Quality of Life, moving forward from deficit thinking to supports

Prof. dr. Claudia Claes

Expertise Centre on Quality of Life
Introduction
Three little stories
The happiest country in the world..
“The gross national product measures everything, except that which makes life worthwhile” (Senator Kennedy, 1968)
Overview

Changing Paradigms
Quality of Life
Supports and Supports Thinking
The Micro, Meso and Macro level

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1. Changing paradigms
Changing Paradigms

“We live in a changing world” (R.L. Schalock, 2010)
The Concept of Disability has changed

The Approach to Human Functioning has changed

Societal views have changed
The concept of disability has changed

- Disability as an individual pathology
- Disability as a social pathology
**Disability seen as an individual pathology**

"Medical model"

- The "problem" lies in the person.
- Disability is the direct consequence of the impairment.
- Disability is a problem related solely to health.
- Solutions are designed by experts based on a diagnosis.
- **Approach:** Eliminate or cure the disability: "normalize."

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**Disability seen as a social pathology**

"Social model"

- The problem lies mainly in the environment and in society, in general.
- Disability is the direct consequence of social limitations to accessibility and to equality of opportunities.
- Disability is a human rights issue.
- Persons with disabilities should participate in designing solutions.

**Approach:** Eliminate physical, social, political, and economic barriers. **Persons with disabilities are considered the citizens they are. HUMAN RIGHTS**
Disability can be defined as the expression of limitations in individual functioning within a social context.
The ICF model

Health Condition
(disorder or disease)

Body Functions & Structure
→ Activity
→ Participation

→

Environmental Factors

Personal Factors
The AAIDD model

I. INTELLECTUAL ABILITIES
II. ADAPTIVE BEHAVIOR
III. HEALTH
IV. PARTICIPATION
V. CONTEXT

SUPPORTS

Human Functioning

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5 assumptions

- Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture.
- Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
• Within an individual, limitations often coexist with strengths.
• An important purpose of describing limitations is to develop a profile of needed supports.
• With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve.
An International Focus on Human Rights
2. Quality of Life
Quality of life

‘A term that everyone understands, but which few can define’ (Campbell, 1977)

What do you think about when hearing the term ‘Quality of Life’?

What makes your life qualitative?
Crosby, Stills & Nash

Our house is a very very very very fine house

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195.627 results in Web of Science
A search for “The Holy Grail”?
“The term quality of life is great in speeches, but when it is given the stature of research concept, it becomes an uncertain tool unless it is controlled by a precise definition and rigorous discipline in thoughts and word (Wolfensberger, 1994:318)”
A little history
The state exists for the sake of a good life, and not for the sake of life only.

(Aristotle)

Epicurus says: “Life is good!
Make sure to enjoy it.”

Happiness may be defined as good fortune joined to virtue, or a independence, or as a life that is both agreeable and secure.

(Aristotle)

It is impossible to live a pleasant life without living wisely and well and justly. And it is impossible to live wisely and well and justly without living a pleasant life.

(Epicurus)
The rise of the concept of QoL

- First use of the term QoL: after World War II
- Goal: describe the effect of material welfare on individuals’ lives ➔ Economic model

- 1960’s: attention for aspects of health, family, housing ➔ Social Indicators Movement

- 1970’s: attention for QoL in health care research and clinical practice, especially for patients with chronic diseases
- Often simplified to a persons’ health status: Health-Related Quality of Life
The rise of the concept of QoL (part II)

• Last two decades: change in the way care and support are provided to people with disabilities and long-term care needs

• Influenced by deinstitutionalisation; community based support, consumer empowerment, person-centered planning

• Shift from strict medical model to support model

⇒ Nowadays: important outcome measure and assessment tool in health care
The Schalock & Verdugo Model
- Universal
- 8 domains
- Context is the community
- More than satisfaction
- Interrelations
The concept QoL is: UNIVERSAL
8 domains

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

**Quality of Life and UN Convention (Schalock & Verdugo, 2011)**

### Domain Quality of Life

<table>
<thead>
<tr>
<th>Domain</th>
<th>Article UN-Convention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Development</td>
<td>24</td>
</tr>
<tr>
<td>Self-Determination</td>
<td>14, 19, 21</td>
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<tr>
<td>Interpersonal Relations</td>
<td>23</td>
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<tr>
<td>Social Inclusion</td>
<td>8, 9, 18, 20, 27, 29, 30</td>
</tr>
<tr>
<td>Rights</td>
<td>5-7, 10-13, 15</td>
</tr>
<tr>
<td>Emotional Well-Being</td>
<td>16, 17</td>
</tr>
<tr>
<td>Physical Well-Being</td>
<td>16, 25, 26</td>
</tr>
<tr>
<td>Material Well-Being</td>
<td>28</td>
</tr>
</tbody>
</table>
Satisfaction ??
Subjective Well-Being

