

Sharing and using SIS information across individuals, organizations, and systems

Lessons from Italy

Luigi Croce[°], Mauro Leoni*

[°]ANFFAS Brescia Onlus; Università Cattolica del Sacro Cuore di
Brescia

*Fondazione Istituto Ospedaliero di Sospiro (Cr); Università di Parma

The Italian experience

- The group is connected with to **AIRIM (the Italian Association on IDD)**
- Group leaders, **Luigi Croce** and **Mauro Leoni**, with more than 20 Professionals Head of Facilities (managing more than 1400 direct care staff professionals)
- **DATABASE:**
 - Direct daily contact with more than **1500 clients**
 - Extensive use of the **AAIDD 10th ed. USERS BOOK (3000 forms collected)**
 - Extensive use of **SIS (4300 forms collected)**
 - Experimental trials of **MODELS for THE ALIGNMENT in QOL** processes (INPUT-THROUGHPUT-OUTPUT)

A few examples of what happened in Italy using QOL Paradigm and SIS





Levels of use

ORGANIZATIONAL LEVEL (2 and 3):

Large group of residential services; smaller day and residential facilities all over Italian context

- S. Corti, M. Leoni, G. Chiodelli, F. Fioriti, L. Croce, W.H.E. Buntinx, R. L. Schalock (2008). **AAIDD and QOL models for Intellectual and Developmental Disabilities: Outcomes in 11 residential services**. IASSID 13th World Congress "People with Intellectual Disabilities: Citizens in the World", Cape Town

INDIVIDUAL LEVEL (1):

More than **1500 clients** per year

- M. Leoni, S. Corti, G. Chiodelli, F. Fioriti, L. Croce, W.H.E. Buntinx & R.L. Schalock (2008). **Aligning Supports paradigm and Quality of Life model: a case study to show the intervention for a person with severe ID**. IASSID 13th World Congress "People with Intellectual Disabilities: Citizens in the World", Cape Town

Promoting QOL issues in Italy

- Associazione Italiana per lo Studio delle Disabilità Intellettive ed Evolutive (AIRIM) (2010). LINEE GUIDA per la definizione degli Standard di Qualità nei servizi per le disabilità in Italia - Assessment, interventi, outcomes. Genova: Autore.
- Caselli, G., Leoni, M., Rovetto, F. (2008). Una psicologia positiva a scuola: estinguere problemi, rinforzare il benessere usando il modello di Qualità della Vita e il modello AAMR. Psicologia e Scuola.
- Cavagnola, R., Croce, L., Fioriti, F. (2000). Il piano educativo per l'adulto con ritardo mentale. Ecosistemi e qualità della vita. Trento: Centro Studi Erickson.
- Cottini, L., Fedeli, D., Leoni, M., & Croce, L. (2008). La Supports Intensity Scale nel panorama riabilitativo italiano – Standardizzazione e procedure psicometriche. American Journal on Mental Retardation, Edizione Italiana, 6, 1, 21-38.
- Cottini, L., Fedeli, D., Leoni, M., Croce (2008). Standardizzazione per il contesto e la lingua italiana – Caratteristiche tecniche e metodologiche. In Thompson et al., Supports Intensity Scale (SIS). Valutazione dell'intensità dei bisogni di sostegno (125-146). Gussago (Bs): Vannini Editoria Scientifica.
- Corti, S., Fioriti, F., Chiodelli, G., Leoni, M. (2007). Il decimo sistema dell'AAIDD nella presa in carico delle persone con disabilità intellettiva ed evolutiva: la sperimentazione italiana in Fondazione sospiro. Psicogeriatría, 2, 61-68.
- Fioriti, F., Corti, S., Chiodelli, G., Leoni, M., Galli, M.L., Merli, P., Ferrano, L., Zagni, A., Cavagnola, R. (2009). L'efficacia di strategie di intervento multicomponentiali nella gestione dei disturbi del comportamento e della condotta. American Journal on Mental Retardation – Edizione Italiana, 7 (2), 276–294.
- Fioriti, F., Corti, S., Chiodelli, G., Leoni, M., Galli, L., Merli, P., Equipe RSD-1. (2008). Intervento psicoeducativo su comportamento di rigurgito alimentare in soggetto istituzionalizzato con disabilità intellettiva grave. American Journal on Mental Retardation – Edizione Italiana, 6 (2), 571–583.
- Leoni, M., Berna, S., Corti, S., Fioriti, F., Chiodelli, G., Galli, L., Equipe IDR, Croce, L. (2008). Allineare il paradigma dei Sostegni e i modelli di Qualità di Vita. Studio su soggetto singolo con gravi disabilità intellettive. American Journal on Mental Retardation – Edizione Italiana, 6 (3), 528–539.
- Leoni, M., Croce, L. (2008). International implementation: The Italian experience. In R.L. Schalock, J. Thompson, M. Tasse (Eds.), Support Intensity Scale Implementation Guide. Purpose, Working Table of Contents, Submission Parameters. Washington, DC: AAIDD.
- Leoni, M., Croce, L., (2007). Presentazione dell'edizione italiana. In Thompson et al. (2007), Support Intensity Scale (SIS). Valutazione dell'intensità dei bisogni di sostegno. Gussago (Bs): Vannini.
- Leoni, M., Croce, L. (2008). Italian Translation of the Supports Intensity Scale. In R.L. Schalock, J.R Thompson, and M.J Tassé (Eds.), International Implementation of the Supports Intensity Scale (p.5-6). Washington, DC: AAIDD.



