Subjective measurement of participation and environmental barriers and facilitators in population surveys: use of standardized tools with a sub-sample of the Quebec Activity Limitations Survey (QALS)

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Partial results of a research on Personal and Environmental Factors associated to poverty progression (Income + Social Participation) of people with disabilities in Quebec—Funded by Fonds québécois de recherche Société et culture (FQRSC) (2003-2005).
Methods

The collection of data was done by phone with a sub-sample (n= 259) of adults with disabilities identified in the Quebec activity limitations survey (QALS-1998), administered by Statistique-Québec (n =3070).

As, the original questionnaire did not document in a conceptually coherent, sufficient and useful way environmental factors and participation dimensions in order to understand their interactions, both Life-H and MQE short versions were added to the sub-sample survey assessing five years later the progression of poverty (2003).

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Disability Creation Process

(RINDCP, 1999)

Risk Factors

Cause

Personal Factors

Organic Systems

Integrity ↔ Impairment

Capabilities

Ability ↔ Disability

Environmental Factors

Facilitator ↔ Obstacle

Interaction

Life habits

Social Participation ↔ Handicap Situation

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Life habits measurement tool is relevant for measuring quality of participation as performance of socially defined activities in real life context.

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Life Habits

A daily activity or social role valued by the person and his/her socio-cultural context ensuring his/her survival and well-being throughout lifetime.

Examples:

• Getting into and out of bed
• Attending to his/her personal hygiene
• Sleeping properly (comfort, duration...).
• Taking part in social activities
• Taking care of children

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Specific measurements of LIFE-H

- The degree of accomplishment of life habits from 2 sub-scales:
  1) the level of difficulty and;
  2) the type of assistance required.
- The satisfaction regarding the accomplishment of each life habit.
- **Long form** (240 items): More in-depth analysis (90 min.)
- **Short form** (69 items): General screening (30 min.)
- **Short version** (16 items): Tracking (10 min.)

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### The accomplishment scale of LIFE-H

<table>
<thead>
<tr>
<th>Level of accomplishment</th>
<th>Type of assistance required</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>Accomplished with no difficulty (No help)</td>
</tr>
<tr>
<td>8</td>
<td>Accomplished with no difficulty (Technical aid or adaptation)</td>
</tr>
<tr>
<td>7</td>
<td>Accomplished with difficulty (No help)</td>
</tr>
<tr>
<td>6</td>
<td>Accomplished with difficulty (Technical aid or adaptation)</td>
</tr>
<tr>
<td>5</td>
<td>Accomplished with no difficulty (Human assistance)</td>
</tr>
<tr>
<td>4</td>
<td>Accomplished with no difficulty (Human assistance and technical aid or adaptation)</td>
</tr>
<tr>
<td>3</td>
<td>Accomplished with difficulty (Human assistance)</td>
</tr>
<tr>
<td>2</td>
<td>Accomplished with difficulty (Human assistance and technical aid or adaptation)</td>
</tr>
<tr>
<td>1</td>
<td>Accomplished by substitution</td>
</tr>
<tr>
<td>0</td>
<td>Not accomplished</td>
</tr>
<tr>
<td>N/A</td>
<td>Not applicable</td>
</tr>
</tbody>
</table>

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Format of LIFE-H (example)

Answer the following two questions. (Check the appropriate boxes.)

1. For each of the following life habits, indicate:
   A. How the person generally accomplishes it, and
   B. The type of assistance required to accomplish it.

2. For each of the following life habits, indicate the level of satisfaction with the way it is accomplished.

Question 1
A. Level of Accomplishment (Check only 1)
   - No difficulty
   - With difficulty

B. Type of Assistance (Check 1 or more, as required)
   - Accomplished by a proxy
   - Not accomplished
   - Not applicable
   - Assistive device
   - Adaptation
   - Human assistance

Question 2
Level of Satisfaction (Check only 1)
- Very dissatisfied
- Dissatisfied
- More or less satisfied
- Satisfied
- Very satisfied

Note: Keep in mind that answers should reflect the person’s usual way of carrying out life habits.
Environmental factors
Objective of the Measure of the Quality of Environment (MQE)

To evaluate the influence of environmental factors on the quality of participation (accomplishment of life habits) of a person or a specific population in relation to their functional capabilities.

Facilitators
(social participation)

Obstacles
handicap situation)
Design of MQE

- 109 (long form) or 26 (short form) questions relating to environmental factors’ QCDCP taxonomy (1991) easily crosswalkable with ICF one.

- A self-administered questionnaire that assesses the perceived influence of environmental factors

- Determination of an influence scale

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Categories of Environmental Factors (MQE)

1. Support and Attitudes (social network) (e3-e4)
2. Incomes, Job and Income Security (e5)
3. Governmental and Public Services (e5)
4. Physical Environment and Accessibility (e1-e2)
5. Aids, Devices and Technology (e1)
6. Equal Opportunity & Political Orientations (e5)

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The influence scale of the MQE

Following each item….

