

The commitment to persons with intellectual disabilities:

Rights and Quality of Life

AFANIAS



1. Presentation

2° DISABILITY PARADIGM

3° The RIGHTS of persons with disabilities and the UN Convention

4° The SUPPORT PARADIGM

5° QUALITY OF LIFE PARADIGM

6° Conclusions and Evaluation



Learning is discovering what you already know

Making means showing that you already know things

Teaching is remembering the others that they know things as good as you do

We are all learners, makers and teachers.

Richard Bach

AND I, WHAT DO I MAKE?



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Association for Persons with Intellectual Disabilities.



What do we make?



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What does a restaurant offer?



WHO ARE THE SERVICE PROVIDERS?



WHO ARE THE CUSTOMERS?



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DG Educación y Cultura

APEE

Programa de aprendizaje permanente



- What quality of life we make/offer?
- Who is the client/supplier?
- How do we know whether what we do is what the client wants?
- In what way does this task determine my job, and the work of the team?
- What satisfies me about my job? What added value do I create to motivate and involve me in contributing to the quality of life of persons with intellectual disabilities?





VIDEOS



WHAT DOES DISABILITY MEAN?

Disability is an evolving concept that includes all the people who have long term impairments which “*in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others*”

United Nations Convention of the Rights of Persons with Disabilities. 2006



A disability is not something given or innate, it is the environment and society at large that give way to disability.



EVOLUTION OF THE TERMINOLOGY

- Abnormal
 - Subnormal
 - Retarded
 - Handicapped
 - Persons with...
- The “boys”
 - “My kids”

WHAT DOES IT MEAN TO BE A PERSON? (Implications of the new paradigm)

- Having a life project***
- Having dreams, not only functionality and rationality***
- Keeping one's dignity: to be entitled to have rights***
- Having a history: present, past and future***
- Recognising the others and being recognised by them.***



THE COMMITMENT TO PERSONS WITH INTELLECTUAL DISABILITIES

The rights of persons with
intellectual disability. The UN
Convention

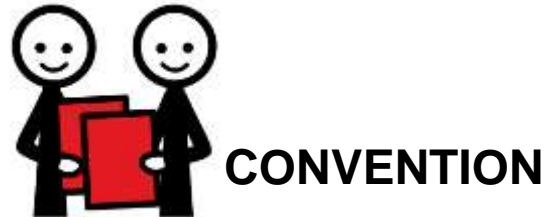


TRAINING OF TRAINERS on the rights of persons with intellectual disabilities

- ✓ Persons with intellectual disabilities can train other persons.
- ✓ Some people want to do it. They need opportunities and support.

TRAINING ON RIGHTS

The training on rights course uses one main document:



The training goals are:

- ➔ Training persons with intellectual disability about their rights
- ➔ Learning how to explain what their rights are to other people

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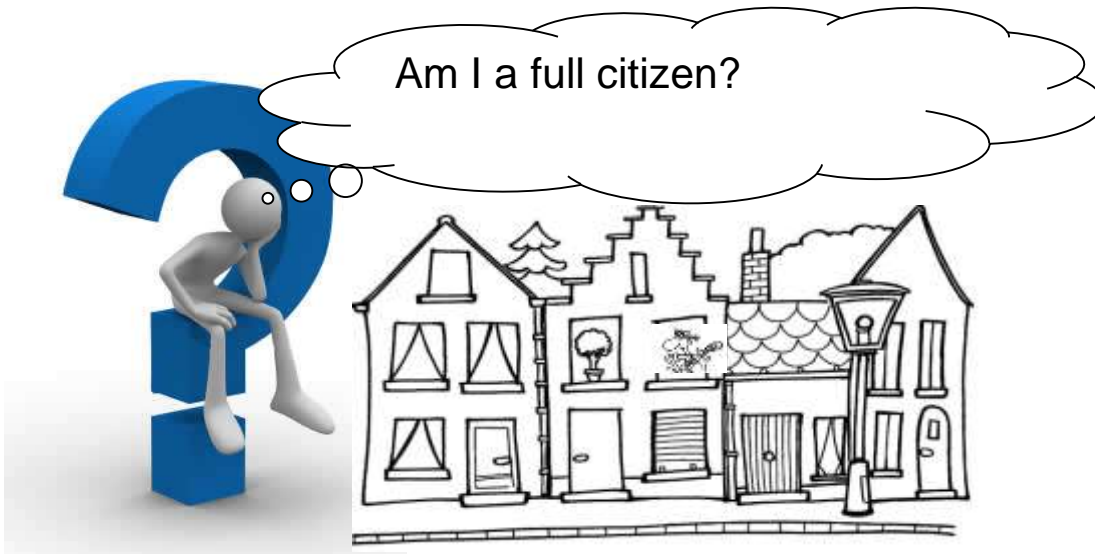
PRESENTATION

