



" Supporting people with intellectual disabilities: the importance of a valued living environment ".

‘in alignment with the contribution of GT .....

*Jos van Loon, september2019*

Or....

It's all about values

# Overview

## Introduction

- My personal reference
- Support to people with intellectual disabilities
- Some considerations

### A. At the basis

- UN Convention on the Rights of People with Disabilities (UNCRPD)
- Quality of Life (QOL)
- Gentle Teaching
- Effective Factors
- Methodical considerations
- Environmental Factors

### B. Developing support based on the dialogue with the person (wishes and support needs)

### C. An appropriate range of methodologies and methodical work forms

### D. An integrated model for concrete support: methods and interventions

# My personal reference

- Orthopedagoog since 1979, in an institute for people with
- Course Gentle Teaching from John McGee in Canada in 1989
- PhD. on Deinstitutionalisation and QOL in 2005
- Started to work with Bob Schalock
- Developed the Personal Outcomes Scale with Schalock, Van Hove, Claes in 2008

# My personal reference

- Orthopedagoog since 1979, in an institute for people with ID
- Course Gentle Teaching from John McGee in Canada in June 1989
- Manager at Arduin: Deinstitutionalisation process
- PhD. With Geert Van Hove on Deinstitutionalisation and QOL, in 2005
- Started to work with Bob Schalock and later Jim Thompson on QOL and Supports
- Developed the Personal Outcomes Scale with Schalock, Van Hove, Claes in 2008
- Etc.

## My personal reference

The task of the "orthopedagogics": to situate within critical orthopedagogics (Van Gennep, 1999)...

- Emancipatory approach
- Bringing out expelled human life back into society (Kobi, 1985)
- Van Gennep: *“Knowledge can never be viewed separately from social change”*
- Rational argumentation of the normative aspect (Van Gennep)
- **Orthopedagogics must, in particular, deal with norms and values.**

## ... and critical normative postmodern orthopedagogics (Van Gennepe)

Some important concepts from postmodern orthopedagogics are:

- environment: proximity, directness, authenticity
- social networks
- integration: being included in a social network
- quality of life
- new normativity

A scientific theory, consisting of descriptive, prescriptive and normative aspects, is distinguished from a social view by **the rational argumentation of the normative aspect**,

while a social view is based on non-rationally argued values and norms (Van Gennepe)

A critical-normative postmodern orthopedagogy has a  
dual task (Haeberlin, 1996)

- Taking **responsibility for solidarity with people with disabilities** as a practice; that solidarity is the foundation for the values of inviolability, equality and dignity
- As a science, it must take **responsibility for the dissemination and continuation of the values** mentioned, but also for the values of **rational argumentation** and intersubjective traceability of scientific knowledge acquisition

# Support to people with intellectual disabilities

## \*Individual-pedagogical / Individual emancipation

- Getting an picture of the person in his situation, diagnostics, treatment, education: support / **Gentle Teaching can be situated here**

## \*Social emancipation

- Developments in vision
  - Human rights, UN Convention Rights of people with disabilities
  - Definitions
  - QOL, on macro, meso, and micro level
  - Supports paradigm

# A model for integrated\* supports and interventions in a support methodology

1. How do we give form and content to a support plan based on the wishes and support needs of a person?
2. How can we then place methodologies and interventions in this?
3. Within a responsible framework (i.e. appropriate to international developments).

\*Referring to Broekaert et al. (2010) who concluded that through the dialectical integration of diverse approaches, **evidence, existence/humanism and social emancipation can be combined** for the benefit of the human prerogative of care.

