



# **From institution settings to community based support: Key aspects of organizational transformation**

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## **From Quality of Care to Quality of Life**

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# I. Introduction

Today many service providers for people with disabilities face quite fundamental challenges that question their existence in their current form

- From congregated settings to community based support?
- EASPD\* (2013): “....It is time to put forward concrete planning for deinstitutionalization and community-based settings involving persons with disability and all mainstream and disability stakeholders.”

- \*European Association of Service Providers for Persons with Disabilities

## But there are more challenges....

- decreasing resources
- a movement from vertical to horizontal organization structure
- from general services to **individualized supports**
- align **values** with service delivery practices
- focus on **evidence** and evidence-based practices
- the need for capacity building in reference to organization-based self-assessment, strategic planning, and performance evaluation (Schalock & Verdugo, 2012).

**The conclusion is that many organizations supporting people with disabilities nowadays face the need for organizational transformation.**

Van Loon, J. & van Wijk, P. (2016) Organizational Transformation. In Schalock, R.L. & Keith, K.D. (ed.) (2016) *Cross-Cultural Quality of Life: Enhancing the lives of people with intellectual disability. Second Edition*. Washington: American Association on Intellectual and Developmental Disabilities.


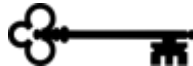
# What are important factors in organizational transformation?

- I. In the proces of deinstitutionalization as such, and also....
- II. In the continuous process of adjusting to new developments

 Most important: 

 A clear focus

# I: Quality of life as leading principle

-  A clear focus on quality of life and on the supports-paradigm during the program changes.
-  Every decision, at the organizational level as well as at the level of the individual client, has to contribute to the personal outcomes, the quality of life, of the clients.
- The eight QOL domains can be used as guidelines in the transformation of the organisation



## II: UN Convention on the Rights of People with Disabilities

Also of importance in this respect is the mondial influence of the UN Convention on the Rights of People with Disabilities (CRPD;2006),

with as General Principles:

- Participation and Inclusion
- Accessibility
- Non-discrimination

And:

✂ Regarding the focus on Quality of Life  
there is no: “Yes, BUT....”

## II. Quality of Life

# Quality of Life (Schalock, 2007):

- a multidimensional concept
- influenced by personal and environmental factors and the interactions between them
- evaluated on the base of subjective and objective indicators
- the quality of life for people with handicaps/ disabilities involves the same factors and relations that are important to everyone,
- quality of life is enhanced by enabling people to participate in decisions that concern their own existence
- accepting people in their own local community and integrating them totally enhances quality of life.

<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

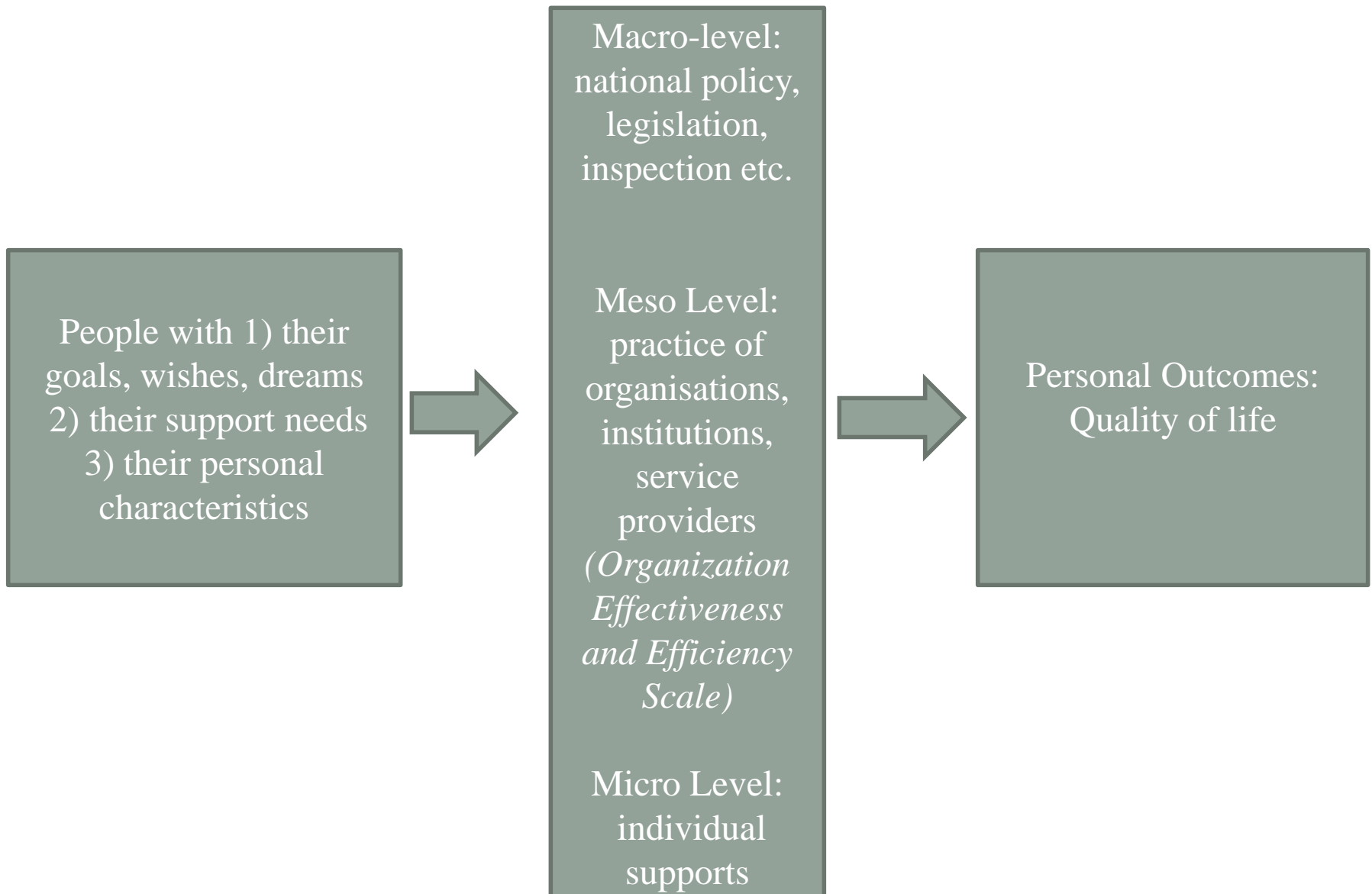
The dimensions in Quality of Life that I see as most essential in the organizational transformation (van Loon, 2005)

- Inclusion,
- Self-determination
- Personal development


**Therefore**: It is important that the implications of the emancipation cornerstone are carried through consistently in all of the resolutions made:

- dismantle the institute
- coaching style of management directed towards autonomy and self-direction
- the opinions of the clients play an important role in structuring the new organization

# Enhancing QOL



# Consequences of this emphasis on QOL

- ❖ Gives guidelines on macro – meso – and micro level
- ❖ The process of change from a focus on quality of care towards quality of life **inevitable leads to the choice of deinstitutionalization**
- ❖ However:
- ❖  Much attention is needed to **develop an adequate support model** or support system for people with intellectual disabilities



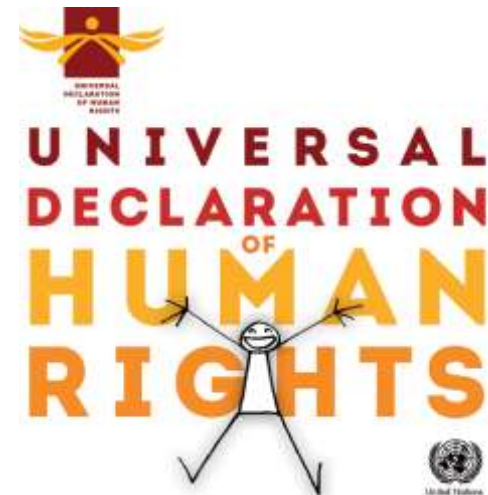
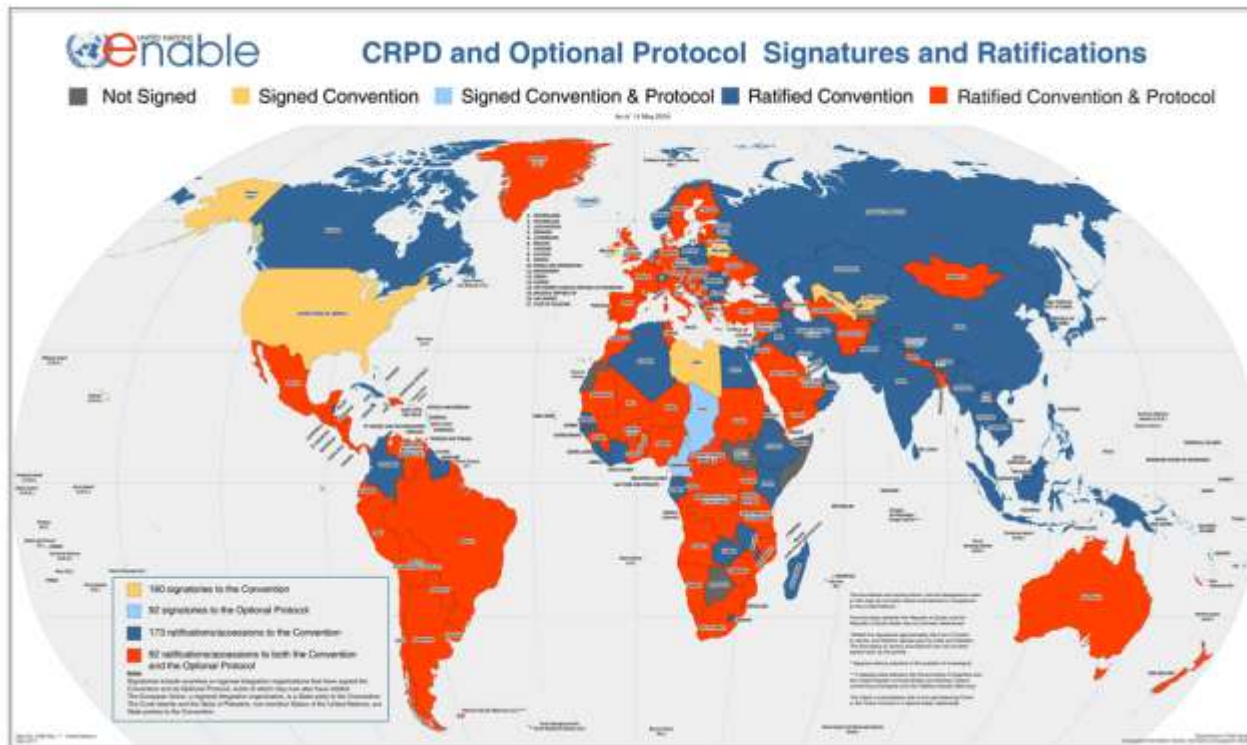
# Consumer involvement

✦ Important for the embedding of improving Quality of Life in an organization is consumer involvement (Schalock et al., 2007):

an essential organizational strategy involves incorporating consumers in meaningful roles.

### III. The UN Convention on the Rights of People with Disabilities (CRPD)

The UN-Convention on the Rights of People with Disabilities (2006) has led to the international recognition, that it is the obligation of the society to guarantee the full Participation of People with Disabilities



# General Principles: Participation and Inclusion

- Participation is important to correctly identify specific needs, and to empower the individual
- Full and effective participation and inclusion in society is recognized in the Convention as:
  - A general principle (article 3)
  - A general obligation (article 4)
  - A right (articles 29 and 30)

# General Principles: Accessibility

- Important as a means to empowerment and inclusion
- Both a general principle and a stand-alone article (article 9)
- Access must be ensured to:
  - Justice (article 13)
  - Living independently and being included in the community (article 19)
  - Information and communication services (article 21)
  - Education (article 24)
  - Health (article 25)
  - Habilitation and rehabilitation (article 26)
  - Work and employment (article 27) - human resource policies and practices
  - Adequate standard of living and social protection (article 28)
  - Participation in political and social life (article 29)
  - Participation in cultural life, recreation, leisure and sport (article 30)

# General Principles: Non-discrimination

- Fundamental principle of international human rights law
- Includes direct and indirect discrimination
- ***Reasonable accommodation*** must be made for persons with disabilities
  - *reasonable accommodation*: ‘necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms’

# Monitoring and Implementation

All activities must include the participation of persons with disabilities:

**‘Nothing about us without us’**

# Relation between the domains of QOL and the articles of the UN Convention for People with Disabilities

<i>• Domain QOL</i>	<i>Applicable Articles 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



## IV. Social Participation

An important theme in QOL and the CRPD is:

## Participation of People with Disabilities

- 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.
- The shift of attention to the environment rather than on the person, explains a focus on social participation as a necessary dimension with regard to human functioning. Policies and political actions must therefore fundamentally focus on facilitating social participation in the daily lives of people with ID (Verdonschot et al, 2009).