Person

Name



FULL CITIZEN



PARTICIPATION

INTEGRATION

RIGHTS



WHAT ARE THE RIGHTS?

WE ARE PERSONS:

We have things in common.

We are different regarding some things





Living well



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We need other people to live.



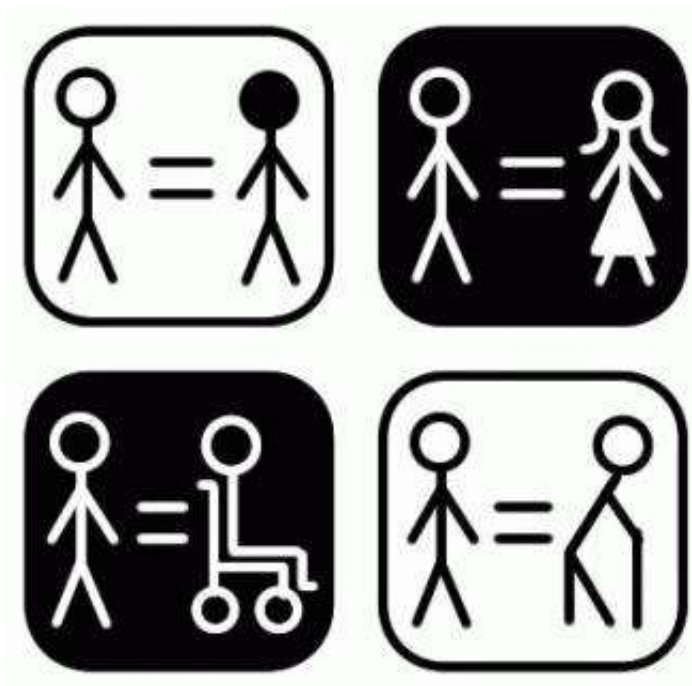
All people need the support from the others.
We can also support other people.



Norms for the people to live together and to participate.



We all have rights that need to be respected.





The UN Convention was drafted so that the rights of persons with disabilities are respected all around the world.

CONVENTION



Respecting the difference and accepting people with disabilities as part of human diversity and condition

Equal opportunities



Non discrimination

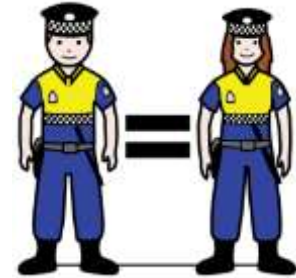


Respect for the people's inherent dignity, self-autonomy, including the freedom to take one's own decisions, and independence



CONVENTION

Equality between men and women



Full participation and integration in the society

Accessibility



Respecting the evolution of the abilities of boys and girls with disabilities and their right to keep their identity





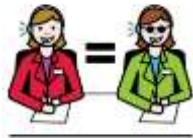
CONVENTION

Accessibility



In order to allow persons with disabilities to live in an independent way, access to all places and information needs to be guaranteed.

Equality and non discrimination



All people are equal before the law and the disability is not a reason to discriminate against.



CONVENTION



RIGHT TO EQUAL RECOGNITION BEFORE THE LAW (art. 12)

It means that persons with disabilities are entitled to inherit, to have properties and to control their goods.