# Some Considerations

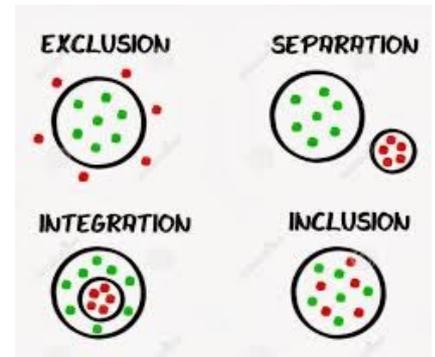
1. The a) **values, based on the UN Convention and the QOL domains**, and b) **evidence based general factors regarding the efficacy of interventions** set the framework, within which interventions and methods should take place. In this framework there is also a place for **methodological and substantive conditions** for which interventions and methods to use.
2. Recent theoretical perspectives on human functioning as the model of the ICF (WHO, 2001) or the AAIDD (Schalock et al, 2010) highlight **the importance of a socio-ecological approach**: a functional and multidimensional conceptualization of disability, in which not the "defect" but the functioning of people is central.
3. There should be good environmental conditions: a good environment to live in.
4. There should be an alignment to QOL and a system of supports
5. Specific evidence-based interventions (aligned to the QOL domains and the system of supports) should comply with the criterion to be called evidence-based: a firm relation should be demonstrated between the specific interventions and measured outcomes.

# **A. At the basis**

## **I. UN CONVENTION on the Rights of People with Disabilities**

On December 13, 2006, the General Assembly of the United Nations adopted the Convention on the Rights of Persons with Disabilities.

This is an important step forward in recognizing and safeguarding the rights of people with disabilities.



The values set out in the UN Convention as being central:

- human dignity,
- participation / inclusion and accessibility of society,
- equality and equal opportunities,
- autonomy and self-determination,
- empowerment and
- physical, emotional and material well-being.

## II. Quality of life as the desired outcome of support

<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

*“By the way:”* It is established that the articles of the UN Convention for People with Disabilities are aligned to the domains of QOL as defined by Schalock and Verdugo

<i>Domain QOL</i>	<i>Applicable Articles UN CRPD</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

### III. What we learned in this respect from John McGee: Gentle Teaching

- Companionship
- Psychology of Interdependence
- Teaching the value of human presence
  
- A morality of consequences vs.  
a morality of connectedness

# Paulo Freire

“Education can never be neutral. Either it is an instrument for liberation of man, or it is an instrument for enslaving, drilling him for oppression”(Freire, 1985).

# Fundamental needs and vulnerabilities

- **Feeling safe and secure**
- **To be engaged** with fellow men
  - **Unconditional valuing**

# The instruments with Gentle Teaching

- Our mouth: language, words, verbality
  - Our hands: touch, tactile contact
  - Our face, mime and our posture

# Gentle Teaching and emancipation

- Often used in individual support for people with severe behavioural problems; one to one interactions: emphasis on **individual emancipation**
- Values: ‘culture of life’ instead of ‘culture of death’: emphasis on **social emancipation**

# IV. Effective Factors? the question of the effectiveness of interventions ....

- A specific method represents only 15% of the result (Van Yperen et. al., 2010)
- More general factors seem to have a stronger influence. Well-known examples of these factors are:
  - Fit the motivation of the client;
  - Good quality of the relationship client-therapist;
  - proper structuring of the intervention (clear objective, planning and phasing);
  - a good 'fit' of the approach to the problem and the demand for assistance;
  - implementation of the intervention as it should be performed;
  - professionalism (good education and training) of the practitioner;
  - good working conditions of the treatment (as bearable caseload, good support, rescuer safety).
- Plus..... LIVING CLIMATE: Van der Helm (2011), like Kok who speaks about the importance of a good first line strategy, speaks about the importance of a good pedagogical climate.

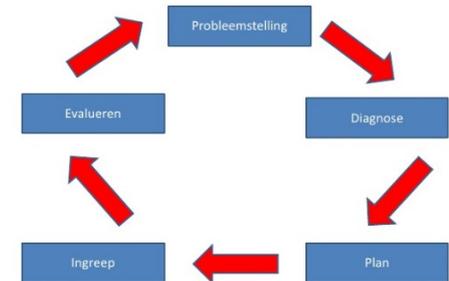
# The seven main characteristics of an open living climate (Jongepier, Struijk & Van der Helm , 2011).

