

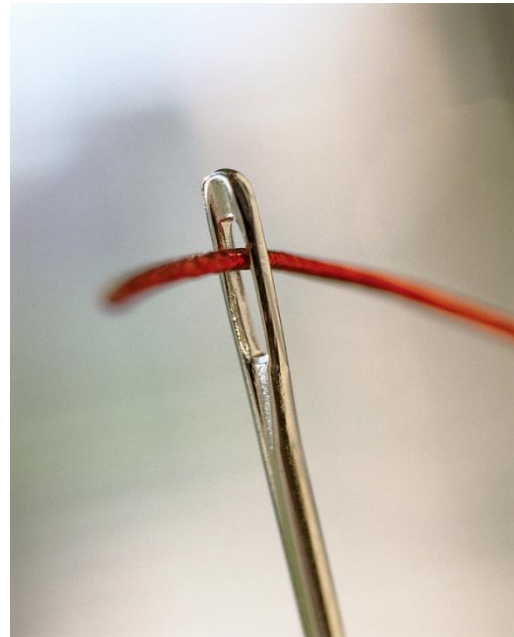


europeanpatients'forum

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Project report:

# Young Patient Perspective



**SOFIA JÖNSSON & STEFAN JOHANSSON, June 2008**

**Project report:**

# **Young patient perspective**

- 1. Summary ..... 3
- 2. About the project ..... 4
  - Two possible gaps: ..... 4
- 3. Method ..... 5
- 4. The participants ..... 6
- 5. Result..... 7
  - 5.1. You spend a lot of time off from school ..... 7
  - 5.2 A lot of different contacts for health and rehabilitation – when you are young ..... 9
    - 5.1. The systems, organizations and people that are supposed to help are regarded as enemies. .... 9
    - 5.2. You start to think like a grown up when you still should be thinking like a kid ..... 11
    - 5.3. Limitations in your own mind and in others beliefs and expectations in you narrows what you can and will achieve in life. .... 12
    - 5.4. Accessibility problems are always something to consider. .... 12
    - 5.5. There are no channels open to the people in charge..... 13
- 6. Recommendations ..... 14
- Focus group documentation, first meeting ..... 15
  - Public transport ..... 15
  - Future, work and study ..... 16
  - Instances that are supposed to help, they prevent rather than facilitate. .... 17
  - Preconceptions and treatment..... 18
  - Access denied ..... 19
  - Relationships, love and children ..... 19
    - Relationships with “regular” boys or girls ..... 20
- Focus group documentation, second meeting ..... 21
  - Contacts with your doctor ..... 21
  - Different contacts within health care and habilitation systems ..... 22
  - At school ..... 22
  - Membership in patient organizations ..... 23
  - Insurances ..... 23
  - Adoption..... 23
  - To travel with an electric wheelchair ..... 24
  - Isabell's trip ..... 25

# 1. Summary

What do young patients think about their own life and the society where they grow up? Are there any difference between this group and other youngsters? No one seems to know. Can a “young perspective” within the EPF do any difference? We believe so. This is a report of a pilot study to find out more about young patients.

On two occasions we had a workshop in the Academy at Ågrenska. 10 young people took part in the workshops to discuss what’s important in their life. The result is mixed. In many ways there are no differences between what’s important for this group compared with other youngsters. The best in life is to meet good friends, have parties, listen to music and grow up by going from school to work and to have a family.

But looking closer to what they say, there seems to be major differences. Being a young patient inflicts on almost every aspect of life. The discussion reveals a society yet far from being equal and accessible.

## **The main problems are:**

- You loose a lot of time from school
- The systems, organizations and people that are supposed to help are regarded as enemies.
- You start to think like a grown up when you still should be thinking like a kid
- Limitations in your own mind and in others beliefs and expectations in you narrows what you can achieve.
- Accessibility problems are always something to consider. You can’t do things spontaneously and simultaneously with others.
- There are no channels open to the people in charge

Young patient’s perspective seems to be ignored or not taken seriously. There are barriers between the young patient and the society. EPF can be a platform for greater influence and understanding. On the other hand: EPF can be seen yet as another barrier. It depends on how you manage to integrate the youth perspective in your daily work.

## 2. About the project

In the pilot study we have met young people having diseases or syndromes that lead to long term or life long conditions. All of them will be patients for their whole life.

### Important questions

- The idea was to find out what young patients think about their situation and possibilities to live and take care of them.
- What will the future look like? Job opportunities and family life?
- We want to find out if the society's idea of these young people is correct, or if it needs to be updated.

### Two possible gaps:

We have identified two possible gaps:

1. **Differences between young patients and young people in general**
2. **Differences between young patients and old patients**

We believe that there are differences in both situations. This study has focused on gap number one. And if the pilot study is right there are significant differences if you are young and having diseases or syndromes that lead to long term or life long conditions.

But we also think that we can recognize some differences between young and old patients.

The problem for the moment is that we can't fully describe any of the gaps. We know that the gap exists. But EPF has to conduct studies over a period of time to be able to describe the whole picture. What we can do for the moment is to present what the young people in the pilot study said. And already with such a small number of persons we can pin point a number of problems.

Being young and being a patient might transform you in to a stranger both in the eyes of other young people and by older patients. If that's so a young patient can be very lonely or heavily depending on the parents (for good and bad).

### 3. Method

- We conducted a pilot study by using a focus group.
- We had a focus group discussion at Ågrenska with 7 participants of different ages, sex and disabilities. All of them are wheel chair users. After two months we had another group discussion. The 7 from the first meeting participated once again and there were also 3 new participants on this occasion.
- The discussion was filmed and documented.
- Another focus group was planned to be held somewhere in Europe with participants from several countries, but we soon learned that there are difficulties to arrange meetings with young patients on short notice.
- The result from the focus group has been confirmed in ad hoc discussions with other young patients, parents and professionals.