RIGHT TO INDEPENDENT LIVING AND TO BE PART OF THE COMMUNITY (art. 19)

It means that people can choose freely who to live with and where to live. To have the same services of the other. To have adapted facilities.



CONVENTION



RIGHT TO EXPRESS, GIVE YOUR OPINION AND ACCESS INFORMATION (art. 21)

People have the right to speak out with freedom, and to communicate the way they want. Information must be accessible.



RIGHT TO PRIVACY (art. 22)

All people with disabilities have the right to protect their private life, their honour and their reputation.



To work:
Respecting privacy



- I get dressed in my room with door closed.
- When I talk on the phone the person supporting me is always present listening to what I say.
- Trainers talk about me as if I wasn't there
- I have a closet to keep my things, and nobody touches them with my permission.

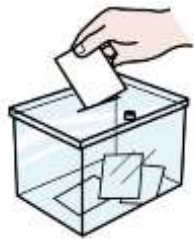


CONVENTION



RIGHT TO RESPECT THE HOME AND THE FAMILY (art. 23)

Persons with disabilities can have sexual intercourse, get married and have children if they want to.



RIGHT TO PARTICIPATE IN POLITICAL AND PUBLIC LIFE (art. 29)

Persons with disabilities can vote, choose their governments, participate in NGOs and in political parties.

DOCUMENTS IN EASY LANGUAGE

- 1) Convention on the Rights of Persons with Disabilities;
- 2) Labour Law;
- 3) Consumer Protection Act.

The Guides can be used by persons with disabilities to :

- KNOW
- EVALUATE
- CLAIM FOR
- HAVE MATERIALS



CUESTIONARIO DE AUTOEVALUACIÓN

NOMBRE Y APELLIDOS: _____
 FECHA DE NACIMIENTO: _____
 FECHA DE HOY: _____

SITUACIONES	VERDE	ROJO
Puedo besar a mi pareja sin que me regañen.	<input type="checkbox"/>	<input type="checkbox"/>
En el lugar donde vivo (casa o residencia), puedo hacer cosas para ayudar y colaborar.	<input type="checkbox"/>	<input type="checkbox"/>
Cuando voy al médico, me habla a mí y no a mi acompañante. También me escucha a mí.	<input type="checkbox"/>	<input type="checkbox"/>
Yo controlo mi dinero.	<input type="checkbox"/>	<input type="checkbox"/>
Me tratan como a una persona adulta.	<input type="checkbox"/>	<input type="checkbox"/>
En mi tiempo libre, si quiero, puedo quedar con mis amigos.	<input type="checkbox"/>	<input type="checkbox"/>
Voy a votar y escojo a quién voto.	<input type="checkbox"/>	<input type="checkbox"/>
Yo decido a qué hora me voy a la cama.	<input type="checkbox"/>	<input type="checkbox"/>
Los profesionales de mi centro, me piden permiso antes de contarme cosas malas a mi familia.	<input type="checkbox"/>	<input type="checkbox"/>
Yo decido qué actividades hacer en mi tiempo libre.	<input type="checkbox"/>	<input type="checkbox"/>
Cuando me estoy duchando, nadie entra sin mi permiso.	<input type="checkbox"/>	<input type="checkbox"/>
Si mi pareja me pega o me falta al respeto, sé qué hacer para defenderme.	<input type="checkbox"/>	<input type="checkbox"/>
Tengo un lugar para estar tranquilo y sentirme seguro.	<input type="checkbox"/>	<input type="checkbox"/>
Tengo oportunidad de hacer cosas fuera de mi casa o residencia, en vez de estar siempre metido en ella.	<input type="checkbox"/>	<input type="checkbox"/>
Mis opciones se tienen en cuenta.	<input type="checkbox"/>	<input type="checkbox"/>
Me dicen por adelantado las cosas que me van a afectar. Tengo información de antemano.	<input type="checkbox"/>	<input type="checkbox"/>

Hay un total de 16 frases. Cuenta y apunta:
 Número de frases coloreadas en verde: _____
 Número de frases coloreadas en rojo: _____



THANK YOU VERY MUCH

...

