

Putting users in control of services by Elaine Johansson Conference in Brussels 4-5th June 2008

I am working as a director of Eldorado centre in Gothenburg, Sweden. We are working with sensory training, music therapy, electrical wheel chair training, motor training and alternative forms of communication, education of staff and parents and finally cultural activities. We are working with persons with severe intellectual disabilities. This group of people is not visitors of the Gothenburg Opera House. But of course some of them would certainly enjoy such a visit.

In my leisure time I work in the handicap movement for instance FUB – the organization for persons with intellectual disability in Sweden.

Last but not at all least I am the mother to Pia, soon 38 years old. Pia has a severe intellectual disability. She needs a wheel chair outdoors, has epilepsy, and cannot speak.

On Saturday the 7th June Pia is going to Mallorca on vacation supported by two personal assistants. This will be the 12th time she travels to Mallorca. She really enjoys this yearly trip.

Pia moved from home 14 years ago on the 1st June 1994. She now lives in a flat of her own fully equipped with kitchen, living room and a bed room. The flat is about 60 square metres big. In the house there are two more flats where two friends of Pia also are living. All three in the house have their own personal assistants. Pia has five different personal assistants working on a schedule 24 hours around. According to the ability of Pia, she has chosen her own personal assistants. That is I have chosen them first and then they are working on probation and if Pia is accepting them they can stay on.

There are about 16 000 persons having personal assistance granted by the Swedish Social Insurance Agency according to the Assistance Benefit Act. The financial responsibility is divided between the 290 municipalities and the Swedish Social Insurance Agencies. The municipalities are paying for the first 20 hours every week and the Insurance Agencies for the rest.

To obtain assistance allowance, the individual must need personal assistance for the basic needs for more than 20 hours per week. Personal assistance with basic needs means help with personal hygiene, dressing and undressing, eating, communicating with other persons or other assistance that requires detailed knowledge about the disability.

It is harder for children with severe disabilities to obtain assistance allowance. There is a discussion going on where the normal responsibility of parents ends and the right to personal assistance is coming in.

Some person from the Social Insurance Agency is making a mapping with the number of hours the person with disability needs. Then there is a decision made about the number of hours per week and months. After that the person with disability

or the legal guardian can decide who is going to administrate the personal assistance – the municipality or a private stakeholder. Every assistant is writing down every hour of work and the administrator is then sending this list to the office of the Insurance Agency and the money is coming every month. The size of the amount per hour is decided every year by the Swedish Parliament (Riksdagen).

During the end of 1980ties I was responsible for 11 group homes and I got knowledge and experience about this service. For sure there are good group homes and there are not so good group homes. I came to the point that I did not want Pia to live like that. The risk to be neglected by the staff was too big She would not have a good life because of staff limit in the group homes. And today there is even less staff in many group homes compared to 20 years ago.

Regarding group homes the municipality is deciding about the location of the group home. The municipality is deciding who is going to live there and the number of residents. The municipality is also deciding how many staff are going to work there. The person with disability or the legal guardian/parent can decide the colour of the wall paper. That's it.

A little more than 40 years ago I chose my husband and he chose me. The municipality has not chosen my husband for me. We choose together whom we spend our time with. The municipality does not choose for us. We choose what to have for Sunday dinner. The municipality does not choose for us. Give me one argument why the municipality shall choose for my daughter.

I do not like the title of this study "special needs...". What kind of needs do people with severe disabilities have which we do not have? Is it not the support that is special? The title is discriminating in itself. I think the message to the policy makers is wrong. It is a pity when the result of the study is so excellent in other respects.

We need a new way of thinking to solve the problems caused by the old way of thinking. This was said by Albert Einstein and I agree.

Finally some words about the separation from Pia. I felt like a mother bird with two baby birds in her nest. (I also have a 34-year-old son). One baby bird was sitting on the edge of the nest and made short flights to the nearest tree. The mother bird had no say in his comings and goings. The baby bird decided for himself. He flew home now and then and were fed and asked for money or permission to use the car. He made his own decision when he left the nest for good.

Deep in the downy warmth nestles the young bird that will never be able to fly. Society demands that the mother bird should pick up the young bird and push it out over the edge. Each one of us knows what happens to the little bird that falls out the nest before it can fly. The personal assistants symbolize a finely meshed net I have woven under the nest. On June 1 st, 1994, I lifted the young bird over the edge of the nest and now she is in the net. Even if the net is not as comfortable as the down in the nest, there is much more to be seen from the net. New things will happen and she will have fresh experiences. Even if the nest is snug and warm, it is still enclosed and the view is limited.