- A normally positive state of mind that involves the whole life experience

- Subjective wellbeing homeostasis

- Each person has a set-point for SWB
Subjective Well-Being Cummins

Set point
Core affect

Internal buffers
Sense of control
Connectedness
Purpose in life

Output
Subjective Wellbeing

External buffers
Money
Relationships
Carer

Potential stressors

Carer-mediated empowerment
### Subjective/objective

<table>
<thead>
<tr>
<th>Objective</th>
<th>Subjective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>Bad</td>
</tr>
<tr>
<td>Good</td>
<td><em>Well-being</em></td>
</tr>
<tr>
<td>Bad</td>
<td><em>Adaptation</em></td>
</tr>
</tbody>
</table>
Interconnectedness

**Internal buffers**
- Selfdetermination
- Personal development
- Physical WB

**External buffers**
- Interpersonal relations
- Material WB
- Rights
- Social inclusion

**Emotional WB**
Discrepancy between HRQoL en QoL

• HRQoL: the effects of a disease or health conditions on the daily functioning of individuals with special attention for their physical and mental health

• HRQoL: Focus on pathology and deficits

• QoL: positive connotation, attention for overall well-being and satisfaction with life

• Absence of pathology ≠ having a good QoL
Interrelatedness

- Functioneren
- Organisatie
- Inclusie
- Support
- Engagement
- Empowerment
- QOL
Emotional Well-Being

Physical Well-Being

Material Well-Being

Interpersonal Relations

Rights

Personal Development

Social Inclusion

Self-Determination

$R^2 = .38$

$R^2 = .43$

$R^2 = .58$

$R^2 = .25$

$R^2 = .08$

$* p < .05$

$** p < .01$
<table>
<thead>
<tr>
<th></th>
<th>(Moonen et al., 2010)</th>
<th>beperking (De Windt &amp; Lannau, 2009)</th>
<th>Windt &amp; Lannau, 2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persoonlijke ontwikkeling</td>
<td>12,72</td>
<td>11,43</td>
<td>12,36</td>
</tr>
<tr>
<td>Zelfbepaling</td>
<td>16,93</td>
<td>15,40</td>
<td>13,09</td>
</tr>
<tr>
<td>Interpersoonlijke relaties</td>
<td>15,66</td>
<td>14,86</td>
<td>12,59</td>
</tr>
<tr>
<td>Sociale inclusie</td>
<td>13,04</td>
<td>12,31</td>
<td>9,34</td>
</tr>
<tr>
<td>Rechten</td>
<td>16,70</td>
<td>15,05</td>
<td>13,21</td>
</tr>
<tr>
<td>Emotioneel welbevinden</td>
<td>15,45</td>
<td>15,69</td>
<td>15,13</td>
</tr>
<tr>
<td>Fysiek welbevinden</td>
<td>13,54</td>
<td>13,46</td>
<td>14,89</td>
</tr>
<tr>
<td>Materieel welbevinden</td>
<td>14,17</td>
<td>13,08</td>
<td>14,25</td>
</tr>
</tbody>
</table>
Conceptualisation and Measurement of Quality of Life Based on Schalock and Verdugo’s Model: A Cross-Disciplinary Review of the Literature

Nele Van Hecke¹ · Claudia Claes² · Wouter Vanderplasschen¹ · Jessica De Maeyer² · Nico De Witte³ · Stijn Vandevelde¹
Conceptual Principles

- QOL is multidimensional construct
- The concept has etic (universal) and emic (culture bound) properties
- QOL is composed of both an objective and a subjective component
- QOL is seen from a system’s perspective
- QOL is dynamic
- QOL is broader than the absence of disease

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Measurement Principles

• Methodological pluralism (different perspectives)
• Involvement of the target group
• Self-report and Proxy report
• Objective and Subjective indicators
3. Supports and Supports Thinking

(Thompson, J (2013)
People with ID are different from the general population because they require more and different types of support to fully participate in the activities of daily life.

Understanding people by their support needs is more functional (i.e., useful) for purposes of planning than understanding their deficits, etiology, etc (Thompson, 2013).
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Supports are Universal & Supports are Uniquely Personal  (Thompson, 2013)
Support Needs & Supports (Thompson, 2013)

- **Support Needs** - “a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning” ~ Thompson et al., 2009, p.135.