WHAT IS SUPPORT?

- o *GLASSES*
- o *WHEELCHAIRS*
- o *BOARD AND CHALK*
- o *GPS*
- o *TOOLS ARE SUPPORT: scissors, pole, ladders, etc.*

“THE SUPPORT IS A SET OF RESOURCES AND STRATEGIES AIMED AT PROMOTING THE DEVELOPMENT, THE EDUCATION, THE INTERESTS, THE PERSONAL WELLBEING AND IMPROVING INDIVIDUAL FUNCTIONING”



***A WISE IMPLEMENTATION OF SUPPORT CAN IMPROVE
THE FUNCTIONAL ABILITIES OF THE PERSONS WITH
INTELLECTUAL DISABILITIES***

***BY PROVIDING RESOURCES THAT ENHANCE
PERSONAL RESULTS AND BY FACILITATING:***

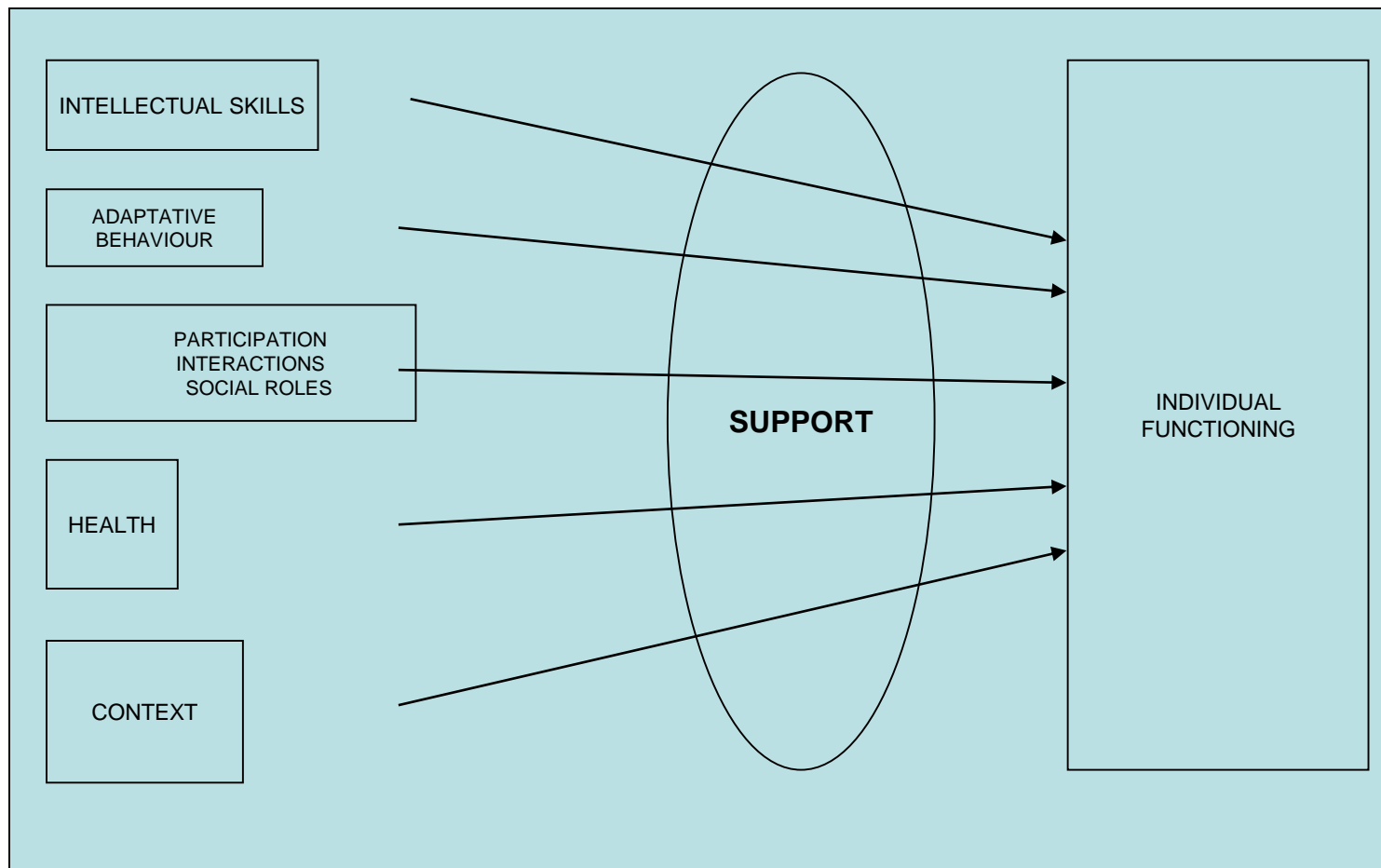
- ✓ ***THEIR EMPOWERMENT***
- ✓ ***INTEGRATION INTO THE COMMUNITY***
- ✓ ***THE OPPORTUNITIES OF PERSONAL GROWTH
AND DEVELOPMENT***



