

**Nordic Forum. March 15. 2007 at 11.30 – 11.50.**

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**A disabled child is above all a child with wishes dreams and hopes for its own life, to live a life as close to normal as possible.**

I will start with a short presentation of my background.

I have a three years education as a social education worker. I have worked with physically and mentally handicapped persons for almost twenty-five years.

The latest ten years I have been head of department on a residential home for children who are severe physically and mentally disabled.

I will use examples from my everyday life to describe the Danish attitude to disabled children to talk about the subject: A disabled child is above all a child with wishes, dreams and hopes for its own life.

Once a little girl moved into the residential home where I work. It had been very hard to her parents to make the decision.

It was hard to them to realize that they did not have the energy to take care of their own child. They had bad conscience. But the girl needed help to everything and she slept only a few hours in the nights.

They could not continue to mobilize the energy to take care of her at home.

The parents came to paint her room before she moved in. They came with some of her things from home. They brought her clothes and some of her toys.

The girl was – like the other children who live there – sitting in a wheelchair – she could not talk and she needed help to everything.

She had her own habits. TV had to be turned on all the time. She woke up several times during the nights – crawled around – and wanted the TV to be turned on. She would not eat if there were no sugar on the food. She was very temperamental. She cried loudly if there was something she was dissatisfied with.

The parents came often to visit their daughter. They were together with their daughter and afterwards they went home to go about doing their duties and take care of their other child. Often the staff talked with the parents about the daughter, and they listened to their worries. The girl was home by the parents some week-ends. When the parents had the energy she came home to the family and they spend nice hours together. But she also liked to return to us. To the place which were now her second home.

The girl settled down very quickly. We respected her wishes, but made a plan how we got her out of the habit from crawling around at nights.

Little by little the parents got more convinced that they had made the right decision. They saw their daughter was happy and they felt they had more energy in their everyday life and more energy to be happy and make fun when they were together with their disabled child.

The parents continued to do a lot of practical things to their child. They bought her clothes, went together with her to see the doctor, hairdresser, dentist and so on.

Every year the staff makes a description of every child. Everything about the child is described and we describe the aims for the child. Aims which are desirable and realistic.

When the little girl had lived by us one year we made such a description. We send it to all the people who work together with the child for example teacher, physiotherapist – and of course the most important people for the child – the parents.

When the parents had read these descriptions they were deeply affected. Since she was born they had met a lot of doctors, physicians and surgeons.

They had got many descriptions of the girl – but this one was the first where there were written something very nice about her. Her resources and potentials were mentioned and pointed out. She was described as a nice girl. Described more as a child than as a disabled.

The overall strategy in the Danish policy concerning disabled children is that disabled children should be able to live a life as close to normal life as possible.

That means that disabled children live at home together with their parents. The parents can receive different kind of support. For example compensation for extra costs, compensation if one of the parents are not able to go to work for a period, day care service which makes it possible for both parents to continue work, which mostly is what the parents want.

Only very few children live at residential homes and if they do it is because of their parents wish.

One of the reasons is, that the disabled child needs very specialised care and the parents do not want their home to be like an institution with staff around the clock.

Our institutions for disabled children are small family like homes.

When the parents then decide that their child is going to live at an institution – it is important that the conditions for good cooperation are present.

We give the parents the possibility to take part in many things about their child, but it is very different how much the parents want to involve and take part.

Some parents visit the child very often and like to buy the clothes to their child, go with the child to hairdresser, dentist and so on as in the story I told before.

Other parents come very seldom and want the staff to take care of all these things.

We ask the parents in what way and how much they want to be involved.

We – the staff – must be ready to meet these differences in wishes and respect the differences in the parent's way to involve.

The aim in our handicap policy is that so many children and young people as possible can be held in the general schools and day-care centres so as few as possible need specialized institutions. Our aim is that disabled and not disabled are at the same school, day care centre and so on. The handicapped children get more help from educated staff, but they are not separated from the normal world. And the children who are not disabled get used to see and be together with the disabled.

