The Research Partnership Program sets out to increase Alberta’s excellence and output of addiction and mental health research findings, and to better translate of these findings into practice improvements.
APPENDIX 1

SKILLS Society
Quality of Life Survey June 2012

How, if at all, has your thinking about QOL shifted as a result of participating in this training?

On a scale of 1 to 5, how much do you think your ideas about quality of life shifted? (where 1 is least and 5 is most)

Was there any learning about anything that stood out for you?

Think about 3 of the people whose support you oversee. What do you think about each individual in relation to their QOL?

How do you see your practices shifting in a way that might support better QOL outcomes?

What would you need to be able to use this training material to work with the teams that you support?

Is there something about QOL you would like to learn more about?