THE MAIN GOAL OF PROVIDING SUPPORT TO PERSONS WITH INTELLECTUAL DISABILITIES IS TO IMPROVE THE PERSONAL RESULTS IN RELATION TO:

- ***INDEPENDENCE***
- ***RELATIONS***
- ***PARTICIPATION INTO THE COMMUNITY***
- ***PERSONAL WELLBEING***





Conceptual framework of Human Development (American Association of Intellectual and Development Disability (AAIDD), 2010).



A Model is proposed for the Planning and Evaluation of the Support Process divided into four steps:

- Identifying the relevant support areas.
- Identifying, for each area, the relevant activities.
- Evaluating the level or intensity of the support needs.
- Planning support

RECOMMENDATIONS:

- *Counting on the personal relations chosen by the person as a main bridge to the individual support*
- *The support must be decent and respectful*

Relevance of the support

“All persons can improve”



Activity

5 NECESSARY THINGS TO INCREASE MY QUALITY OF LIFE

1. _

2. _

3. _

4. _

5. _



Activity

5 NECESSARY THINGS TO INCREASE THE QUALITY OF LIFE OF

1._

2._

3._

4._

5._



QUALITY OF LIFE

- ✓ It is MULTIDIMENSIONAL and it is influenced by PERSONAL AND ENVIRONMENTAL FACTORS and by their interactions
- ✓ It presents the SAME DIMENSIONS for all the people
- ✓ It has COMPONENTS that are both SUBJECTIVE and OBJECTIVE
- ✓ It improves the SELF-DETERMINATION, THE RESOURCES AND THE GOALS IN LIFE.

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Physical Wellbeing *I am in good health*