# Social participation

- Speaking about social participation is speaking about quality of life. If QOL is an important goal **for all people**, this is also true for people with disabilities.
- Social participation should also be operationalized for this group into concrete actions:
  - (1) Social participation as an inherent element of QOL;
  - (2) Living in the community as a necessary step towards social participation, and
  - (3) The support thinking and specific individualized support methods as facilitator towards social participation.
- Empirical research shows that often social participation is prevented for persons with disabilities, but especially for people with severe multiple disabilities.

# Participation in the literature:

## 1. The Voice of People with Disabilities

- Self-advocacy groups representing people with disabilities have clear positions on residential services and supports. They demand smaller, community-based, person-centered residential services that promote community living and participation.

## 2. Research on Community Living and Participation

- Large institutions do not promote positive outcomes for people with IDD and limit community interaction and involvement for some of our most vulnerable citizens. These settings have negative outcomes for their health, well-being, quality of life, independence, and overall happiness (AAIDD and AUCD, 2015).
- People who move from institutions to smaller community settings are happier, healthier, have more control over their lives, and are better able to function independently after they move (Larson, Lakin & Hill, 2013).
- Those who live in their own homes report the greatest amount of choice compared to those living in an institution, community residence, family home, or foster care (Bradley et al., 2015).

- Smaller settings, on average, produce better QOL outcomes for people with IDD, more independence and more satisfaction with their lives (Nord et al., 2014)
- The benefits of living in smaller, community settings include:
  - increased choice and self-determination,
  - larger social networks and more friends,
  - increased access to mainstream community facilities,
  - greater participation in community life,
  - more chances to develop and maintain skills that foster independence,
  - a better material standard of living,
  - increased acceptance from other members of the community,
  - and greater overall satisfaction with their lives as expressed by people with IDD themselves and their families (Kozma, et al., 2009; Larson, Lakin & Hill, 2013).

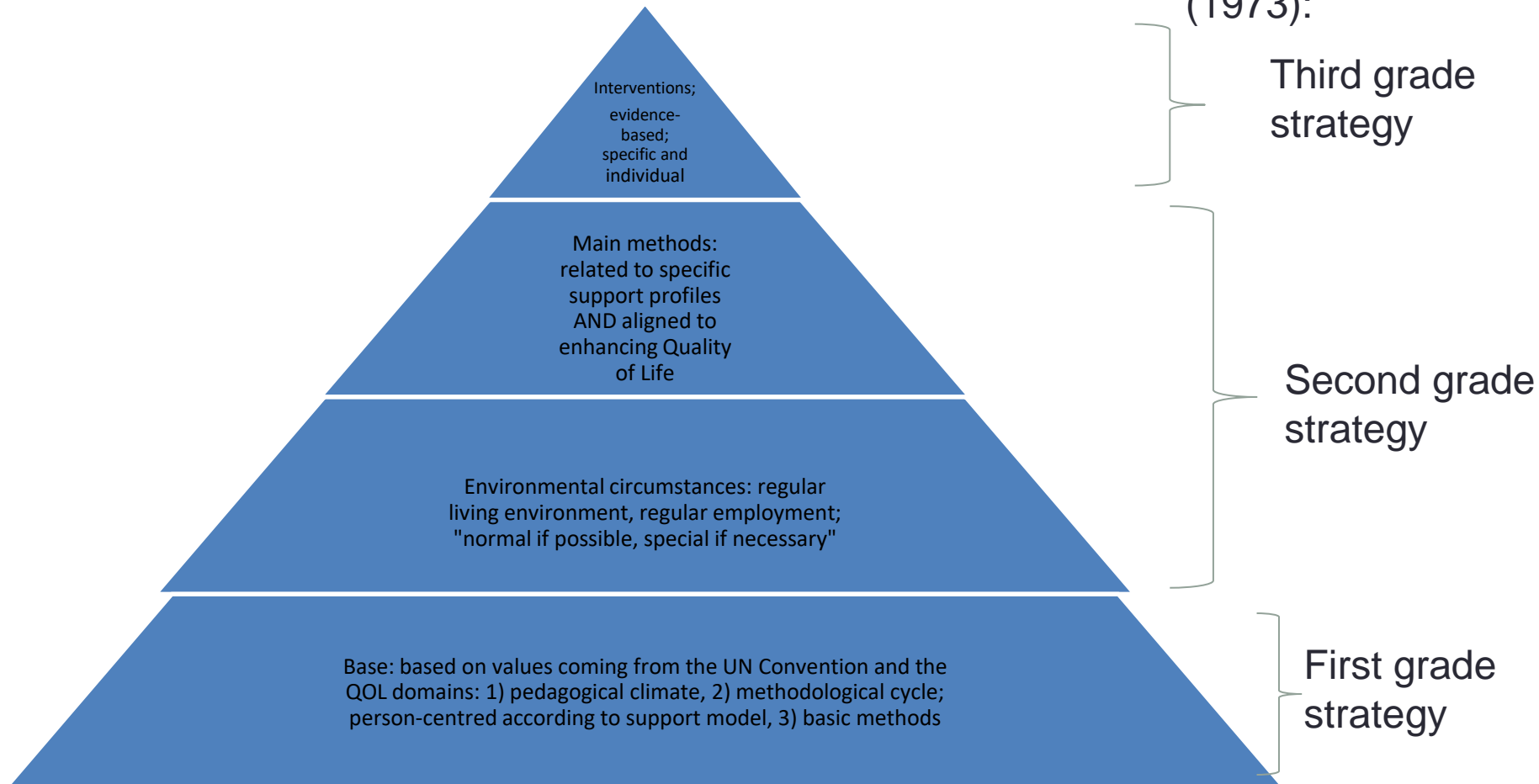
# What People with Significant Disabilities say on Social Participation ( study by van Loon, 2016)

- Conclusion: People with significant disabilities or multiple profound intellectual disabilities want the same with regard to Social Participation as other people:
  - Good contacts with family and friends
  - Participation in normal activities in the community, as well as for example participation in church
  - Support to participate, for example from volunteers
  - Good contacts with neighbours
  - I want people to knock at my door before entering
  - Privacy
  - Pets
  - Being well-informed

## V. What and How?



## Model for concrete support: methods and interventions



# How can we find an answer to these developments?

- Quality of life keeps guiding us!
- More emphasis on participation in the community: more community based **organising**! More appeal to regular solutions in living, work, transport, education and leisure time.
- More emphasis on community context and financial ‘lawfulness’ (**Normal what can**, special what is necessary’)
- Better respond to specific support needs (**Normal what can**, **special what is necessary**’)
- Stronger personal client support, e.g. through a function as a Personal Assistant! (‘Nothing about us, without us’)

# Horizontal and vertical alignment

- At the individual level, alignment occurs when personal goals and assessed support needs (input) lead logically to the provision of a system of supports (throughput), which in turn produces valued personal outcomes (output).
- At the organization level, alignment occurs when the organization's resources are used as a basis for an organization's services that lead logically to performance-based outcomes such as aggregated personal outcomes.