I still remember when I was a child. I was not used to see disabled people and once me and my mother met a disabled man. My mother said emphatically “Don’t look at him”. At that time disabled people were separated from the society. Now the aim is to integrate them.

The disabled children are not patients but they are children with some kind of handicaps. They are children with the same needs for a good childhood as other children.

Here come some elements to a good childhood with focus on attitude and values:

Our basis is the childrens qualifications and potentials.

It is very easy to see, what the disabled children can’t do. But everyone has some resources we can bring into focus and develop. We must concentrate our attention on the things the children are able to do.

About the child I mentioned at the beginning: We had focus on her temperament which we saw as a strong point. She cried every time she could not see TV. She was persevering to reach her goal. When she cried every time she could not see the TV we looked at it as a positive reaction. It may be right that her crying disturb and irritate us, but we have to concentrate on her. Why does she cry? What does she want to obtain? Can she obtain the same in another way? Is she bored and cry because she wants contact?

It is a great resource to be able to express something you want or something you want to change. And it is a resource when you think it will be worth your while to express it. If she often cry without any reaction from the adults she would never get the feeling to be understood. It might happen she gives up and becomes apathetic and indifferent.

It is a fundamental idea that everybody has potentials and everybody always want to do their best.

To think about other people in that way bring a positive attitude and mind.

Our attitudes are seen in the words we use and how we talk to each other and about each other. We must be very aware how great power our words have.

Words can destroy an atmosphere but words can also enrich an atmosphere.

Where I work all the staff has a meeting once a month. We talk about every child. We inform about our observations, discuss and agree about how to work with the child in the future

At these meetings you can feel the enthusiasm of the staff. Often it is very hard to be chairperson because the staff really want to tell each other about the good experiences they have had with the children.

The enthusiasm from the staff is very important. The parents can feel it and all parents wish their child is well liked.

In the work with disabled children we have a great power. We can decide everything. We have to respect that we are different. That disabled teenagers – like other teenagers want to do things or want to look in a way adults find totally hopeless.

Where I work lives a girl. Her mother comes very often. They go for a walk – the mother and her daughter in the wheelchair. The child has always loved these walks. Suddenly – when she was fourteen – she didn’t want to go together with the mother, when she came to pick her up. The mother was of course sorry about it, but the girl tell us with her body language, that she wants to

stay together with us. It was at the beginning very hard to the mother to accept, but the choice of the girl was respected.

We must accept that the child with his handicap maybe behave in an other way than we would like it to do –or look different from others. But we must always remember that the child need appreciation. Need to be loved in spite of the handicap, where he is different from common standards.

Disabled children are children with wishes and dreams.

To the severe disabled it will often be the challenges to the parents or the staff to interpret what the dreams and wishes are. It can be hard to the children to express it and we must then just do more of the things the children express happiness about.

There must be laughter and happiness around the children. Only when the atmosphere is good you can develop.

Where I work I mean the greatest success is when the children are happy. When the atmosphere is good and I can feel and see the children are well. To have smiles and laughter from the children is success.

I have a pedagogue in the residential home. She has worked in the house for seventeen years. She has just said it in this way: “It is a bad day, if we didn’t make fun. We know that when the staff is happy and spreads happiness around it starts a good circle. The children show us what they are able to and they spread happiness further. We have bad days – hard days where the happiness has bad conditions. But these days throw the bad days into relief.”

To a good childhood belongs security, warmth and care. There must be comforting hands when something hurts. And if a child is sorry – maybe because it can’t join other children of the same age in some activities – if the child feel excluded. We can’t prevent the disabled children from getting these feelings, but we can listen to them and show them our understanding. To the children who can’t talk we can try to match their feelings. If a child expresses he is angry by shouting we say “ I see you are angry” I saw you became angry when the other children ran past you” “I think you are angry because you can’t run together with them – and I understand you”

We must do our best so that the child has the feeling of being seen, listened to and understood.

Relations are important. It is very important, that the child keeps the contact to the parents. It is also important that children gets contact to other children at their own age.