Material Wellbeing *I have the resources I need*

Emotional Wellbeing *I feel calm and safe*

Interpersonal Relations *There are people who love me: family, friends,...*

Social Inclusion *I use the resources of my neighbourhood*

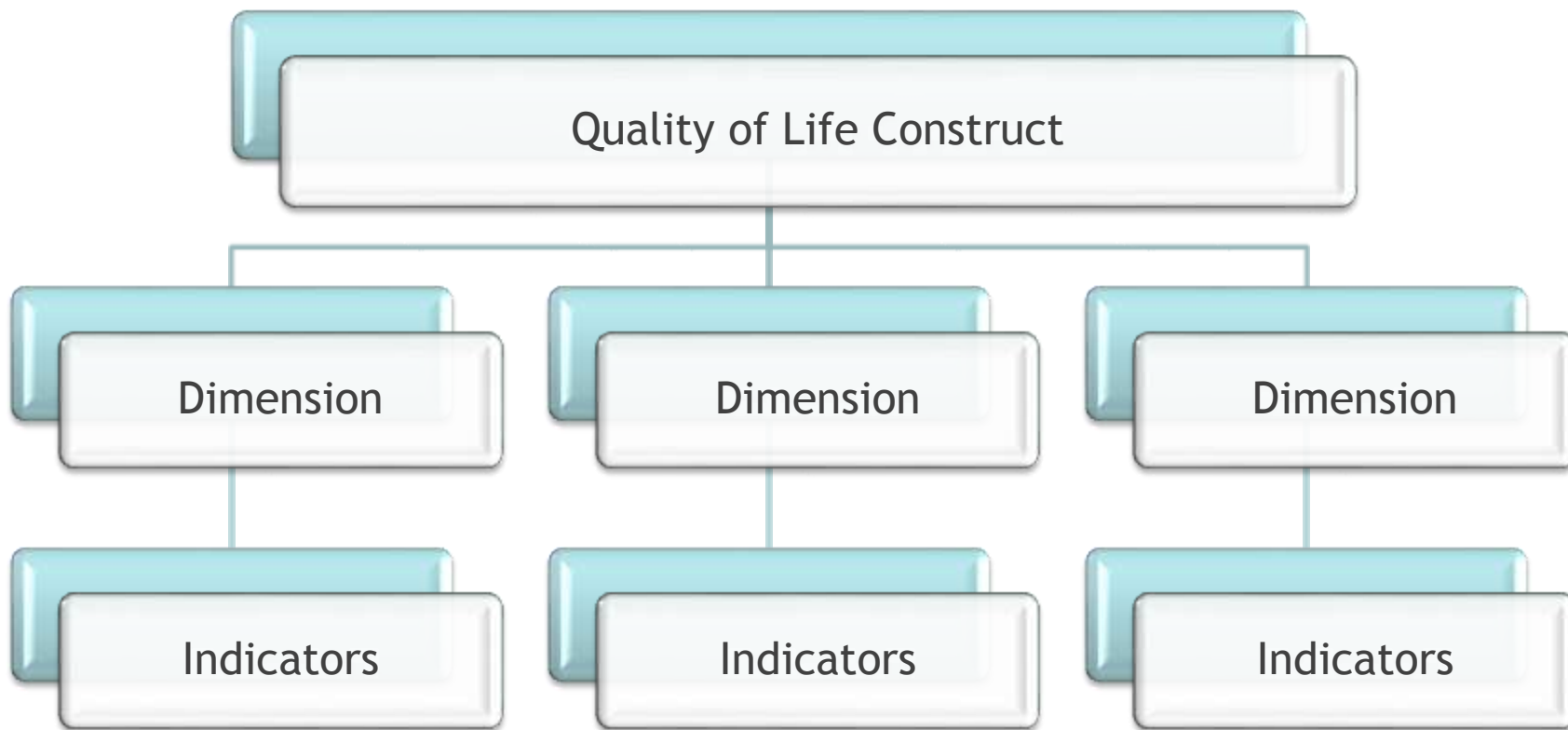
Self-determination *I made decision in my life*

Personal Development *I can learn new things*

Rights *My basic rights are respected*







Project *“I improve my quality of life when I...”*

MATERIAL WELFARE

1. Participate in the decoration of my home.
2. I feel fine in my home or room.
3. Can use the money I need.
4. Spend my money in what I want.
5. Know how much money I have to spend.
6. Have my belongings to feel well
7. Have a cell phone and know how to use it.
8. Have memories of my life at home.
9. Spend money to do what I want (shopping, travel,...).

SELFDETERMINATION

1. Have the keys to my home.
2. Choose my routine and habits.
3. Choose and buy what I need according to my style (cloths, personal hygiene products,...).
4. Buy what I need for my home (food, decoration,...).
5. Make decisions about our living together (norms, task distribution, schedules,...).
6. Choose what to do and where to go in my free time.
7. Decide how and with whom I want to live.
8. Choose the people I want as support (in leisure, personal care, etc...)
9. Choose the things I want to learn and improve in my life.
10. Have goals and plans for the future and I can meet them.
11. Can solve the problems I encounter.
12. Do daily activities in an autonomous way.

