HoGent MENS EN WELZIJN

Quality of Life, moving forward from deficit thinking to supports

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Expertise Centre on Quality of Life

Ghent...



Introduction

New York Institution for the Blind

The New York Institution for the Blind (NY18) was bounded in 1831 or the Bret actional in the United Status dedicated to



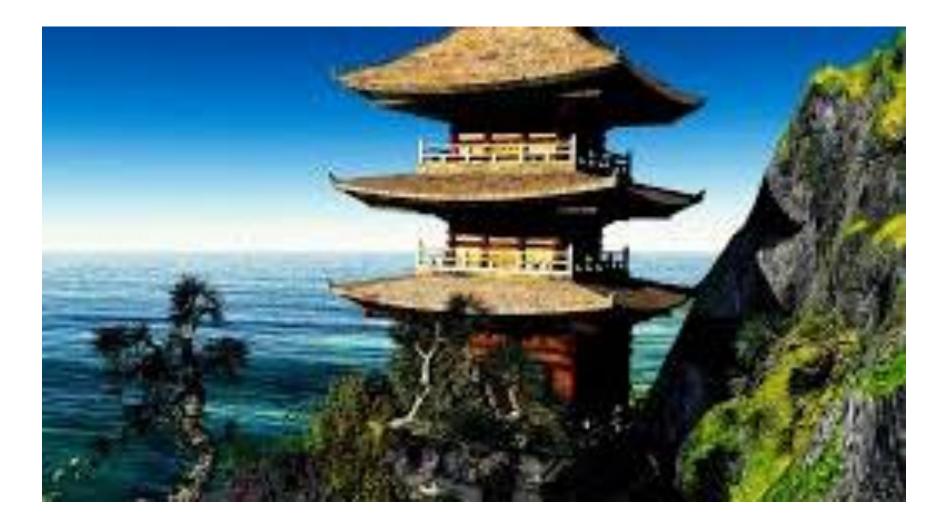




Three little stories



The happiest country in the world..



"The gross national product measures everything, except that which makes life worthwile" (Senator Kennedy, 1968)

Are you happy ? (Ignace, 1998, 2008)



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



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

HoGent 10-7-2017

The concept of disability has changed

• Disability as an individual pathology

• Disability as a social pathology

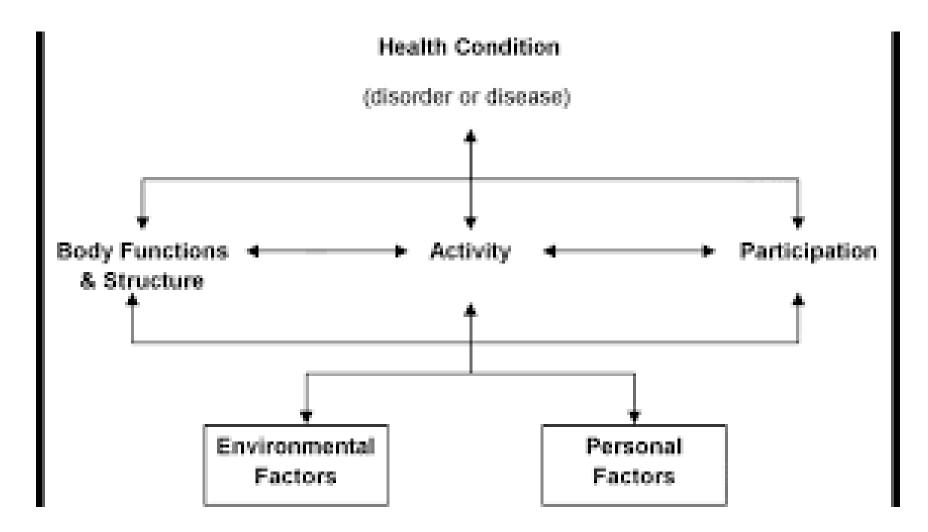
Rioux

Disability seen as an <mark>individual</mark> pathology	Disability seen as a social pathology
"Medical model"	"Social model"
 The "problem" lies in the person. 	 The problem lies mainly in the environment and in society, in general.
• Disability is the direct consequence of the impairment.	• Disability is the direct consequence of social limitations to accessibility and to
 Disability is a problem related solely to health. 	 equality of opportunities. Disability is a human rights issue. Persons with disabilities should participate in designing solutions.
 Solutions are designed by experts based on a diagnosis. 	<u>Approach</u> : Eliminate physical, social, political, and economic barriers. <i>Persons</i>
 <u>Approach</u>: Eliminate or cure the disability: "normalize." 	with disabilities are considered the citizens they are. HUMAN RIGHTS

