



Barcelona, 23rd of October 2003

Elaboration of the Case Studies

Dear friends and STEPS partners,

As you already know, we are enthusiastically organising the next STEPS Conference in Barcelona, that will take place at the end of November. One of the central aims of the Conference is the detection of possible reasons for discrimination of people with learning disabilities. We would suggest taking into account their ordinary and daily lives. Thus, we will be able to analyse and study, on the basis of the different national backgrounds, whether or not it is possible to remove obstacles concerning the realisation of participation, self-determination, and legal and financial equalisation.

In order to deal with these issues during the Barcelona Conference, we would like to suggest to each of the local partnerships to develop two short case studies, or life reports, taking into account the guidelines offered below. In other words, you should select real cases within your own community or your local area. To choose the cases the following criteria could be helpful:

- One could be the case of a person who has lived in an institution while he / she was a child and has not been able to develop his / her life inside a family or in a normalised community. A second case could be that of a person who has been able to live his / her life in a more normalised family context.
- One of them should have high needs, being very dependent and unable to make clear decisions. The second person should have fewer needs, being relatively independent and able to make informed choices.
- We would like to suggest concentrating on cases which reflect important problems and obstacles in the field of legal and financial regulations which you would like to overcome.



Please find below a guideline which would be useful to develop the case studies.

If you have any questions or doubts please let us know through the Barcelona's group co-ordinator, Xabier Ballesteros.

His e-mail is: xballesteros@mail.bcn.es

Thank you for your collaboration.

Warm regards and best wishes

The Barcelona Partnership

Xabier Ballesteros, Carmen Buisán, Francesc Durà, Isabel Paula, Guadalupe Pulido, Assumpció Pujol, Maria T. Sans, Esther Sesma, Josep Tresserras



GUIDELINE FOR THE ELABORATION OF THE STUDY OF CASES

We consider that every person develops his / her life in a series of areas in which he / she has the right to satisfy his/her needs.

We understand by needs the lack of something necessary regarding to anything defined as desirable.

Certain needs are universal, the same to all human beings. The individual right is to satisfy the needs.

The person discriminated is that whose rights have been violated by the fact of belonging to a certain group, and by the fact of being perceived differently. Then, he / she cannot satisfy his / her needs.

In the histories of life, we should observe how these individual needs have been - and are being satisfied - in the different areas and in the different stages of the person's life.

For the case studies we would like to ask you to include as far as possible the following aspects (the order does not indicate any priority, or importance over the rest):

- personal details (gender, age, family situation etc.)
- recollecting the very disabled person's point of view in all the areas: family, professionals who have attended him /her, work...
- and respect of the violation of rights in the different level of needs:
 - Self-fulfilment: Being what oneself is able to. Development of potentialities.
 - Self-determination: taking decisions, ability to act, self-worthiness, prestige.
 - Affection: friendship, belonging, and love.
 - Honourable Treatment: physic and psychological, respect to intimacy,
 - Basic Needs: food, hygiene, sex.



In order to facilitate the trans-national comparative we suggest resuming information using the following table:

	Education	Health Services	Work	Housing	Transport	Leisure	Family
Self-fulfilment							
Self-determination							
Affection							
Honourable Treatment							
Basic Needs							

Last but not least, please take the following questions into account to give first hints for the discussion at the Conference.

- From your point of view, what are important risks faced by the person with learning disabilities?
- What are the problems and obstacles which you would like to overcome in the context of legal and financial regulations?

We would like to ask you to limit the description of the case study to **five pages**.

Please send the life reports by email to Anne Ernst (aernst@rauheshaus.de) by

20th of November 2003

The case studies will distributed among the STEPS-partner in order to enable them to prepare for the Conference.



Some of you perhaps will have the opportunity to carry out interviews with the person, his/her relatives and professional staff working for her/him about the different aspects mentioned above.

According to the current Spanish legislation about data protection, this is the form to be signed by the people interviewed.

We recommend to every partner to adapt it to his country current legislation:

DECLARATION OF INFORMED CONSENT	
Project: Study of a History of Life Responsible: Xavier Piqué Sánchez (Fundació Catalana Tutelar Aspanias)	
<p>I, (name of the participant), understanding the contents of this act, hereby declare that I accept freely to participate in the project of the study of the History of a Life, and I declare that I have been properly informed about its significance. I understand that my participation implies the acceptance of the following conditions and guaranties:</p> <ol style="list-style-type: none">1. The participation is free. In any moment and under any circumstance or reason, the participants may dissociate themselves from the project.2. There is no risk to participate in this study.3. The method of evaluation of this project implies:<ol style="list-style-type: none">a. Be observed in the context of daily life (housing, foundation..)b. The filling out of the STEPS questionnaire, andc. Be interviewed.4. The data obtained will be able to registered and transcript by any publication and will only be used for the purposes of this study.5. The results of this study will be able to be published by any publication and the confidentiality of the participants' data is guaranteed.	
Participant's Signature	Responsible's Signature
Place and Date	