

An Introduction to:



What does quality of life mean?

Experiencing quality of life depends on whether or not a person's needs are being met and whether or not they can make choices to change or improve things in their life. Since every person's needs are different, it can be difficult to measure quality of life.

Community Living British Columbia (CLBC) uses a framework that was developed by Dr. Robert Schalock to describe quality of life. The framework is made up of eight areas:

- personal development
- self-determination
- relationships with people
- social inclusion
- rights
- physical well-being
- emotional well-being
- material well-being

Dr. Schalock's framework fits well with CLBC's vision of supporting individuals with developmental disabilities to lead good lives in welcoming communities. The table on the next page describes the different parts of the framework.

How is quality of life measured?

CLBC measures QoL using a survey that asks individuals to let us know if they are having the opportunities they would like to:

- learn and do new things
- make choices about the big and little things in their lives
- participate in their community and neighbourhood
- make friends and spend time with the people they care about
- take care of themselves and be healthy
- earn money and spend it on things that are important to them

The survey includes 53 questions - 6 for each of Dr Schalock's 8 QoL domains, 2 about transportation, 2 about employment, and 1 about overall quality of life. The survey is typically administered in person by adults with a developmental disability who have been hired and trained by a research company called R A Malatest & Associates. Telephone and online options are also available.

How was the survey that is used in *include Me!* developed?

CLBC uses a survey that was developed by a national research company under contract with the Persons with Developmental Disabilities Edmonton Region Community Board. PDD Edmonton consulted Dr. Schalock throughout the 2-year development process and involved many individuals, family members, service providers, community living experts, and PDD Edmonton staff. The final version that was released in 2009 has been proven to have strong statistical reliability and validity.

Why is the survey process called *include Me!* ?

Dr. Schalock believes that the person must be at the centre of the process when we measure and talk about quality of life. This principle is reflected in the design of this process and the name of this initiative. By hiring individuals with disabilities as surveyors and by going directly to individuals to answer questions that relate to their life, the process honours the expression "nothing about us without us."

How did *include Me!* get started?

CLBC and service providers wanted to know if we were truly helping people lead good lives in welcoming communities. We wanted to know what we are doing well and how we could make the services we offer even better. When thinking about these questions, CLBC learned about the PDD Edmonton **My Life** survey project. CLBC liked this approach because:

- it is based on a framework that applies to all people – disability or no disability
- Dr. Schalock's framework is based on 25 years of scientific research in different countries
- people with developmental disabilities play an important role in the survey process – they ask and answer the survey questions themselves

We decided to test the survey process in our province by asking 335 people to be interviewed. We learned that the survey could help CLBC and service providers understand what they could do to make a positive difference in people's lives. The individuals and service providers who took part said it was a positive and helpful experience.

Based on the project's success, CLBC decided to proceed with provincial implementation of the survey process. We began in 2012-13 in the Vancouver-Coastal and South Fraser regions and have since expanded to the Southern Interior region. To date, nearly 6,000 individuals have completed the survey. During the 2019-20 year, we plan to conduct approximately 1,800 additional surveys and move into the Thompson Cariboo and Vancouver Island regions.

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Do surveyors with developmental disabilities do a good job?

Yes. In the PDD Edmonton project, surveyors with developmental disabilities produced results that were as good as surveyors without disabilities. In fact, people said they felt more comfortable answering questions asked by surveyors with developmental disabilities than by surveyors without disabilities. Our experience in BC has been exactly the same. The surveyors who have worked with Malatest over the past 4 years, have been well-trained and take their jobs very seriously. Their professionalism and sensitivity has made the survey process extremely positive for the individuals, families, and service providers that have participated.

What role will CLBC play in the *include Me!* survey process?

The survey process provides a great opportunity for people who support adults with developmental disabilities and their families to talk about how to make supports and services better reflect their needs.

CLBC is committed to working with individuals, family members, service providers, and community members to support this new approach. All of CLBC's staff will have an understanding of *include Me!*. They will use quality of life to measure whether their work is making the lives of people with developmental disabilities better.

CLBC's *include Me!* team will support:

- the introduction of the survey process across the province
- service providers to make changes that improve the quality of life of the individuals they support
- individuals, families, and others to have conversations about quality of life

The team is available to answer questions that individuals, family member, service providers CLBC staff, and others have about *include Me!*.

How will the survey results help CLBC and service providers?

Survey results will help CLBC and service providers:

- better understand the influence that supports and services have on a person's quality of life
- choose areas they could work on to make an individual's quality of life even better
- make decisions about policies and services that will help people with developmental disabilities lead good lives in welcoming communities

Service providers will not be expected to get specific scores. The results can help providers make decisions on how they can have a positive impact on the quality of life of those they serve.

How will the survey results help individuals and families?

The survey offers individuals a way to think and talk about their quality of life with their families and the people who support them. It can help individuals and families decide what type of supports and services are the best fit for them.

Quality of Life Framework

| DOMAIN | INDICATORS |
|------------------------------------|---|
| <i>INDEPENDENCE FACTOR</i> | |
| Personal development | - Education - Personal competence - Performance |
| Self-determination | - Autonomy - Goals and Values - Choices |
| <i>SOCIAL PARTICIPATION FACTOR</i> | |
| Interpersonal relationships | - Interactions - Relationships - Supports - Recreation |
| Social inclusion | - Community integration - Community roles - Social supports |
| Rights | - Human - Legal |
| <i>WELL-BEING FACTOR</i> | |
| Emotional well-being | - Contentment - Self-concept - Lack of stress |
| Physical well-being | - Health - Activities of daily living - Physical activities |
| Material well-being | - Financial status - Employment - Housing |

Who else is measuring QoL using this kind of process?

Community living jurisdictions in Canada, the US, and other parts of the world are looking at how they can measure outcomes in ways that are meaningful to the individuals they serve. Dr. Schalock's framework and the measurement approach we have used here have an appeal that is attracting interest. The Alberta Ministry of Human Services has moved to a provincial expansion of this survey process. CLBC has been consulted by Ontario and Nova Scotia as both of those provinces are beginning to consider ways in which they can adopt this kind of approach. Spain, the Netherlands, China, and New Zealand are all using similar measures that are based on Dr. Schalock framework. We are excited to be part of this cutting edge approach.

More Information

Learn more at www.communitylivingbc.ca/include-me. If you have questions, please contact:

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