1. Contacting clients (1. 'Responsibility')
2. Ensure that clients understand the need for their residential treatment and can learn from their treatment (2. "Growth")
3. Ensure a good atmosphere (3. 'Structure, security and positive interactions')
4. All this has to be organized with as little coercion and punishment, without many and often incomprehensible rules, with the highest degree of clarity, structure and self-determination (4. 'No repression')
5. An open climate is characterized by an adequate conflict management style by supportworkers aimed at solving problems rather than conflict and dominance (5. Adequate conflict management in social problems)
6. Clients are respected at all times (6. "Do not reject the client but his behavior")
7. In an open environment for children and adults with a mild intellectual disability, there is also day-structuring (7. Day Structure) because these clients have difficulty constructing their own structure (learning how to structure themselves in the day can also be an important treatment goal).

# V. Methodical considerations

- Support according to the methodical cycle

Regulatieve cyclus van Van Strien (1986)



- Person-centred support
- Working according to the input-throughput-output-outcome model.
- The importance of evidence-based working

For example: Lombardi, Croce, Claes, Vandeveldde & Schalock (2016) did research into factors that predict the quality of life of people with intellectual disabilities:

the emphasis should be on providing support that is 1) tailored to the specific domain of quality of life, and 2) based on the support needs of the individual. 3) The support process must be person-oriented and 4) be based on personal wishes and goals.)

# 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 wishes, goals, perspectives and support needs  
Which supports are to be given on which QOL-domains  
Which supports are to be given on which QOL-related support areas

**Quality of Life.**  
This QOL therefore should be measured as a personal outcome of supports.  
**Personal Outcomes Scale.**



Right to left thinking



# VI. Environmental Factors.

Also environmental circumstances are important in enhancing Quality of Life:

- Schalock (2017) in this regard speaks of the importance of **focusing on creating environments instead of focusing on services**, as main task of an organization.
- A study by Claes, Van Hove, Vandevælde, van Loon & Schalock (2012), in an organization for people with ID, shows that environmental factors (living independently, a regular job or having volunteer job) were related to a higher QOL.
- Lombardi, Croce, Claes Vandevælde & Schalock (2016) found that people who live in smaller residential settings and participate in community activities, such as a regular job and / or a volunteer job, have a better quality of life

## B. Developing support based on the dialogue with the person (wishes and support needs).

- When formulating a support plan concretely and when offering support in day-to-day practice, one must first of all take **the person's wishes and personal aspirations as a starting point**. These are discussed and recorded with the client.
- The **person's support needs** are then determined (e.g. with the Supports Intensity Scale, Thompson et al., 2004).
- These two elements form the input of the support methodology.
- This input should directly result in a individual support plan (throughput).
- The procedural results (output) of the support are then monitored by the support team, and the outcomes evaluated, for example with the POS

Component 1  
**Wishes, personal aspirations and goals:**  
structured interview with the client

Component 2  
**Determining Support Needs:**  
Interview with Supports Intensity Scale

Component 3: Developing an Individual Supports plan  
a. The client with his personal assistant synthesize the wishes and goals with the support needs and come to an idea for an individual support plan: how do I want to be supported?  
b. This idea is discussed with the supportworkers (and the psychologist).  
c. Together they decide on a ISP in which the personal assistant writes down which support the person wants so he can fully participate in the community.