We also conducted a small survey to check what the participants liked to do and their opinion in some questions.

## 4. The participants

**Marika** is a 23 year old student who is studying to become a pedagogue. She is active in a political party to the left. Marika is very driven and wants to change things. She has many thoughts. She lives in her own apartment in Angered.

**Rebecca** is a 23-year-old mother who lives with her daughter and boyfriend in Sollebrunn. She studied before to become an assistant but she had too much problem with her disability, she was in a lot of pain and missed a lot of time at school so she quit. Both Rebecca and Marika lived a very adult life so they had more to say about adult problems like insurances.

**Felicia** is 18 years old and attends upper secondary school. She lives with her parents in Kålltorp but she wants to move to her own place soon. Felicia works with children.



**Hugo** is 15 and is in eighth-grade. He has troubles with the public transport which he uses every day to get to school. He is the youngest of the participants. Hugo lives with his parents in Billdal.

**Isabell** is 18 years old and attends upper secondary school in Angered. She has had many problems with Färdtjänst since she often has to use them when she goes to visit her family in Örebro.

**Sayam** is 18 years old and attends upper secondary school in Angered. He has a lot of special medication that needs to be cold so he always has to think about that. He plays in a band. Sayam lives in Gothenburg city with his parents.

**Hanna** is 17 years old and attends upper secondary school in Angered. She has recently been operated and she's having a hard time at the moment. Her parents live in Ullared.

**Angela** is 19 years old and attends upper secondary school in Mölndal. She is very interested in music. In her second year at school she took a sabbatical year because she needed a break. The school and her disability took up too much of her time.

**Emil** is 20 years old and lives in Trollhättan. This year he is going to start his education to become a teacher. Emil has had a lot of problems with getting as much personal assistants as he needs. When he moved out to live on his own he needed more help than before.

**Magdalena** is 24 years old and lives in Gothenburg. She is a member of the board called Unga Rörelsehindrade which is an organisation for young disabled. She is also active in a lot of other patient organisations.

The whole group had a very positive atmosphere and was very constructive. Almost every participant came up with at least one brilliant solution to the problems we discussed. It may seem as if they spent the whole day complaining but that was absolutely not the case! They shared and learned from each other's experiences.

## **5. Result**

We have only met a small group of young patients but there are conclusions that we believe represents experiences from large groups of young patients in Europe. When being chronically ill means that you are different from other young people. You are different both in your own and in others perspective. To be a patient sometimes overrules being you. If you have to spend a lot of time being a patient you have to learn a lot that no other young people have to care about. And the time and energy you put into the patient role might cause you problems even when grown up. If you for example are away a lot from school it might inflict on your life as a grown up.

### **5.1. You spend a lot of time off from school**

All participants were asked to calculate how much time it took to visit their doctor and other professionals due to their long term condition or disability. The result is quite upsetting. All of them have missed a lot of school hours per year, some of them up to 200 hours per year. Often they were called to different kind of meetings on school time. No one has ever been asked if this is appropriate or if they for example wanted meeting times in the afternoon, when the school day is over. The different kind of doctors and specialists they meet on regular basis don't seem to recognize this as a problem. Each one of them maybe meets the person only a couple of hours per year. But these patients have a lot of contacts. So the health care system as a whole should be better prepared to deal with the fact that it is important for these patients not to lose time from school.

And how does the school cope with this situation? Do they compensate the loss of time? Do they take special actions to help these patients? The short answer seems to be no. The participants couldn't describe any specific action from the school. Some of them had specially adapted support due to their condition and how it is inflicting

for example learning possibilities but no attention seems to be made to the time they lose.

No one could give any example of contacts between the health care system and the school in order to solve this problem. The problem seems to be ignored by everyone. Even by the participants themselves. They seem to accept the situation as something you can't do anything about. And in a short perspective it can be nice to get of school now and then. They were surprised when they calculated the total number of ours from school.

**As an example:**

The total time for math in Sweden is 900 hours for pupils between 7-16 years. Losing up to 200 hours a year under the same period is 1 800 hours off from school.

Many pupils with long term conditions will probably also lose time from school caused by their condition. There are days and periods when they aren't able to go to school.

Parents seem to believe that school compensates this loss but that seems not to be the case. The result: Children with long term condition doesn't get as high grades as others. In Sweden this is the fact. A government group of audits conducted a study presented in 2006 saying that pupils in nine-year compulsory school with special needs caused by long term conditions and disabilities only reached the mark "passed" in 57% of what is regarded as key subjects: Swedish, English and Maths. The level for other pupils was 87%. Both groups had the same intellectual capacity. If you are not "passed" in those subjects you can't go to the next level in the Swedish school system (the Gymnasium).