# Questions on Meso Level: the Organization:

1. Does the organization contribute to the Personal Development of the client?: (What can we do to make the organization contribute ....)

- Does the organization stimulate the client to follow a course?
- Does the policy of the organization contribute to increasing his / her personal competence?
- Does the policy of the organization contribute to improving / maintaining skills?

2. Does the policy of the organization contribute to the self determination of the client?:

- Does the organization stimulate the client in his / her autonomy,
- Does the organization's policy enable the client to experience personal control over what is important to him / her in life
- Personal goals and values, choices

### 3. Does the organization contribute to experiencing good Interpersonal Relationships:

- Good support in interactions, relationships / friendships (emotional, physical, feedback).

### 4. Does the organization contribute to the Inclusion of the client:

- Integration and participation in society,
- Having meaningful roles in society

### 5. Does the organization contribute to the experience of Equal Rights by the client ?:

- Are clients helped to experience human rights as respect, dignity and equality?
- Are clients helped to experience legal rights (citizenship, access, just treatment)?

6. Does the organization contribute to the Emotional Well-being of the client?:

- To his satisfaction,
- To experience a positive self-image,
- To be free from stress

7. Does the organization contribute to the physical well-being of the client?:

- Is sufficient attention paid to health?
- Is sufficient attention paid to stimulating ADL activities?
- Is the client sufficiently supported in experiencing meaningful and enjoyable free time?

8. Does the organization contribute to the Materiel Wellbeing of the client?:

- Is there enough attention for his / her financial status?
- Is the client sufficiently supported in (finding / keeping) work?
- Is the client adequately supported in his / her living?

# Questions on Meso Level: the Support Workers:

1. Does the support that the employees offer contribute to the Personal Development of the client? (What support can a support worker offer to.....)

- Do they encourage the client to follow a course?
- Does their support contribute to increasing his / her personal competence?
- Does their support contribute to improving / maintaining skills?

2. Does the support offered by the employees contribute to the self determination of the client ?:

- Encourage the client in his / her autonomy,
- Does their support enable the client to experience personal control over the themes that are important to him / her in life
- Personal goals and values, choices

3. Does the support offered by the employees contribute to experiencing good Interpersonal Relations of the client ?:

- Good support in interactions, relationships / friendships (emotional, physical, feedback).

4. Does the support offered by the employees contribute to the Inclusion of the client:

- Integration and participation in society,
- Having meaningful roles in society

5. Does the support offered by the employees contribute to the experience of Equal Rights by the client ?:

- Do I help the client experience human rights as respect, dignity and equality?
- Do they help the client experience legal rights (citizenship, access, just treatment)?



6. Does the support offered by the employees contribute to the client's Emotional Well-being ?:

- To his satisfaction,
- To experience a positive self-image,
- To be free from stress

7. Does the support that the employees offer contribute to the physical well-being of the client ?:

- Do they pay sufficient attention to health?
- Do they pay sufficient attention to the stimulation of ADL activities?
- Do they adequately support the client in experiencing meaningful and enjoyable free time?

8. Does the support offered by the employees contribute to the Material Well-being of the client:

- Do the employees pay sufficient attention to his / her financial status?
- Do they support the client in (finding / keeping) work?
- Do they support the client sufficiently in his / her living?

## The ‘Model Arduin’

With respect to the actual provision of support, it is important that the implications of the QOL Framework are carried through consistently in all of the decisions made in the management of the organization.

This is accentuated in the choice to dismantle the institution, as well as in choosing a coaching style of management directed towards autonomy and self-direction.

Only a facilitating organization remains, focused on support of the self-determining client, focused on supported living. An important motto in shaping this organization is **“Normal if possible, special if necessary”**.

✂ The separation between the three life spheres - accommodation, work/daily activities and leisure – is fundamentally important in the process of deinstitutionalization and promotion of quality of life.

The value of work/day occupation is considered to be of more fundamental importance in one's life.

An important side -effect of work/day occupation is that **one only gets the feeling of coming home, being at home, even having a home, if one comes home** after a days work / daily activities. When one is in the same accommodation for the whole day, there arises no feeling of home.

Consequently, many 'bureaucratic trimmings' can be abolished in the organization: there should be as little overhead as possible. The resources that become available are greatly needed in the primary process of the small scale living arrangements and the work/ day occupation for everyone.

The functions of most staff are effected by necessary fundamental changes in this process and they will continue to change. This process is not always easy for the staff members, nor for the parents. It is important that at the start of this process the members of staff are given (job and salary) security.

# Quality Management

- Evidence based
- Focusing, in quality management, on QOL instead of quality of care

## In a quality of care:

- perspectives of staff and facility are usually more influential than perspectives of the clients.
- value-based evaluation is less popular.
  - The quality of care system gives no guarantee that existing knowledge about good predictors for quality of life, such as social inclusion, self-determination and personal development, are implemented (van Loon & Van Hove, 2001).
- one frequently finds an emphasis on impairment, categorization, homogenous grouping, health and safety, and control (De Waele & Van Hove, 2005).
- the main concern for quality of care strategies is typically the process (Maes et al., 2000).
  - This focus on the process allows organisations to invest a lot of time and energy in their own (management) structures and arrangements,

## **The practice of self-determination**

Leading principle in support:  
Everyone can make important decisions in his / her life (with the support of a personal assistant)  
Option of accommodation: the housing bureau  
Option of work: the vacancy bank

## **The practice of inclusion:**

Normal houses for all clients  
Foster families for children  
Work or daily activities in companies and daycentres in the community

## **The practice of personal development**

Learning by experience:  
*Participating in the community*

Schooling of clients:  
*Focused on emancipation and self-determination*

## **The practice of supports:**

People live in an house where they want to live themselves and work where they want to work themselves and get the supports they subsequently need.

# Work / Daily activities companies and centres in the community



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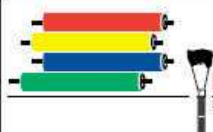




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2e hands verkoop en recycling

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# Centres for daily activities for people with severe intellectual disabilities





# Schooling: Academy for Quality of Life



# The support worker

- Clients are supported in their homes by supportworkers.
- One of the problems encountered in the deinstitutionalization / the reorganization of Arduin, was that the staff who were trained to work in an institution were therefore not automatically trained to work in supporting people in community based working and living situations:
- A new education for this profession is suggested and implemented

From a respectful attitude to the individual's choices and dignity, this professional must provide and / or organize the support that the person needs in order to function in his environment.