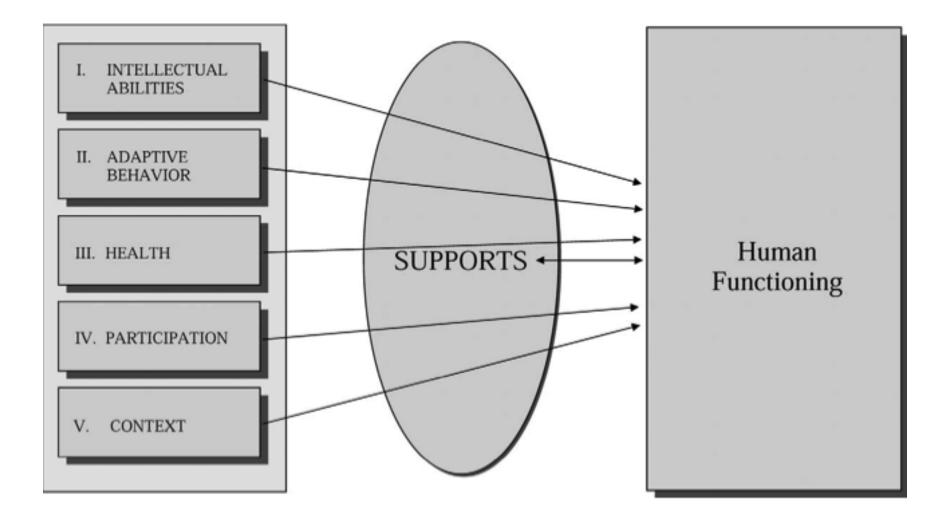
A Holistic Approach to Human Functioning

Disability can be defined as the expression of limitations in individual functioning within a social context

The ICF model



The AAIDD model



5 assumptions

- Limitations in present functioning must be considered within the context of community environments typical of the individual's 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'?

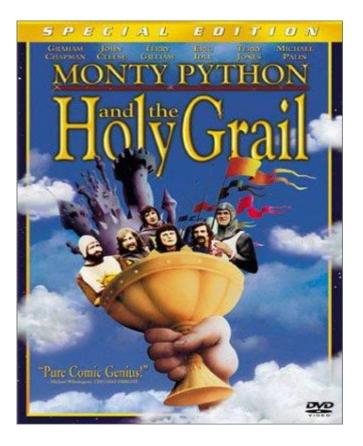
What makes your life qualitative?

Crosby, Stills & Nash



195.627 results in Web of Science

The Fit 100 Research Areas (by record outh) are shown. For advanced refine options, use [] Analyze results 0 ONCOLGOY (18.273)	Research Areas Refine Excl	ude Cancel Sort these by: Record Co	ount 💌		
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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

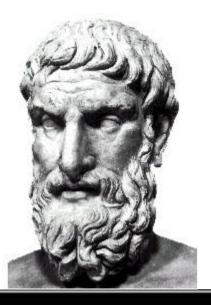


The state exists for the sake of a good life, and not for the sake of life only.

(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

HoGent

meetville.com

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

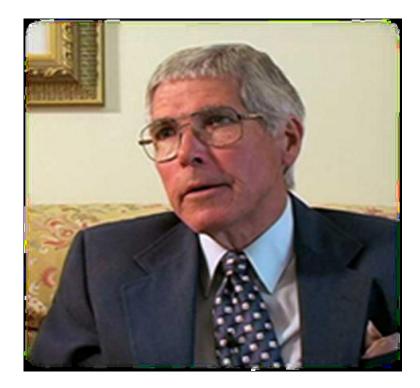
The rise of the concept of QoL (part II)

