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MENS
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WELZIJN

Quality of Life, moving forward from deficit thinking to supports

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Expertise Centre on Quality of Life

Ghent...



HoGent

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)

Are you happy ? (Ignace, 1998, 2008)

Overview

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

The concept of disability has changed

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

Disability seen as an **individual pathology**

Disability seen as a **social 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."

"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.

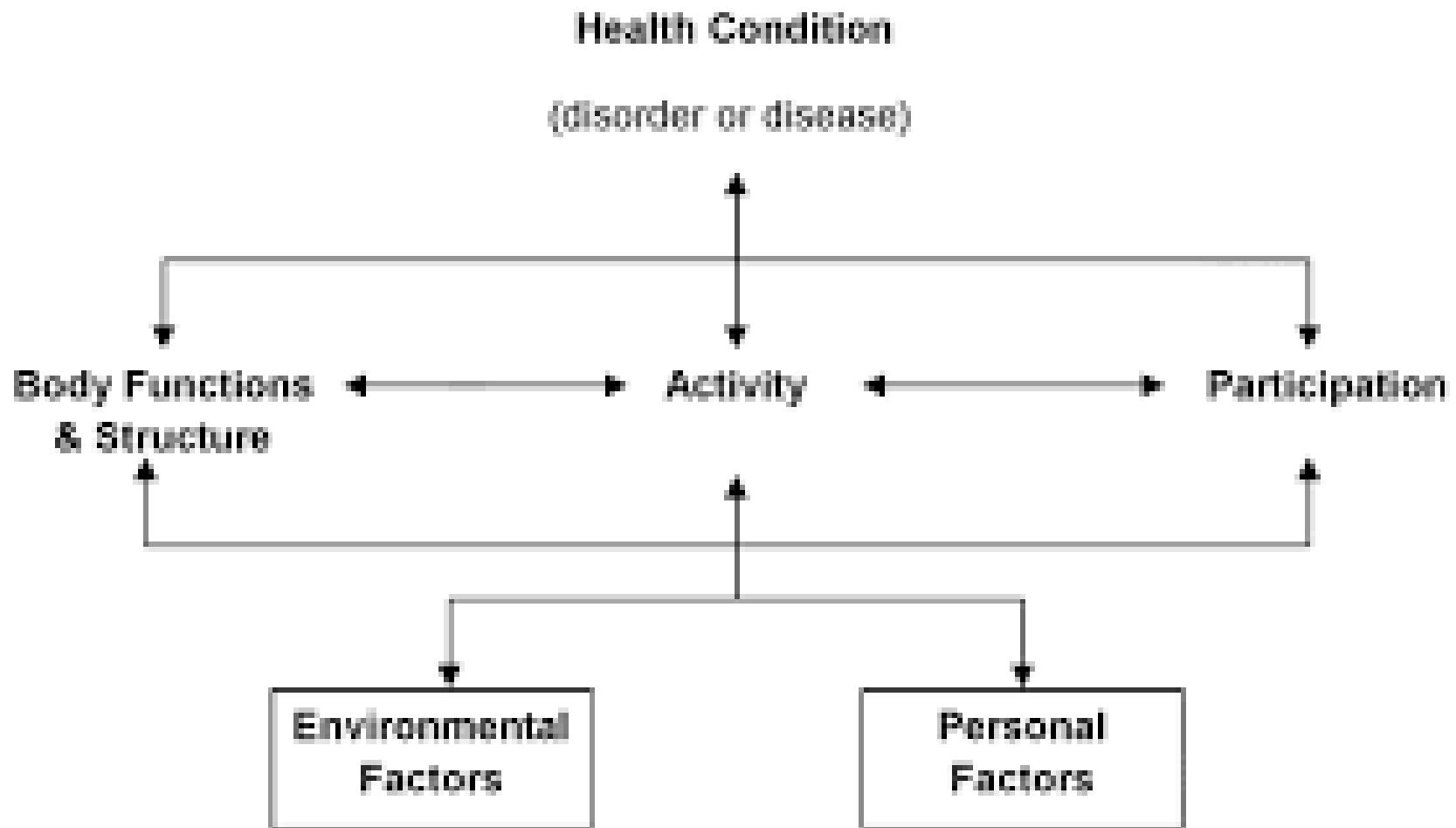
Approach: Eliminate physical, social, political, and economic barriers. *Persons with disabilities are considered the citizens they are. HUMAN RIGHTS*



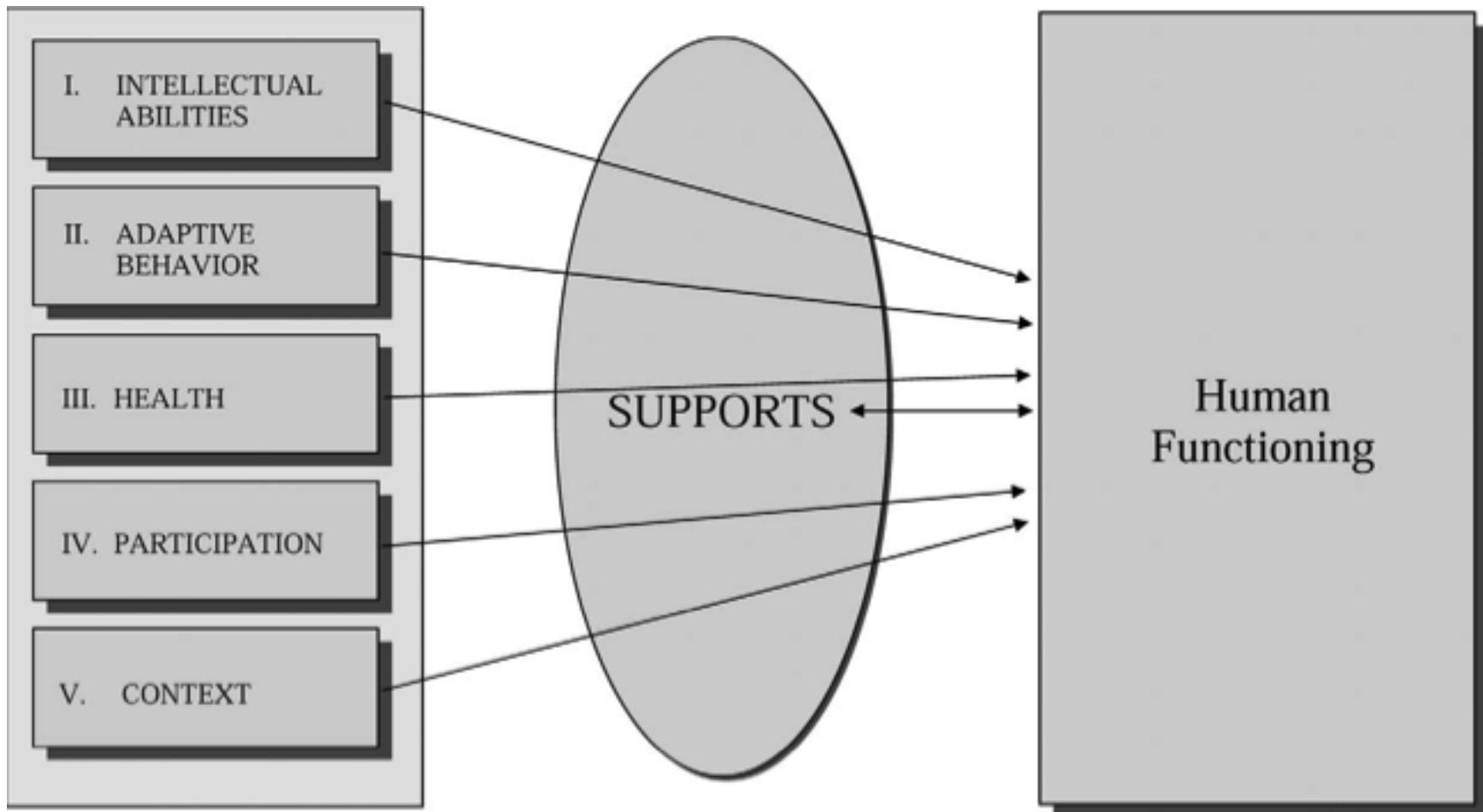
A Holistic Approach to Human Functioning