General Aim

HOW CAN WE HELP **STAFF MEMBERS TO DECIDE AND PLAN AN INDIVIDUALISED SUPPORTS PLAN ALIGNED TO INPUT DATA?**

Where we started from...

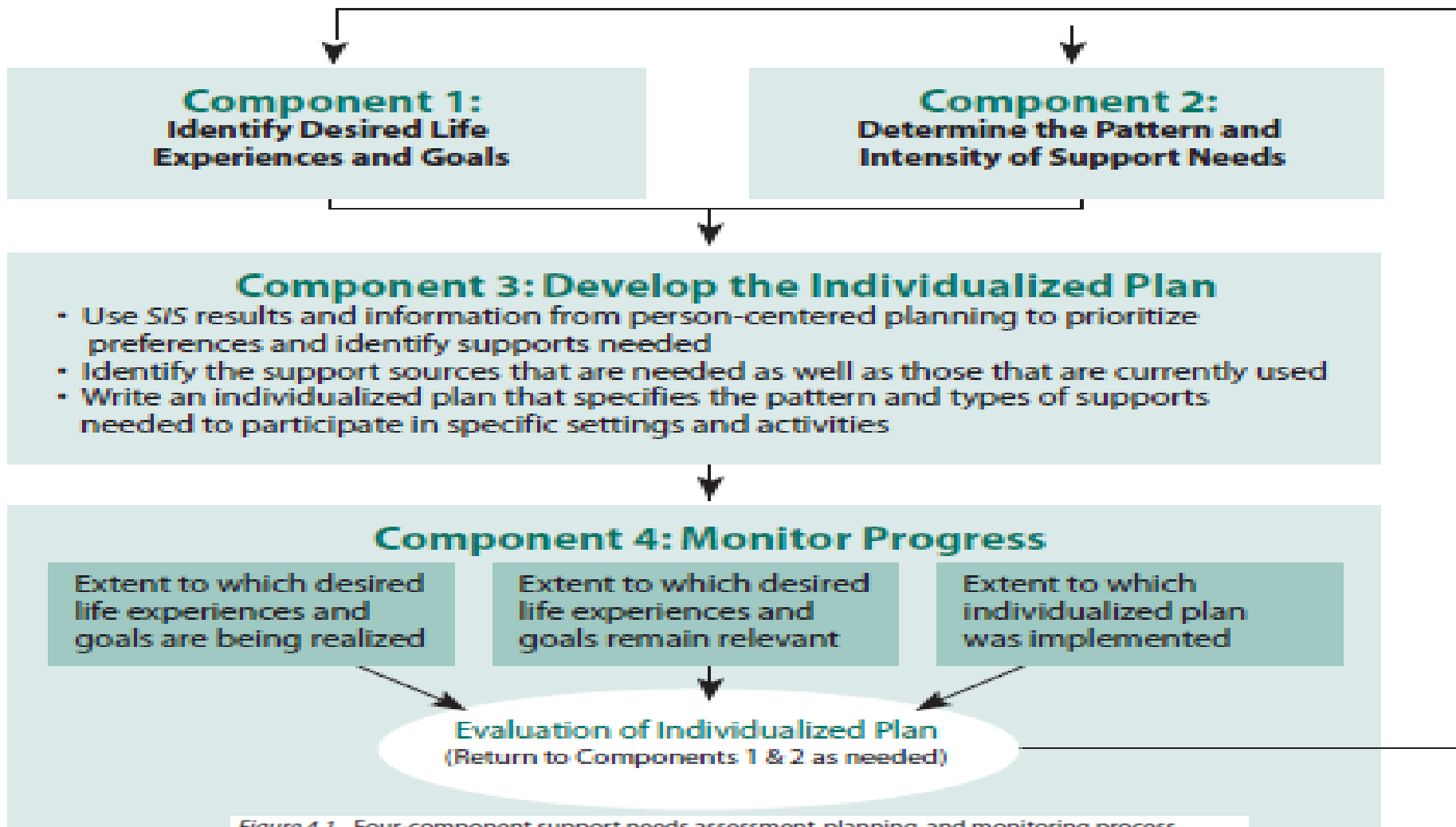



Figure 4.1. Four-component support needs assessment, planning, and monitoring process.

Adapted from "Integrating Supports in Assessment and Planning," by J. R. Thompson, C. Hughes, R. L. Schalock, W. Silverman, M. J. Tassé, B. Bryant, et al., 2002, *Mental Retardation* 40, p. 391. Copyright 2002 by American Association on Mental Retardation. Adapted with permission of American Association on Mental Retardation.



