

# The development of the Personal Outcomes Scale

## Measuring Quality of Life

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# The concept of Quality of Life

- From a concept to a measurable construct
- From a model that describes what to a framework that suggests how
- From an idiographic (microsystem) focus to a multi-system perspective
- From an idea to an action-oriented change agent

# Empirically based Model of QOL

an important conceptual and measurement  
framework for

- assessing personal outcomes
- guiding organization and systems-level policies and practices
- and implementing quality improvement strategies

# QUALITY OF LIFE CONCEPT CONCEPTUAL FRAMEWORK

<u>Component</u>	<u>Definition and Examples</u>
QOL Factor	Higher Order Construct (e.g. Independence, Social Participation, and Well-Being)
QOL Domains	Set of Factors Defining Multidimensionality of QOL <ul style="list-style-type: none"><li>&gt;<u>Personal Development &amp; Self-Determination</u> (<i>Independence</i>)</li><li>&gt;<u>Interpersonal Relations, Social Inclusion, Rights</u> (<i>Social Participation</i>)</li><li>&gt;<u>Emotional, Physical, Material Well-Being</u> (<i>Well-Being</i>)</li></ul>
QOL Indicators	QOL-Related Perceptions, Behaviors and Conditions That Define Operationally Each QOL Domain <ul style="list-style-type: none"><li>&gt;<u>Personal Development</u>: ADLs and IADLs</li><li>&gt;<u>Self-Determination</u>: choices/decisions, personal goals</li><li>&gt;<u>Interpersonal Relations</u>: social networks, friendships</li><li>&gt;<u>Social Inclusion</u>: community integration/participation</li><li>&gt;<u>Rights</u>: human and legal</li><li>&gt;<u>Emotional Well-Being</u>: safety and security</li><li>&gt;<u>Physical Well-Being</u>: health and nutritional status</li><li>&gt;<u>Material Well-Being</u>: financial status, employment</li></ul>
Indicator Items	Specific Items Used to Assess Personal Outcomes On The Basis of Perceived Well-Being ('Self Report') or An Objective Indicator of the Person's Life Experiences/Circumstances ('Direct Observation')

<u>QOL Factor</u>	<u>QOL Domain</u>	<u>Exemplary QOL Indicators</u>
<b>Independence</b>	Personal Development  Self-Determination	Education status, personal skills, adaptive behavior (ADLs IADLs) Choices/decisions, autonomy, personal control, personal goals
<b>Social Participation</b>	Interpersonal Relations  Social Inclusion  Rights	Social networks, friendships, social activities, interactions, relationships Community integration/participation, community roles, supports Human (respect, dignity, equality) Legal (legal access, due process)
<b>Well-Being</b>	Emotional Well-Being  Physical Well-Being  Material Well-Being	Safety & security, positive experiences, contentment, self-concept, lack of stress Health Status Nutritional Status Recreation/Physical Exertion Financial status, employment status, housing status, possessions

# QUALITY OF LIFE MEASUREMENT FRAMEWORK

- **Focus on Personal Outcomes**
  - Referenced to Core QOL Domains and Indicators
  - Measured on Basis of Self-Report and Direct Observation of Indicator Items
- **Emphasis on Stakeholder Involvement**
  - Indicator Item Selection (Focus Groups, Etic Items)
  - Survey Administration (Consumer-Based)
  - User Friendly Assessment Strategies
- **Quantification of Self-Report and Direct Observation Items**
  - Each Indicator Item is Assessed on the Basis of Self-Report and Direct Observation
  - Likert (3-5 point) Ratings are Used for Both Self-Report and Direct Observation Assessments

# Ten steps in the Scale's development

1. The initial item pool was derived from previous research and published literature regarding domain-specific indicator items such as those shown herefore.
2. From the beginning our intent was to develop parallel forms of a scale that would allow for the measurement of both subjective and objective indicators. Our intent was operationalized in the *Personal Outcomes Scale* in the form of a Self Report and a Direct Observation version. For comparability purposes, the content of each item should be (and eventually was) the same for Self Report and Direct Observation.
3. Expert judges in the field evaluated each item in reference to four criteria; (a) reflect what people want in their lives ("importance"); (b) relate to current an future policy issues ("relevance"); (c) those that the service/supports provider has some control over ("feasibility"); and (d) can be used for reporting and quality improvement purposes.