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 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

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<input type="checkbox"/> REHABILITATION (6,499)	<input type="checkbox"/> GENETICS HEREDITY (1,098)	<input type="checkbox"/> FISHERIES (386)	<input type="checkbox"/> FISHERIES (386)
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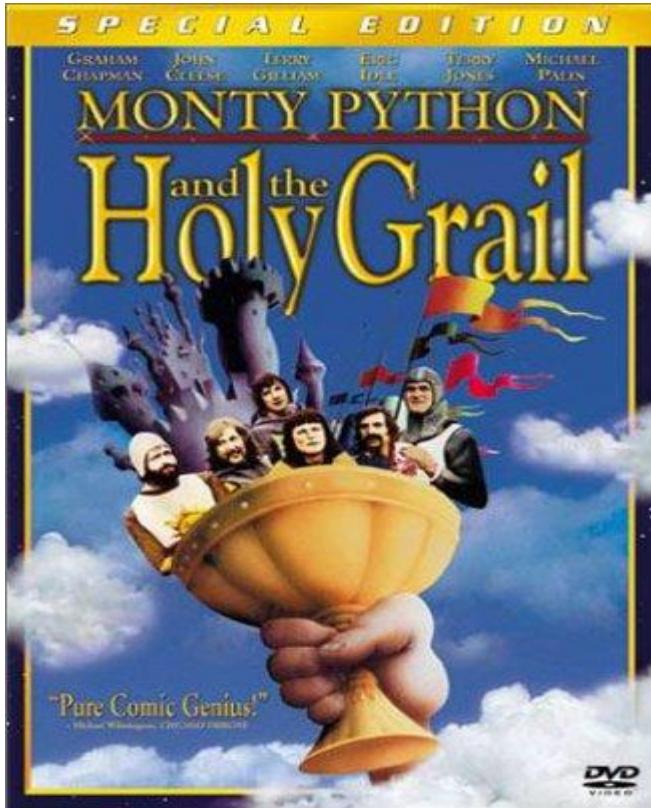
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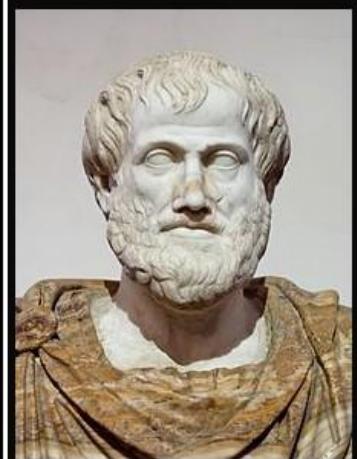


A search for “The Holy Grail” ?



“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

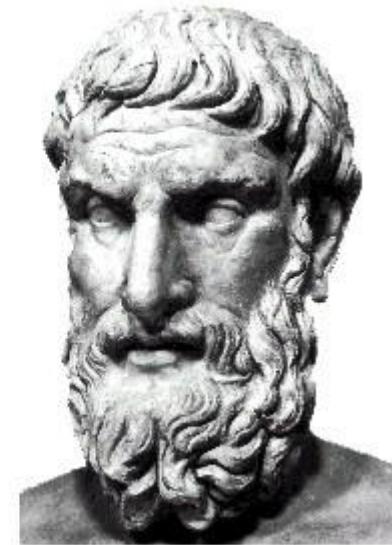


The state exists for the sake of a good life, and
not for the sake of life only.

(Aristotle)

Epicurus says:
“Life is good!

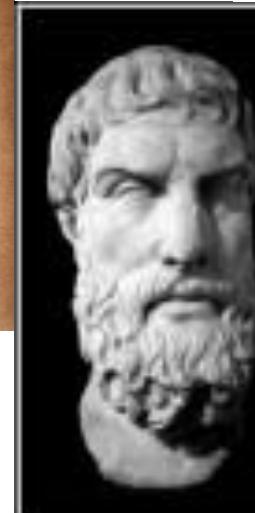
Make sure to
enjoy it.”