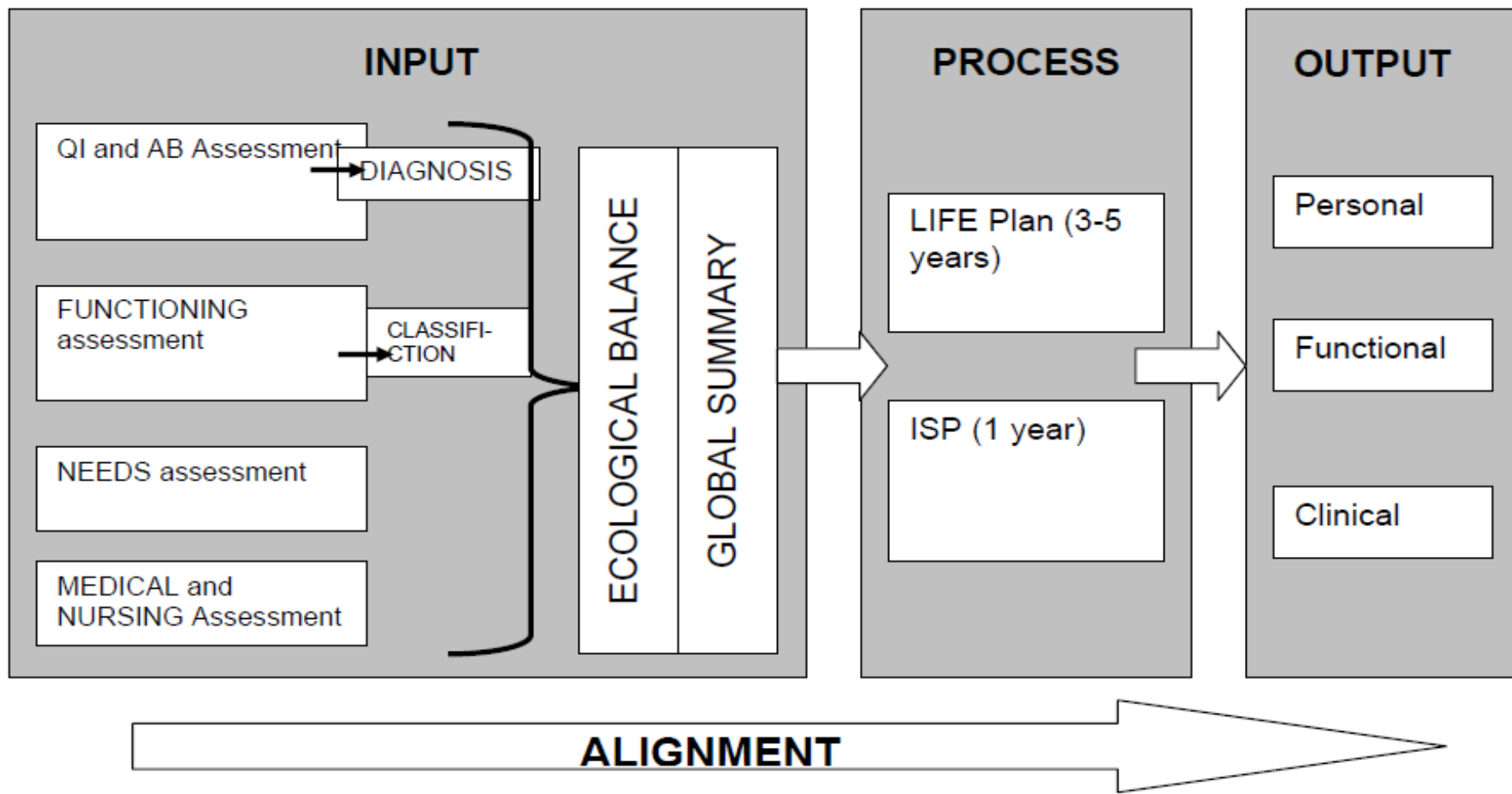
But...