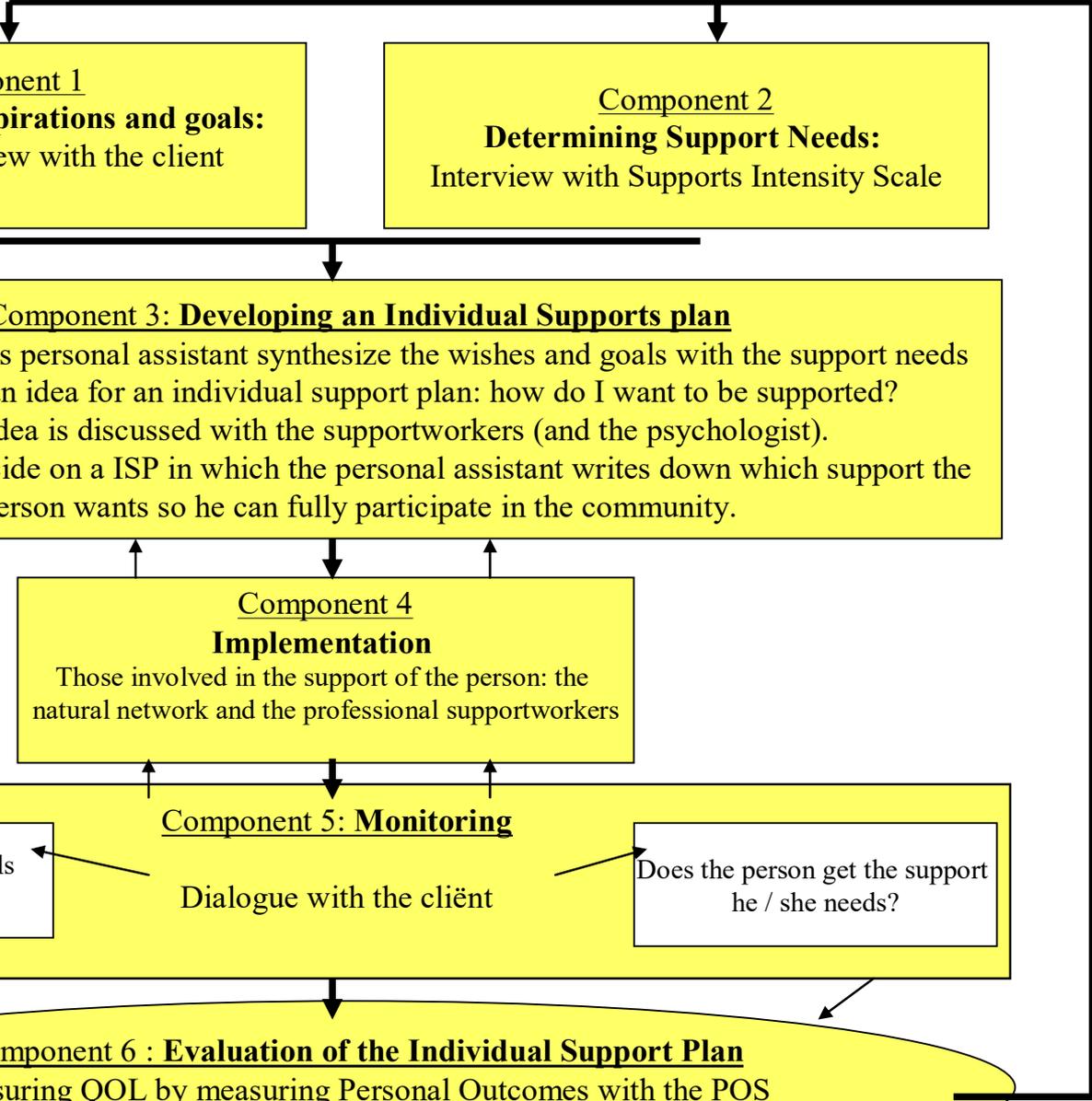
Component 4  
**Implementation**  
Those involved in the support of the person: the natural network and the professional supportworkers