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

Aristotle

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)

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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)

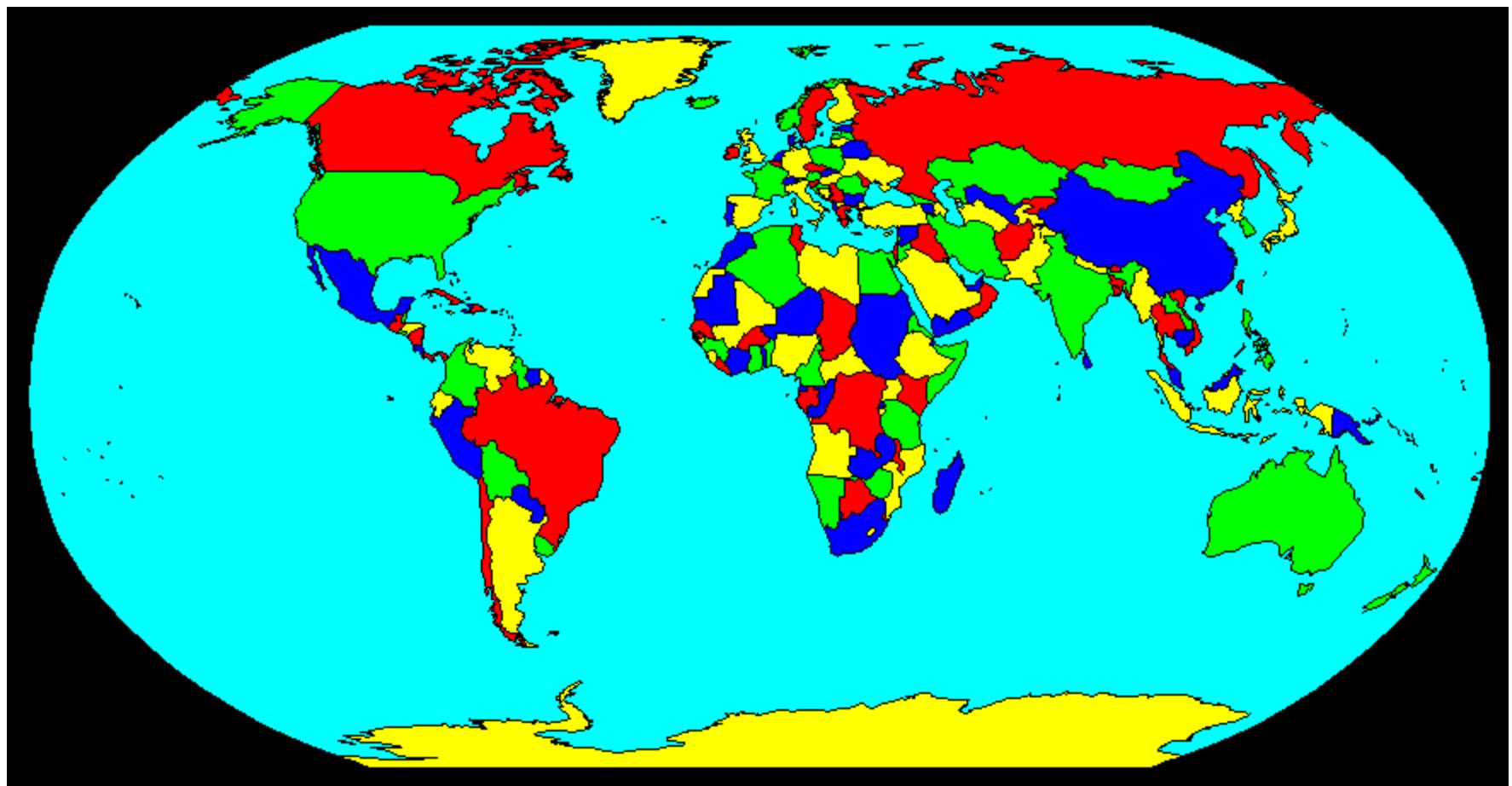
- Last two decades: change in the way care and support are provided to people with disabilities and long-term care needs
 - Influenced by deinstitutionalisation; community based support, consumer empowerment, person-centered planning
 - Shift from strict medical model to support model
- Nowadays: important 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

**Social
Inclusion**

**Material
Well-Being**

**Emotional
Well-Being**

**Self-
determination**

**Personal
Development**

<u>QOL Factor</u>	<u>QOL Domain</u>	<u>Exemplary QOL Indicators</u>
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)

<i>Domain Quality of Life</i>	<i>Article UN-Convention</i>
Personal Development	24
Self-Determination	14, 19, 21
Interpersonal Relations	23
Social Inclusion	8, 9, 18, 20, 27, 29, 30
Rights	5-7, 10-13, 15
Emotional Well-Being	16, 17
Physical Well-Being	16, 25, 26
Material Well-Being	28

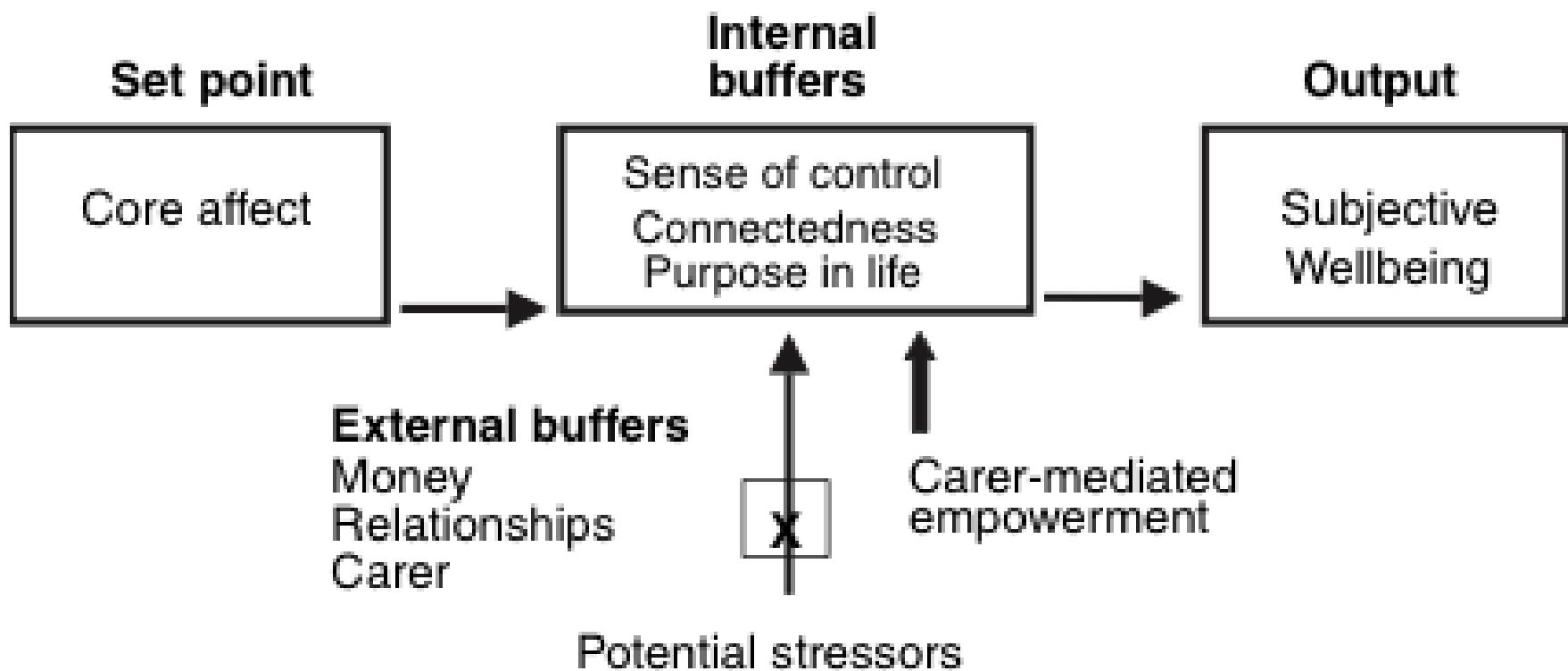
Satisfaction ??