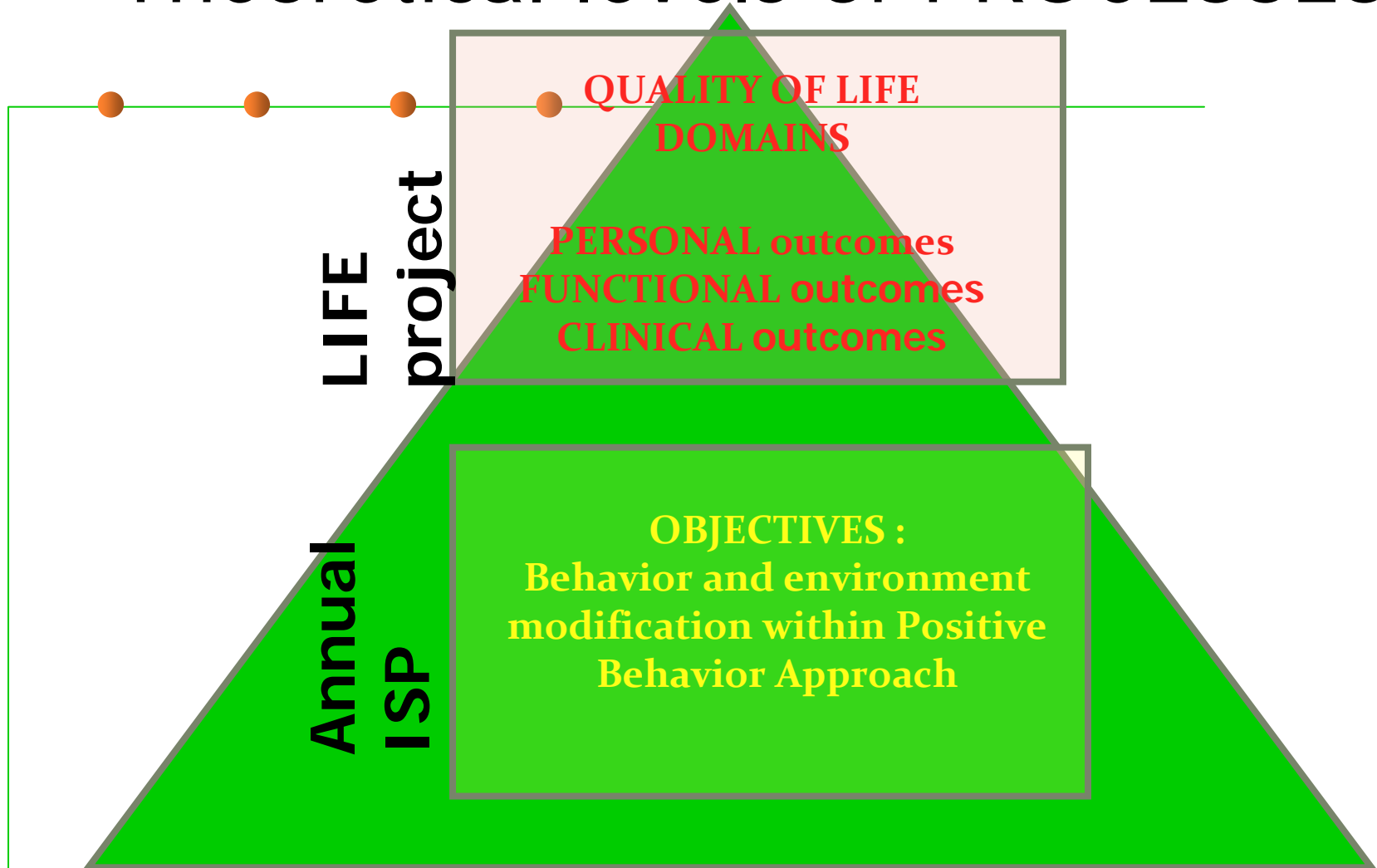
...it easn't enough to help in a
practical way...