- 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

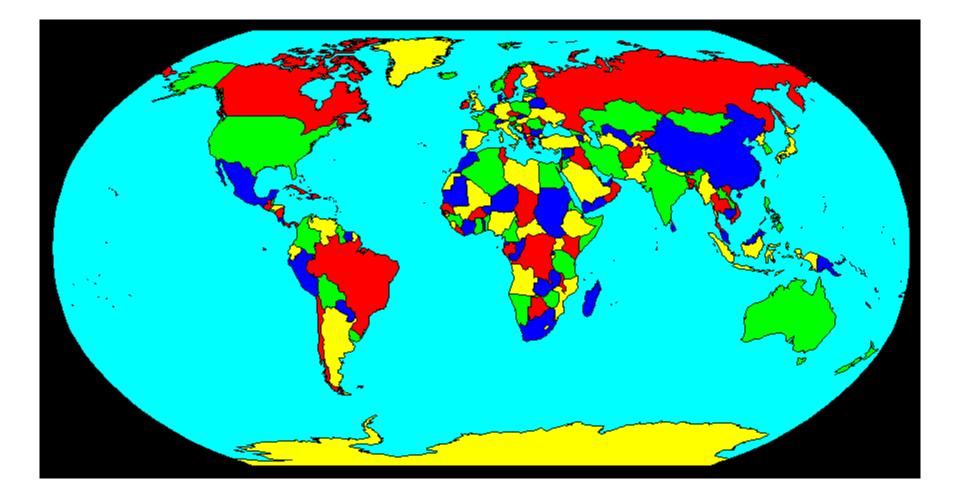
➔ Nowadays: important outcome measure and assessment tool in health care

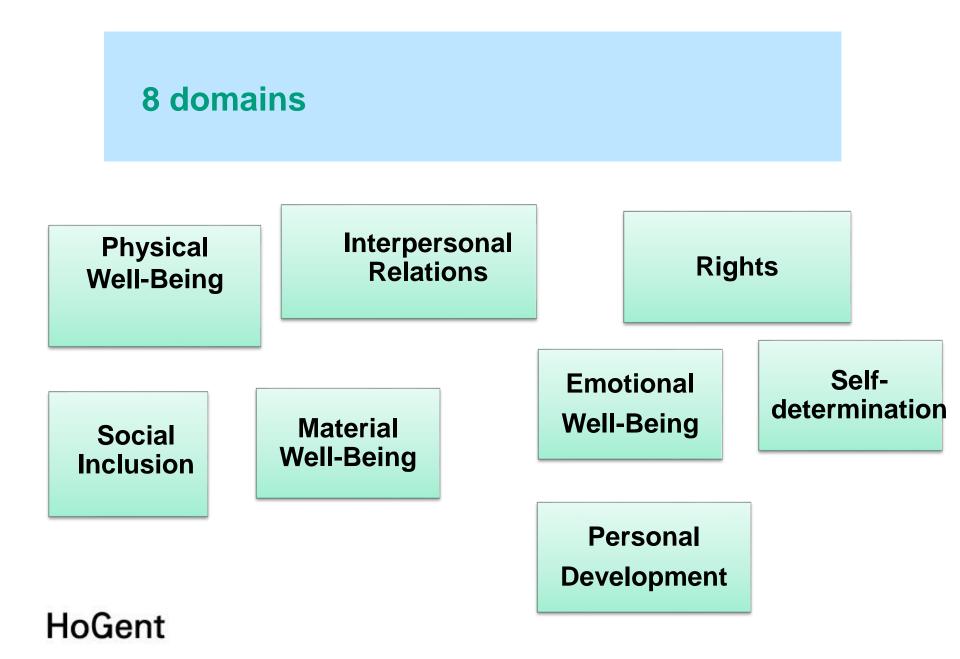
The Schalock & Verdugo Model

- Universal
- 8 domains
- Context is the community
- More than satisfaction
- Interrelations



The concept QoL is: UNIVERSAL





QOL Factor	QOL Domain	Exemplary QOL Indicators
Independence	Personal Development Self-Determination	Education status, personal skills, adaptive behavior (ADLs IADLs) Choices/decisions, autonomy, personal control, personal goals
Social Participation	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)
Well-Being	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

The Context is the Community Quality of Life and UN Convention (Schalock & Verdugo, 2011)

Domain Quality of Life Article UN-Convention

20, 27, 29, 30

Personal Development	24
Self-Determination	14, 19, 21
Interpersonal Relations	23
Social Inclusion	8, 9, 18, 20, 27
Rights	5-7, 10-13, 15
Rights Emotional Well-Being	5-7, 10-13, 15 16, 17
•	, ,
Emotional Well-Being	16, 17

Satisfaction ??