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	<i>Well-being</i>	<i>Dissonance</i>
Bad	<i>Adaptation</i>	<i>Deprivation</i>

Interconnectedness

Internal buffers

Selfdetermination
Personal development
Physical WB

Emotional WB

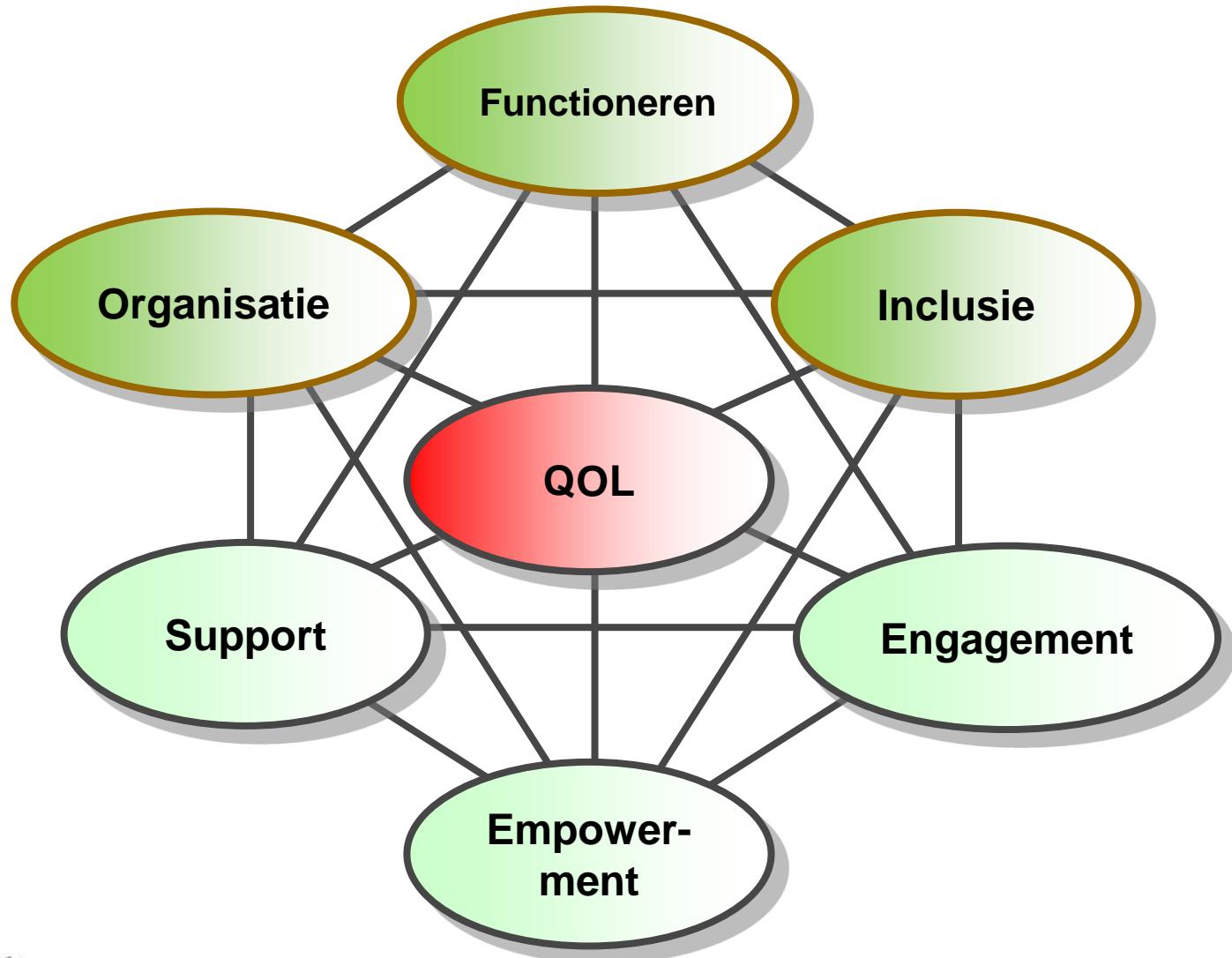
External buffers

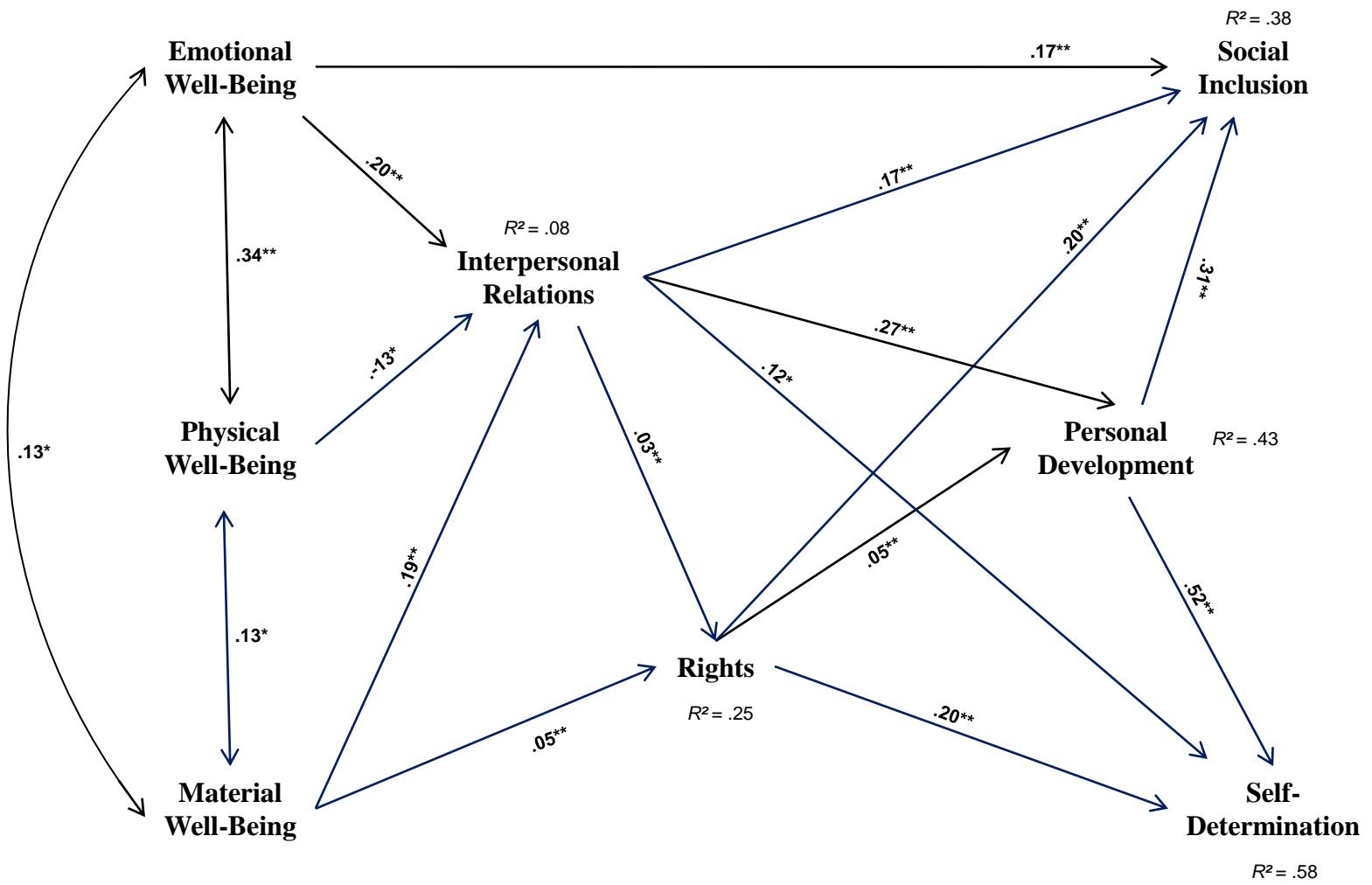
Interpersonal relations
Material WB
Rights
Social inclusion

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





* $p < .05$

** $p < .01$

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

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