4. Focus groups composed of important stakeholders (e.g. professionals, organization personnel, consumers, persons with different diagnoses, and families) evaluated each potential item/indicator in reference to its value and importance to them.
5. A 3-point Likert scale format was developed for the respondent to evaluate each item on two subscales: a Self Report Scale and Direct Observation Scale.
6. A pilot version of the Scale was developed and administered to a representative sample of about 90 clients of the population(s) for whom the Scale will be used.
7. Pilot study data were analyzed to confirm the reliability, core QOL domain loading, robustness, and etic property of the respective item. Items were selected that met the criteria listed in steps 2 and 3.
8. A second pilot version of the Scale was developed and administered to a representative sample of 79 clients of the population(s) for whom the Scale will be used.
9. Pilot study data were analyzed to confirm the reliability, core QOL domain loading, and robustness of the respective item. Final items were selected that met the criteria listed in steps 2 and 3.
10. The assessment instrument was finalized, including administration and scoring instructions.

# Administration Procedures

- Interviewer Qualifications
- The Personal Outcomes Scale (P.O.S.) should be administered by a professional who has extensive experiences in the field of intellectual disabilities and training in the administration and scoring of behavioural assessments.
- This professional should be familiar with the QOL conceptual and measurement frameworks. In addition the interviewer should understand the importance of the concept of QOL in both the person's life and the services and supports provided to the person.
- In administering the Scale, the interviewer should be sensitive to the cultural characteristics of respondents, the feelings of the client or respondent who is being interviewed, and the fact that the experiences of most clients with disabilities have not been good since previous evaluations have typically led to a diagnosis or imposed intervention.
- The interviewer should also be aware that responses may vary due to personal characteristics, experiences, and circumstances of respondents, and that accommodation may need to be made with respect to the language spoken and interviewing techniques, such as using prompts, augmentative and alternative communication techniques

# SELF REPORT ASSESSMENT

- Assessment Focus

- The interviewer needs to remind the client/proxy that they should think about “what is true generally.” That is, the respondent should think about life events and circumstances in general, realizing that transitory or momentary changes in one’s life should not determine how they score each item.

- Pre-Interview ‘Getting to Know One Another’

- Respondent Ratings

- The client is asked to provide a rating of his/her status on the respective item
- All items on the Scale must be scored

- Proxy Qualifications and Scoring

- If proxies are used they must have known the person being rated for at least three months and have had the recent opportunity to observe the person in one or more environments for substantial periods of time (3-6 months).

# DIRECT OBSERVATION ASSESSMENT

- Respondent Qualifications
  - Respondents must have known the person for at least three months and have the recent opportunity to observe the person in one or more environments for a substantial period of time (3-6 months).
- Assessment Focus
  - The interviewer needs to remind the respondent that they should think about “what is generally true for the client.” That is, the respondent should think about life events and circumstances in general, (transitory or momentary changes in the life of the person should not determine how they score each item.)
- Pre-Interview ‘Getting to Know One Another’
- Respondent Ratings
  - The respondent is asked to provide a rating of how they see the client’s life events and circumstances.
  - All items on the Scale must be scored

# Standardization Procedures

## *Interviewer Training Guidelines*

1. Overview of the concept of quality of life and the QOL conceptual and measurement frameworks.
2. Overview of the POS including two sections (self report and direct observation), response format (3-point Likert rating scale), and Interviewer and Respondent Qualifications.
3. Scoring of the POS and transferring scores to the POS Summary Profile.

4. Administration procedures: (a) review administration procedures; (b) have person introduce self and the purpose of the field test; (c) have interviewer desensitize the respondent (is NOT a measure of the person's ability and will not affect eligibility for services/supports; information will be used only for feedback and to improve services and supports); (d) clarify/ explain any items that respondent doesn't understand or needs additional clarification (assisting the respondent produces better data and information that is more reliable and more valid).
5. Practice session. Each potential interviewer should actually administer the Scale to a partner during the training session. The person should score the profile, and demonstrate that he/she can determine raw and total scores and enter the data correctly on the Summary Form
6. Validation procedure: The instructor/master trainer needs to observe # 5 and provide feedback about any problems encountered in the practice session and provide the opportunity for a second practice session.

# Psychometric properties

## Standardization Data

- Our approach to standardization has been to focus on establishing three indices of reliability and three indices of validity.
- The reliability indices are
  - a measure of internal consistency (Alpha coefficients),
  - inter-rater reliability
  - the consistency between self report and direct observation.
- The validity indices include
  - content,
  - construct, and
  - concurrent validity.

# Internal Consistency

Data were collected on 79 clients and 79 respondents (direct support staff or family members) during the second pilot study.

These data were used to calculate Cronbach Alpha's.