QUALITY STANDARDS FOR DISABILITY PROGRAMS

Guidelines for Assessment, Support and Outcomes

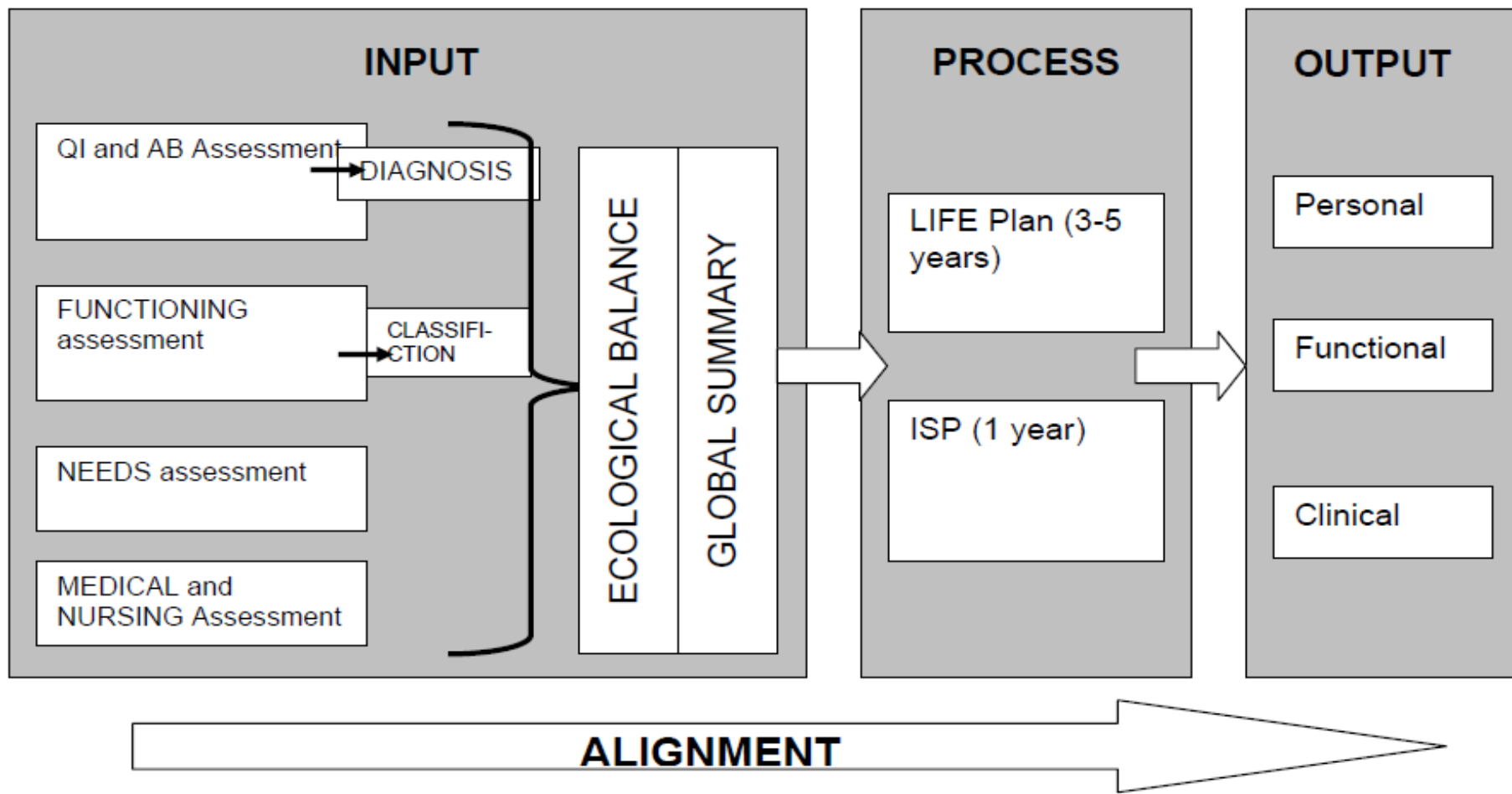


Theoretical levels of PROCESSES



QUALITY STANDARDS FOR DISABILITY PROGRAMS

Guidelines for Assessment, Support and Outcomes





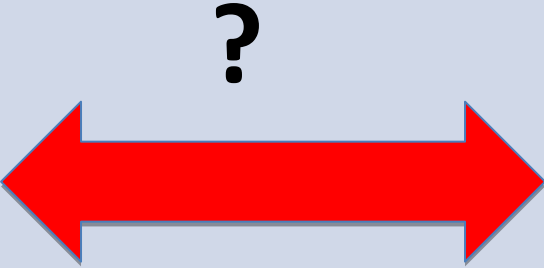
Let's go through this tool:

The ECOLOGICAL
ASSESSMENT workbook

(AIRIM, 2009-2011)

The “pill” for today: not a simple problem to solve...let’s see the right way!

Aligning Functioning to Quality of Life Domains

Quality of life Domains	Ecological Variables and Parameters	Objectives
Physical Wellbeing		
Material Wellbeing		
Emotional Wellbeing		
Personal Development		
Self determination		
Interpersonal Relationships		What is important TO...
Social Inclusion		What is important FOR...
Rights and Empowerment		

When an ISP Objective is good?

Behavioral Objectives

When we are able to:

- ① Specify the behavior wished, expected, desirable, adaptive in terms of QoL (the behavior should be set as observable measurable action/actions)
- ② Specify the performance criteria, that is the description of the quantitative and qualitative level of the behavior
- ③ Specify conditions, contingencies, and circumstances through which the expected behavior should be performed
- ④ **But particularly...when the outcome of the reached target is represented by a real improvement of the Person, in terms of better satisfaction and adaptation to his/her life ecosystems with the needed support provided**

Activity/Environmental/Facilitator/Support Objectives

Ecological Variables and Parameters 1

1. Expectation and wishes of the Person
2. Requests by the ecosystems, settings where the Person lives, learns, works, socializes and has fun
3. Functioning (functions, activities, participations, context, personal factors)
4. Performances not expressed and not required by the usual living environment
5. Basic needs

Ecological Variables and Parameters 2

6. Adaptations /Skills/Adaptive Behaviors
7. Intellectual abilities
8. Interactions and Social Roles
9. Challenging Behaviors
10. Physical health condition, genetics, environmental and age related risk factors, lifestyles...
11. Mental health condition and Psychopathology
12. Available resources and and support provided
- 13. Support Needs SIS**

Aligning Functioning to Quality of Life Domains

Quality of life Domains	Ecological Variables and Parameters	Objectives	
Physical Wellbeing	To manage the information complexity		
Material Wellbeing			
Emotional Wellbeing		To integrate systematically and not simply intuitively the values and the quotes of the different variables and parameters to generate objectives aligned with QofL improvement	
Personal Development			
Self determination			
Interpersonal Relationships			
Social Inclusion			
Rights and Empowerment			