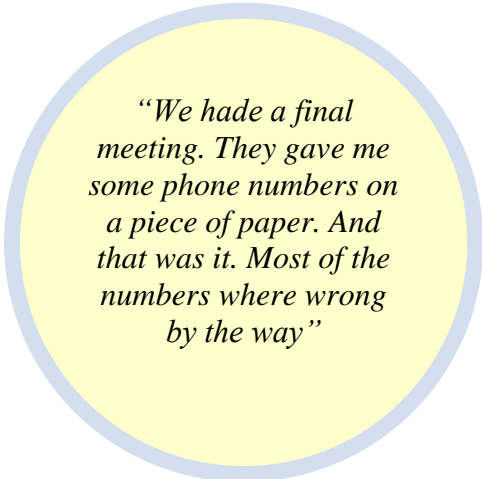
The auditors focused on the schools lacking ability to compensate the special needs. But they did not focus on the time loss. They seem to believe that those kids are at school as many ours as the others and that there are factors at school causing the gap. Of course there are such factors. For example pupils with dyslexia don't get enough reading practice and they don't get technical aids such as speech synthesizers and electronic books. But the fact that many of the pupils in this group seem to be away many ours from school was not recognized by the auditors. This might be something to EPF to focus on. All time scheduled activities including pupils should be off school time. That is late afternoon, evening and off school days (in Sweden Saturday and Sunday). The EPF demand should be that doctors and other professionals organized their systems and working schedules so that pupils with long term conditions could be at school as much as possible. Each one of them must understand that the pupil might have many scheduled meetings with other professionals. EPF should also



focus on getting the doctors and the school to cooperate to find the best solutions for the patient.

## **5.2 A lot of different contacts for health and rehabilitation – when you are young**

The participants could tell of a similar pattern: When they were children they had a lot of contacts with different professionals due to their long term condition. Their parents coordinated much of these contacts and some coordination was also done by an institution called Child Habilitation. We asked the participants to draw a mind map over their contacts when they were children and another to describe how the situation is today. As children they could have between 10-30 different contacts. But when they get 18 all this stops. At that age they are regarded as adults. Most of them got one final meeting with the Child Habilitation and after that they are supposed to take full responsibility for their own further treatment. Many of them thought this was too abrupt. They would have liked a smoother change from childhood to adolescence.



*“We had a final meeting. They gave me some phone numbers on a piece of paper. And that was it. Most of the numbers were wrong by the way”*

As a child you get calls for meetings. As adult you are supposed to call for appointment. This change was regarded as difficult

## **5.1. The systems, organizations and people that are supposed to help are regarded as enemies.**

One very important thing we learned from the participants was that nothing comes easy. As a patient you have needs and it's very hard when nothing comes exactly when you need it or as you want it. The participants in our study were young but they already see the helping systems as enemies. Their experience was that either you conquer them or you give up and adapt “to the system perspective”.

Their opinion was that the systems were preventing them, rather than helping them, to live as normal as they wanted. Naturally the systems intentions are good, they want to help them but somehow they tend to do the opposite. Why is that? Can we change that?

The participants all agreed that dealing with systems takes up a lot of energy that they need to put on other things like their education. So the systems cause energy drainage even when it provides support. You might get the help you need but then you always have to struggle, beg, be “system smart” to get it.

This is all very upsetting and it might come as a surprise to many people but it's the reality. All seven participants could tell stories where they had to exaggerate how ill they are to get the support they need. They say they get the feeling that you have to hide if you're feeling good at the moment, the support might get withdrawn and it's difficult to get it back.

Swedish support systems such as Färdtjänst (transportations), Samhall (employment for working disabled) and Försäkringskassan (social security) are disliked and mistrusted among the young patients. In some cases they're even hated. One very interesting matter of fact is that these systems think very highly of themselves. They get rewards and prizes. So they have no idea what the young patients think. We hope that this survey will help them and show them what the reality looks like for young patients.

Nothing comes easy. Nothing comes exactly when you need it. Nothing comes as you want it. Soon you tend to see the helping systems as enemies. Either you conquer them or you give up and adapt “the system perspective”.

All of the patients agreed that the systems were preventing them to live as normal as they wanted.

They don't like to waste the energy they have got on dealing with the systems. The systems cause energy drainage even when it provides support. You might get help but you always have to struggle, beg, be “system smart” to get what you need.

#### **Example**

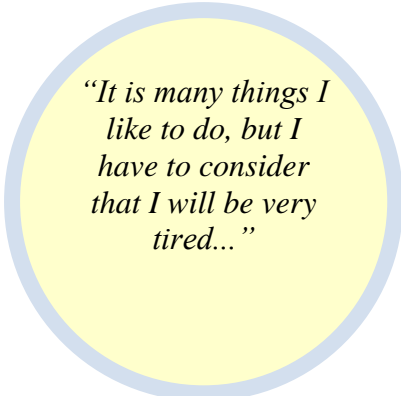
- All seven participants could tell several stories where they had to exaggerate how ill they are to get the support they need. If they say that they are feeling good for the moment, the support might get withdrawn and you can't get it back easy.
- Swedish support systems such as Färdtjänsten (transportations), Samhall (employment for working disabled) and Försäkringskassan (social security) are disliked and mistrusted among young patients. In some cases they are even hated.

## 5.2. You start to think like a grown up when you still should be thinking like a kid

The participants were in different stages of life, but all of them were mature for their ages. Regular teenagers are living pretty much for the moment, but the youngsters involved in our project planned several years ahead. They also have to plan their day in detail. Spontaneous changes are difficult.

All of them had thought a lot about their future. Every kid has such thoughts. At first they want to be fireman, train driver, pop star or something and as they grow older they might dream about other occupations. The difference is that our group early in life seems to have focus on what they can't be. Even as really young they seem to know that there won't be many options. The question is who provides this limitation? What causes them to think "...well, being a person like me it's better to be very realistic from the beginning. No dreams of being a pilot or a supermodel".

Detailed planning is a part of the every day routine. Early in life they learn to take responsibility for advanced planning and also to conduct tasks that wouldn't be even thought of if they were normal kids. For example a 7-8 year old with diabetes can use advanced technical and medical equipment. He can plan his medication and forecast when he is low or high on insulin. At the same age his friends can't tie a shoelace or cross a street and they are not the least aware on how what they eat inflict on their body.



