



Quality of Life

Research Unit

Quality of Life for People with Developmental Disabilities

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Overview

The Quality of Life Project was completed in March, 1999, after ten years of hard work, determined effort, and the contribution of numerous people.

This description of the project provides an overview of the process we undertook to achieve our goals. The reports mentioned below examine the project in detail.

Reports

Summary reports from each stage of the study are available in PDF format by clicking a selection on the right. The full reports cited below may be purchased through our [publications](#) page.

Quality of Life - Dream or Reality? Life For People With Developmental Disabilities in Ontario.

Ivan Brown, Dennis Raphael, and Rebecca Renwick
Toronto, Canada: Centre for Health Promotion. 1997
(ISBN 0-7727-8712-3)

This publication reports on the overall findings from the cross-sectional portion of the study: an assessment of 502 participants from across Ontario. 133 pages.

Quality of Life and Life Changes for Adults with Developmental Disabilities in Ontario

Ivan Brown, Dennis Raphael, and Rebecca Renwick
Toronto, Canada: Centre for Health Promotion. 1999
(ISBN 0-7727-6100-0)

This is the final report from the Quality of Life Project. It discusses the findings from the longitudinal portion of the four year study, reporting on two followup

assessments of 184 participants from the cross-sectional study and 30 new participants.

Project Background

In Ontario, persons with developmental disabilities are those who possess an intellectual disability and whose adaptive behaviour is such that they require services. The program of research was in response to a perceived need to have quality of life assessments constitute part of an evaluation of a thrust towards community-based service provision to persons with developmental disabilities.

Since an important journal editorial almost 10 years ago called for an increased emphasis upon the quality of life of persons with developmental disabilities, a number of conceptualizations and measures have been developed. At least four recent volumes have been devoted to quality of life and disabilities issues.

Our analysis indicated that any one of the available approaches, by itself, was not entirely satisfactory in providing a means of assessing the complexities involved in assessing quality of life. More specifically, we felt it necessary to develop an approach which would separate quality of life from quality of personal care; make explicit our assumption that degree of disability and/or dependence is separate from quality of life; focus upon the abilities rather than disabilities of individuals; and emphasize the perspective of persons with developmental disabilities. Additionally, we felt it was necessary to carefully outline the assumptions underlying our approach towards quality of life, and define the domains of life for which quality assessments would be made.

Finally, we felt it necessary to develop a package of instruments which could capture the perspectives of the person with developmental disabilities, service providers, and that of an independent assessor. The last was necessary since we were concerned with being able to determine whether certain agreed-upon standards associated with provision of government-funded services were being met.

We developed our model paying careful attention to important current trends in developmental disabilities, while at the same time, closely following a number of principles that we considered central to the concept of quality of life.

Principles in Model Development

- focus upon the abilities and competencies of persons with developmental disabilities rather than their limitations
- extensive consultative activities during each stage of the development of the model and instruments
- individuals are potentially the best judges of the quality of their own lives

- a variety of innovative means is needed to collect information from individuals whose opinions had infrequently been elicited in the past
- the need to provide clear evidence of the reliability and validity of our data

Controversies and Issues

We were also aware of some of the philosophical and practical arguments concerning the nature of reality and how this translates into the development of measures of quality of life. This is especially important for study of persons with developmental disabilities since the strengths and weaknesses of objective and subjective measures of quality of life become more pronounced when the life satisfaction and circumstances of individuals who may have lived their lives under somewhat limited and highly controlled situations are assessed. These issues constantly came up as we met with service providers, parents, and policy-makers during the development process. Our solution to these issues was one of accepting the view that one's own reality is ultimately a personal construction based upon one's specific life circumstances.

Similarly, any analysis of results of quality of life assessments were also seen as social constructions requiring shared consensus and agreement among the data users. As a result, we strive to make our assumptions explicit, recognize limitations of our approach, and remain open to viewpoints concerning our model and procedures. These and other issues concerning the assessment of quality of life of persons with developmental disabilities led to our emphasizing multiple data types, multiple sources, and development of a bottom-line checklist concerning acceptable standards of living conditions. How these decisions became translated into instrumentation is detailed below.

Instrumentation and Measurement

Assessment of quality of life of persons with developmental disabilities is a complex task and is especially important since many aspects of individuals' lives may be affected by policy or programming changes resulting from such assessments. In recognition of this, our approach calls for a number of measures to collect several types of data from a variety of sources. This multi-method, multi-source approach requires spending a full working day with each person, including 90 minutes with a significant other person who knows the person well. Measures include interviews, checklists, observations, with data provided by the persons with disabilities, a close other, and the trained assessor.

Overview of the Quality of Life Project

Phase I, completed in 1991 and 1992, developed the conceptual framework and ways to measure quality of life of persons with developmental disabilities.

