

**The Quality of Life Project**  
**Report on Followup Studies**  
**March 31, 1999**

**Executive Summary**

**About The Quality Of Life Project**

The Quality of Life Project is an initiative that assesses the quality of life of adults with developmental disabilities who live in Ontario and who are associated with service organizations in some way. The project was funded by the Ontario Ministry of Community and Social Services (MCSS) and was carried out by the Centre for Health Promotion at the University of Toronto.

**Background**

MCSS and service organizations have traditionally held improving quality of life for people with developmental disabilities as one of their implicit goals. The explicit use of quality of life began in 1987 when the policy document *Challenges and Opportunities: Community Living for People with Developmental Handicaps* was published. Many of its recommendations were implemented through MCSS's Multi-Year Plan. Soon after, MCSS established quality of life as a priority for evaluating its Multi-Year Plan. In particular, it sought to use quality of life as a key outcome measure to evaluate the success for specific policy objectives, such as promoting and supporting independence, personal control, community living, and integration into mainstream society. As the Quality of Life Project took form its role expanded to: (1) promoting quality of life as one way to evaluate the overall goals of the field of developmental disabilities, (2) collecting broad-based data about adults with developmental disabilities in Ontario as a population, and (3) providing a methodology for assessing and using quality of life at an individual level.

**Purposes of the project**

- Evaluate the overall goal of improving quality of life of people with developmental disabilities
- Evaluate specific policy objectives of MCSS
- Acquire demographic and descriptive information about people with developmental disabilities in Ontario
- Make quality of life measures and conceptual components available throughout Ontario through the development of a *Quality of Life Instrument Package*

**Three phases of the project**

Phase 1, completed in 1991 and 1992, developed a comprehensive method of conceptualizing and measuring quality of life for people with developmental disabilities. Phase 2, completed in 1993, tested the measurement procedures that were developed, as well as the reliability and validity of the measurement instruments. Phase 3 was a 4½-year longitudinal study, begun in August of 1994 and

completed in March 1999, that assessed the quality of life of a sample of adults with developmental disabilities throughout Ontario, and followed some people from this sample over a 3-year period.

## **The Participants**

For Phases III of the project, a sample of 504 participants were drawn from 23 randomly selected areas across Ontario. Participants were selected from each of 5 regions of Ontario, and from 4 living options: large care, small care, independent living, and living with families. In the two followup studies, quality of life was assessed for 200 of these participants.

## **Demographic and Service Information**

Key findings from the demographic and service information collected include:

### **People who continue to live in facilities**

- Continue to receive about the same kinds of supports over the three times periods studied.
- Are more likely to have personal support plans than they were in 1995.
- Are *less* likely now to have a formal occupational activity than they were in 1995.
- Are seen by others as having more capacity for independence than was the case in 1995.

### **People who moved from facilities to communities**

- Had little or no involvement in choosing the geographic location or the specific home to which they moved.
- Moved to stable, urban houses that are not especially characterized by diversity.
- Have more privacy, spending money, possessions, and personal freedom than when they lived in facilities.
- Are substantially *less* likely now to have a formal occupational activity.
- Are very likely to have personal support plans.
- Get more in practical and emotional support from their parents and siblings than they did in facilities.
- Have *not* experienced a decrease in the use of psychotropic medications.
- Use their communities much more than they did when they lived in facilities, although cost, ability to get around, and especially being accepted are still problematic for some.
- Are seen by others as having more capacity for independence than was the case when they lived in facilities.

### **People who continue to live in communities**

- Have experienced little change in their life conditions in recent years.
- Are experiencing more difficulty participating in their communities than in 1995.
- Are much more likely recently to have no formal occupational activity than in 1995.

## **Quality Of Life and Life Changes**

Quality of life was assessed and followed over time for: people who continued to live in large congregate care, people who moved from large congregate care to community living, and people who continued to live in communities. The key findings for each of the three groups are:

#### **People who continued to live in large congregate care**

- Overall, quality of life scores are quite low.
- Quality of life scores did not change significantly over time.

#### **People who moved from facilities to communities**

- Improved quality of life is associated with moves from large care facility living to community living.
- Quality of life scores continue to be fairly low even for people who moved to communities, especially for nonverbal people.

#### **People who lived in communities**

- Quality of life scores are higher for verbal people than for nonverbal people.
- Quality of life scores do not differ significantly for people living independently, with families, or in small congregate care.
- Some quality of life scores increased for verbal people over time.
- Some quality of life scores for nonverbal people in small congregate care have been falling in recent years.

### **Quality Of Life and Four Key MCSS Principles**

Four key MCSS principles were examined: (1) personal control, including decision making and opportunities from which decisions can be made; (2) independence, including personal independence and environmental independence; (3) integration, including social integration and community activities integration, and (4) personal support, including practical support and emotional support. The degree to which each of the four principles changed over time, and were related to quality of life was examined. The key main findings are:

#### **Personal control**

- Decision making and opportunities scores are higher for verbal than for nonverbal people.
- Decision making and opportunities scores increased when people moved from facilities to communities.
- Decision making and opportunities scores for people who have moved from facilities to communities are similar to the same scores for people who have always lived in communities.
- The degree to which people make decisions and have opportunities from which decisions can be made is related to quality of life, especially for nonverbal people. This suggest we should promote more decision making and provide more opportunities.

#### **Independence**

- Independence scores are higher for verbal than for nonverbal people.
- Independence scores are higher for people who live in communities than for people who live in large care facilities.
- Independence scores increase when people move from large care facilities to communities.
- There is a stronger relationship between independence scores and quality of life scores for people who move toward independence than for people who do not move toward independence. This suggests that one way to enhance good quality of life might be to foster a high degree of personal independence and an environment that promotes independent behaviour.

### **Integration**

- Both interpersonal and community activity integration scores were higher for people who always lived in communities than for people who either continue to live in facilities or have moved from facilities to communities.
- Changes in integration scores were not related to whether or not people moved toward independent living.
- There is a stronger relationship between integration scores and quality of life scores for people who move toward independence than for people who do not move toward independence. This suggests that one way to enhance quality of life for people with developmental disabilities might be to foster increased interpersonal and community activities integration for people who live independently.

### **Personal support**

- There is no evidence that a broader range of natural supports is developing for people with developmental disabilities whose life situations remained stable.
- Moves to independent living are associated with greater practical and emotional support for adults with developmental disabilities.
- Independent living may be an important condition for personal support being related to quality of life. One way of enhancing quality of life among adults with developmental disabilities might be to broaden practical and emotional support among those who live more independently.

## **Overall Significance Of Ontario's Quality Of Life Project**

Ontario's Quality of Life Project has:

- Made Ontario an international leader in the field of quality of life and developmental disabilities.
- Established quality of life as a key service principle within developmental services throughout Ontario.
- Reaffirmed the importance of improving the lives of people with developmental disabilities.
- Gathered valuable information about the lives of adults with developmental disabilities in Ontario who receive MCSS funded services.