*"It is many things I like to do, but I have to consider that I will be very tired..."*

This is an example of mature thinking. As a mature you know that being on a late concert with the Backstreet Boys on a Tuesday will cause you problems on Wednesday morning. But being young you shouldn't bother. If you are a fan of the band you will go anyway (If your evil mother or father doesn't stop you)

You're not allowed to be a child as long as others if you are permanently sick or have a disability.

### **5.3. Limitations in your own mind and in others beliefs and expectations in you narrows what you can and will achieve in life.**

It's what you expect of yourself and what you want out of life that decides what you can and can't do. Your environment also controls you.

Prejudices are everywhere. The patronizing talk that makes you feel like an imbecile is humiliating. It's not just old people, its staff that works with patients too, and young people the same age as them who talk like that.

#### **Example**

- All of the participants where sure that they wouldn't be able to work full time even if no one yet was established on the labour market. This is a significant difference between this group of young people and other youngsters.
- Most of the participants could tell that they loose a lot of time from school because they have to see their doctor or a number of other professionals on school day time. And parents, teachers and doctors seem to accept this. This might result in lower grades.

### **5.4. Accessibility problems are always something to consider.**

The biggest issue we discussed was the public transport. It's not accessible for wheel-chair users. Also different buildings have accessibility problems.

Most young people are spontaneous. Young patients should also be able to be spontaneous. The alternative to public transport, "Färdtjänst", is not working as most would want it to. It's complicated and not flexible.

Handicap toilets "down town" that all people with special needs can use are extremely rare, if existing at all.

#### **Example**

- The public transportation company in the Gothenburg area is getting prizes and awards for their fine approach in accessibility matters.
- But the youngsters can tell several stories of bus drivers who don't let them travel with the bus with their wheel chairs. Lifts are out of function on a regular basis and a lot of busses don't have lifts.
- In 1974 Swedish laws regulated that public transports over a period of time should be accessible, but the public transportation companies still fails to live up to the rules...

## **5.5. There are no channels open to the people in charge**

All the participants in both focus groups were active people. They are interested in changing things and they are active and have many social contacts. There is another group: Young people who are passive and isolated. Who don't go out, who don't work. People from this group said no thanks to the opportunity to be a part of the focus group.

"It's like they have given up from the beginning", one participant said.

Though being critical to a wide range of things in the society no one seems to know how to work for a change. For example many of them are strongly critical to the local bus company, but no one has contacted the company board or CEO. They nag at individual bus drivers but they don't organize their frustration in protests that can be noticed by the people in charge.

So even when they strongly feel that something is wrong, they don't know how to work for a change. Only one of seven participants in the focus group was active in a political party.

No one is an active member in a patient organization.

A general feeling is that the focus group is one of very few occasions when someone really wants to hear their opinion. The group wanted to meet again to follow up the response from EPF on what they have expressed.

So there is a will to change but they don't seem to have the tools and organization to do it. And the people in charge is either ignoring this group or just don't know that there are problems. Maybe EPF can be a bridge between young patients and the people in charge?

## 6. Recommendations

- EPF should have a young patient perspective in every decision and demand.
- EPF should conduct regular surveys/reports on a European level.
- EPF should publish a “Youth Barometer” on a regular basis.
- EPF should be a bridge between young patients and the people in charge.
- EPF should develop tools and methods so that young patients can make their opinion heard.
- EPF should demand that time scheduled activities such as meetings with doctors are off school time.

There is a position to be taken. No organization represents a young patient perspective. No one seems to communicate with this group. There is an “impact potential” for the organization who takes this empty position.

### **High profile issues:**

Among this material there are some high profile issues. EPF can be the organisation who communicates those issues. For example:

- Time scheduled activities for young patients should be off school time.
- The young patient should have a “manager” who coordinates and plans contacts with different stakeholders in the young patients’ life.
- A young perspective should be adapted in every patient related process

This is only a small study. To be the voice of young patient EPF should build a strong knowledge base regarding what young patients think and need. There has to be some kind of ongoing regularly conducted surveys/studies to monitor what young patients need and how they think. To be trustworthy most of the work should be done by young people themselves. A report every year or every second year on young patient perspective can be seen as an important document from EPF. There are a good potential for mass media coverage and EPF can profile itself by presenting the young perspective. EPF can be an open channel for young patients and EPF can be an organization that has a substantial knowledge about the conditions for young patients in Europe.

If this report is true, young patients don’t feel that their opinion can make any difference. EPF could act as a bridge between young patients and both public health care systems and the pharmaceutical industry. EPF can both be the platform for such activities and provide tools to teach young patients how to make an impact on policy- and decision makers.

# Focus group documentation, first meeting

## Public transport

All the participants at the workshop agreed that the public transport wasn't working nor were accessible for the disabled. Everyone would have liked to be able to use it since it allows you to be spontaneous and just be able to go somewhere with your friends wherever you want whenever you want.

Fardtjanst<sup>1</sup> is not a popular organization among the participants. Of course it's good that the service is available but fardtjanst is complicated, expensive and both drivers and operators are often ignorant and rude. If the fardtjanst system had worked, maybe the wish and need of being able to use public transport wouldn't be so big. But the way it is today, you have to book your car well in advance, preferably the day before and decide exactly what time you want to leave and return. If you miss your car a new one won't come in 10-15 minutes like the bus does. You then have to call and make a new booking and it can take several hours before a new car can come. So everyone agreed that it would be better to get rid of fardtjanst and fix the public transport system so that everyone can use it. Politicians claim that everything will be accessible by 2010 but that is soon and it's not looking bright at the moment.

Once, Rebecca wasn't allowed to take the bus because the driver said that she had fardtjanst and she should use that instead. But why adjust buses, trams and subways for people in wheelchairs if they're not allowed to use them? Every wheelchair user has the right to have fardtjanst.