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 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).



Evolution



Evolution

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



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,

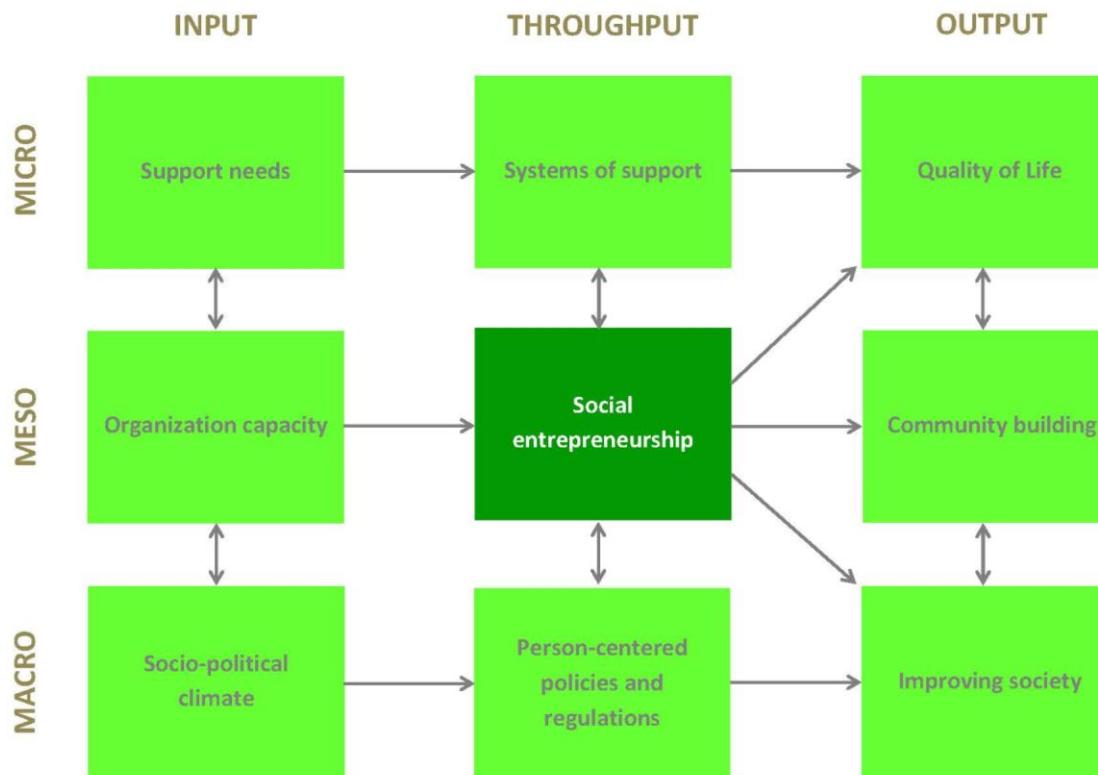
Maslow? (Thompson, 2013)



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 → Throughput → 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

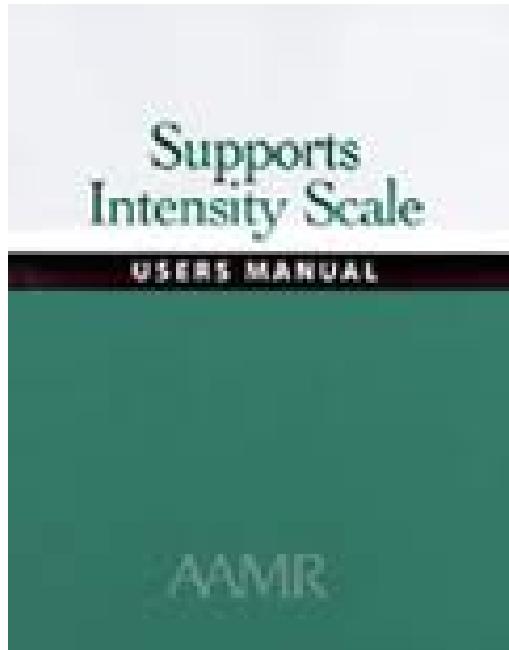
An Individual Supports Plan, based on and in line with the input

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



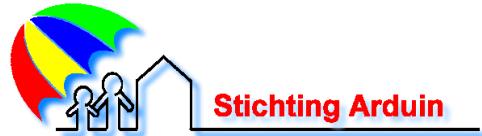
Right to left (outcome based) thinking! (Schalock)

