

Parents and professionals working together, Barcelona 2011

Session 4: Transition to adult life; after school what?

Charlotte Holmberg, Sweden is authorized social worker and a parent to a now grown up son with cerebral palsy and two ordinary sons. Her background includes twenty-four years as a counsellor in an adult habilitation team. She is now working in a community based organisation with conversational therapy. She has been an active member of the Swedish organisation RBU, The Swedish National Association for Disabled Children and Young People for over 25 years. She has also been a board member of ICPS. In 2004 she got involved in Transition work in Toronto and since then she has worked to implement new ideas in Sweden based on the work from Bloorview Kid's Rehab in Toronto.

Background

Picture 1

My presentation is presupposed from Per, my 31-year-old son. He lives a pleasant life in a flat of his own and with personal assistance 24 hours a day. He is satisfied with his life, has something to do every day at a day-care-center, which he says is good enough. He has some friends and a caring family. He would like to have a real work but says at the same time: "I have no choice so it will do". His dream is to work with music and theater. He has been fortunate in having a full life with a daily occupation, friends and family. Daily occupation, personal assistants and a resident of your own is part of civil rights in Sweden. Those rights are not always easy to get hold of for all individuals who are entitled to them. The saying "it looks good on paper" fits well here, since it's usually just in theory that things are as good as they sound.

Presentation

Picture 2

- Swedish welfare system
- The bright future is ours
- Perspectives or counterpart pictures
- Concerns
- Getting a life of your own

Swedish welfare system

Picture 3

Surely you have heard about the Swedish welfare system.

It gives us for example free schools, free school lunches and a paid parental leave for 18 months when a baby is born is another great asset.

Our social security system provides us with a low but manageable income if we are sick, out of work and when we cannot support ourselves. Medical care is not free but almost. Technical aids for people who need them are free or at a low cost, travel services for old or disabled individuals is lowpriced. From the beginning of the 1970ies there are hardly any residential institutions at all. The ones that still exist are for old age, developmentally challenged people who have lived in institutions all their lives and would suffer badly if they would be separated. They live in shared apartments or small detached houses.

On the whole, one might say that all young adults with impairments are offered good housing adapted to their needs where they can live on their own with or without support, in accordance with their wishes.

Picture 4

In 1993 a government act was passed that has been considered to be perhaps the most revolutionary law implicated in modern life in Sweden. It contains many fundamental rights, but the most important part is the one that gives anyone who has a need of personal assistance the right to have such assistance. It's your personal needs that decide the amount of time for this assistance, not your economy or any other circumstances. This act has been called the first opportunity for a heavily impaired person to have the human right to chose when and where and what to do from their own choice and it certainly is a milestone in our national history. This right costs nothing for the user, it's free of charge. It is called LSS which means The Law of Support and Service.

The bright future is ours Picture 5

Young people of today with or without disability have grown up going to mainstream schools and have had a life like most young kids in their younger years. When graduating from school the all have the same kind of hope for the future.

Picture 6

Life seemed like a beautiful dream, now it would really happen, all the things they had hoped for... There's a line in a well known students' song in Sweden that goes like this: "And the bright future ahead is ours." Everybody sings it and expect their life to be like that, young people with impairments as well.

Counterpart picture Picture 7

- Being in mainstream life does not turn one into being nearly not disabled
- You still have to cope with real, existing challenges and closed doors

From parents horizon we knew about challenges. But it was hard to cope with them and talk to Per without sounding awfully pessimistic. He had to have his dreams like youth in general. We didn't want to make him disapointed.

Concerns Picture 8

I want to tell you about myself and my concerns. The first time as a new parent I was very weak. My little baby son Per became the comfort in my pain and sorrow.

And I realized as time went by that I could not change his injury. I had to accept it and deal with it. I tried to comfort him and my concerns of him changed over time as he grew up. We have always had a strong bound to each other. My worries are about him.

Picture 9

Very early I got aware that he had a will of his own. He was abled in many ways to speak up for himself.

I am certain that this ability is one of the most important things growing up to be an independent person.

Studies Picture 10

I have looked up essayes about kids and parent and saw an interesting interview research **I am an teenager**, made at the Univeristy of Stockholm 2005 by Carola Berglund and Jessica Lucic at the department of psychology.

The essay discuss teenagers with disabilities and their possibilities to get a more grown up relation with their parents.

During the years as a teenager the relationship with the parents changes. To make it possible the teenager needs access to privacy, activities outside the family, friends and opportunity to make own decisions.
Several obstacles was identified.

Picture 11

There are often problematic relations with friends and small possibilities to make own decisions. There were tendencies to overprotection and infantilization both from the parents as from the surrounding community.

Picture 12

As Per grew up, he went to music festivals with personal assistants and deamt about his bright and gloving future. When he was 18 years he dreamt like this:

In Ten Years

(How old am I then?)

