

### **3 KEY CONCEPTS:**

#### **SELF-DETERMINATION      ADVOCACY      GUARDIANSHIP**

We have been receiving along these last months many documents, papers and newsletters from Lidingö. We have also had many discussions and debates at our many meetings among the STEPS partners. In all of them -papers and discussions- I have observed, realised, and pointed out the difficulties that we -STEPS partners- have to comprehend the meaning of some important and key concepts that we use in our communications all the time. I am very pleased to hear that Anne and Paul Cambridge have committed themselves to clarify such concepts, as they told us in Newsletter 9.

Language barriers -which on many occasions do happen to exist- may be also an element of discrimination to a certain extent if there are misunderstandings in the communication. However, I don't think this is our real problem. The real problem in the communication is not based on our different languages, since this is something we can overcome with a willing attitude and disposition. Our problem goes further: We know the morphology and syntax of the key concepts. We can write them. We use them in our own different languages. But we have quite a lot of difficulties in understanding clearly their exact and accurate meaning. In other words, we are not sure about their semantic value, because a morpho-syntactic term is understood differently depending on their context, and depending also on the language, or on the culture, whether Latin or German. In other words, we give these key concepts a different value.

We have dealt with along these months three different key concepts upon which I would like to reflect, because I think these are one of the bases of many debates and discussions.

#### **Spanish**

**Autodeterminación  
Defensa-mediación  
Tutela**

#### **English**

**Selfdetermination  
Advocacy  
Guardianship**

#### **German**

**Selbstbestimmung  
Bretroeur/der Vormund**

I think that the understanding of these three key concepts -and when I say understanding, I say semantic meaning- will help us to deal much easier with the problem of people with learning disabilities. Therefore, we will be able to fight with them against their discrimination and/or exclusion.

1.

Spanish

English

German

**Autodeterminación**

**selfdetermination**

**Selbstbestimmung**

I would define this concept as the possibility of any of us to choose and take decisions about our own life. When I talk about choice I don't mean only the great choices and decisions about our life (where to live, who live with) but to all kind of choices and decisions -from the easiest and most simple to the most difficult and complex ones-.

We talked and discussed quite a lot about this issue in our Congress in Rotterdam. Our English colleagues (Zenobia, Hector, and Paul) talked to us about that and they introduced us a system or handbook explaining ways to help people with learning disabilities to take decisions about their lives.

Patricia Ericsson also talked about it. At that moment, our hostesses taught us methods and ways of Self-Determination, a concept that is the clearest of all.

If I had to frame **Self-Determination** in the **Guardianship** field, I would say that it is the assumption and acknowledgement of the capability of people to decide by themselves upon their own lives. The way to achieve this Self-Determination is a more complex matter. We are working on it all the time. We have to assess and assume the risks of making mistakes. Our commitment as guardians is the improvement of every individual's welfare. We must, and we wish, to have the capacity to establish a relationship with our person in charge (*tutees*)<sup>1</sup> in order to know and assume their aspirations, their wishes, and needs, and behave consequently. I repeat that We assume the possibility of making mistakes. We are obliged to learn about the support and services available in order to use those which carry about meaningful consequences on the life of every individual.

The guardianship implies the transfer of part of the responsibility on the practise of the individual rights. Thus, we encourage the person to take decisions by himself/herself even upon those areas in which the guardian must take an important part.

I will provide an example, which we have recently experienced in our Foundation: We took the risk that a disable person would leave his job voluntarily, in spite of knowing that it was a wrong decision and it might bring serious and financial consequences for him. But we assumed the risk in the name of his personal and global development as individual. At this moment, he is looking for another job.

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<sup>1</sup> I'll use the term *tutee* (*tutelado*) for those people under the guardianship of the Fundació.

## 2.

### Spanish

### English

### German

**Defensa-Mediación**

**Advocacy**

**Befürwortung**

This is one of the most complex concepts because of its multiple meanings. If we look up in the dictionary the term **Advocacy**, we are given the alternative "Defence". But this is not the appropriate and complete meaning for the context we have been working on in our first meetings. In fact, the dictionary gives us all the possible meanings, but the difficulty lies in the lack of a direct translation into Spanish. So, this time we have decided to translate it into a double term **Defensa-Mediación** (**Defence and Mediation**). **Mediación** (**Mediation**), only, is pretty far away from the English term **Advocacy**, since **Mediación** is the action that takes part between two or more people in order to get a mutual agreement. Our translation into German would be "Vermittlung".