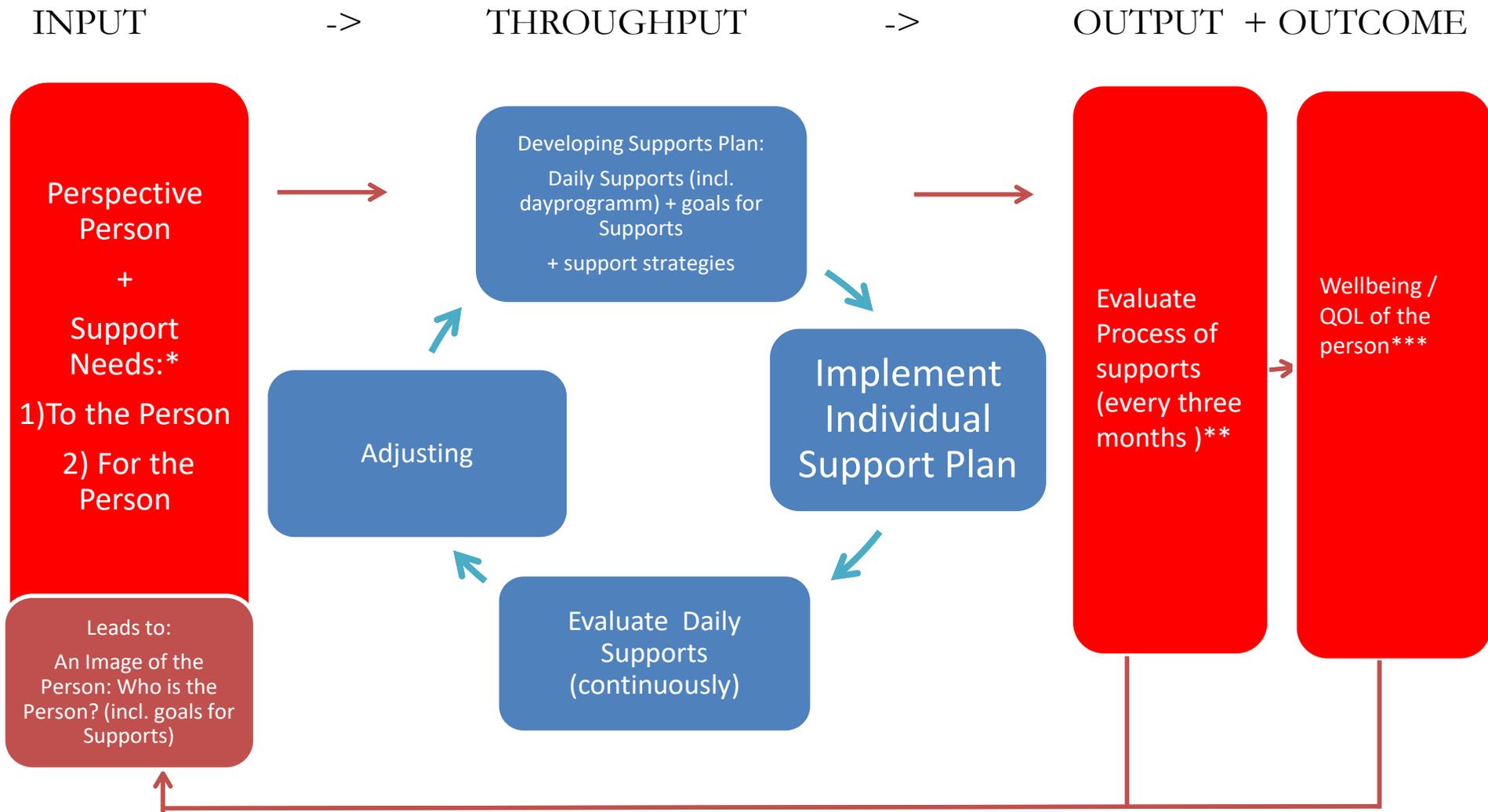
Component 5: Monitoring  
Dialogue with the cliënt

To what extent are goals and wishes realised?

Does the person get the support he / she needs?

Component 6 : Evaluation of the Individual Support Plan  
Measuring QOL by measuring Personal Outcomes with the POS