*28 years, then I have a computer company
or study computers.*

My goal is anyway to have a computer company

Then I live in an apartment with my girl.

We live in Karlstad.

We will live together, that's the first

After that I'm not really sure..

I'm will engage myself in handicap issues;

jobs, assistants, aid

and activities for disabled people.

I also want all handicapped people who

has got the ability to think ahead

to be special-educated

I think it's important to be able to think ahead and not back to

the forties when handicapped people wasn't that much worth

Those who doesn't want to be on a daycentre

shouldn't be placed there but

they should get more real jobs.

That's what I think many have forgotten

in today's society.

All careers guidance officers should think ahead that

handicapped people also want to have real jobs.

because I think they forget that.

They are happy to place handicapped students in daycentres as soon as they can.

Daycentre sounds like the forties and institution

and there I don't want to be.

Concerns and counterpart picture: **Picture 13**

There is a big challenge in finding the balance between over-protection and abandonment.

Picture 14

After ending ordinary school at 20 years Per went to a boarding school for people with disabilities. He did not want to bring his personal assistants because he wanted to find himself he said.

The counterpart picture we had as parents were big, big worries about his health and how the staff at school 750 km way from home would deal with it.

As he left home I felt a big emptiness and it seemed like I lost the engine of my life. When a colleague ask me how I was doing I started to cry, went home and took some days off to recover.

After some months Per came home for Christmas and sorry to say we had to take him to the hospital. His hips were badly inflamed and with a stomach ulcer of too much painkillers. He could not eat nor drink. His whole body had got into a dead-end.

The doctor found nothing and told us that it could be caused by us parents worrying so much. He recommended us to psychiatric treatment. We never went there by the way. But during his ten days treatment in the hospital an expert on Cerebral Palsy established that the pain made the symptoms of the cerebral palsy very severe.

This is one of many situations during the years with a growing son when balancing between own responsibility and caring becomes too difficult.

Per got injection with cortison, painreduction and botoxin and became fit for school again. When he came home again after one year at the boardingschool he wanted to move to an apartment of his own.

It made me worried because I saw so many upcoming problems we had to solve.

Picture 15

We decided to ask for an individual plan.

We had several meetings with people, experts and everybody tried to do their best to make life working for Per.

Picture 16

Per moved to an apartment of his own. It is accessible. It is now more than seven years ago. He has got pension from the social insurance agency.

Per stays with us, his parents, about two weekends per month. In the beginning he stayed just a couple of nights a week in his apartment but slowly we have managed to get things working.

Now we ask Per "Come and see us" instead of "Come home" We have finally realized that his home is in his apartment...

Per's checklist for moving out Picture 17

Per has made a checklist of things that he thinks is important when moving away from parents to start a life of your own.

- Allow the parents to get used to the change, it will take a long time. Live partly at home and in your new apartment. That is good for the parents and you get away from worried parents.
- Talk to each other, have a dialog if there are complications with different things.
- Make an individual plan together with all the people that are concerned so that everyone gets an overallpicture.
- Technical aids that works, adjusted telephone, etc.
- Occupation, work... something to do is very important
- Invite friends, have parties.

- Let your siblings come home to you and sleep on the couch, eat supper and fix your computer if you have one.
- Invite people; the physiotherapist, the occupational therapist and all the people you have to see can come home to your place instead of you going to them.

Picture 18

Now time has passed. Per is 31 years old, he has become an uncle to a little girl. He is enjoying her company very much.

Per says he takes life day by day,. He also found out that television has much to offer and enjoys that.

Every morning he ask the staff for the day how things are going with her or him. He wants to find out what he can ask them to do. He is managing the situation.

He told me it was easier in many ways when he had parents living with him who took care and communicated with people entering his life. Now he has no one but himself. He has to relay on himself, he says.

Picture 19

He also loves the company of his youngest brother. Here they are sailing at a summer camp on the west coast of Sweden last summer.

Picture 20

The very best in his life and made his dreams come true was when he joined Share Music. This is from a performance Dawn in Galamanta in the central station in Stockholm 2009. Next year they will perform in London.

A life on our own

Picture 21

Per has lived on his own for many years. My story is deeply connected with my son. Life has worked out well enough for him, he is laid back and relaxed. So I am able to relax as well.

After 35 years together Sune and I have sold our house to live in an apartment in the city. We now feel we can look on life in a positive way.

For example Pers dad does not drive in to town every time Per is going away for the weekend to pack his bags, we rely on the personal assistants that they remember every need. We don't really know what he is up to every day or week.

I still worry about Per, but he also worries and has concerns about me and his dad. Per says he still needs us in the background.

And actually and very truly I need him too, very much. We care about each other.

Thank you!!

Charlotte Holmberg