If I had apply the term **Advocacy** to the **Guardianship** field, I would say that **Defence** is pretty near its meaning, because our function as guardians is the defence of the people against any aggression of his/her rights or any exclusion action. **Mediation** is farther from our function as guardians. Our function is not to mediate between two people to achieve a mutual agreement, but to act together with the tutee and guarantee that all his/her rights are respected, get his/her inclusion, and not be discriminated from any field.

But sometimes, we do mediate between people. Sometimes we have to conciliate the tutee with his/her family broken relationships, in the interest of his/her welfare.

I think that these examples will help us to understand what I try to explain.

#### "Advocacy" as **Defence**:

In Barcelona this is developed by the "*Síndic de Greuges*" Catalan version of The Ombudsman. The Social Services workers, - both of the municipality and particular-, and the social workers of the Foundation develop this task too. Their function is to keep on watch the rights of the users and citizens in general.

#### "Advocacy" as **Mediation**:

The *Fundació Tutelar Aspanias* is guardian of a group of people coming from very broken and unstructured gypsy (roman) families. At first, it was very difficult to understand these people who claimed constantly -and rightly- their belonging to a different cultural group. Due to that, at first, the communication and understanding with them was completely impossible in two different situations:

- A) We tried to make them understand those people that our aim was to help them and to find points of contact. The advocate is helping us to contact with those people.
- B) In other cases, our understanding with those people was correct, but it was absolutely impossible an agreement with their families. Their families did not accept that we -no gypsy people- could keep any relationship with them. As a consequence, our attempts to approach the tutee to his family became useless, because he did not accept our suggestions. The advocate helped us to manage to make his relatives - in this case, his mother- visit him in his housing-residence, always under the advocate's supervision and ours too. In this particular case, we acted in a double rol as **Advocates**: We defend and support the person's claim to see his mother, a fact that helps him to diminish his syndrome of anguish. On the other hand, we mediate, because we are an important part of those meetings mentioned.

### 3.

#### Spanish

#### English

#### German

#### Tutela

#### Guardianship

#### Bretroeur/der Vormund

**Guardianship**, is a judicial term that goes beyond the concept of **Self-determination** or **Advocacy**, although both concepts are included in a more complex totality, the **Guardianship**. This is circumscribed to what the judge establishes. In all the cases, the judge determines to which fields or areas of the person the incapability affects.

In a very simplifying way, **Guardianship** would be the function of representing **the person, for the person, and with the person**. Without this last phrase, our task would be empty of contents and out of context.

By means of this, we try to include the people in all the spheres of their lives, searching for their welfare and the most appropriate situation for them.

The aim is to achieve the following goals in all the services offered to the users:

Participation: Mechanisms of control and participation: the users themselves, their parents or their guardians.

Accessibility: Acceptable for everybody involved in the situation.

Integration: The services offered to the users must be located in places where anybody would be willing to make use of them.

Dynamism: Services susceptible of change according the necessities of the individuals.

**The main characteristics of Guardianship are:**

**a) Personal characteristics:**

1. Quality of life
2. Welfare of the person.
3. Respect for the person's rights.
4. Affective and human treatment.
5. Knowledge of the person, likes and dislikes, preferences, hobbies.
6. Attention to his/her real necessities: Housing. Leisure, job, relative and social relationships,
7. Monitoring of the person.

**a) Patrimonial features:**

1. Administration of goods and properties.
2. Individual management.
3. Searching of resources of every person in order to guarantee his/her better welfare.
4. Proceedings of requests of financial help.

In the Guardianship it is prior the personal aspect, and within this, the most important goal is to know every single person, promoting actions leading to that knowledge.

We must not forget that we believe and defend that we cannot combine the function of guardians and providers of services at the same time. If we developed both functions we could not be impartial to support the *tutees* in case the services (that they pay for) do not give them the adequate treatment which they deserve. This criterion is not always shared by all the organisms, but a new legislation on that issue is being drafted.

I would like to finish to let the discussion go on, answering the question, How to solve the needs of the people with learning disabilities? My answer is very simple: Being close to them. Acting with a lot of humanity, not being afraid of making mistakes with them, and encouraging their capacities, specially their capacity of Self-Determination.