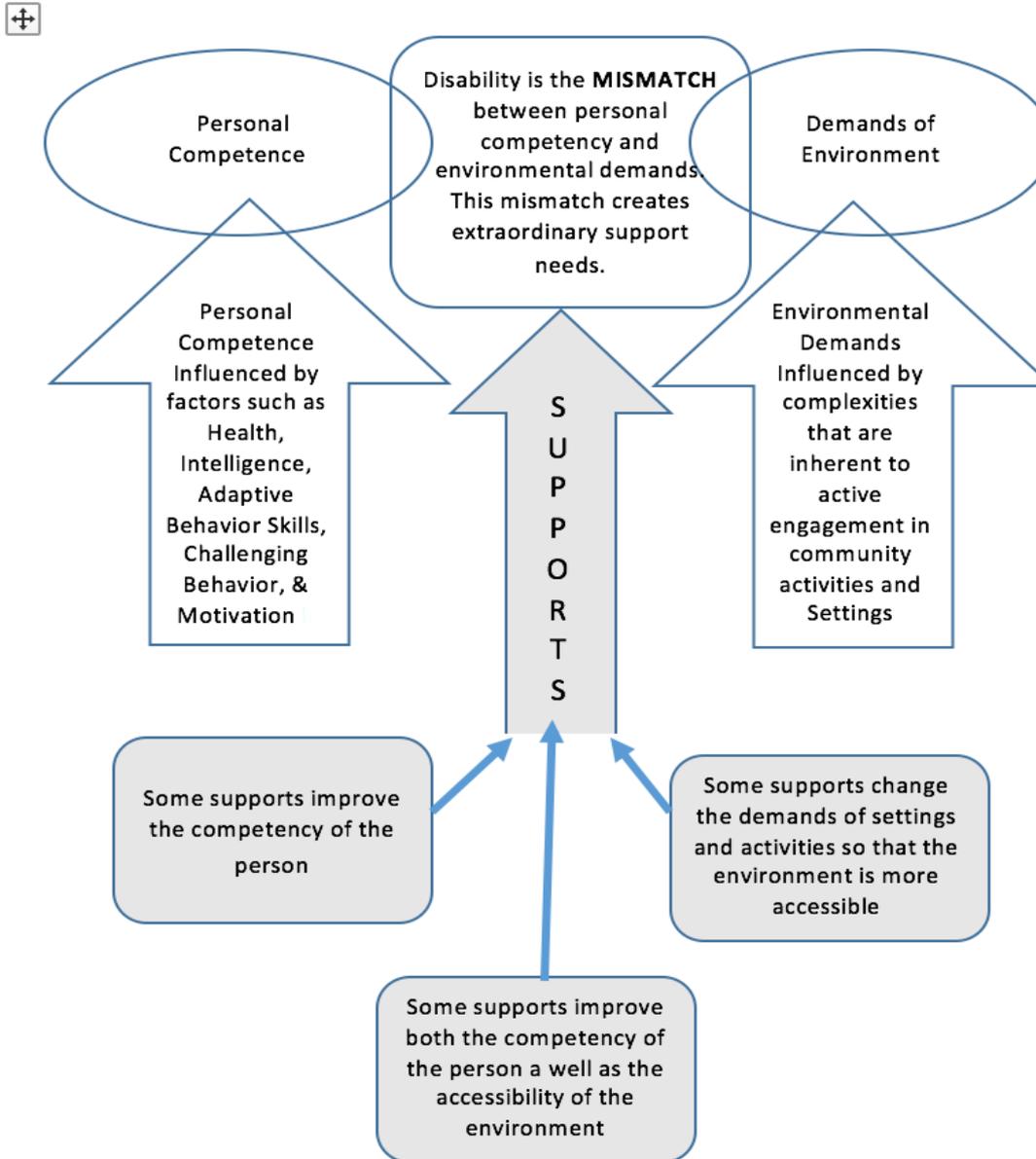


\*The support needs are specified by administering the Supports Intensity Scale (SIS) with the client plus at least one person who knows the client well. This information is complemented with information from the dossier and from diagnostics.

\*\*The frequency varies according to the person

\*\*\*The Quality of Life is evaluated with the Personal Outcomes Scale (POS).

# What is support?



# Support can also take various forms:

We are then talking about **components of a system of supports**: support can be provided through:

- environmental accommodation,
- technology,
- tools,
- learning / education,
- natural or professional support, etc.

When a support plan is drawn up, it is then also important that this is **aligned with the domains of quality of life**.