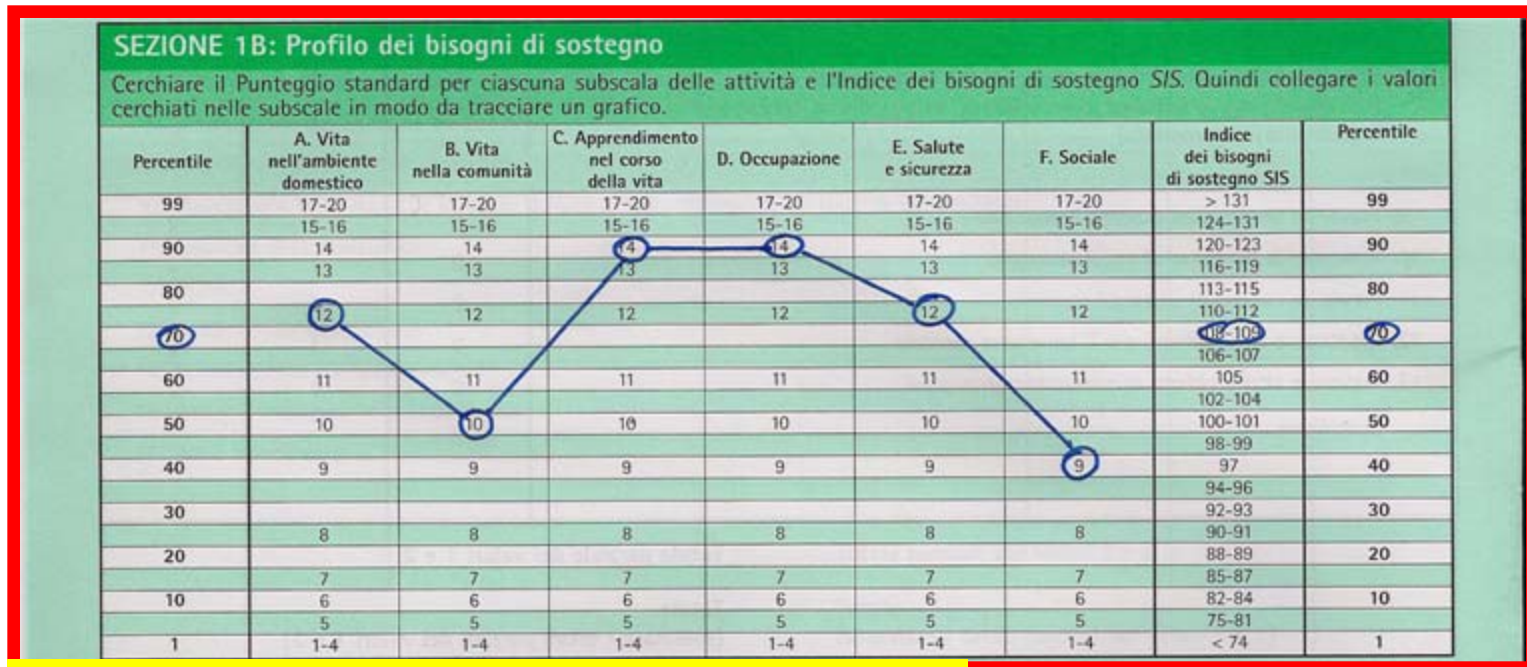


Concept of relevance: it is the criterion which defines the ecological variable impact level on the quality of life domain in the determination of the target