Hugo often takes public transport to school and he's in a mini crosser. Buses have often left him at the bus stop and the access ramp that's supposed to be there rarely works. He said that the bus driver has a button in the front that he has to push to make the access ramp work. But the drivers aren't always aware that someone needs to use it and not everybody knows there is a ramp. The general opinion is that the drivers need better education so they know how to handle disabled customers. One suggestion is that there should be fardtjanst buses on some sort of schedule like the regular buses. But that would probably be too expensive.

At the end of the workshop we talked about solutions to the problems we had been discussing during the day. The group agreed that there should be a test group, all in wheelchairs, who would go out for a whole day and see how it works to travel on public transport in the city. Maybe with a video camera so you can show to Vasttrafik, the public transport company in Gothenburg, what it's like. Because Vasttrafik have received many awards for being so accessible and wheelchair friendly and within Vasttrafik they think that they are very good. None of the participants agreed. They all thought that you need to show the facts to their faces. It's hard to deny if you have it on a video tape.

*"Maybe there should be a disabled person on the board of Vasttrafik who would think of things like this."*

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<sup>1</sup> Fardtjanst is a transport service in Sweden for disabled people. The state owned organisation hires taxi companies to drive disabled customers.

That also applies to other instances like the Health Insurance Fund and the Unemployment Office.

## **Future, work and study**

One interesting thing was that everyone who participated in the workshop was certain that they would not be able to work full time in the future. Most of them said that they thought that they would work approximately 50% of full time. One thing you noticed was that everyone had been forced to grow up earlier than regular teenagers. Most of them planned a couple of years ahead, even Hugo who is only 15 years old. He was worried that the upper secondary school that he wanted to attend won't be accessible.

The participants were in very different phases in life. Marika and Rebecca who are 22 and 23 years old both have independent lives with their own housing and studies. Marika is studying part time, 25%, to become a pedagogue and she likes it but she is aware that it will take a very long time for her to finish her education, maybe up to six years. But still, she has accepted her situation and wasn't that dissatisfied. The school Marika is attending is very accessible and she has only been treated well. She does what she can and when she is in too much pain she leaves the classroom. She says that all the teachers are great and understanding. She really feels like she takes part in what the class is doing.

Rebecca is studying to become a pupil's assistant and she has problems with the fact that she is in so much pain that she often is late for school and get rude comments about it from her (adult) classmates. When she began her education she told them about her disability and everything went well. But then it got worse. New people joined the class and they didn't treat her so well. She thinks it feels very heavy when someone says "Oh, so you slept through the morning today?" when she has been awake since 6 o'clock in the morning but has had so much pain that she hasn't been able to go to school. Now she's thinking about if she is going to tell them again or just ignore it.

But during her education her disability has been useful to her at trainee jobs. She uses it to reach out to the pupil she's working with. When someone didn't want to do his math she said "but you have to help me get the books because I can't reach them". She also wrote in her application that she had a disability so she got help from the study adviser with classrooms and adaptation.

Felicia is going to work in a kindergarten this summer where she has been a trainee many times before. She was very happy that they wanted to have her back and the kindergarten pays all of her salary and doesn't get any contribution to the salary. She says that it makes her feel like they think that she can do the same job as the others and that feels very good.

The fact that everyone has realized their limitations so early was surprising. But on the other hand it's not so strange that you grow up a little faster when you have to consider your disability in everything you do. But no one seems sad that they can't work full time. Maybe you have to reconsider the concept full time. Full time for a person without a disability is eight hours a day. But maybe it's just as hard for a disabled person to work four hours. Shouldn't that be full time too, it's just full time for that person? Or should focus be on what kind of work you can do on a full time basis despite your disability? Every participant in Gothenburg had full intellectual capacity, but no one seems aiming to be working with their minds rather than with their body.



For many of the participants, time is a big problem. There isn't enough time. You have a lot of pain or the daily care you need takes a lot of time, it differs but almost everyone thought that there isn't enough time. That's why we can't work full time and that's why it takes more time in school. Hugo writes slowly and he gets very tired doing it. Now they are about to have their national exams and he is worried that he won't make it or withstand to finish the exams in the time they have. If you have a physical disability that makes it harder for you to write you have writing difficulties, at school people with dyslexia have much more time to finish their exams. Although a physical disability isn't dyslexia, it is a writing difficulty so you should have the same time as the dyslexics. His school should have offered him that so he wouldn't have to worry about it.

So how can we make time last? Maybe it's good to adjust the concept full time or the so called full time to each and every person's ability. At least this issue is something that needs to be investigated. Because you also have to have time to do nothing at all. That's important too.

### **Instances that are supposed to help, they prevent rather than facilitate.**

Something that many find really difficult is that when you are in contact with the Health Insurance Fund you always have to exaggerate all the bad things and go through every little private detail like how much time you spend in the bathroom. Because if you make something sound good you don't get any help. You always have to fortify the bad things and maybe sometimes even lie a little to make sure you get the help you need. That makes you feel mentally bad. To focus on the worst things in your life gets you down.

There are also many administrative things you need to deal with if you have a disability. There are plenty of different licenses that need to be updated after a couple of years even if your physical state will never change. The handicap parking license, fardtjanst license just to name a few are licenses you'll always need.

*"Shouldn't that be the doctor's or the habilitation's responsibility to report if the disability changes so you don't need the parking license or fardtjanst?"*

Insurances are another problem. According to Marika and Rebecca you can't get insurance if you have a disability. But you should really be able to get insurances for things that don't have anything to do with the disability. Take a life insurance for example. It should be possible to get an insurance that applies if something happens to you that isn't a cause of the disability, like getting hit by a bus. But today that's not possible. According to the insurance companies, everything that happens has some connection to the disability. Even though, that's not always the case.