He / she must be flexible with the variety of support questions of a client who fully participates in society, with the fundamental intention to make himself superfluous in the end.

# A new schooling for Support Workers, based on:

## 1) *Support functions and representative activities (AAMR,2002)*

Support function	Representative activities		
Teaching	Supervising Giving Feedback Organizing the learning environment	Training Evaluating Supporting Inclusive classrooms	Instructing Collecting data Individualizing instruction
Befriending	Advocating Car pooling Supervising	Evaluating Communicating Training	Reciprocating Associating & Dissociating
Financial planning	Instructing Working with Health assurance Advocating for benefits	Giving feedback Assisting with money management Protection and legal assistance	Socializing Budgeting Income assistance & planning considerations
Employee assistance	Counselling Procuring / using assistive technology devices	Supervisory training Job performance enhancement	Crisis intervention / assistance Job/task accommodation and redesigning job / work duties
Behavioural support	Functional analysis Multicomponent instruction Emphasis on ante-cedent manipulation	Manipulation of ecological & setting events Teaching adaptive behaviour	Building environment with effective consequences
In-home living assistance	Personal maintenance / care Transfer & mobility Dressing & clothing care Architectural modifications	Communication devices Behavioural support Eating & Food management Housekeeping	Respite care Attendant care Home-health aides Homemaker services
Community access and use	Carpooling / rides program Transportation training Personal protection skills	Recreation / leisure involvement Community awareness opportunities Vehicle modification	Community use opportunities & interacting with generic agencies Personal protection skills
Health assistance	Medical appointments Medical interventions Supervision	Emergency procedures Mobility (assistive devices) Counselling appointments Medication taking	Hazard awareness Safety training Physical therapy & related activities Counselling interventions



## And 2) The following interventions aligned to the QOL domains

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 Development	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	-Facilitates motivation and internal locus of control
		Implement self-management, self-evaluation, self-instruction programs	-Increases personal motivation and goal setting
		Maximize incentives (e.g. rewards, opportunities to be successful)	

	<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>
Self-Determination	Technology	<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>

	Personal strengths/assets	<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>
Interpersonal Relations	Natural Supports	<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</p> <p>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. 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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# Coming together in a New Profile for a Support Worker:

- Knowledge:
  - E.g. regarding support, community building, socialisation of persons, networks, social patterns, human right, insights regarding Quality of Life and self-determination, etc.
- Methodical skills:
  - E.g. working methodically, acting supportive: active listening, clarifying questions and translating back, social skills, supporting the development and maintenance of networks, agological skills, communicative skills; teaching to learn, creating conditions; creating opportunities to have experiences, promoting say and control, coordinate and planning, working together: giving feedback, sharing relevant information, estimating risks, etc.
- Attitude and personality traits:
  - E.g. being able to support in stead of caring or controlling, Beings conscious of one's own norms, Thinking with the focus on the process, steering, thinking in steps, Being able to reflect on one's own acting, Being able to think and act unorthodox and creative, Self steering, Independence, etc.



# The Personal Assistant

- Each client has a personal assistant that he/she can call upon for support in the dialogue with the organization, in formulating wishes and support requests directed at the organization.
- The personal assistant has a regular contact with the client to speak about his wishes (concerning living, working and leisure), and the ways to give this content and shape.
- The results of this dialogue can be written down in the Personal Plan of the client.
- He or she maintains the communication between the various staff members of the organization, the client, his family and/or legal representative of the client.
- He/she sees to it that the agreed service and care is carried out in conformity with the wishes of the individual client. Therefore, it is fundamental that a personal director is not a direct caregiver towards his/her client.

# Securing the quality of the medical care

- In stead of one institute-doctor, the ‘family-doctor’ for all residents, quite some more local general practitioners will be asked for their medical support:
- Give the local practitioners the support of one specialist doctor, provided by the service-provider! Especially for ‘handicap-related’ problems
- With good arrangements as to allocation of tasks

# The Individual Supports Plan

# Micro level: the individual supports plan (ISP)

1. Are there personal goals and actions in the ISP regarding the personal development of the client ?:

- Encouraging the client to follow a course?
- Increasing his / her personal competence?
- Improve / maintain skills?

2. Are there personal goals and actions in the ISP regarding the self determination of the client ?:

- Encouraging the client in his / her autonomy,
- To experience personal control on the themes that are important to him / her in life
- Personal goals and values, choices

3. Are there any goals and actions in the ISP regarding the promotion of good Interpersonal Relationships of the client ?:

- Good support in interactions, relationships / friendships (emotional, physical, feedback).

4. Are there any goals and actions in the ISP with regard to promoting the client's Inclusion ?:

- Integration and participation in society,
- Having meaningful roles in society

5. Does the ISP pay attention to the experience of Equal Rights by the client ?:

- Experiencing human rights as respect, privacy, dignity and equality?
- Experiencing legal rights (citizenship, access, just treatment)?