Ecological Planning Matrix

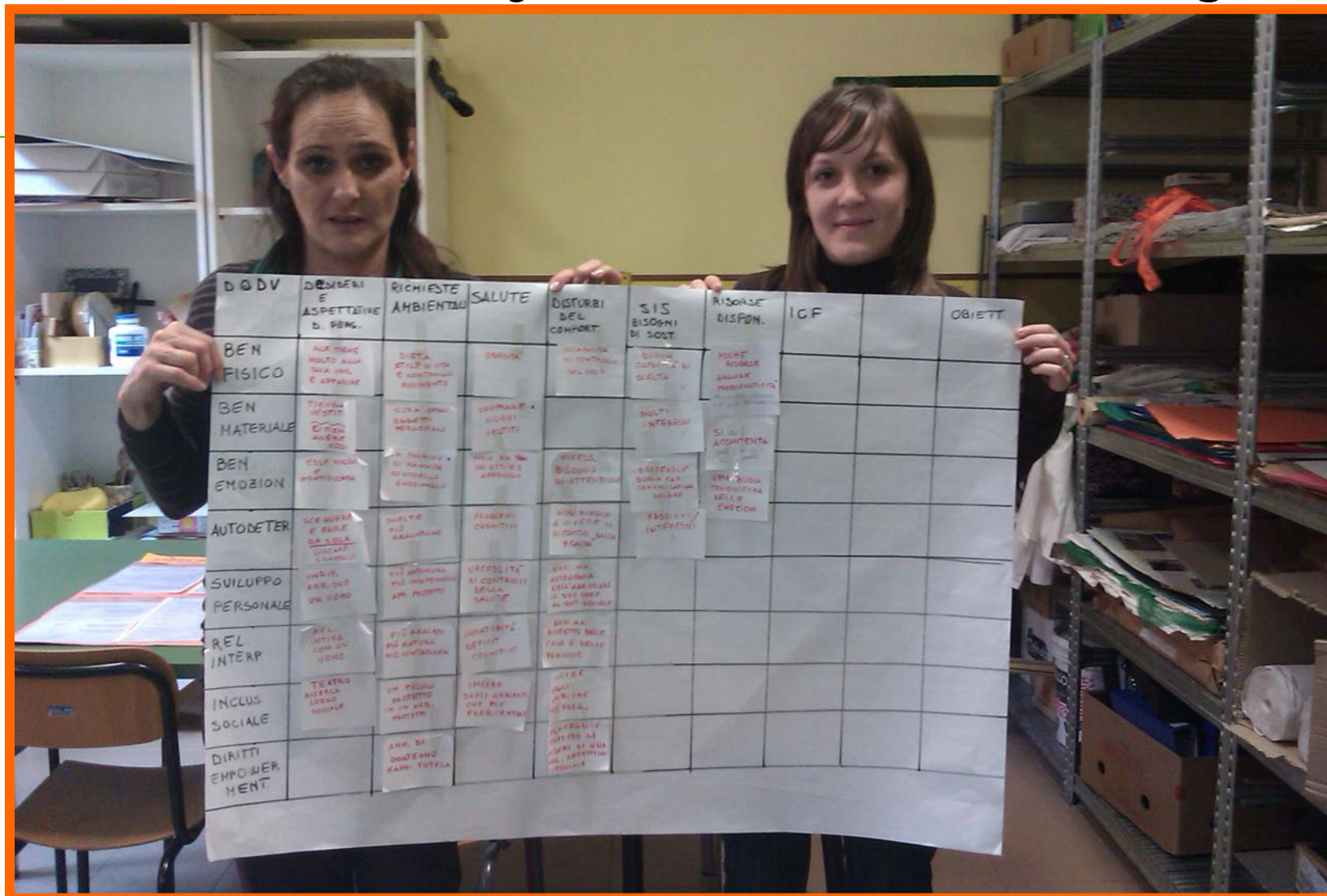
QOL	W	AB/E R	F ICF	BN	PnA	IQ	CB/P SYP	SP	SIS	AR Act	E	Obj
MWB	Which are the person wishes?			Are the primary needs satisfied?			Are there any psychopathologies or CB impeding		Which practicality in terms of resources?		Integration point balance	
PWB							QoL		What does SIS read?			
EWB	Which behavioural requests?			Do we note any performances that the environment isn't currently requesting?			Do any somatic diseases impede QoL?					
SD	Adaptation											
PD	Vineland											
IR	Which is the ICF profile with relation to the adaptation and satisfaction ecosystems?						How much does the I.Q. gravity bear on?					
SI												
RE												

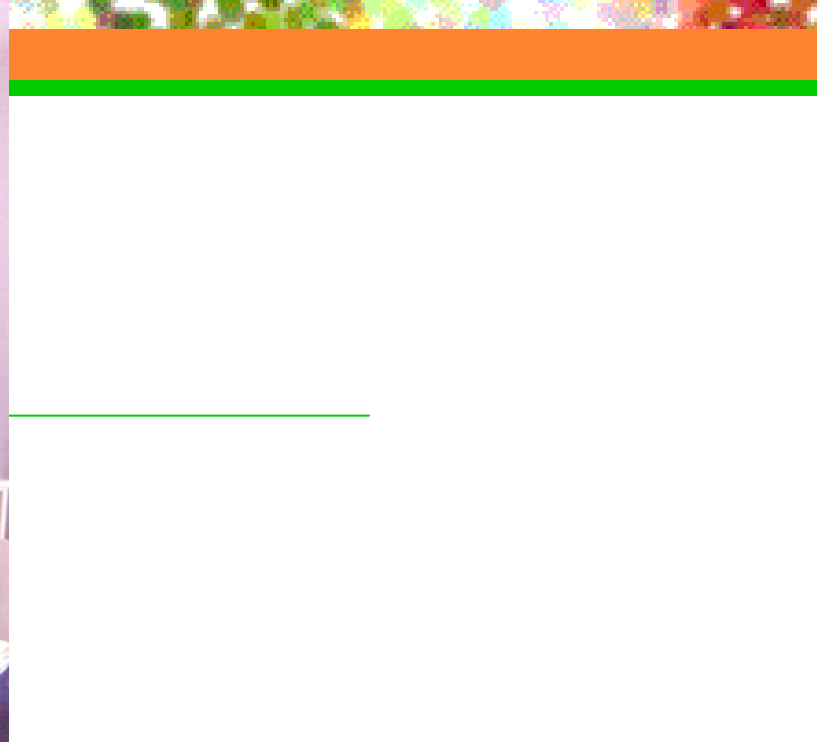
SIS Support Needs Profile



Warning!
Non ordinary Behavioral Support needs high

From Theory into Practice: working





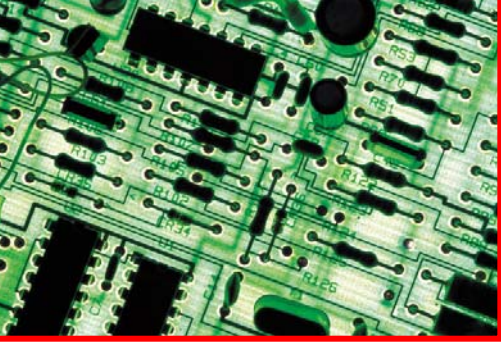
Ecological Planning Matrix: progressive data input