# Aligning components of a system of supports and support strategies to the QOL domains: a finger exercise

**Table 2. Interventions aligned tot the QOL domains**

<i>QOL domain</i>	<i>Related Components of a system of supports</i>	<i>Exemplary Support Strategies</i>	<i>Anticipated Effects</i>
Personal <u>Development</u>	Technology	Provide assistive technology (e.g. communication devices, computers, memory aides, medication dispensers, med alert monitors)	-Facilitates learning, independence, interactions, and communication
	Reasonable accommodation	Ensuring physical accessibility of buildings, transport, and work spaces; creating secure and predictable environments; and providing physical and other accommodations that allow individuals to negotiate their environment and carry out daily tasks.	-Increase access and use and independence
	Professional support	Facilitate personal goal setting  Implement self-management, self-evaluation, self-instruction programs  Maximize incentives (e.g. rewards, opportunities to be successful)	-Facilitates motivation and internal locus of control  -Increases personal motivation and goal setting

	<p>Prosthetics</p> <p><u>Education across the lifespan</u></p>	<p>Implement skill development programs</p> <p>Providing sensory aids and motoric assistance devices that support the body to undertake functions it cannot. Examples include wheel chairs, robotic arms or legs, special glasses/ visual aids, hearing aids, and orthotic devices.</p> <p>Emphasize personal strengths (e.g. attitudes, skills, knowledge sharing)</p> <p>Developing new skills and behaviors through behavioral techniques (e.g. modeling, manipulation of antecedents and consequences), task analysis, and education and training strategies such as Universal Design for Learning</p>	<p>Enhanced functioning</p> <p>-Enhances successful performance and increases sense of self efficacy (belief one can do it themselves)</p> <p>Increased independence</p> <p>Increased cognitive functioning, self-determination, and live-long learning</p>
<p>Self-Determination</p>	<p>Technology</p>	<p>Using assistive and information devices to enhance an individual's ability to communicate, maintain health and well-being, and to function successfully within his/her environment. Examples include communication aides, smart phones, electronic tablets/</p>	<p>Increased cognitive functioning, self-determination, and live-long learning, making <u>choices</u></p> <p>-Enhances personal control</p>

	<p>Personal strengths/assets</p>	<p>devices, medication dispensing devices, medical alert monitors, and speech recognition devices</p> <p>Use smart technology</p> <p>Facilitating individual preferences, personal goals and interests, choice and decision making, motivation, skills and knowledge, positive attitudes and expectations, self-management strategies, and self-advocacy skills.</p> <p>Allow/facilitate choice and decision making</p> <p>Teach self-regulation</p>	<p>Increased self-regulation, autonomy and self-determination</p> <p>-Facilitates internal locus of control, self-esteem, and sense of empowerment</p> <p>-Enhances personal control</p>
<p>Interpersonal Relations</p>	<p>Natural Supports</p>	<p>Building and maintaining support networks (e.g. family, friends, peers, colleagues) and fostering self-advocacy, friendships, community involvement, and social engagement.</p> <p>Use communication/social media devices</p> <p>Maximize family involvement</p>	<p>-Increases social engagement</p> <p>-Increase social networks</p> <p>Increased social inclusion, interpersonal relations,</p>

	Professional services	<p>Providing medical, educational, psychological, psychiatric, counseling, nursing, and dental services; physical, occupational, and speech therapy, career coaching when relevant, futures planning, and supports for housing and accommodation</p> <p>Involve in social skills training program</p> <p>Involve in social skills training program Involve in peer-group (e.g. PALS, Best Buddies)</p> <p>Emphasize personal strengths (e.g. attitudes, skills, knowledge sharing)</p>	<p>social-emotional well-being</p> <p>-Increases perceived societal contribution</p>
Social Inclusion	<p>Natural Supports</p> <p>Reasonable accommodation</p>	<p>Access/interface with natural supports</p> <p>Ensuring physical accessibility of buildings, transport, and work spaces; creating secure and predictable environments; and providing physical and other accommodations that allow individuals to negotiate their environment and carry out daily tasks</p>	<p>-Increased community access, participation, and involvement</p> <p>Enhanced personal development, community living, integrated employment</p> <p>Increased social inclusion, interpersonal relations, social-emotional well-being</p>

