

Empowerment of families.

Niels-Anton Svendsen, Brain Injured and Families – European Cooperation

First of all I want to thank Inclusion Europe for asking me to join the project as member of the policy committee.

It has been a great pleasure for me to join this important study and meet new friends.

Secondly I will – like many of the other speakers – apologize for my “monkey-english”!

The basic reason why I’m here today is that I’m part of a brain injured family – and in a way a result of my personal empowerment-process.

In my situation the subject “empowerment of families” is not a theoretical subject – but a very close an existential issue!

And I want to add after what we have read in the reports – and what we heard yesterday – that empowerment of the family seems to be one of the most important elements to reduce the risks for discrimination – against the person with complex dependency needs and the family.

Just think about the situation if the family are not able to handle all the things that the authorities are responsible for – but still not do!!

But building up empowerment in this situation is hard work – up-the-hill!

Luk expressed very clearly yesterday, that for service providers it was without any doubt the family who should take the driver seat!

But we also have to face that the kind of empowerment we shall talk about in this case is not normal empowerment – it has to be a special kind of empowerment.

Every time we have a person with complex dependency needs this has started with 2 things nearly at the same moment – independent on if we talk about a newborn child with complex dependency needs – or we talk about a person who has lived a normal life until e.g. a traffic accident gave him a severe brain injury:

- The family get into a crisis
- And the family get in contact with the hospital system

When I talk about family it include of course also brothers and sisters! – and most of all the person with complex dependency needs – the one who need most empowerment!

The family in crisis:

All crisis can be good for something if they are handled the right way – and in this case the crisis could lead to empowerment.

Some people are good to handle personal crisis – others are not – so when we know that the family is extremely important in the rehabilitation process, we have to be aware – and take care – of those family members who need help to get through the crisis.

Brothers and sisters are often overseen and the consequence could very well be that they come into a position where they could name themselves as “The forgotten children”.

The parents should have the advice that they must not forget to take care of each other and themselves – because they must not burn out!

The hospital

Every time I step into a hospital I have the feeling that now it is not me who make decisions – but the doctors!

If I ask too many questions or raise critic they might find me a grumbler – and after that - dialogue is difficult!

The real challenge for the hospital is to support the families work with empowerment. They should accept the family as a resource – understand that families reaction is based on need – and love.

The conclusion on this is,

1. that the authorities has to offer help to those families who wants it – and the “helper” should not be an ordinary professionals – but a wise one!
2. a culture-revolution in the hospitals

Empowerment – empowerment

Empowerment is power! – and there is good power – and bad power.

In this special situation it is extremely important, that the family develop the right empowerment – and are very much aware about the ethical problems.

They shall not take over – they shall not strengthen the umbilical chord – but as much as possible support the person with complex dependency needs to be as free as possible – be able to make as many decisions for himself as possible etc.

For persons with complex dependency needs unable to speak for themselves – the family should be as good as possible to understand signs – and only try to be the disabled persons voice.

To illustrate my points I will now give you some concrete and personal examples – and I have got Asgers accept to tell this things about him:

The 28. February 1992 our youngest son – Asger – suddenly and without any prediction was hid by a heart stop in an age of 19 years. He survived – but with a severe brain injury as a consequence.

From that moment all our lives chanced totally!

In 1991 he finished school as a mathematic student – and wants to take a job for one year before he continues his education.

The crisis:

The sorrow over what has happen - I think no one can take from the family – and in fact no one should try to do it! – but I can tell you, that when my wife and I arrived together with Asger to the hospital the 28. February in the afternoon we cried – we didn't know exactly what has happened – if our son would survive – and we had to be ready if the doctor maybe in a few minutes would ask us if they were allowed to use his organs for transplantation.

He survived but in coma – but we were still crying – until one day we talked about what we would like our son to see if he one day opened up his eyes again.

Should he see 2 crying faces – even if he was not able to remember us – or should he see our happiness and joy over his return to life? - The answer was easy! – Our tears could not put back the clock, so we had to make a mental work – recapture joy of life - and place our sorrow some place where it could not overwhelm us.

Our tears could do nothing good for him – but our joy might help him finding the energy to recapture as much as possible of his “old life”. – And so it should be!

Hospital:

Here I will tell you 3 stories.

Asger was in the intensive department. – We was asked if they should revive him if he was hid by a new heart stop. We decided that they should not.

At that time he got food through a tube and has had pneumonia several times – but every time they gave him penicillin.

After a scanning we had a meeting with the head doctor a Friday afternoon.

She told us, that the picture showed, that Asgers brain was very much damage. – On our way out she just said, that the best thing that could happen for him was an untreated pneumonia!

My wife and I began to cry so much that we took directly home. We felt that she has made us total powerless!

But we decided that we would not be powerless. So next morning we went to hospital. Asger was very warm and because of Saturday the head doctor was not at work, but we

told another doctor, that we want a copy of his journal! – Our only reason was to tell them that we would not accept the feeling of powerlessness.

This doctor wants to ask us why we wanted the journal, but before we start talking we asked here why Asger was so warm.

He has a new pneumonia she told us. Remembering yesterday's "message" we asked if they have started the treatment – the answer was no!!! – Then we just said that now we would call the police if she didn't begin the treatment right away. – And so she did.

In the end of his period in hospital he very loudly expressed that he wanted to die – that we should kill him.

The head doctor called me at my work and told me, that Asger was psychotic and he needed more medicine.

Of course it is not nice to hear that your son doesn't want to live – but I had to say to the doctor, that this was the first real sign that he was beginning to reflect his new situation.

In 1992 the hospital told us, that our son would be discharged to a nursing home because at that moment he could do nothing – and he was heavily drugged.

But we took our son home for summer-holiday and he did not return to hospital. We started to reduce the medicine after advice from our own doctor. 3 weeks after - Asger took the "first step" for the second time in his life – and in a few months he was again able to walk, run, go on a tandem bike etc. – and totally free of medicine – except vitamin pills.

So one day we put on our helmets and went on a tandem bike to the hospital. The young man we brought out of hospital was now coming back on a bike! – They would not believe their own eyes!!

Later on we decided that if we could find the energy we would work in the Danish Brain Injury Ass. To use our experience for the benefit of those families coming after us. They should not experience the same negative things as we did.

Now this activity also includes work on European level.

Let me just finish by saying that Asger is enjoying life – he has got an ileostomy – and needs care 24 hours – but he also lives as independent as possible, loves to travel – he has been in China, in Australia, in Africa and most European countries and has a very developed humorous sense and normally in good humor.

We never get our old son back – and life is not always easy – and my wife and I know, that we do not live forever – but Asger has never expressed in signs, actions or words that he wants to move - so for the moment it is the less worst solution!

Thanks for your attention.