While taking into consideration your abilities and personal limits, indicate to what extent the following situations or factors generally influence your daily life.

<table>
<thead>
<tr>
<th>Score</th>
<th>Correspondance</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>Major obstacle</td>
</tr>
<tr>
<td>-2</td>
<td>Medium obstacle</td>
</tr>
<tr>
<td>-1</td>
<td>Minor obstacle</td>
</tr>
<tr>
<td>0</td>
<td>No influence</td>
</tr>
<tr>
<td>1</td>
<td>Minor facilitator</td>
</tr>
<tr>
<td>2</td>
<td>Medium facilitator</td>
</tr>
<tr>
<td>3</td>
<td>Major facilitator</td>
</tr>
<tr>
<td>n</td>
<td>Does not apply</td>
</tr>
<tr>
<td>p</td>
<td>I do not know</td>
</tr>
</tbody>
</table>

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Indicate to what extent the following factors or situations influence your daily activities and social roles by taking into account your abilities and personal limits.

<table>
<thead>
<tr>
<th>Support and attitudes of your family and friends</th>
<th>Influence Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1- Your family situation (you live alone, with a spouse, or with children).</td>
<td>-3 -2 -1 0 1 2 3</td>
</tr>
<tr>
<td>2- Support from the members of your family (presence, physical or household assistance).</td>
<td>-3 -2 -1 0 1 2 3</td>
</tr>
<tr>
<td>3- Support from your friends.</td>
<td>-3 -2 -1 0 1 2 3</td>
</tr>
<tr>
<td>4- Support from your neighbours.</td>
<td>-3 -2 -1 0 1 2 3</td>
</tr>
<tr>
<td>5- The attitudes of your family towards you.</td>
<td>-3 -2 -1 0 1 2 3</td>
</tr>
<tr>
<td>6- The attitudes of your friends towards you.</td>
<td>-3 -2 -1 0 1 2 3</td>
</tr>
</tbody>
</table>
## Characteristics of the sample

<table>
<thead>
<tr>
<th>Current age (years)</th>
<th>57 (±14)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>42.5%</td>
</tr>
<tr>
<td>Female</td>
<td>57.5%</td>
</tr>
<tr>
<td><strong>Nature of the disability</strong></td>
<td></td>
</tr>
<tr>
<td>motricity</td>
<td>64.5%</td>
</tr>
<tr>
<td>communication</td>
<td>8.5%</td>
</tr>
<tr>
<td>psychism</td>
<td>4.2%</td>
</tr>
<tr>
<td>multiples limitations</td>
<td>22.8%</td>
</tr>
<tr>
<td><strong>Since 1998, your principal disability ...</strong></td>
<td></td>
</tr>
<tr>
<td>decreased</td>
<td>14.3%</td>
</tr>
<tr>
<td>is remained stable</td>
<td>31.3%</td>
</tr>
<tr>
<td>is variable</td>
<td>18.5%</td>
</tr>
<tr>
<td>increased</td>
<td>35.9%</td>
</tr>
</tbody>
</table>

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Results part 1
Social participation restrictions
Significant participation restrictions in the accomplishment of 4 life habits

<table>
<thead>
<tr>
<th>Life habits</th>
<th>Participation restrictions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Severe (score ≤ 3)</td>
</tr>
<tr>
<td>Carrying out activities related to your home (maintenance, furnishing, and equipment)</td>
<td>47,9</td>
</tr>
<tr>
<td>Shopping and accessing services in your community</td>
<td>27,4</td>
</tr>
<tr>
<td>Participating in recreational activities (arts, sports, hobbies, outings, etc.)</td>
<td>23,2</td>
</tr>
<tr>
<td>Maintaining your physical fitness and your mental well-being</td>
<td>25,4</td>
</tr>
</tbody>
</table>

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Carrying out activities related to your home and severity of the disability (functional)

Severity of the disability
- Minor
- Moderate
- Severe

Participation restrictions

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Carrying out activities related to your home and change of the principal disability

Since 1998, your principal disability
- decreased
- is remained stable
- is variable
- increased

Participation restrictions

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Shopping and accessing services in your community and severity of the disability

The diagram illustrates the participation restrictions and severity of disabilities.