Supports Intensity Scale



Personal Outcomes Scale

A Scale to Assess an Individual's Quality of Life

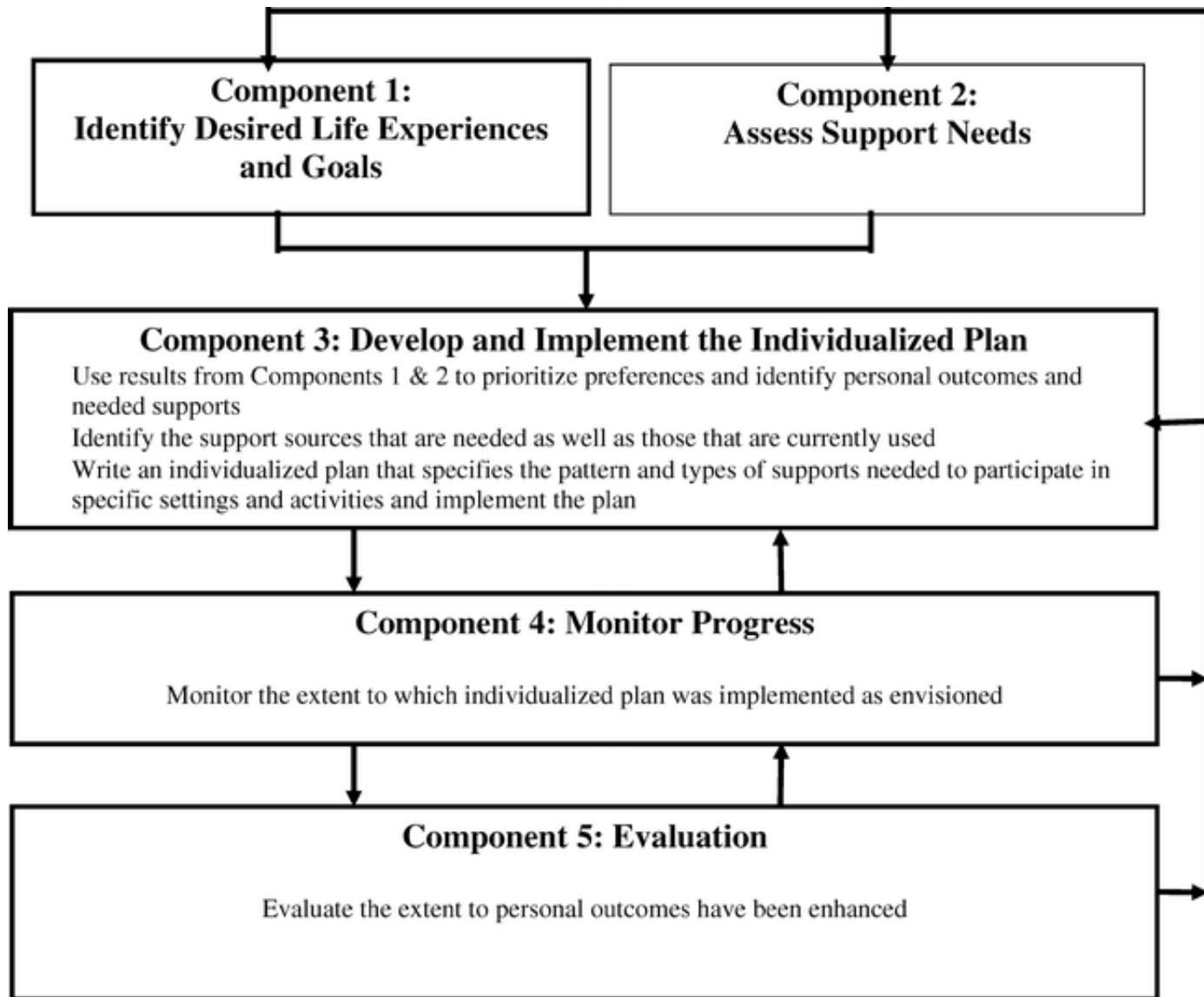


[Stichting Arduin](#)



Dr. Jos van Loon
Prof.dr. Geert van Hove
Prof.dr. Robert Schalock
Lic. Claudia Claes
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	C1 - C6 (Lifelong Learning) 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 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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Abstract

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

The Meso Level

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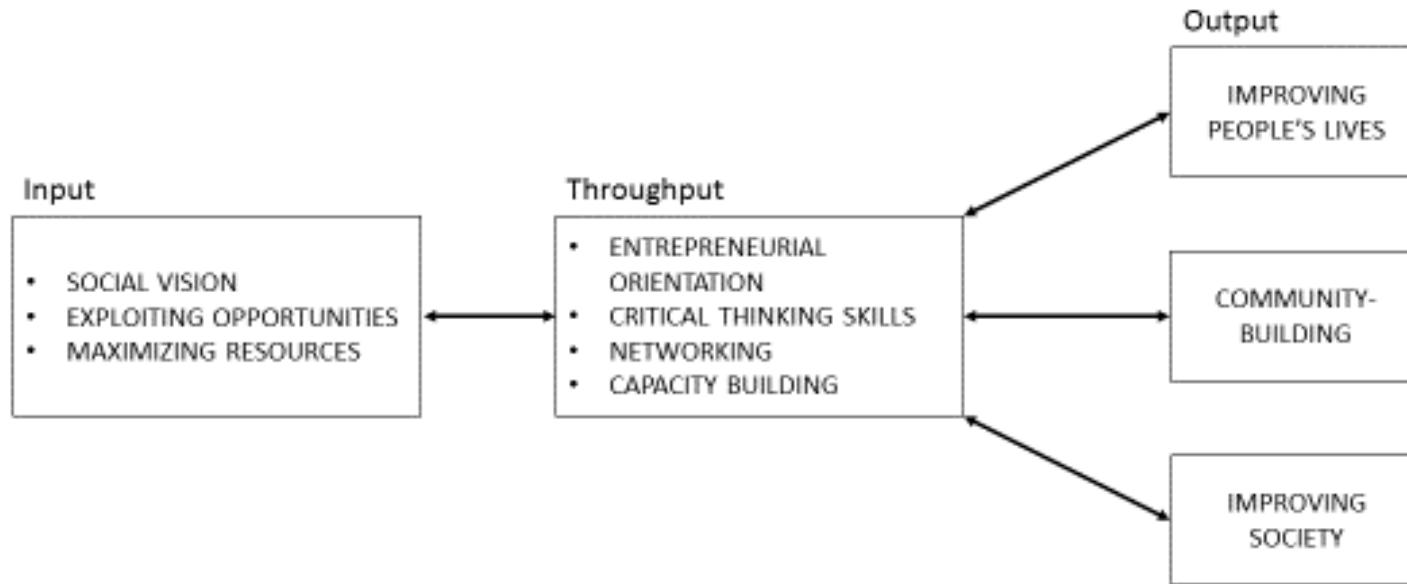
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Abstract