6. Are there any goals and actions in the ISP with regard to promoting the emotional well-being of the client ?:

- Satisfaction,
- A positive self-image,
- Freedom from stress

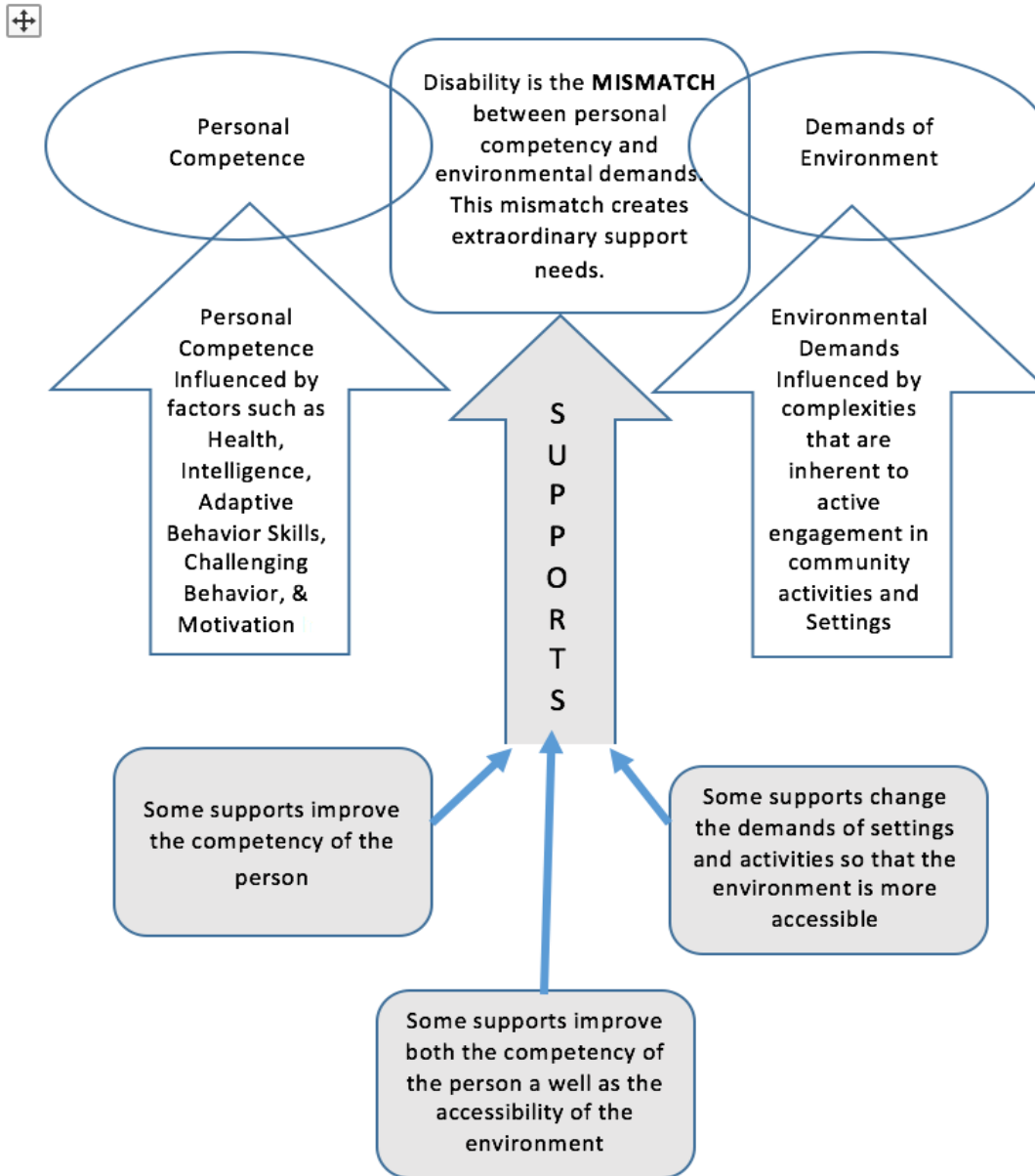
7. Are there goals and actions in the ISP with regard to promoting the client's physical well-being ?:

- Does it pay sufficient attention to health and healthy living?
- Does it pay sufficient attention to the stimulation of ADL activities?
- Does the personal plan pay attention to experiencing meaningful and enjoyable free time?

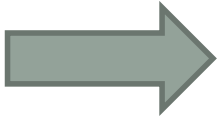



8. Does the ISP pay attention to the Materiel Well-being of the client:

- His / her financial status
- Support the client in (finding / keeping) work
- Supporting the client in living

# What is support?



# System of Supports

- Improving Quality of Life: an essential organizational strategy **involves incorporating consumers in meaningful roles.**
-  Nothing about us without us
-  Individualized (person centered) Supports System
-  The outcomes of an individual supports plan for a person should be an enhanced quality of life. Determining whether this outcome occurs, requires the **reliable and valid assessment of QOL-related domains**. E.g. with the Personal Outcomes Scale (POS, van Loon et al. 2008)
-  Central element in a support methodology is **the dialogue with the person.**



# An Individual Supports Plan should:

- Explore goals and personal perspectives: what does a person want in his life
- Explore what support a person needs and wants: which supports are important for and which are important to the person
- Formulate support strategies in answer to the personal goals, wants and needs
- Monitor in dialogue with the person the process of support
- Measure personal outcomes
- Comprise an ongoing system of fine-tuning and adjusting
- Use evidence based practices in doing so
- Be transparent and comprehensible for the person

## Important Questions:

What do you need to know if you want to support a person in a good way?

■ .....

■ .....

■ .....

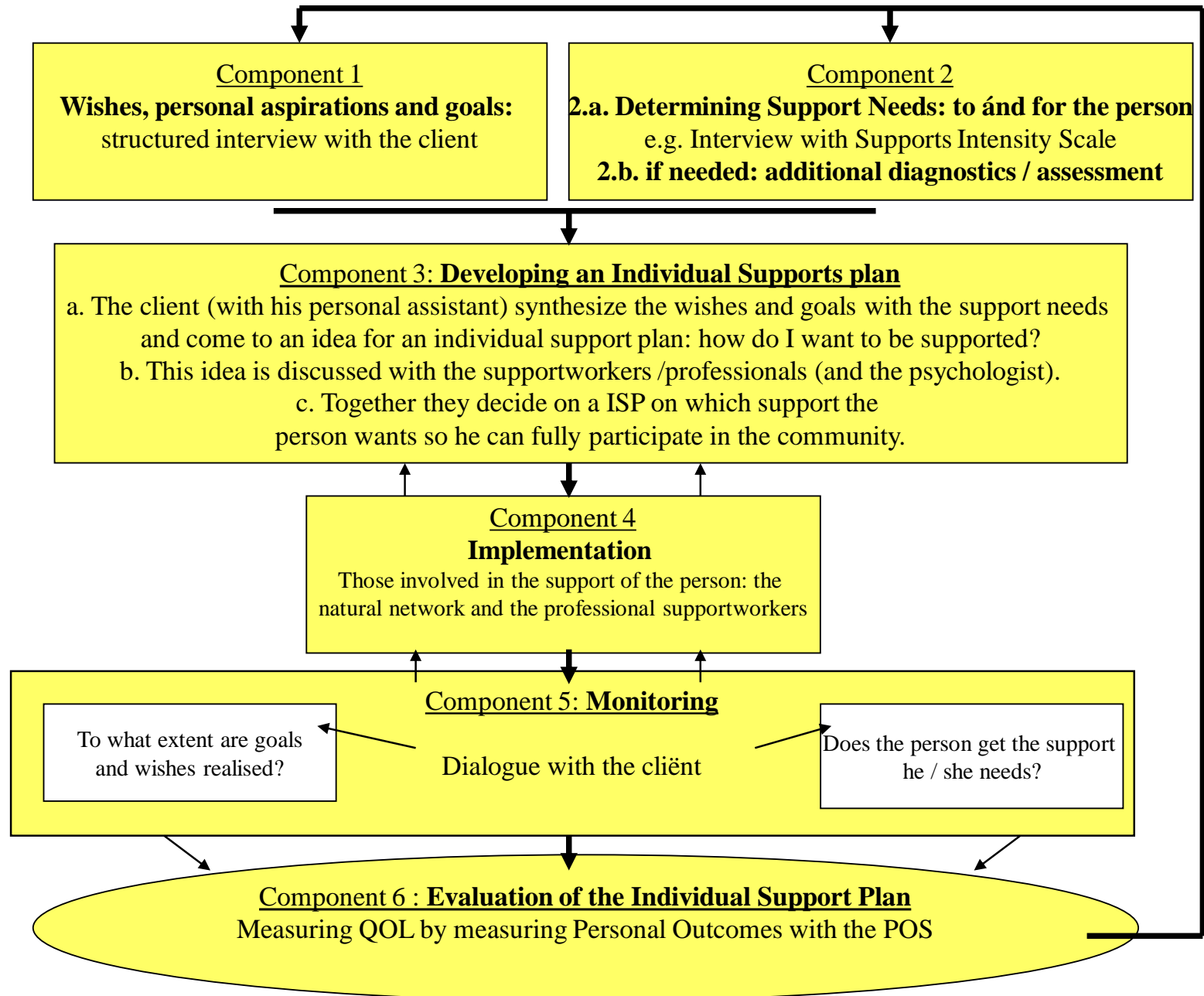
■ .....