- **Supports** - “resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning” ~ Luckasson et al., 2002, p. 151.
Demands of the Environment

- Settings
- Activities
- Health
- Intelligence
- Problem Behavior
- AB

MIND THE GAP

Personal Competence
People that Perform Roles compared to People that Have a Fulfilling Life (thompson, 2013)

<table>
<thead>
<tr>
<th>Domains of Life</th>
<th>Performers</th>
<th>Fulfilled People</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Living</td>
<td>A Shelter</td>
<td>A home</td>
</tr>
<tr>
<td>Community Living</td>
<td>Get out and around to get what is needed</td>
<td>Active members of an interdependent world - know others and others know them</td>
</tr>
<tr>
<td>Life-long Learning</td>
<td>Learning Goals are imposed</td>
<td>Learning goals are chosen based on interests</td>
</tr>
<tr>
<td>Employment</td>
<td>Have work to do</td>
<td>Have a contribution to make</td>
</tr>
<tr>
<td>Health &amp; Safety</td>
<td>Minimize Risks &amp; Mistakes</td>
<td>Take some chances &amp; learn from mistakes</td>
</tr>
<tr>
<td>Social</td>
<td>Have acquaintances</td>
<td>Have friends</td>
</tr>
<tr>
<td>Protection &amp; Advocacy</td>
<td>Advocate for self based on laws, rules, etc.</td>
<td>Know there is a time to take a stand, and know there are times to give &amp; take,</td>
</tr>
</tbody>
</table>
Supports provided to people with multiple and profound ID limited to lower level human needs?
4. The Micro, the Meso and the Macro Level
QOL – micro – meso - macro
The Micro Level
A person centered support system

Input ➔ Througput ➔ Output

- the goals and perspectives of a person,
- his or her support needs and
- the quality of his / her life at a certain moment in time

An Individual Supports Plan, based on and in line with the input

Quality of Life. This QOL therefore should be measured as a personal outcome of supports.

Right to left (outcome based) thinking! (Schalock)
Supports Intensity Scale
Personal Outcomes Scale
A Scale to Assess an Individual’s Quality of Life

Dr. Jos van Loon
Prof.dr. Geert van Hove
Prof.dr. Robert Schalock
Lic. Claudia Claes
2008
Component 1: Identify Desired Life Experiences and Goals

Component 2: Assess Support Needs

Component 3: Develop and Implement the Individualized Plan
- Use results from Components 1 & 2 to prioritize preferences and identify personal outcomes and needed supports
- Identify the support sources that are needed as well as those that are currently used
- Write an individualized plan that specifies the pattern and types of supports needed to participate in specific settings and activities and implement the plan

Component 4: Monitor Progress
- Monitor the extent to which individualized plan was implemented as envisioned

Component 5: Evaluation
- Evaluate the extent to which personal outcomes have been enhanced
<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1 - C3 (Lifelong Learning)</td>
<td>Protection &amp; Advocacy 1, 5 &amp; 7</td>
</tr>
<tr>
<td>Self-Determination</td>
<td>C 8 (Lifelong Learning) Protection &amp; Advocacy 1, 5 &amp; 7</td>
</tr>
<tr>
<td>Interpersonal Relations</td>
<td>B4, B7 (Community Living) D3, D4 (Employment) F1 - F7 (Social Activities)</td>
</tr>
<tr>
<td>Social Inclusion</td>
<td>B1, 2, 3, 5, 6, 8 (Community Living) F8 (Social Activities)</td>
</tr>
<tr>
<td>Rights</td>
<td>Protection &amp; Advocacy 3, 4, 6, 8</td>
</tr>
<tr>
<td>Emotional Well-being</td>
<td>C9 (Lifelong Learning) E8 Exceptionals medical support needs</td>
</tr>
<tr>
<td>Physical Well-being</td>
<td>C7 E1 - E7 (Health and Safety)</td>
</tr>
</tbody>
</table>
The influence of supports strategies, environmental factors, and client characteristics on quality of life-related personal outcomes

Claudia Claes a, Geert Van Hove b, Stijn Vandeveldt a, Jos van Loon b, Robert Schalock c

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https://doi.org/10.1016/j.ridd.2011.08.024

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Abstract

The concept of quality of life (QOL) is increasingly being used as a support provision and outcomes evaluation framework in the field of intellectual disability.
Abstract

Currently, disabilities organizations are increasingly being challenged by the requirement for...
A Systems Approach to Social Entrepreneurship; Identifying Input-Throughput-Output Factors

- Input:
  - Social Vision
  - Exploiting Opportunities
  - Maximizing Resources

- Throughput:
  - Entrepreneurial Orientation
  - Critical Thinking Skills
  - Networking
  - Capacity Building

- Output:
  - Improving People’s Lives
  - Community-Building
  - Improving Society
• “Social entrepreneurship should facilitate the growth and development of a community” (Peredo & Chrisman, 2006)