INTERPERSONAL RELATIONSHIPS

1. Make plans with my friends.
2. Make plans with my partner.
3. Receive the visit of my friends or partner when I want
4. Receive the visit of my family when I want.
5. Go to my family's home when I want.
6. Decide whom to invite to my birthday party and how to celebrate it.
7. I have a diary with my friends' and family's phone numbers.
8. Respect the norms of living together
9. Have a good relationship with my flat mates.

PHYSICAL WELFARE

1. My privacy is respected.
2. Know and control the medicines I take.
3. Know what to do when I feel bad.
4. Know how to relax when it is necessary.
5. Take care of my food and health.
6. Take care of my image and personal hygiene
7. Sleep the hours I need.
8. Can rest when I want.
9. Am informed and made decisions about my sexuality.

EMOTIONAL WELFARE

1. Identify and handle my emotions properly.
2. Feel satisfy with my life.
3. Have hobbies I have fun with (at home and in the community).
4. Have a positive concept of myself.
5. Feel able to do new things and learn.

PERSONAL DEVELOPMENT

1. Can prepare simple foods (salads, sandwiches, omelets)
2. Keep my home in ordered and clean.
3. Can do the basic tasks of the home.
4. Know and express what mu likings and dislikes
5. Know what I am good at and what is difficult for me.
6. Have the chance to help other people.
7. Know how to use the appliances in my home.

SOCIAL INTEGRATION

1. Know the neighbourhood I live in and the services provided in it.
2. Use the public transportation means.
3. Know people in my neighbourhood and I share with them.
4. Know where to go when I have a problem in the neighbourhood.
5. Make plans with my friends in the neighbourhood and in other places of Madrid.
6. Participate in community and mainstream leisure activities.
7. Move around the neighbourhood autonomously.
8. Get in touch in an appropriate way with the people I meet on the street.
9. Belong to a leisure services, club or association.

RIGHTS

1. My schedule, habits and daily routines are respected.
2. Get the support I need to communicate and the people I live with understand me.
3. Am informed about what happens in my home and at the residence.
4. Am informed about my appointments, celebrations, and important moments.
5. Have dreams I would like to fulfil.
6. Know my rights and duties and advocate them.
7. Know how to say no, and tell what I don't like freely.
8. Know my schedule and am informed about what is going to happen and about the changes.
9. The people who support me know me and understand my behaviour.



Quality of Life

Objective Conditions

Subjective View

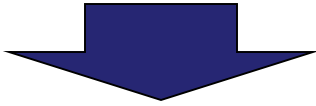
QUALITY OF LIFE INDICATORS

Basic conditions of quality of life

PERSONAL RESULTS

What is important and significant for the person





- Base line of quality of life
- Identify improvement areas.
- Propose improvement actions centred on their life style.



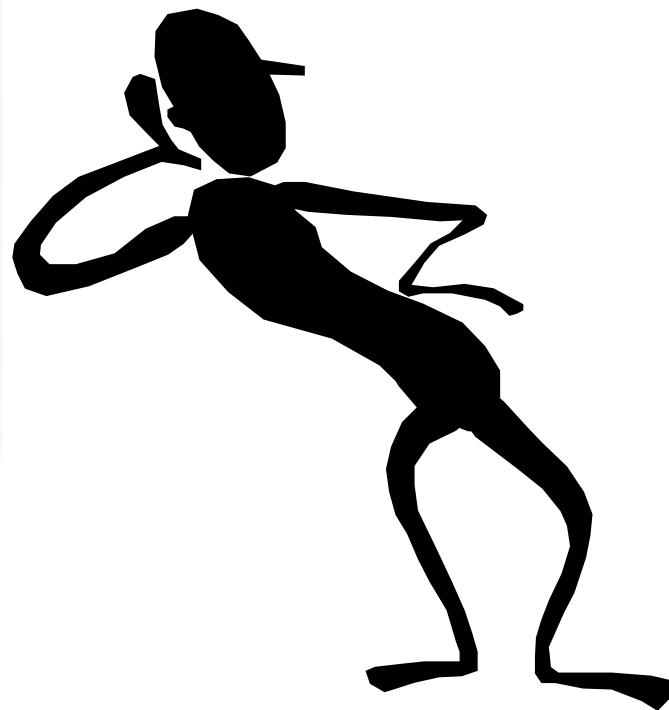
- Identify their personal results.
- Propose actions to support them on their way to reach them.