	Self-Report	Direct Observation
Personal development	.73	.65
Self-Determination	.72	.75
Interpersonal Relations	.72	.67
Social Inclusion	.81	.77
Rights	.50	.40
Emotional Wellbeing	.70	.60
Physical Wellbeing	.68	.59
Material wellbeing	.56	.44
Total	.89	.86

# Interrespondent Reliability

	Self Report Client versus Proxy	Direct Observation Staff Member 1 versus Staff Member 2
Personal development	.57*	.67*
Self-Determination	.47*	.29
Interpersonal Relations	.68*	.67*
Social Inclusion	.76*	.78*
Rights	.78*	.76*
Emotional Wellbeing	.60*	.69*
Physical Wellbeing	.45*	.79*
Material wellbeing	.55*	.79*
Total	.70*	.78*

\*  $p < 0.01$

# Consistency Between Self Report and Direct Observation

	Pearson's Correlation Coefficients Between Self Report and Direct Observation	
Personal development	.78*	
Self-Determination	.72*	
Interpersonal Relations	.52*	
Social Inclusion	.74*	
Rights	.80*	
Emotional Wellbeing	.42*	
Physical Wellbeing	.63*	
Material wellbeing	.71*	
Total	.83*	* $p < 0.01$

# Content validity

## Three processes

### 1. Literature Review

- 6-9 potential indicators/outcome measures were developed, based on the 8 core domains on QOL and their indicators

### 2. Expert judgment on 4 criteria:

- does the item reflect what people want in their lives (“importance”);
- does the item relate to current and future policy issues (“relevance”);
- are the items assessed those that the service/supports provider has some control over (“feasibility”); and
- can the ratings on the items be used for reporting and quality improvement purposes.

### 3. Focus groups in Belgium and the Netherlands composed of important stakeholders (e.g. professionals, organization personnel, clients, and families) evaluated each potential item/indicator identified in step three in reference to its value and importance (that is its cultural relevance) to them

# Construct Validity

## Inter-correlations of POS Subscales and the total (n=79): Self Report

	PD	SD	IPR	SI	R	EWB	PHWB	MWB
Total score	.71**	.67**	.73**	.69**	.73**	.59**	.41**	.54**

$p < 0.01$  (two-tailed)

Key: PD (Personal Development), SD (Self-Determination), IPR (Interpersonal Relations), SI (Social Inclusion), R (Rights), EMB (Emotional Well-Being), PHWB (Physical Well-Being), MWB (Material Well-Being)

# Construct Validity

## Inter-correlations of POS Subscales and the total (n=79): Direct Observation

	PD	SD	IPR	SI	R	EWB	PHWB	MWB
Total score	.64**	.71**	.69**	.72**	.77**	.57**	.35**	.59**

$p < 0.01$  (two-tailed)

Key: PD (Personal Development), SD (Self-Determination), IPR (Interpersonal Relations), SI (Social Inclusion), R (Rights), EMB (Emotional Well-Being), PHWB (Physical Well-Being), MWB (Material Well-Being)

# Sample Characteristics (n=79)

<b>Gender</b>	%
Male	54,4
Female	45,6

**Age** 45,82 (range 18-79)

<b>ID</b>	
Mild	29,1
Moderate	36,7
Severe	16,5
Profound	17,7

<b>Residential status</b>	
Community living	73,3
Small groups	13,9
Large facility	12,7

# Concurrent Validity

## Pearson's Correlation Coefficients Between Direct Observation Version of the POS and the GENCAT (n=58)

Domain	<i>Correlation between Direct Observation POS and GENCAT</i>
Personal Development	.61*
Self-Determination	.79*
Interpersonal Relations	.57*
Social Inclusion	.37*
Rights	.47*
Emotional Well-being	.55*
Physical Well-being	.65*
Material Well-being	.23
Total	.87*

# Conclusion:

## The POS:

- is inductively developed and theory-based
- collected data prove reliability and validity
- and development procedures underscore the importance of involvement of stakeholders in the development and in the QOL-assessment as such

# Personal Outcomes Scale

A Scale to Assess an Individual's Quality of Life



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PERSONAL OUTCOMES SCALE:  
DOMAINS AND INDICATOR QUESTIONS

**Self-Report**

**Domain: Personal Development**

Personal development deals with your education (including lifelong learning), and personal competences (including learning and demonstrating skills). Before completing the items you can first think about the following:

- *Learning about the things you are interested in.*
- *Learning skills to become more independent.*
- *Being able to take care of yourself.*
- *Being able to follow your own interest.*
- *Having access to information.*