Community development organizations are increasingly being challenged by the requirement for

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



The output

- “Social entrepreneurship should facilitate the growth and development of a community”
(Peredo & Chrisman, 2006)
- “Quality of Life” (Schalock)

<i>Outcome Category</i>	<i>Measurable Indicators</i>
Improving Peoples' Lives (Individual and Family Quality of Life)	<ul style="list-style-type: none"> - 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)	<ul style="list-style-type: none"> - 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)	<ul style="list-style-type: none"> - 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

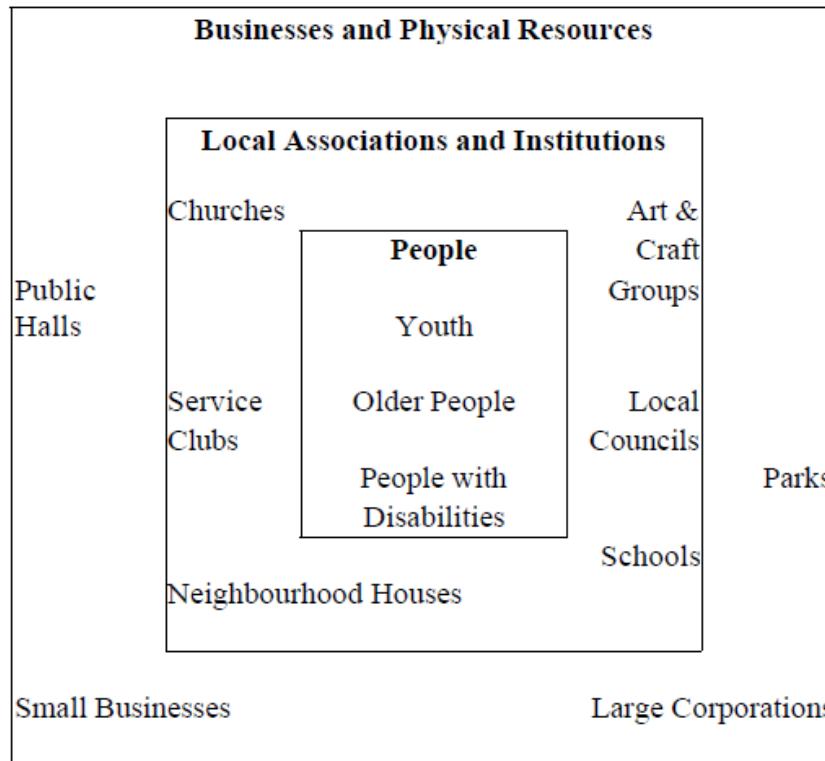
A clear vision

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

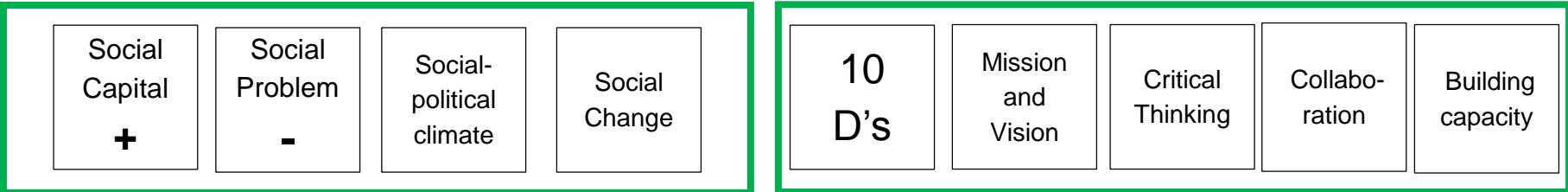


Exploring opportunities

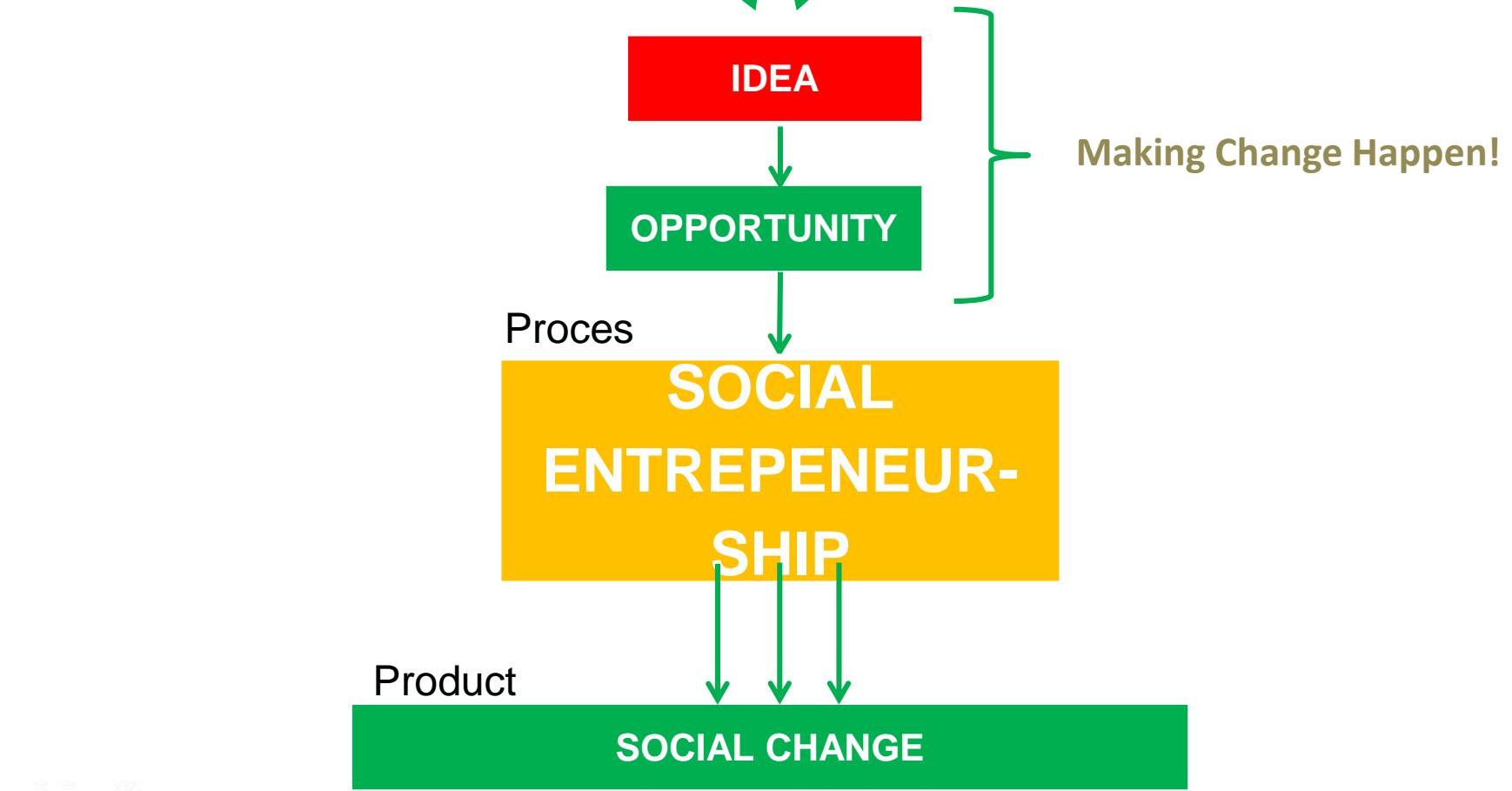
(Kretzmann & McKnight, 1993)