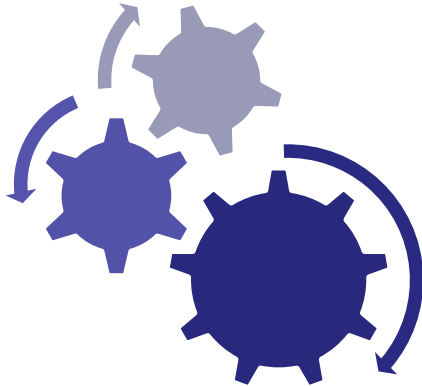
Person centred support (Personal result oriented)



How do we do this?

**BY LISTENING TO
THE PERSONS**





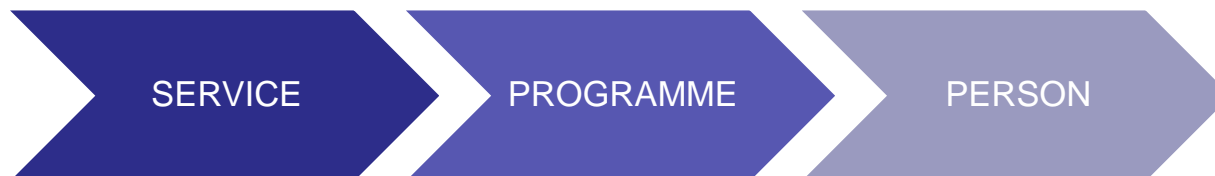
The people's life is NOT divided into CLOSED COMPARTMENTS. The situations, the environment, the thoughts and feeling make up the engine that moves the people's lives.

The life of persons we work with can not be divided only into the area in which I work with him/her.

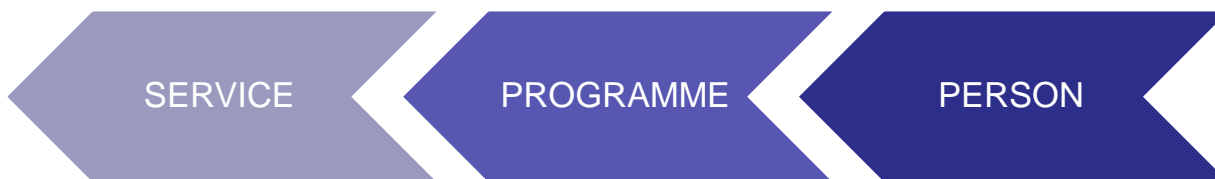
CHANGE IN MY ROLE AS A PROFESSIONAL
CHANGE IN THE ROLE OF THE ORGANISATIONS

WHAT DOES AN ORGANISATIONAL CHANGE INVOLVE?

- HORIZONTALITY
- COMMUNITY BASED ORGANISATIONS
- GENERATORS OF EVIDENCE BASED PRACTICES
- PRODUCERS AND GENERATORS OF KNOWLEDGE
- BECOMING COORDINATORS OF SUPPORT



"From a service centred process to a process centred on the person, his/her wellbeing and quality of life"



Surviving



Living



Living well



**“THEIR RIGHT, OUR
OBLIGATION”**



With the coordination of the Quality of Life Leading Team we are going to:

- Encourage to set up a Quality of Life Leading Team at each centre or service.
- The Leading Team will produce a quality of life plan of the centre/service.





➤ Families will be incorporated as a main actor.

➤ More training will be provided regarding these aspects.



➤ Persons with intellectual disabilities will be the key part in all the actions carried out.





WHAT DO CARRY IN YOUR BACKPACK?



***THANK
YOU!***