## Self-Report

- 
1. To what degree are you able to feed yourself, get up and down, use the toilet, and dress yourself?
- |                       |                 |                       |
|-----------------------|-----------------|-----------------------|
| Generally Independent | With Assistance | Can't Do<br>On My Own |
|-----------------------|-----------------|-----------------------|
- 
2. To what degree are you able to prepare meals, keep house, move around on your own, take medication?
- |                       |                 |                       |
|-----------------------|-----------------|-----------------------|
| Generally Independent | With Assistance | Can't Do<br>On My Own |
|-----------------------|-----------------|-----------------------|
- 
3. Are you learning skills to do more things, or do you follow courses / are you engaged in some type of education?
- |      |      |             |
|------|------|-------------|
| Many | Some | Few, if any |
|------|------|-------------|
- 
4. Do you have an opportunity to demonstrate skills you have?
- |            |           |                 |
|------------|-----------|-----------------|
| Frequently | Sometimes | Seldom or never |
|------------|-----------|-----------------|
- 
5. Do you have access to information that you are interested in: e.g. newspaper, magazine/ journal, internet, library?
- |              |          |                 |
|--------------|----------|-----------------|
| Considerably | Somewhat | Seldom or never |
|--------------|----------|-----------------|
- 
6. Do you use a computer, a cell phone, or a calculator?
- |            |           |                 |
|------------|-----------|-----------------|
| Frequently | Sometimes | Seldom or never |
|------------|-----------|-----------------|
-

## Domain: Self-Determination

Self-determination deals with your personal goals and objectives, decision making and making your own choices. Before completing the items you can first think about the following:

- *Making your own choices*
- *Deciding yourself what to wear*
- *Expressing your own opinion*
- *Acting on your personal goals and aspirations*

## Self-Report

- |   |                      |              |                 |
|---|----------------------|--------------|-----------------|
| 1. Are you given choices (e.g. what to wear, what to eat, places to go)?                            | Frequently           | Sometimes    | Seldom or never |
| 2. If you are given choices, do you make them ?   | Always               | Sometimes    | Seldom or never |
| 3. Can you decide not to do something asked of you?   | Always               | Sometimes    | Seldom or never |
| 4. Do people take seriously your decisions?   | Always               | Sometimes    | Never           |
| 5. Do you control at least part of your money?  | Considerable control | Some control | No control      |
| 6. Do you have the opportunity to express your opinion on what you prefer to do, wear, go, eat etc. | Always               | Sometimes    | Seldom or never |

# PERSONAL OUTCOMES SCALE: DOMAINS AND INDICATOR QUESTIONS

## Direct Observation

Domain: Personal Development

Personal development deals with the person's education (including lifelong learning), and personal competence (including learning and demonstrating skills). Before completing the direct observation items one should first collect information on the person in relation to Personal Development by answering the following questions.

### Objective measures

- 1. Does the person follow a course or is he engaged in some type of education at this moment?*
- 2. Does the person read a newspaper or a magazine / journal?*
- 3. Does the person goes to a library?*
- 4. Does the person own a computer or does he has the use of a computer?*

### Direct Observation

1. How would you rate the degree to which the person does the following activities of daily living, feeds self, gets up and down, toilets, dresses self ?

Generally Independent

With Assistance

Can't Do  
On Own

2. How would you rate the degree to which the person does the following instrumental activities of daily living: prepares meals, keeps house, moves around on own, takes medication?

Generally Independent

With Assistance

Can't Do  
On Own

3. How many skills has the person learned, or educational experiences has the person had in the last 6-12 months?

Many

Some

Few, if any

4. How often is the person able to demonstrate the skills (e.g. work, school, at home) that he/she has?

Frequently

Sometimes

Seldom or never

5. To what degree has the person access to information he / she has an interest in (e.g. newspaper, magazine/ journal, internet, library)?

Considerably

Somewhat

Seldom or never

6. How often does the person use assistive technology?

Frequently

Sometimes

Seldom or never

# PERSONAL OUTCOMES SCALE: DOMAINS AND INDICATOR QUESTIONS

## Direct Observation

### Domain: Self-Determination

Self determination includes personal control, personal goals and objectives, decision making, and making choices. Before completing the direct observation items one should first collect information on the person in relation to self-determination by answering the following questions.

#### Objective measures

1. *Does the person dream of a career (what job to perform in the future?)*
2. *Does he person has concrete ideas on a job?*
3. *What has to change to realise the job he dreams of?*
4. *What can the person do to make it happen?*
5. *Does the person has plans for his life?*
6. *Does the person have a budget?*
7. *Can the person decide how to spend this budget?*

## Direct Observation

1 To what degree does the person have control over what to wear, what to eat, places to go, etc.?

Considerable

Some

Little or none

2 When presented with choices, to what degree does the person exercise them?

Frequently

Sometimes

Seldom or never

3 To what extent does the person makes decisions that are important to him /her—even though it might not be what others want?

Considerably

Somewhat

Seldom or never

4. To what degree are the decisions made by the person respected (regardless of the specific decision)?

Greatly respected &  
followed

Respected somewhat

Not respected

5 To what degree does the person control at least some portion of their money?

Considerable control

Some control

No control

6 To what degree does the person have the opportunity to express what he/she wants?

Always

Sometimes

Seldom or never



# More about the Personal Outcomes Scale:

[www.poswebsite.org](http://www.poswebsite.org)



Thank you very much  
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