When someone brought up Samhall<sup>2</sup> the whole group shivered. Apparently ending up at Samhall is a failure. The participants felt like it's an insult to sit and perform meaningless tasks locked up at some institution. There was coverage on the news where they brought up disabled and the ability to work and support yourself. They said that if a person had come in to the world of Samhall it was almost impossible to get a real job and get back to the labor market again.

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2 Samhall is a state owned organisation which offers work to disabled who have trouble finding a job.

But how can we avoid making Samhall into something disgraceful? You have to give the people who are there real job assignments or real jobs. There are people who are unable to work off course, but on the other hand there are many people who are fully capable of doing some kind of work. They just need the job site to be well-adjusted to them. People with physical disabilities can work with their minds and people who have problems working with their minds can work with their bodies. It's actually just the people who can't do neither of these things that are unable to work. And a decent payment. Sure, you can understand that it's not possible to get a normal salary but at least a little more than it is now. Otherwise you feel undignified.

## **Preconceptions and treatment**

The worst thing is when you get treated badly because of your disability. Everyone thought so and I haven't met one single disabled who is okay with it. Of course no one likes to be treated badly but it happens to us pretty often. It is cashiers who ask if you can talk, it's physiotherapists who talk to you as if you were a dog, and it is taxi drivers who don't believe you know where you live.

But there are two different kinds of bad treatment, there is pure discrimination but there are also cases where you get treated better than the others because of your disability and that is not always good. It creates a distance from your classmates, when you can get away with things the regular classmates wouldn't get away with. When you have a long-term disease some special treatment is necessary but when it's not necessary you don't want it. The disability makes a person different and that is often something you feel sorry about so most people want to be treated just like everyone else as much as possible. So the disability doesn't make you an alien!

Another kind of bad treatment is from the health care that doesn't believe you can be ill without there being some connection to your disability. "Oh, your stomach aches, but you had a surgery five years ago. Don't you think it has something to do with that?" As soon as you visit the E.R. you have to explain that you are just ill and that it has nothing to do with your disability. Sometimes it has, but not always. And when you are really ill it's very annoying to have to explain yourself.

But the patronizing baby-talk must be the worst of all. When old ladies come up to you and say "Ooh, aren't you cute! How nice for you to come out and get some fresh air! Here, have a strawberry!" This old-fashioned way of assuming that all disabled persons are locked up at institutions and never get to go out and do normal things, is still common. Even young people sometimes say things like "So you can go out and party? I didn't know you were allowed to drink alcohol." At times like that you just want to die.

But what should we do about it? I think the best thing is for disabled to go out even more and be around regular people so they learn that we are just like everybody else and not so weird. Because if the society sees disabled do normal things maybe the preconceptions will fade away. Of course, information is always good too. Let disabled persons star in films just like everyone else and let them be a natural part of the society. Then people will notice them and there will be more disabled celebrities who can show the world what it's like being disabled. And a sense of humor! Instead of feeling ashamed and run away and hide you say "Yes but

you're pretty cute yourself! Nice for you too to come out and get some fresh air! No, I think you need that strawberry yourself, little Lady!”

## **Access denied**

To practically not being able to participate because of a stair or a narrow door is something disabled has to deal with all the time. It's cafés, clubs and cinemas. Every time it's so terribly annoying! Just small things would have helped enormously. Most of the times all you need are a small ramp. But it surprises you more if there actually is one than if there isn't and that says quite a lot. Still, Sweden is rather good. So you can only imagine what it's like being disabled in Rumania, for instance.

You could say that we in Sweden whine about luxury problems. But your life quality increases when you are able to try on clothes with your friends in a store. If you sit in an electric wheelchair you can almost never get into the dressing rooms. But okay, let's say that's a luxury problem, being able to go to the bathroom is not a luxury problem. It's a big problem. At the workshop we came up to the solution that there should be one or a couple of large well-equipped handicap toilets in the city with nursing tables and lifts. So you can go to them instead of going home when you need to use the bathroom. In many places there is indeed a handicap toilet but a handicap toilet is often just a bigger room and a toilet seat with bars on both sides. That isn't much help for most people. If that's the only thing you need you can usually use a regular bathroom. But of course it's better than nothing at all! But it could be so much better.

## **Relationships, love and children**

As for the any young people relations are important. All participants wanted to find someone to love and they wanted to live in relationships and have children. Not all of the girls will be able to get birth to a child but instead they were thinking about adoption. They may have difficulties with their bodies but in their mind they have the same dreams as anybody else.

Can a person in a wheel chair have sex? That is something many other young people want to know and frequently asks about.

*”Of course! I put him on top of myself in the wheelchair, and then I drive over a bump or something back and forth!” .*

Marika has lectured for upper secondary school classes about sex and disabilities. At school they never talk about sex like that. They should. At least if there's someone disabled in the class. Or maybe that special pupil should be offered extra sexual education about how their disease/condition inflicts when it comes to sex?

Marika is usually very open and jokes about it to break the ice when she lectures.

*”The first question everybody asks is: “can you..?” And of course we can. It's harder for some people but you do what you can and learn to improvise.”*

But sex isn't everything in a relationship. When we asked everyone and talked about love most of them thought that they had just as much chance to find a ”regular” partner as a

disabled one. They all agreed that it was harder in junior high school when you are young and most people are rather immature, but that gets easier the older you get.