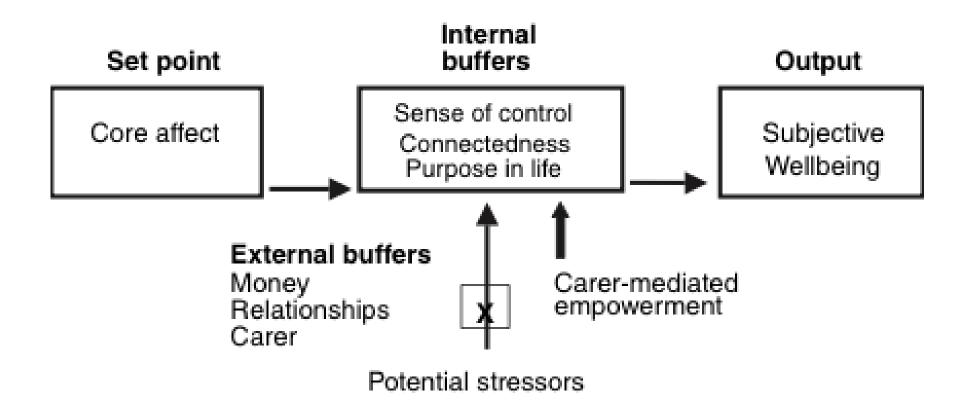
Subjective Well-Being

• 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



Subjective/objective

Objective	Subjective	
	Good	Bad
Good	Well-being	Dissonance
Bad	Adaptation	Deprivation

Interconnectedness

Internal buffers Selfdetermination Personal development Physical WB

Emotional WB

External buffers

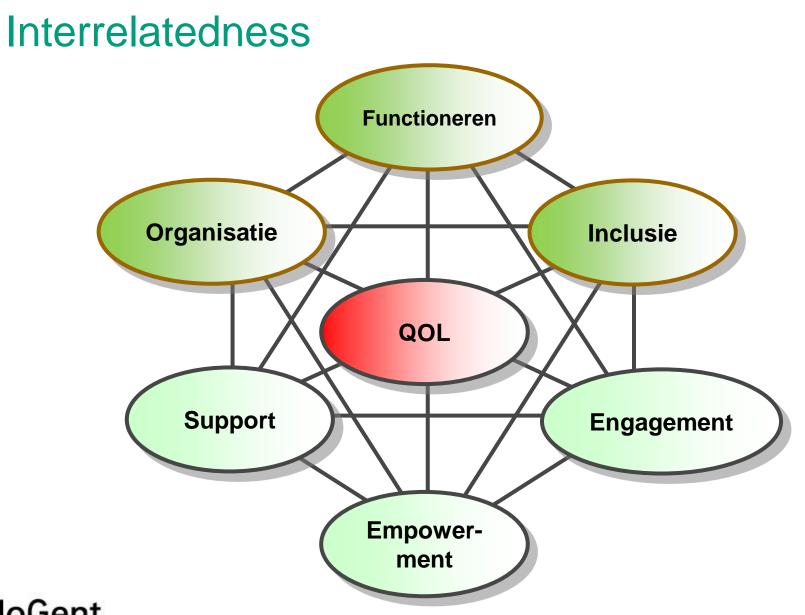
Interpersonal relations Material WB Rights Social inclusion

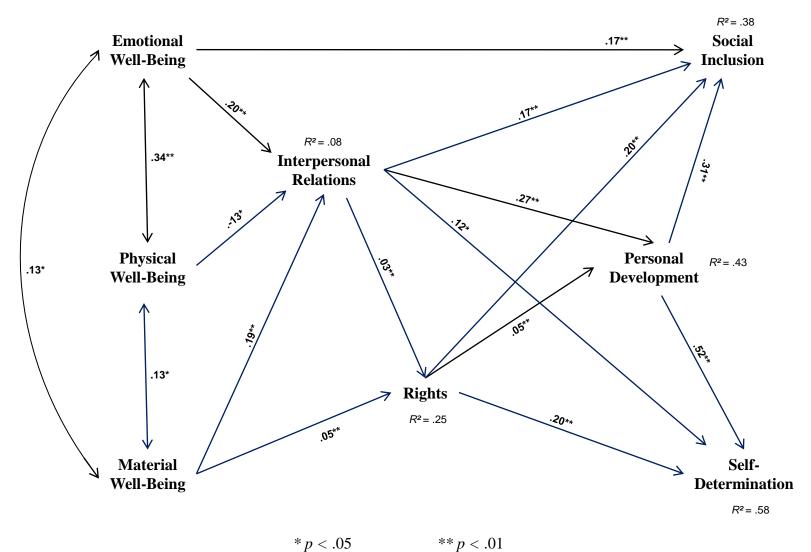
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Discrepancy between HRQoL en QoL