We have after school centers to disabled where they can meet other children with same possibilities and problems as them self.

To the severe disabled we can make the conditions to friendship and relations by placing the children near to each other in their wheelchairs – or lay them together on the floor so that they can hear the sound from each other or can feel each other.

We draw their attention to each other. Mary comes with me in her wheelchair into Lauras room, when I go to say good morning to Laura. Paul is sitting close to David – and suddenly they start reaching out for each other.

The children must feel dignity.

The disabled children must have the same possibility as other children to participate – in the way they can manage. They must have options and possibilities to decide as much as possible in their own life.

To the severe disabled a possibility to decide for example is about what to drink. To make a choice between two kinds of drinks. Maybe he can show with the eyes what he wants. Maybe he can hit with the arm what he wants. Maybe he doesn't drink and then you have to offer him something else. A child at my place can decide whom from the staff shall take care of her the day concerned. She has a sign for "yes" and "no" and for example will we ask her: "Do you want to be together with Lena today or do you want to be together with Karin." When we ask it is very important to respect her answer. If you know it is not possible to respect her answer it is better not to ask her.

To a good childhood comes experiences. Depending on the kind of handicap it can be sense impression, a tour, a history, song, going to cinema, listen to loud music or talking together. Disabled children have the same wishes as other children, and when they do not succeed to fulfil them it is very often because of lack of resources and will from the surroundings.

Children like challenges. We all know a little child proudly shouting: "See me – see what I can do" It is when the child will show something he has just learnt – He has been challenged or he has challenged himself and he has succeeded in it.

Maybe the disabled child can't shout like this, but he has the same need for success.

At my place lives a little boy. He can hardly move his arms because of severe spastic paralysis. If we put a glass with water near to him, he really makes an effort to reach it and push it. He is so tired afterwards because of his effort.

He really feels success when he manages to do it. He looks very happy. Of course it is not okay that he pushes to the glasses at the table. But he shows us that he is able to pursue an aim if the aim is something funny. This we can use and apply in more suitable situations.

The education at school must be individual and tailored to fit every single child then the children will feel self-confidence and a greater self-worth.

To be responsible to give children a good childhood is a very important job. This we know when we are parents. The society has a great responsibility to create the framework.

I can't know how much the children I work for – can remember later in their life. But the aim to my job is – that if they can remember something – it will be something good.

The little girl I told about in the beginning – moved four years ago to an institution for adults. Sometimes she comes to visit us together with her mother. Her mother takes her out of the wheelchair and places her on the floor. Very quickly she moves to certain places in the house – the places she liked mostly when she lived in the house. It is in front of the dishwasher and in front of a mirror. We see a big smile on her face and she lays – as she did as a child – and taps on the floor. This girl shows me, that what we do are very important. She remembers her childhood with happiness. She got the elements in life which gives a good childhood even if she is severe physically and mentally disabled.

My intention with these examples is to show how much attitudes to the disabled mean.

It takes more money and personal help to give the disabled children same possibilities as other children.

The society has a great responsibility to create the framework which makes it possible.

The parents organizations have a special purpose I think – to communicate and prove the needs. In Denmark we have a “Handicapboard” in each municipality. In these handicapboards are parents represented and the board has to see and make a statement in all political questions about disabled.

But we all have an important role in marking the way the society look at the disabled

It is us who know the needs for improvements and it is us who know what can be done.

I feel very enriched to have known so many disabled persons. They have learned me to look at my own life in another way and they have spread a lot of joy to my life. This I like to tell about when I have a chance to do it.

I think we have to be more open to talk about the disabled people.

Make articles, invite guests to the institutions and so on. Not to display the disabled, but to tell about them – and ask the disabled to tell about them selves when they are able to do it.

And we shall remember to tell the good stories and our wishes for better conditions

In Denmark television has told about two boys with Downs syndrome. You saw Peter and Morten in their everydaylife. It was programmes many people talked about and I am sure that people realized that the two boys were boys with the same needs as other boys.