Some of them thought that the internet was good for meeting people because there you don't have to tell him or her right away that you have a disease or a disability. You can say it after a while when you have gotten to know the person better. But the bad side of it is that it's much easier to ignore someone you've just known over the internet. There's a pretty big risk that the one you talk to gets scared and stops writing. Of course there are also people who are open minded and understanding.

### **Relationships with “regular” boys or girls**

Rebecca is in a relationship with a “regular” guy who’s name is Martin. They met at a driving school and now they live together and have a two-year-old daughter. When they told their parents that they were a couple and pregnant the mothers were pretty upset. The mothers both thought that she should have an abortion, and when they refused Martin's mother thought they should move in with them, because Rebecca couldn't possibly take care of a baby. Luckily both of the fathers were supportive. Beside from the fact that Rebecca is disabled they were both very young, only 19 years old. So they had a lot against them keeping the baby but now they're a very happy family living on their own.

Some of the participants have had serious relationships, both with “regular” and disabled. I don't think there was anybody who thought they could only get disabled partners. But overall the participants were rather positive and optimistic persons. Marika has had one relationship with a “regular” guy and one with a wheelchair using guy, and she said that there wasn't any big difference.

Marika told us that when it came to kids her mother was rather negative. Marika thinks that her mother has realized she probably won't become a grandmother, because Marika is on very strong medication. And you can't take them when you're pregnant. Also, Marika is in constant pain and she doesn't want her child to have that. So that alone is a pretty big reason why she doesn't think she'll have children of her own. She also said that it's practically impossible for a disabled to adopt. The adoption agencies can't say no because of your disability (that's discrimination) but they can say that you are unable to take care of a child.

Adoption is a big problem that EPF really should look into. If you are in a relationship with someone and you would make a good parent you should absolutely be able to adopt, even though you have a disability. A lot of disabled prefer adoption, either because they don't want to risk passing the disability on to the child, or because they physically can't go through a pregnancy. Will these people never be able to have children? Disabled should at least have the same possibility to adopt as everyone else. Does a disability really make you a bad parent? Isn't it possible that it makes you a better parent or at least as good as the not disabled because you can teach your child to accept people who are different?

Most of the participants were sure they wanted to have kids in the future. Some wanted to have kids of their own and some wanted to adopt. But we discussed the parents’ attitude to the possibility of having grandchildren some day and most of them were supportive. Now most of the participants were young and maybe they haven't given it so much thought yet.

# Focus group documentation, second meeting

## Contacts with your doctor

All of the participating youngsters could give both good and bad examples. Some of them had regular and frequent contacts other only met their doctor once or twice a year.

Good examples	Bad examples
<ul style="list-style-type: none"> <li>• When they listen to what I have to say.</li> <li>• When you can get a good contact</li> <li>• When they see me and not my illness/condition.</li> <li>• When they don't start with prejudices and believe that they know my problem although we never have met before</li> <li>• Well experienced and calm. Gives the right medicine with regular follow up meetings.</li> <li>• When they write adequate and thorough notes in medical certificates and journals. When they understand that I need good documentation, otherwise I get trouble in contacts with other authorities.</li> <li>• When they can explain how things works in a way that I can understand.</li> <li>• When they talk to me and not to my parent or my personal assistant.</li> <li>• When you can meet the same one over a long period of time.</li> <li>• A human and friendly approach.</li> <li>• When you can feel that they are devoted and not only perform a cold routine task.</li> </ul>	<ul style="list-style-type: none"> <li>• When they are difficult to get in to contact with. "I even have pretended to be a relative to the doctor just to get through by phone".</li> <li>• Suddenly my doctor just has disappeared to a new job, without informing me.</li> <li>• When they give mixed signals. One time they say: "Yes an operation is an option". Next time they say: "You are not too ill to go to surgery".</li> <li>• When they ridicules what you say or just says "Well that's what usually happens" and not really consider what you say. They have already made up their mind on what's wrong and what you can do about it.</li> <li>• When they don't write detailed and accurate notes in journals and medical certificates.</li> <li>• When they keep sending you to yet another doctor or specialist or whoever and it never stops.</li> <li>• When they don't read my journal before we meet. Example: On girl hade done a surgery. Doctor had said to the personnel "When she is up on her feet and can stand for her own she can be sent home" Problem is the girl cant walk. She is using a wheelchair. He would have known if ha had read the journal.</li> <li>• When they don't inform you of what is going to happen.</li> <li>• When it takes a long time.</li> <li>• When you have to nag and nag to make them understand what you need and how you feel.</li> <li>• When you have to get angry to make them understand.</li> </ul>

	<ul style="list-style-type: none"> <li>• When they are too fixed to the diagnose information. “This is normal for this diagnose. Therefore you can not feel what you feel”.</li> <li>• When they can’t separate conditions connected to my disorder with some other problems caused maybe by another and new disease. Some doctors tend to explain all problems with the original diagnose.</li> <li>• When they discover that you have a rare disease and start to se you as an interesting object to study, for strict academically end personal reasons.</li> <li>• When you get really hurt by what they say or rather how they say it.</li> <li>• When they create expectations that they can’t live up to.</li> <li>• When they start a meeting by reading in another persons journal.</li> </ul>
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### **Different contacts within health care and habilitation systems**

One issue to discuss was to se how many different contacts the participant’s hade under a period of time. The picture in Sweden is that when you are under 18 you have a lot of contacts. You have a big web of professionals who meet you on regular basis. This might cause some specific problems. The most important is that the different persons in the web don’t coordinate their actions with each other. So you can’t describe it as a network, rather as a web of solitaire professionals supporting you from time to time. To make this work your mother has to be some kind of manager or coordinator. (Yes is seems to be the role for most mothers. No one said that their father has done this).