- 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 \neq having a good QoL





* *p* < .05

		(Moonen et al., 2010)	beperкing (De Windt & Lannau, 2009)	Windt & Lannau, 2009)
Persoonlijke ontwikkeling	12,72	11,43	12,36	16,71
Zelfbepaling	16,93	15,40	13,09	17,11
Interpersoonlijke relaties	15,66	14,86	12,59	16,50
Sociale inclusie	13,04	12,31	9,34	14,21
Rechten	16,70	15,05	13,21	17,30
Emotioneel welbevinden	15,45	15,69	15,13	17,07
Fysiek welbevinden	13,54	13,46	14,89	14,93
Materieel welbevinden	14,17	13,08	14,25	17,05

Soc Indic Res DOI 10.1007/s11205-017-1596-2



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 abscence of disease

Measurement Principles

- Methodological pluralism (different perspectives)
- Involvement of the target group
- Self-report and Proxy report
- Objective and Subjective indicators

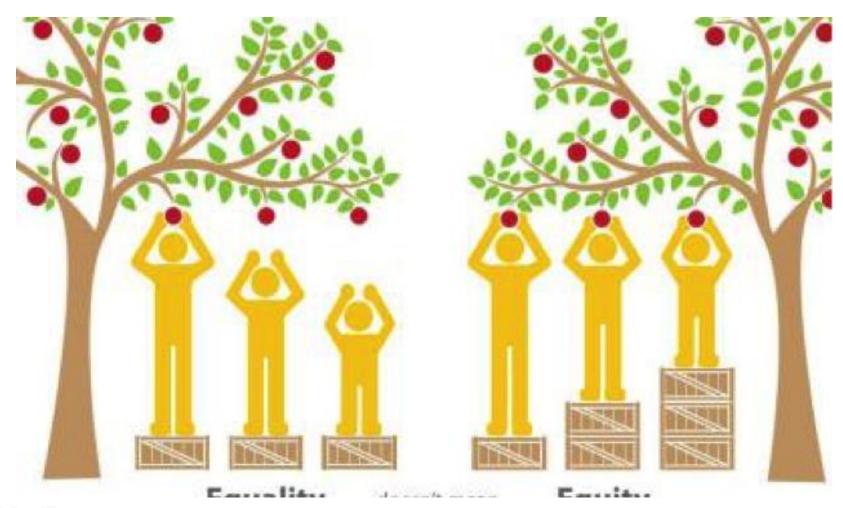
3. Supports and Supports Thinking

(Thompson, J (2013)



Support Needs and People with ID

- People with ID are different from the general population because they require <u>more and</u> <u>different types of support</u> 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).