- **Severity of the disability**:
  - Minor
  - Moderate
  - Severe

- **Participation restrictions**

- **Percent**
  - 0%
  - 20%
  - 40%
  - 60%
  - 80%
  - 100%

The graph shows the percentage of individuals with different severity levels experiencing participation restrictions in their community.
Shopping and accessing services in your community and change of the principal disability

Since 1998, your principal disability
- decreased
- is remained stable
- is variable
- increased

Participation restrictions

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Results part 2
Environmental factors
Factors identified as *facilitators* to the quality of social participation:

<table>
<thead>
<tr>
<th>Factor</th>
<th>% of subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support from those around you (family, friends, colleagues)</td>
<td>75</td>
</tr>
<tr>
<td>Personal vehicle that you use</td>
<td>72</td>
</tr>
<tr>
<td>Electronic communication (telephone, Internet, fax)</td>
<td>69</td>
</tr>
<tr>
<td>Assistive devices (availability, use, maintenance)</td>
<td>67</td>
</tr>
<tr>
<td>Home care services (health, housekeeping, rehabilitation)</td>
<td>67</td>
</tr>
<tr>
<td>Attitudes of those around you (family, friends, colleagues)</td>
<td>62</td>
</tr>
</tbody>
</table>
Factors identified as *obstacles* to the quality of social participation

<table>
<thead>
<tr>
<th>Factor</th>
<th>% of subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Climatic conditions</td>
<td>59</td>
</tr>
<tr>
<td>Time allowed to carry out tasks</td>
<td>56</td>
</tr>
<tr>
<td>Noise or sound intensity</td>
<td>42</td>
</tr>
<tr>
<td>Rules and administrative procedures</td>
<td>33</td>
</tr>
<tr>
<td>Personal income</td>
<td>32</td>
</tr>
<tr>
<td>Current availability of jobs in your community</td>
<td>29</td>
</tr>
</tbody>
</table>

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Climatic conditions and severity of the disability

Gravity of the disability
- Minor
- Moderate
- Severe

E.F. Influence scale

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Climatic conditions and change of the principal disability

Since 1998, your principal disability

- Decreased
- Is remained stable
- Is variable
- Increased

E.F. Influence scale

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The time allowed to carry out tasks and severity of the disability

![Bar chart showing severity of disability and time allowed to carry out tasks](chart.png)

- **Severity of the disability**: Minor, Moderate, Severe
- **E.F Influence scale**: Percent

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Results part 3
Exemplifying the interaction between perceived quality of participation and perceived influence of environmental factors

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Carrying out activities related to your home and support from those around you

Support from those around you

- Obstacle
- No influence
- Facilitator

Carrying out activities related to your home

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Carrying out activities related to your home and attitudes of those around you

Attitudes from those around you

- Obstacle
- No influence
- Facilitator

Carrying out activities related to your home

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Carrying out activities related to your home and time allowed to carry out tasks

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Shopping and accessing services in your community and personal vehicle that you use

- **Severe**
  - Obstacle: 50%
  - No influence: 10%
  - Facilitator: 40%

- **Moderate**
  - Obstacle: 20%
  - No influence: 20%
  - Facilitator: 60%

- **Minor**
  - Obstacle: 10%
  - No influence: 50%
  - Facilitator: 40%

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Shopping and accessing services in your community and physical accessibility of building that you need to go into your community.

Physical accessibility of building that you need to go into your community

- **Severe**
  - Obstacle: 50%
  - No influence: 30%
  - Facilitator: 20%

- **Moderate**
  - Obstacle: 40%
  - No influence: 30%
  - Facilitator: 30%

- **Minor**
  - Obstacle: 20%
  - No influence: 50%
  - Facilitator: 30%

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Shopping and accessing services in your community and assistive devices

<table>
<thead>
<tr>
<th>Obstacle</th>
<th>Severe</th>
<th>Moderate</th>
<th>Minor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10</td>
<td>20</td>
<td>30</td>
</tr>
</tbody>
</table>

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Participating in recreational activities and personal income

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Participating in recreational activities and insurance and other financial compensation programs

- Severe
- Moderate
- Minor

Insurance and other financial compensation programs

- Obstacle
- No influence
- Facilitator

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Participating in recreational activities and personal vehicle that you use

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Participating in recreational activities and physical accessibility of building where you need to go into your community.
Participating in recreational activities and time allowed to carry out tasks

Time allowed to carry out tasks

- Obstacle
- No influence
- Facilitator

Participating in recreational activities

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Conclusion

- Actual canadian disability population surveys (PALS, QALS) don’t document in a conceptually sound and complete way socially defined participation or life situations and their E.F. determinants. The responsibility weight is still mainly on the individual.

- Lack of sound indicators for measuring impact of social policies and contextual change on the outcome of the personal factors/EF interaction.

- Short forms of Life-H and MQE tools revealed to be useful to do so and indicate us ways for monitoring EF change on exercise of human rights and quality of perceived social participation.

- Need of parallel development of subjective and objective participation indicators including EF influence.


• International Network on Disability Creation Process (INDCP) /Réseau international sur le processus de production du handicap (RIPPH); [www.ripph.qc.ca](http://www.ripph.qc.ca)

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