• “Quality of Life” (Schalock)
<table>
<thead>
<tr>
<th>Outcome Category</th>
<th>Measurable Indicators</th>
</tr>
</thead>
</table>
| Improving Peoples’ Lives (Individual and Family Quality of Life) | - Individual referenced quality of life domains: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being, material well-being  
- Family referenced quality of life domains: family interactions, parenting, emotional well-being, personal development, physical well-being, financial well-being, community involvement, disability-related supports |
| Community Building (Social Capital)    | - Social capital networks  
- Norms of reciprocity and trust  
- Inclusion and community involvement  
- Mutual support systems (‘circles of supports’)  
- Community ties/affiliation |
| Improving Society (The Good Life)      | - Socio-economic position (education, occupation, income)  
- Health (longevity, wellness, access to health care)  
- Environmental quality (air, water, green space)  
- Subjective well-being (life satisfaction, positive affect (happiness, contentment), absence of negative affect (sadness/worry, helplessness) |
The throughput

• Entrepreneurial Orientation

“A social entrepreneur is an individual, group, network, organization or alliance of organizations that seeks sustainable, large-scale change through pattern breaking ideas in what and/or how governments, nonprofits and businesses do to address significant social problems” (Light, 2005)
The input

A clear vision

• A strategic roadmap
• Mental picture
• A shared view
• Important questions
  – What
  – Who
  – Why
Exploring opportunities

(Kretzmann & McKnight, 1993)
Social Capital + Social Problem - Social-political climate Social Change

Leadership

10 D’s
Mission and Vision Critical Thinking Collaboration Building capacity

Context

IDEA

OPPORTUNITY

SOCIAL ENTREPRENEURSHIP

Proces

Making Change Happen!

Product

SOCIAL CHANGE

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The Macro Level
A policy evaluation framework

Figure 1. Policy Evaluation Framework
Policy Evaluation Process

1. Identify policy-related goals and/or objectives

2. Operationalize goals/objectives into outcome areas associated with personal, family, or societal benefits or changes

3. Select measureable indicators per type of category (structure, process, outcome)

4. Gather evidence

5. Establish the credibility of the evidence

6. Use the evidence/outcomes for multiple purposes
Exemplary Structure/Process and Outcome indicators based on a study in Flanders

<table>
<thead>
<tr>
<th>Policy Goal</th>
<th>Potential Outcomes Relative to Structure, Process, and Personal Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guaranteed care and support</td>
<td>Structure:</td>
</tr>
<tr>
<td></td>
<td>• Continuity of care</td>
</tr>
<tr>
<td></td>
<td>• Accessible care and support (now and in the future)</td>
</tr>
<tr>
<td></td>
<td>• Care covers the support needs of basic human needs (now and in the future)</td>
</tr>
<tr>
<td></td>
<td>• Adequate specialized care and medical follow-up</td>
</tr>
<tr>
<td></td>
<td>• The amount of budget that covers the costs related to the level of support needs</td>
</tr>
<tr>
<td></td>
<td>• Cost effectiveness</td>
</tr>
<tr>
<td>Quality of care</td>
<td>Process:</td>
</tr>
<tr>
<td></td>
<td>• Participation of the person in each step of the support planning process</td>
</tr>
<tr>
<td></td>
<td>• Choice and control of the planning process</td>
</tr>
<tr>
<td></td>
<td>• Personal treatment</td>
</tr>
<tr>
<td></td>
<td>• Information, level of understanding, access and use of information with regard to the planning process</td>
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<tr>
<td></td>
<td>• Satisfaction with the given services and support</td>
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<tr>
<td></td>
<td>• Provider impact</td>
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<tr>
<td>Inclusive care and support</td>
<td>Outcomes:</td>
</tr>
<tr>
<td></td>
<td>• Persons engaging in social roles</td>
</tr>
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<td></td>
<td>• Rate of loneliness</td>
</tr>
<tr>
<td></td>
<td>• Income</td>
</tr>
<tr>
<td></td>
<td>• Persons living in society</td>
</tr>
<tr>
<td></td>
<td>• Persons taking regular jobs, activities in society</td>
</tr>
<tr>
<td></td>
<td>• The development of personal skills; educational setting; lifelong learning</td>
</tr>
<tr>
<td></td>
<td>• Home (ownership)</td>
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<td></td>
<td>• Safety and security</td>
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<td></td>
<td>• Persons’ ability to set up a family if they want to</td>
</tr>
<tr>
<td></td>
<td>• Presence in cultural events; presence in recreational or leisure events</td>
</tr>
<tr>
<td></td>
<td>• Physical access in community buildings; physical access on community streets; physical access to public transportation</td>
</tr>
<tr>
<td></td>
<td>• A way to be personally mobile; a way</td>
</tr>
</tbody>
</table>
QOL, a promising concept..

• Start from support needs
• Start from talents/opportunities
• People are experts in their own life
• QOL /human rights
Thank You!

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