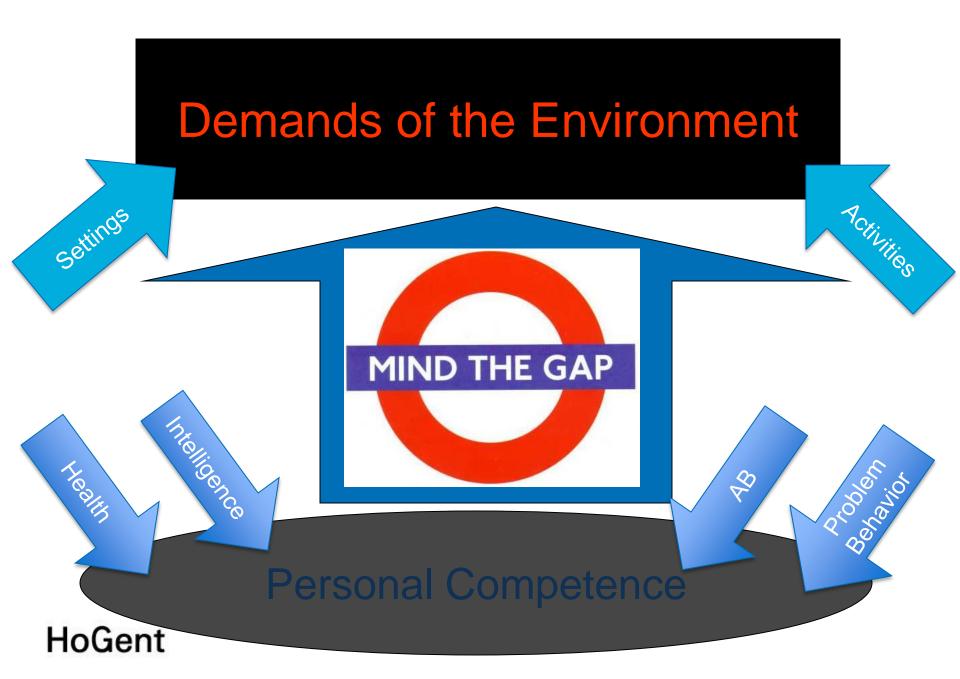


Supports are Universal & Supports are Uniquely Personal (Thompson, 2013)



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.



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

Domains of Life	Performers	Fulfilled People
Home Living	A Shelter	A home
Community Living	Get out and around to get what is needed	Active members of an interdependent world - know others and others know them
Life-long Learning	Learning Goals are imposed	Learning goals are chosen based on interests
Employment	Have work to do	Have a contribution to make
Health & Safety	Minimize Risks & Mistakes	Take some chances & learn from mistakes
Social	Have acquaintances	Have friends
Protection & Advocacy	Advocate for self based on laws, rules, etc.	Know there is a time to take a stand, and know there are times to give & take,

Maslow? (Thompson, 2013)

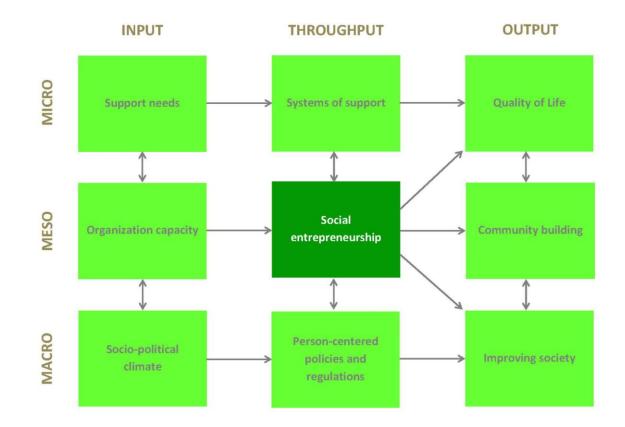


Supports provided to people with multiple and profound ID limited to lower level human needs?

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

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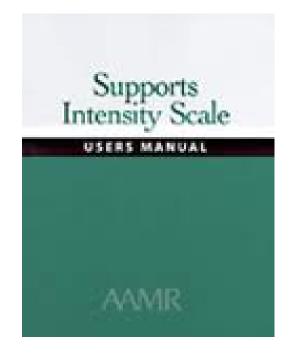
An Individual Supports Plan, based on and in line with the input Quality of Life.

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



Right to left (outcome based) thinking! (Schalock)

