



PDD My Life: Personal Outcomes Index™

fact sheet for families and guardians

WHY IS PDD USING THE MY LIFE: PERSONAL OUTCOMES INDEX™ SURVEY?

PDD and its partners worked over a period of three years to develop a way to gather valid and reliable data that measures the quality of life of individuals who receive PDD funded supports and services. Using the *My Life: Personal Outcomes Index™* survey to get information from individuals with developmental disabilities (individuals) about their quality of life and personal outcomes will help PDD and agencies improve how they support individuals.

WHAT IS THE MY LIFE: PERSONAL OUTCOMES INDEX™ SURVEY?

The *My Life: Personal Outcomes Index™* survey is one of PDD's ways to measure personal outcomes of individuals that receive PDD funded supports. The survey measures how individuals experience their life across eight personal outcome areas:

- **Emotional well being:** happiness and safety, and how individuals feel about their life
- **Interpersonal relations:** type of support and help individuals get, relationships with family and friends, and the types of activities that individuals do with people in their life
- **Social inclusion:** the activities and things individuals do and would like to do in the community, the people individuals do things with and places they go in their community

- **Personal development:** the things that individuals are interested in learning about, and things that they enjoy and are important to them
- **Self-determination:** the choices and decisions individuals make about areas that matter to them in their life
- **Physical well-being:** energy levels, being able to get medical help, health and lifestyle
- **Material well-being:** personal possessions that are important to individuals, how much individuals can use money for things they want or need
- **Rights:** individuals' right to privacy, how individuals are treated by people, how much individuals are listened to

HOW WAS THE MY LIFE: PERSONAL OUTCOMES INDEX™ DEVELOPED?

The research, development and test phases of the *My Life: Personal Outcomes Index™* occurred in the PDD Edmonton Region via a partnership with individuals, families, service providers, industry experts and PDD Regional staff. Throughout this process, Dr. Robert Schalock, a recognized leader in the field of quality of life measurement for adults with developmental disabilities was engaged to help PDD in its endeavor to develop a personal outcome measurement framework.



Embedded in Dr. Robert Schalock's work is the idea that the measurement of personal outcomes must place the individual at the center of the process.

With guidance from Dr. Schalock and Dr. Dale Howard of Howard Research & Management Consulting, an expert in research and methodology of measuring Quality of Life, an extensive and detailed development and testing process was followed. The result was the formulation of survey questions made specifically for Alberta citizens and a survey process that included training surveyors, creating a user-friendly survey for individuals and learning about how the information can be used in the best way to improve services with the result being improved personal outcomes.

HOW IS THE MY LIFE INDEX ROLLING OUT ACROSS THE PROVINCE?

PDD has one Region's learning from their experience collecting personal outcomes evaluation data using the My Life survey. During the 2011 – 2012 year the My Life survey will be tested in other Regions. PDD will use a "test centre approach" which will maximize efforts related to continuous improvement of the survey tool, survey processes and implementation plan.

HOW WILL THE MY LIFE SURVEY HELP INDIVIDUALS?

PDD and service providers will use the *My Life: Personal Outcomes Index™* survey results to:

- Understand the impact of funded supports on individuals and their quality of life.
- Identify continuous improvement strategies that will improve personal outcomes for individuals funded by PDD
- Inform decision-making about policies and practices that will support quality of life for individuals

WHO IS RESPONSIBLE FOR SEEING THAT THE MY LIFE SURVEY GETS DONE?

PDD through a contract with Gateway Association, an independent firm, is responsible for seeing that the survey gets done. The independent firm's involvement deals with all aspects of the survey work such as scheduling survey times, training surveyors, providing transportation for surveys to occur and working with families and service providers to facilitate their involvement.

DO I HAVE TO PARTICIPATE IN THE MY LIFE SURVEY?

No. It is each individual's choice, either by themselves or with the input and support of a legal guardian who has authority in this area. Participation is encouraged. This is an opportunity for individuals to tell PDD about their lives.

HOW IS THE SURVEY COMPLETED?

The *My Life: Personal Outcomes Index™* survey has been specifically designed with the expectation that whenever possible the individual with development disabilities is the person answering the questions. Modifications have been built into the survey process to ensure that as many individuals as possible are able to self-report on their personal experiences.

For individuals who are unable to self-report, either verbally or non-verbally, two others who know the individual well will be invited to complete the survey on the individual's behalf by answering the questions in the way the individual would have answered them. These surveys are called proxy surveys.

ARE THERE RISKS FOR CHOOSING NOT TO PARTICIPATE?

No. There is no risk if you decide not to participate in the survey.

IS THE INFORMATION KEPT PRIVATE?

Yes, all information is kept private. PDD and service providers that participate in the survey will see a non-identifying report that is compiled by an outside research and data analysis firm. No information on an individual-by-individual basis is recorded in any reports. Results will be used for continuous improvement purposes.

WHY SHOULD INDIVIDUALS CONSENT TO THIS SURVEY?

This is an opportunity for individuals funded by PDD to tell us how they feel about many things that are not usually covered in other surveys. The survey answers will let PDD and service providers know what individuals think about their lives. This will allow PDD and service providers to work together to make the supports individuals receive better.

HOW ARE PEOPLE CHOSEN?

Names are randomly selected from a list of all individuals served by each service provider. In order to provide data back to service providers that can be used for continuous improvement purposes, a set number of interviews must be conducted. The number of interviews will vary across each service provider and will ensure that the data received is statistically valid.

WHO WILL CONDUCT THE SURVEYS?

People hired and trained by Gateway Association, an independent survey firm will conduct the surveys. Surveyors will also include people who have a developmental disability. This is in keeping with the expert

advice that PDD has received from Dr. Schalock and the success of the initial work that was done on this survey. Interviewers work in groups of two; one asks the questions and one records the responses.

HOW LONG DOES IT TAKE TO ANSWER THE SURVEY?

It takes about half an hour to answer the questions.

WHERE CAN I FIND MORE INFORMATION ABOUT THE MY LIFE: PERSONAL OUTCOMES INDEX™ SURVEY?

You can get more information on the *My Life: Personal Outcomes Index™* and the work of the Provincial Personal Outcomes Initiative (POI) and/or express your interest in participating in the survey process by contacting your PDD coordinator, the POI liaison in your region or the Provincial Coordinator. Regional liaison and provincial coordinator contacts are as follows:

Northeast Region:

Barb Holmberg @ 780-645-6208

Northwest Region:

Cheryl Bjorklund @ 780-538-5612

Edmonton Region:

Vince Pasqua @ 780-427-3367

Central Region:

Gerald Scotvold @ 403-340-5957

Calgary Region:

Yvonne Gaudet @ 403-355-4134

South Region:

Leah Roedler @ 403-381-5458

Provincial Coordinator:

Gloria Wesley @ 780-644-4677 or
Gloria.Wesley@gov.ab.ca.

Additional information can be found at:

www.seniors.alberta.ca/pdd/changeinitiatives.