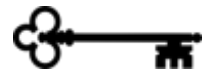
■ .....

■ .....

# Ánd...What should be the outcome of the support you offer a person?

- .....  
.....
- .....  
.....
- .....  
.....
- .....  
.....
- .....  
.....





**Using aggregated Evidence Based  
Outcomes on an organizational level**

For example: Measuring Outcomes with the

# Personal Outcomes Scale for Adults POS-A



Jos van Loon, Ph.D.  
Claudia Claes, Ph.D.  
Robert Schalock, Ph.D.  
Geert van Hove, Ph.D.

Version 2.0  
2013

### 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  
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  
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

**Qualitative Comments**(E.g. What is important for your life, what personal goals do you have for your life, what is needed to improve your quality of life and what is needed to improve the supports you receive?)

### Report of Others

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

**Qualitative Comments** (E.g. What is important for the person's life, what personal goals does he or she has for his or her life, what is needed to improve his or her quality of life and what is needed to improve the supports he or she receives?)



# Example of a report of a POS-interview (self-report)

## Personal Outcomes Scale Bakker

### Personal details



Name Dhr. A. Bakker  
Social Security Number 941331490  
Team Training alle modules



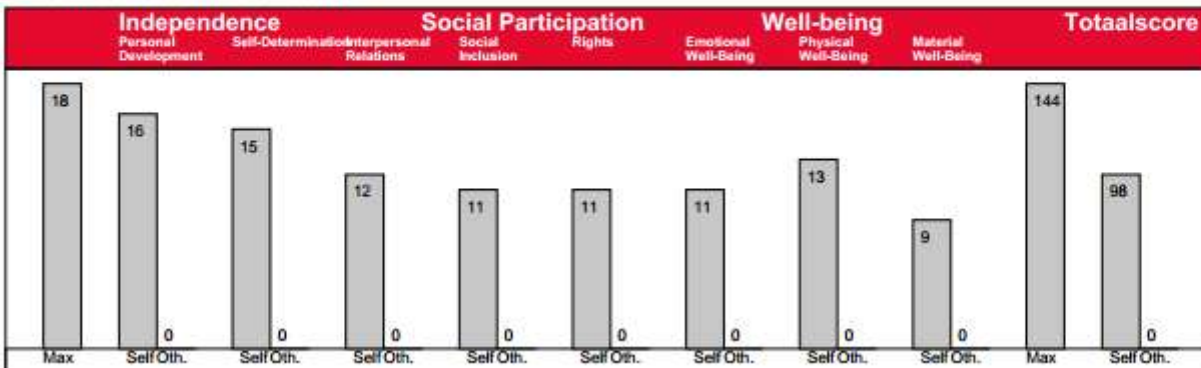
Print made by Trainer1 Alles  
Print made on 11-07-2014

Date self-report

12-11-2013

## 1. Results

The most recent POS results



## 2. Details

The following scores are made:

Factor	Domain	Question	Self	Other
Independence	Personal Development	1	3	
		2	2	
		3	3	
		4	3	
		5	2	
		6	3	
Totals for this domain			16	0

### Remarks

Self-Report: I would like to learn how to make simple meals like spaghetti and pasta. I also want to learn to pick up bread at the bakery around the corner independently.

Factor	Domain	Question	Self	Other
Independence	Self-Determination	1	3	
		2	3	
		3	2	
		4	2	
		5	2	
		6	3	
Totals for this domain			15	0

### Remarks

Self-Report: I would not be so patronized! I can decide what time I want to go to bed. And my brother does not have to decide on my allowance.

Factor	Domain	Question	Self	Other
Social Participation	Interpersonal Relations	1	3	
		2	2	
		3	2	
		4	2	
		5	1	
		6	2	
Totals for this domain			12	0

#### Remarks

Self-Report: I would like to see my brother and sister more often. And want to be invited for their birthdays.

Factor	Domain	Question	Self	Other
Social Participation	Social Inclusion	1	2	
		2	2	
		3	1	
		4	2	
		5	2	
		6	2	
Totals for this domain			11	0

#### Remarks

Self-Report: I would like to go to the neighborhood activities at the community center. How can I better get in touch with people in the neighborhood?

Factor	Domain	Question	Self	Other
Social Participation	Rights	1	2	
		2	2	
		3	2	
		4	1	
		5	3	
		6	1	
Totals for this domain			11	0

#### Remarks

Self-Report: Why can not I have dogs. I love dogs. I do not know how it is: vote ...

Factor	Domain	Question	Self	Other
Well-being	Emotional Well-Being	1	2	
		2	2	
		3	2	
		4	1	
		5	2	
		6	2	
Totals for this domain			11	0

#### Remarks

Self-Report: I do not always feel good. I'm afraid I make mistakes. I find it hard to talk about it with someone of my support workers and the psychologist I see so little.

Factor	Domain	Question	Self	Other
Well-being	Physical Well-Being	1	2	
		2	2	
		3	2	
		4	3	
		5	2	
		6	2	
Totals for this domain			13	0

#### Remarks

Self-Report: Sometimes I do not feel well.... Would there be something wrong? I do eat healthy!

Factor	Domain	Question	Self	Other
Well-being	Material Well-Being	1	1	
		2	1	
		3	2	
		4	1	
		5	2	
		6	2	
Totals for this domain			9	0

#### Remarks

Self-Report: I could maybe use more money. Would I be able to get a paid job. For example in the weekend?

