

Alf Anvedsen

Fjelltun 12, N5532 Haugesund, Norway. E-mail: alf.anvedsen@bluezone.no

FAMILY ADVOCACY

I am the Vice President of NFU (Norwegian Association for Persons with Developmental Disabilities), and a volunteer. That means that I am not employed by NFU. I work for a local savings bank.

My youngest daughter, Mari has Down syndrom. She is 19. I am not going to talk about Mari and the story about my family.

In stead I will talk about Jonas Nicolai who is lucky to have a mother and father, as well as to sisters, 5 and 8 years old. Jonas Nicolai will become two years in January, and has multiple handicaps. He has a very rare genetic anomaly. There are no other living persons known in this world having the same genetic anomaly. Most children with this diagnosis will be aborted or die within weeks. Jonas Nicolai did undergo several operations during his first year. It is a miracle that he is alive.

The medical progress has been considerable during the past ten to fifteen years. This has saved the life of the boy. Ethics within medicine has also developed. Jonas Nicolai, he was not left to die. Supported by the development within medicine and by great effort one managed to save his life. Despite a high risk of death a considerable amount of money was spent to save his life. And yet, the risk of death is still high.

Supported by a high standard of values, medical knowledge, good economy of the Norwegian health care and hospitals as well as legislation, one managed to save the boys life. This is a good example of progress and the welfare state. We talk about the system level.

Just a few words about the individual level. Without a caring family who have been trained to act like health personell and have developed the ability to notice small signals from the child, he has not only survived. He shows strength and happiness. The parents should be proud of what has been achieved.

Back to the system level. Norway has a high standard of living. It is a welfare state with good economy and legislation. Not all is at good level. What went wrong? I will tell you in a while. Let me tell you first that the family is well satisfied with the health care, the school of the eldest child, the play school of the youngest sister and Jonas Nicolai himself and so on. With one exception. Relief!

The local authorities in my home town, Haugesund, decided to give the family 12 hours per month in the beginning, till the boy was about ten months. However, no such service was rendered. I was called in as a helper for the family who authorized me as their representative.

I managed to have the number of hours increased from 12 to 60 hours per month, and I was quite proud of my self. This should be more in accordance with the needs of the family. The

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relief should take place in the home of the family, and the service should also comprise the two other children.

This appeared to be ideal. The parents would be able to get away from all responsibility a weekend per month, and attend a meeting, go to cinema or visit friends for a two-hours period on a weekly basis. The parents need time to care for each other and to mourn.

The decision was good. The service provided was bad. Nobody turned up to provide the relief, months elapsed. The family was without relief for a period of 18 months.

It may be difficult for some of you to understand the problems this is causing. This family has a small network with no relatives in the neighbourhood.

I helped the family to formulate a complaint on the lack of fulfillment of the decision, regrettably to little avail. We wrote letters, contacted the major, politicians, municipal control system. The family went to the local newspaper which gave extensive coverage. We asked for meetings, and pressed on every button we could see in order to get a solution.

Now we are going towards a solution. The municipality did find a family who could give relief in their home. Why did it take so much time to fulfill the decision with respect to relief?

In the first place one must consider the task and the responsibility for a relief family with less sleep, very close attendance 24 hours per day, need for knowledge on health care, possibility for sudden and dramatic need for ambulance and hospitalisation as well as the risk of death.

This can partly explain the problem. However, it is no excuse for not providing the service needed and approved. The family has a legal demand.

I have the theory that we as parents will have to focus more on attitudes and values to obtain better services and the rights of our children and the family. The influence we make is important to the many. In order to get the service providers in touch with their own values it will be beneficial if they can see the whole person or family receiving the service. Each tend to concentrate on their own area of responsibility.

We all want to be seen as a whole.

Haugesund, Norway, Nov. 3rd, 2006