DQDV	DESIDERI E ASPETTATIVE D. PENS.	RICHIESTE AMBIENTAU	SALUTE	DISTURBI DEL CONFORT.	SIS BISOGNI DI SOST.	RISORSE DISPON.	ICF	OBIETT.
BEN FISICO	ALC TIENE MOLTO ALLA SUA INH. E APPARIRE	DIETA STILE DI VITA E CONTROLLO MOVIMENTO	OBESITA'	INCAPACITA' DI CONTARDO SUL CIBO	BUONA CAPACITA' DI SCELTA	POCHE RISORSE GRANDE PROBLEMATICITA'		
BEN MATERIALE	TIENE VESTITI C'EN QUERE COS.	CURA DEGLI OBBETTI PERSONALI	COMPRARE NUOVI VESTITI		MOLTI INTERESSI	SI E' ACCONTENTA		
BEN EMZION	ESSE RICON. E PRATIFICATA	UN POCHI DI MAGGIOR CONTROLLO EMZIONALE	NON HA MA UN OTTIMO APPROCIO	EXCESS. BISOGNO DI ATTENCIONE	SOCIEDEE BUONA CAP. COMUNICATIVA SOLARE	UNA BUONA CONOSCEZA DELLE EMZIONI		
AUTODETER	SCEGLIERE E FARE DA SOLA GIOCARE A BARDOL	SCELTE PIU' REALISTICHE	PROBLEMI COGNITIVI	NON RIESCE A VIVERE IL BISTORCO DELLA REALTA'	PASSIONI INTERESSI			
SUIVUPPO PERSONALE	INDIP. ANH. SUO UN VOHO	PIU' AUTONOMA PIU' INSIPENDENTE APP. PROTETTO	NECESSITA' DI CONTROLLI DELLA SALUTE	NON HA AUTONOMIA NELL'ADEGUARE IL SUO COMP. AL COUT. SOCIALE				
REL. INTERP.	REL. INTINA CON UN VOHO	PIU' REALISA PIU' NATURA PIU' CONTROLATA	INHABILITA' DEFICIT COGNITIVO	NON HA RISPETTO DELLE COSE E DELLE PERSONE				
INCLUS. SOCIALE	TEATRO RICERCA LOGGO SOCIALE	UN PICCOLO PROTETTO IN UN ANH. PROTETTO	INCIDE SUGLI AMBIENTI CHE POE' FREQUENTABE	INCIDE SUGLI ANH. CHE PIU' FREQ.				
DIRITTI EMPOWERMENT		ANH. DI DOBTEHO MAGG. TUTELA		ULNERABILE RISPETTO AI RISCHI DI DUA NEL. AFFETTIVA SESSUALE				



Facing complexity when defining Objectives:
what users, team members and families are expected to do

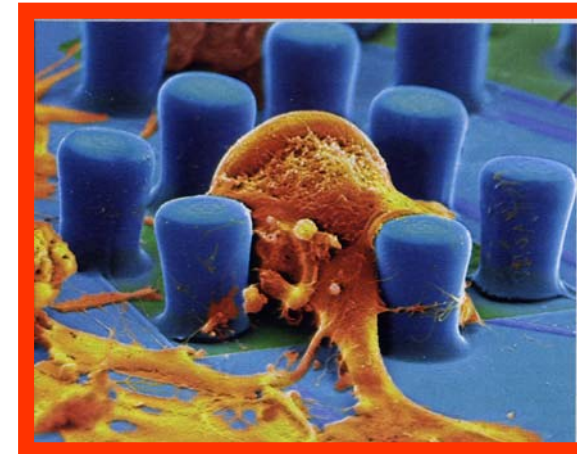
- To define **general and specific objectives** in terms of Quality of Life improvement, the **number of informations** which must be integrated into the ecological data processing equals the **product** of the number of the considered QofL domains multiplied for the number of **functional variables and parameters** measured and evaluated during assessment



**8 QOL Domains \times 10
Ecological Variables = 80 sets**



**Objectives aligned to
QOL improvement**



Navigator physical wellbeing



Ecological variable	Critical questions	Information to integrate
Wishes and expectations	What does she-he want/like?	
Requires from the ecosystems	What do we want?	
Functioning	Which ICF profile?	
Needs	Maslow hierarchy answers?	
Intellective capacities	Which IQ?	
Problematic behaviours psychopatology	DSM IVTR scores scale PsicoH?	
Somatic pathologies	ICD 10 vulnerability	
Support needs	SIS profile?	
Resources- schedules	Activities provided	
Not experienced	What hasn't it been requested	



Balance



Specific target

At the end of the support the D



Since initial
chaos

Conclusions

Ecological Planning Matrix SIS integrated

To complexity: a
possible path

Luigi Croce

luigi.croce@unicatt.it

Mauro Leoni

mauro.leoni@fondazioneospiro.it