	Self	Other
Independence	31	0
Social Participation	34	0
Well-being	33	0
Personal Outcomes Scale	98	0

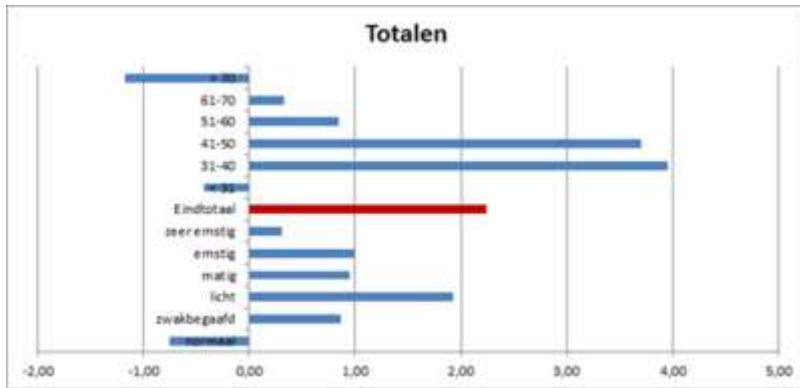
# Uses of QOL outcomes include

- The most important: the use in an ISP to improve individuals QOL
- Measuring Personal Outcomes gives valuable management information
- And is important to do research e.g. to study predictors in QOL

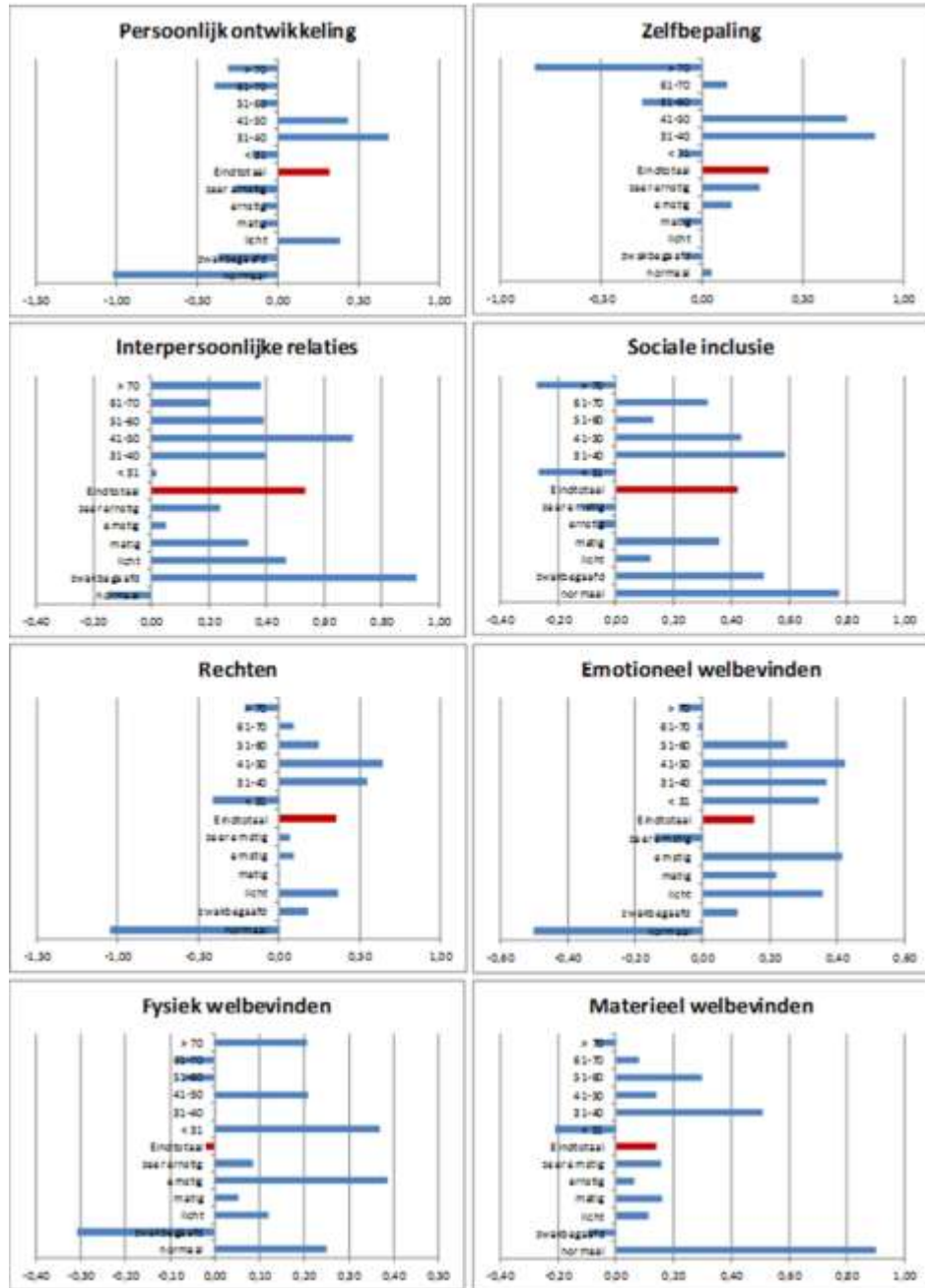
# Using Evidence Based Outcomes on an organizational level

- The data collected in the interviews with the Personal Outcomes Scale are aggregated to give Evidence Based Outcomes information regarding the individual, organization program, or the organization as a whole (Van Loon et al., 2012).
- An electronic application is used to handle the data

# Comparing QOL outcomes measures last interview with earlier interview: total organization



Verandering POS-uitkomsten t.o.v. vorige meting per domein en categorie (Totalen)





# In summary: key aspects in organizational transformation

- A clear focus on quality of life and on the supports-paradigm during the program changes.
- Every decision, at the organizational level as well as at the level of the individual client, has to contribute to the personal outcomes, the quality of life, of the clients.
- Regarding the focus on Quality of Life, there is no: “Yes, BUT....”
- Much attention is needed to develop an adequate support model or support system for people with intellectual disabilities
- Important for the embedding of improving Quality of Life in an organization is consumer involvement (Schalock et al., 2007)
- The separation between the three life spheres - accommodation, work/daily activities and leisure – is fundamentally important in the process of deinstitutionalization and promotion of quality of life.
- Individualized (person centered) Supports System
- The outcomes of an individual supports plan for a person should be an enhanced quality of life. Determining whether this outcome occurs, requires the reliable and valid assessment of QOL-related domains.
- Central element in a support methodology is the dialogue with the person.
- A New Profile for a Support Worker should be developed
- Use of aggregated Evidence Based Outcomes on an organizational level





Thank you very much  
for your attention!

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[vanloon.jos@gmail.com](mailto:vanloon.jos@gmail.com)