Supports Intensity Scale



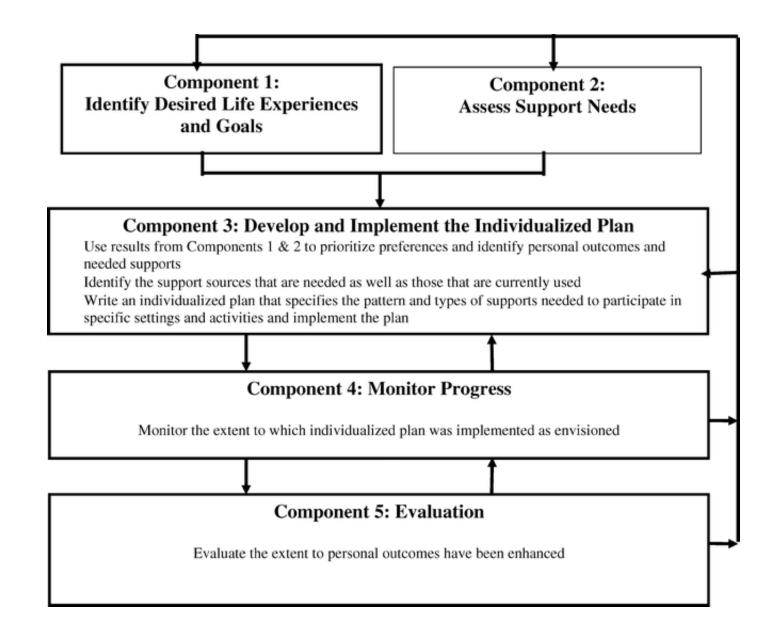
Personal Outcomes Scale

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



	Protection & Advocacy 2
Self-Determination	C 8 (Lifelong Learning) Protection &Advocacy 1, 5 & 7
Interpersonal Relations	B4, B7 (Community Living) D3, D4 (Employment) F1 - F7 (Social Activities)
Social Inclusion	B1, 2, 3, 5, 6, 8 (Community Living) F8 (Social Activities)
Rights	Protection & Advocacy 3, 4, 6, 8
Emotional Well-being	C9 (Lifelong Learning) E8 Exceptionals medical support needs
Physical Well-being	C7 E1 - E7 (Health and Safety)

The influence of supports strategies, environmental factors, and client characteristics on quality of liferelated personal outcomes

Claudia Claes ^a 옷 쩛, Geert Van Hove ^b 쩛, Stijn Vandevelde ^a 쩛, Jos van Loon ^b 쩛, Robert Schalock ^c ⊠

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Abstract

The concept of quality of life (QOL) is increasingly being used as a support

The Meso Level

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C. De Ruysscher 🖂 , C. Claes, T. Lee, F. Cui, J. Van Loon, J. De Maeyer, R. Schalock

Original Paper

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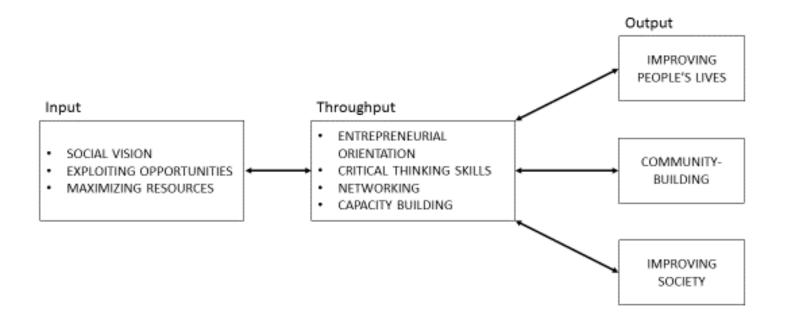
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Abstract

Currently disabilities enconinations are increasingly being shallonged by the requirement for

A Systems Approach to Social Entrepeneurship; Identifying Input-Throughput-Output Factors



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The output

 "Social entrepeneurship should facilitate the growth and development of a community" (Peredo & Chrisman, 2006)

• "Quality of Life" (Schalock)

Outcome Category	Measurable Indicators
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 networks
(Social Capital)	 Norms of reciprocity and trust Inclusion and community involvement Mutual support systems ('circles of supports') Community ties/affiliation
Improving Society	 Socio-economic position (education,
(The Good Life)	 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)

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The throughput

Entrepreneurial Orientation

"A social entrepeneur is an individual, group, network, organization or alliance of organizations that seeks sustainable, largescale change through pattern breaking ideas in what and/or how goverrnments, nonprofits and businesses do to address significant social problems" (Light, 2005)

The input

A clear vision

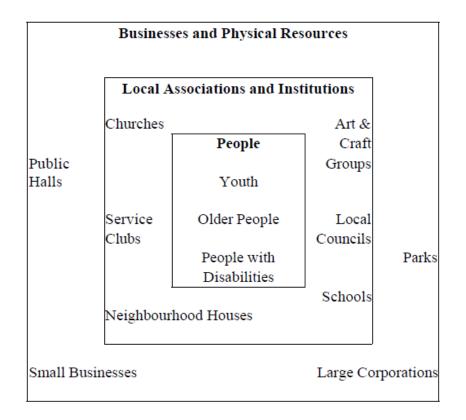
- A strategic roadmap
- Mental picture
- A shared view
- Important questions
 - What
 - Who
 - Why