	Professional services	<p>Gebruik social media</p> <p>Facilitate transportation</p> <p>Use prosthetics (sensory or motor devices)</p> <p>Active support</p>	<p>Make sure that people who need support have the chance to be fully involved in their lives and receive the right range and level of support to be successful</p>
Rights		<p>Advocate for full citizenship, access, due process</p> <p>Involve in self-advocacy</p> <p>Treat with respect (e.g. privacy, recognition, dignity)</p>	<p>-Ensures equity, inclusion, and legal rights</p> <p>-Maximize empowerment and inclusion</p> <p>-Respect human rights</p>
Emotional Well-Being	<p>Natural Supports</p> <p>Professional services</p>	<p>Building and maintaining support networks</p> <p>Provide safe and predictable environments</p> <p>Access professional services</p> <p>Maximize incentives (e.g. rewards, opportunities to be successful)</p> <p>Use positive behavioral supports</p>	<p>-Reduce fear and anxiety</p> <p>-Increase motivation and satisfaction</p> <p>-Reduce challenging behaviors and increase positive interactions</p> <p>-Maximize mental/ behavioral health</p> <p>Increased motivation and achievement</p>

	Dignity and respect	<p>Gentle Teaching</p> <p>Enhancing social role status through community involvement, equal opportunity, recognition, appreciation, financial security, honors, personal goal setting, empowerment, and control of an individual supports plan.</p>	Safety, security, engagement, being unconditionally valued
Physical Well-Being	Professional services	<p>Providing medical, educational, psychological, psychiatric, counseling, nursing, and dental services; physical, occupational, and speech therapy, career coaching when relevant, futures planning, and supports for housing and accommodation</p> <p>Provide prosthetics (i.e. sensory or motor enhancement devices)</p> <p>Implement nutritional programs</p> <p>Implement or increase involvement in exercise programs</p> <p>Access professional services</p>	<p>Increased personal development, physical and behavioral health, interpersonal relations, and emotional well-being</p> <p>-Increase sensory processing and physical mobility</p> <p>-Maintain weight control and encourage proper and balanced nutrition</p> <p>-Enhance human functioning and reduce negative effects of obesity and/or inactivity</p> <p>Maintain or improve medical/physical condition</p>

Material Well-Being	<u>Reasonable accommodation</u>	<p>Ensuring physical accessibility of buildings, transport, and work spaces; creating secure and predictable environments; and providing physical and other accommodations that allow individuals to negotiate their environment and carry out daily tasks.</p> <p>Involve in supported employment program</p> <p>Provide paid sheltered workshop employment</p> <p>Enroll in vocational training program</p> <p>Network with generic employers</p> <p>Participate as a volunteer</p>	<p>Enhanced personal development, community living, integrated employment</p> <p>-Increase economic self-sufficiency and sense of accomplishment</p> <p>-Increase job-related skills and behaviors</p> <p>-Increase sense of contribution and purpose</p>
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## **C. An appropriate range of methodologies and methodical work forms**

- Which available methodologies (basic methodologies and main methodologies) can be applied adequately?
- These methodologies and methodical work forms can in many cases be linked to different support profiles:
  - aging people,
  - children,
  - people with behavioral problems,
  - people with severe (multiple) disabilities,
  - etc ..

## D. An integrated model for concrete support: methods and interventions

According to "Kok" (1973):

Third grade strategy

Interventions;  
evidence-based;  
specific and individual

Main methods: related to specific support  
profiles AND aligned to enhancing Quality  
of Life

Second grade strategy

Environmental circumstances: regular living environment,  
regular employment; "normal if possible, special if  
necessary"

Basic methods: principles of general support

Methodological cycle; person-centred according to support model,

First grade strategy

Base: based on values coming from the UN Convention  
and the QOL domains: pedagogical climate:

Culture of Life



Thank you very much  
for your attention!

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