Context



Leadership



The Macro Level

A policy evaluation framework

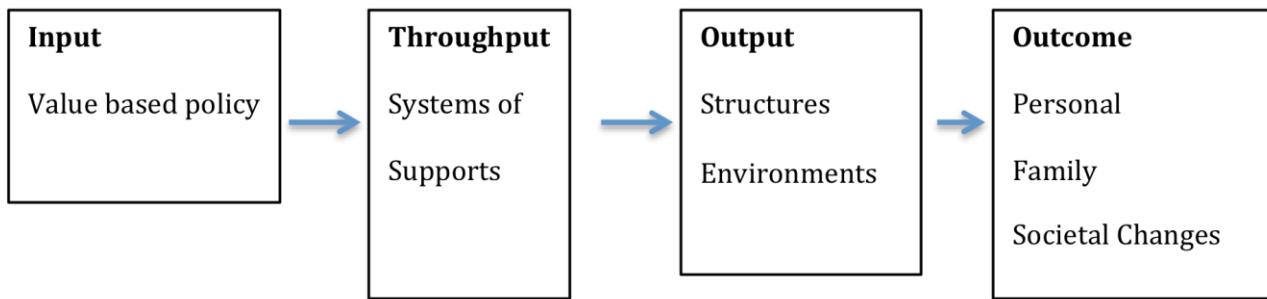
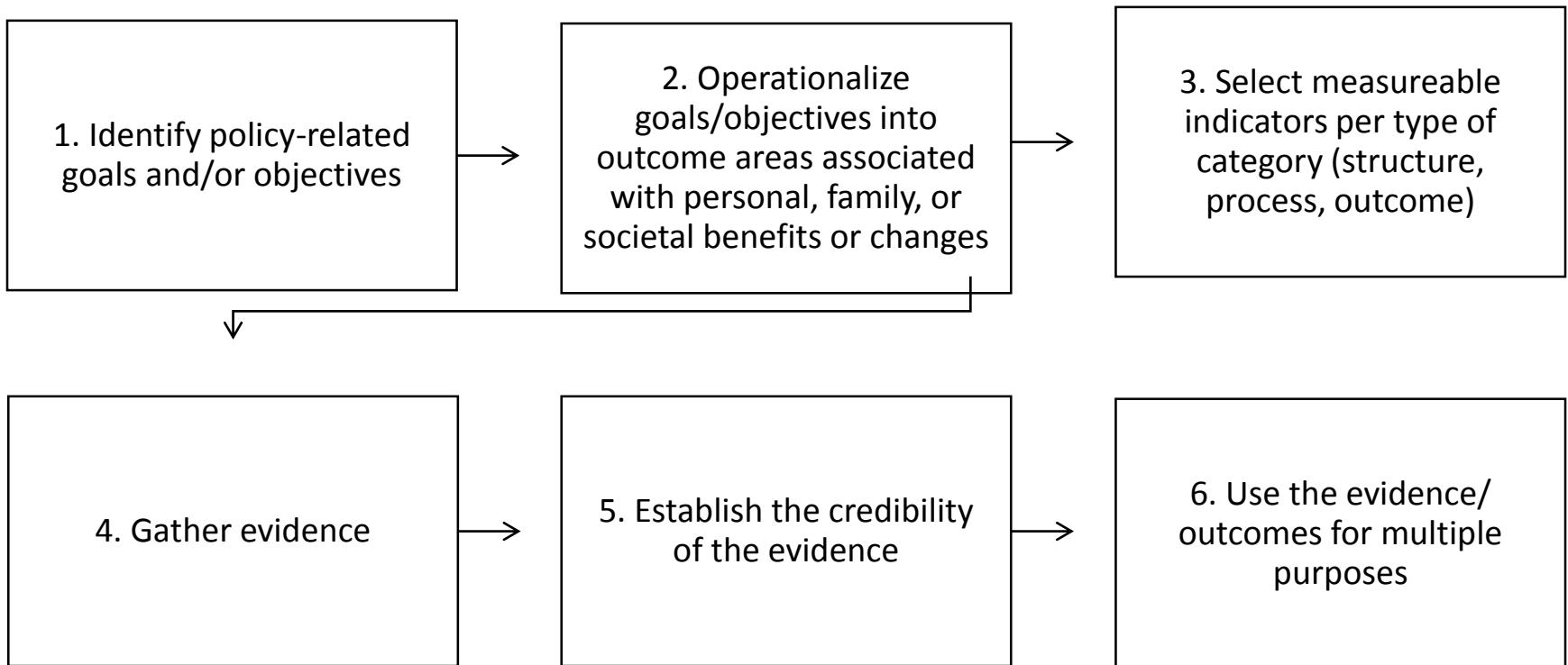


Figure 1. Policy Evaluation Framework

Policy Evaluation Process



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

<i>Policy Goal</i>	<i>Potential Outcomes Relative to Structure, Process, and Personal Outcomes</i>
Guaranteed care and support	Structure: <ul style="list-style-type: none">• 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: <ul style="list-style-type: none">• 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	Outcomes: <ul style="list-style-type: none">• Persons engaging in social roles• Rate of loneliness• Income• Persons living in society• Persons taking regular Jobs, activities 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 in community buildings; physical access on community streets; physical access to public transportation• A way to be personally mobile; a way

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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