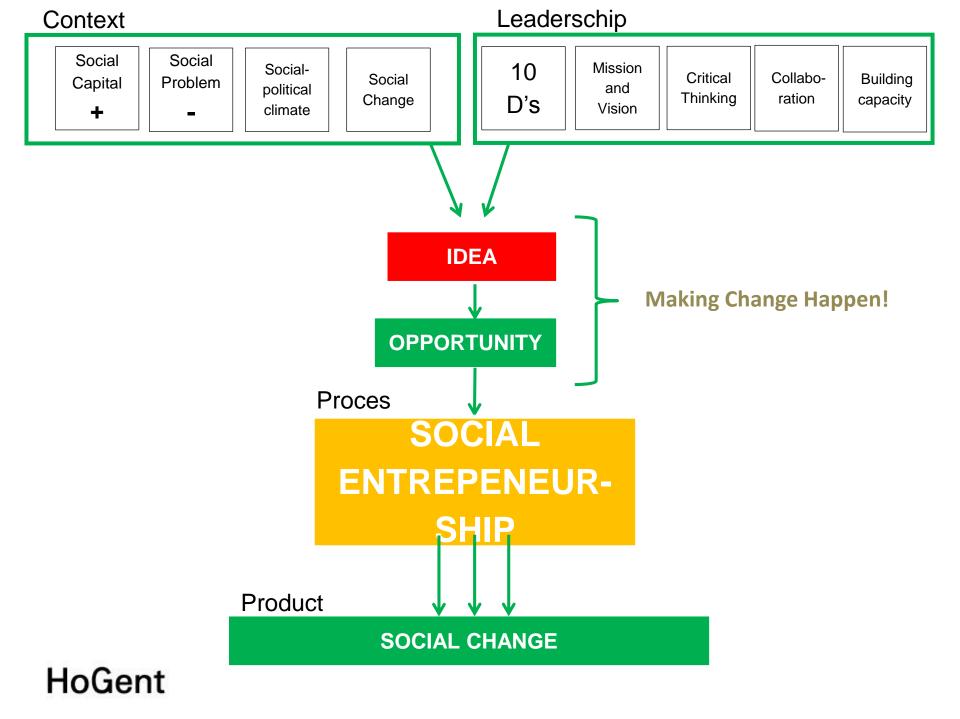


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Exploring opportunities

(Kretzmann & McKnight, 1993)





The Macro Level

A policy evaluation framework

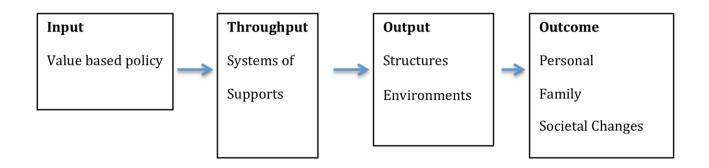
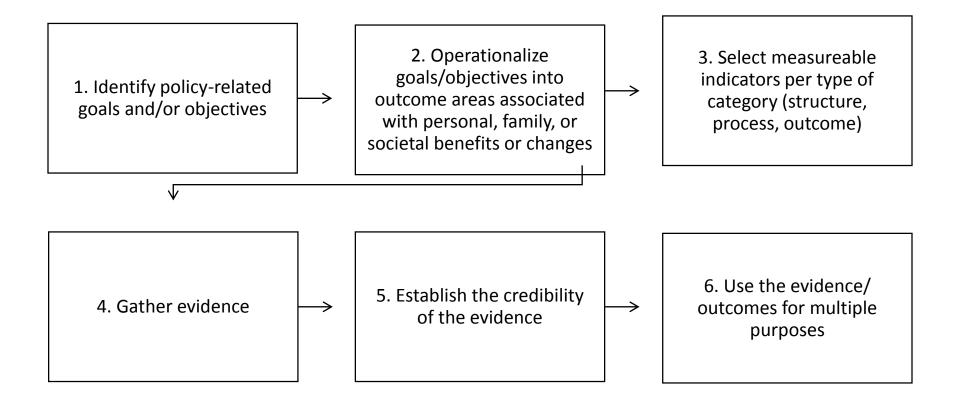


Figure 1. Policy Evaluation Framework

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Policy Evaluation Process



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Examplary Structure/Process and Outcome indicators based on a study in Flanders

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

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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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