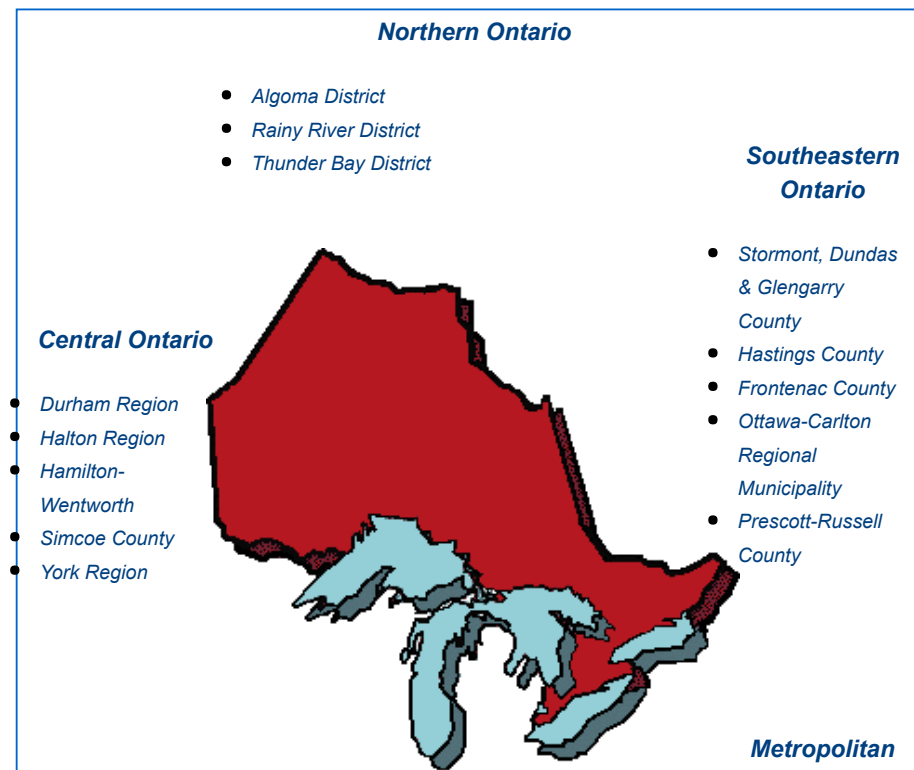
Phase II, completed in 1993, involved validation of the measures and field testing the methodology.

Phase III of the project was initiated in August 1994 and completed in March 1999. The purpose of Phase III was to assess, over time, the quality of life of a representative sample of adults with developmental disabilities who live in Ontario, with a view to assessing the policy objectives of the Ministry of Community and Social Services.

The Quality of Life Project assessed the quality of life of 504 adults with developmental disabilities. The participants were randomly selected from among those who receive support from community agencies in 23 areas throughout Ontario. These 23 areas were also randomly selected from all of Ontario's counties, regional municipalities, cities, and districts. In addition, participants were selected from all Schedule I and some Schedule II facilities across the province.

Our sample included men and women who:

- represent the population of people with developmental disabilities in Ontario
- are in several age groups, ranging from young adults to seniors
- live in a variety of housing, such as with family, in group homes, in large facilities, or on their own
- use services to varying degrees, ranging from services that affect all areas of life to no services
- have a variety of daytime activities, ranging from unstructured time at home to full community-based employment



- Brant County
- Haldimand-Bruce County
- Essex County
- Niagara Region
- County
- 5 Regions

Organizations and facilities that serve people with developmental disabilities play an important part in the project by:

- identifying potential participants for the study
- introducing participants to quality of life assessors
- offering the time of a few employees, who will be trained by the Centre for Health Promotion, as part-time quality of life assessors
- ensuring that we get a sample that reflects the characteristics of adults with developmental disabilities as a whole, living in Ontario

Purpose of Our Research

MCSS Policy Development

The overall purpose of the Quality of Life Project is to evaluate the main policy initiatives of the Ministry of Community and Social Services. We need to know whether policies such as community living, independence (or interdependence), increased personal control, and others, are resulting in improvements in the quality of people's lives. This information will be very useful to the Ministry for setting its policy priorities.

Development of Quality of Life Assessment Methods

The Quality of Life Project's conceptual framework outlines nine areas of life that are important to all people--including people at all levels of developmental disability. These nine areas should provide ideas for the kinds of things that community agencies and facilities can implement to foster improvement in the lives of those with disabilities. They may also be transposed to assessments of other individuals and their specific needs and living environments.

Service Provision and Program Development

The great deal of information for each person assessed --more information than is actually required simply to evaluate current policy objectives - will allow us to offer a much fuller analysis of

quality of life as it relates to a wide variety of services and life circumstances.

(* note: Results for specific individuals are not available. Those who were asked to participate in the study were assured their responses are confidential. Although the assessors need to know who the individual participants are, those of us at the Centre for Health Promotion do not. No names are recorded on the data sheets, nor are the names of agencies or facilities from whom individual participants receive support.)

This additional information will allow us to contrast quality of life scores for people in various living situations, at various levels of disability and so on. It is also an opportunity to compare the perceptions of quality of life of people with disabilities, the significant others in their lives, and our trained interviewers. Such a comparison should provide an interesting way for us to evaluate our own perceptions.

For agencies and facilities, such an analysis should prove very useful for self-evaluation. If it is found, for example, that a service provider is committing a lot of resources to one area of service, but QOL assessment shows that participants' quality of life is not improving in the desired ways, the agency or facility might want to reallocate their resources or change the service. On the other hand, if it is found that an area of life is rarely supported, but needs to be, agencies and facilities might give that area of life more attention. Thus the project and the results it provides, may function as a springboard for offering ideas to service providers regarding ways that they might enhance their services in order to foster quality within the lives of people who use their services.

Principles in Quality of Life Assessment

- **Quality of life for people with developmental disabilities consists of the same aspects of life as for all other people.**
- **Quality of life is based on common aspects of life for all humans, but it also reflects, from person to person, varying degrees of importance placed on those aspects of life.**
- **Quality of life for all people reflects how satisfied they are with aspects of life that are important to them.**
- **People live in environments. Thus, quality of life results from the interconnection between people and the environments in which they live.**

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