But as a youngster you can feel rather safe when this works. And when your family understands how the system you can get the support you need. Suddenly all this stops. It happens when you get 18 years old. Then you are moved from the child habilitation system and you are regarded as an adult. The result: You are left on your own. You are used to get calls from all members in the web when they want to meet you. Now you must establish new contacts and no one calls. You have to call them when you need help. The trouble is that no one has educated you in what kind of help there is to ask for and where you can find it. This happens at the same time when you are supposed to live more on your own and not depend on your parents. Suddenly you feel very alone. There should be a period in between when you prepare for this situation to happen.

### **At school**

When discussing how it works at school a similar pattern can be recognized. All of the participants could tell of situations where they have lost a lot of time being off from school.

We asked them to estimate the time:

*“Between 7-9<sup>th</sup> grade I lost a lot of time because of complications after surgical treatment and illness”*

*“I was away from school a lot due to my long term condition, but I managed to get G or higher anyway”.*

*“I was away almost a year”*

*“I was away about 15 days a year”*

*“192 ours per year due to meetings with different kind of specialists and meetings with my doctor”*

All participants said that they have lost a lot of school time during the years. Added up we can see that the number is days or weeks rather than ours. The school doesn't seem to recognize this as a problem. No one could tell of any specific action taken by the school to minimize the time they loose. Mostly they had to catch up what they have missed by working harder at home.

## **Membership in patient organizations**

All of them are members in at least one patient organization. Often it starts with their parents being members and then they are “kindly forced” into a membership.

“Many organizations seems to be more for the parents needs than for us”

The organizations are rather boring and work in a way that is to slow for young people. All of them say that they are interested in activities striving for direct action. For example it would be interesting to form a “test patrol”, a group who visited different places and tested the degree of accessibility.

## **Insurances**

One participant mentioned that there are difficulties when you want to sign up for different kind of insurances.

## **Adoption**

If you can't give birth to a child or if you have a genetic disorder that there is a risk that you give to your child and adoption should be an alternative. But you won't pass the test parents who want adopt has to go through. Disabled persons don't pass that test so this option is closed. The rules are that disabled are not allowed to adopt, but they are allowed to have their own children. The participants agreed on that this is wrong.

## Appendix: Stories from reality...

### To travel with an electric wheelchair

This is the year 2008, and you can think that it should be possible to travel with an electric wheelchair by airplane. I experienced that unfortunately it's not. When you travel with a wheelchair as sensitive and heavy as I do it's very, very important that the staffs that takes care of the wheelchair handles it carefully. Because when you travel by airplane, you often go very far and if your wheelchair breaks it's very hard to find someone who can fix it.

I was going to Brussels to do a job. First of all, it was very hard to find a flight for me, and when we finally found a company who agreed to take my wheelchair with them I had to fly via Stockholm to Brussels, I live in Gothenburg. Even though it was a very complicated flight, it worked. Actually, it went very well. We laughed and joked about it on the flight to Stockholm "As long as the wheelchair doesn't break, or we miss a plane!" I should have known: never ever do those! When we landed in Brussels, and I got to my chair again, of course it was broken! There was something wrong with it, mechanically. And I never know what to do with the electricity and since it is an electric wheelchair, it's useless for me when the electricity doesn't work.

Since I don't know what to do when there is an electrical problem, I don't trust anyone unless it's not an expert at electric wheelchairs. The airport brought me the only electrician they had, but of course he knew nothing about wheelchairs. So he examined the chair as much as he could and dared (I checked him all the time: what are you doing? No, don't touch that!), but he couldn't find the problem.

After two hours at the airport, I gave up and went to the hotel. The whole time my assistants had to push my 150 kg wheelchair everywhere we went. By the time, we got to the hotel we were all very hungry and tired, so we ate and then they pushed me back to the hotel room. During dinner my mentor, Stefan called his friend, who also is a wheelchair user, they told me about a main switch, I had no idea such thing existed. So when we were back inside the room, we read the manuals very carefully and found the location of the main switch. It was extremely well hidden, under the chair. Jessica finally managed to turn the switch on and off and then it worked! Like magic!

So it all worked out, finally! But what if we hadn't found the main switch? We had to use a flashlight to see the hole where the switch was hidden. When we discovered that the chair was broken it was around five o'clock and it's about then all the offices close. But I am too dependent on my wheelchair, it cannot be out of order for such a long time, what I mean is I couldn't possibly wait until the morning to fix it. My back would hurt, my assistants would be exhausted from all the pushing, and so on. What we need is an all around the clock open office for wheelchair emergencies! Maybe not one in every country but there needs to be one, at least for every wheelchair trademark. Like Permobil (my trademark and the biggest I've heard of) and Moover.

It's important to create support systems that work even when you're not at home. As the society gets more and more accessible, more and more people are going to travel with electric wheelchairs. This requires another way of thinking when it comes to service and reparations. What are you supposed to do when stuff breaks while travelling? I called Permobil and asked them. I talked to Tommy Nilsson who works at Permobil and he told me that they have



people working in almost every country in Europe. But if the damage needs special parts it takes at least a week before the parts get there. So if you're on a short trip like I was you will just have to wait until you get home. If your wheelchair breaks between 8 to 5 and you still have your warranty you can call Permobil directly otherwise you have to call your service central and hope that they have duty. But still it's hard to get help fast. Tommy said that it's impossible to have a support system that works all around the world.

## Isabell's trip

This is a story that makes a good example of how Färdtjänst can make your life harder.

Isabell attends this upper secondary school in Gothenburg but her family lives outside Örebro and she visits them now and then. One time when she was on her way to her parents' house the taxi driver was a little strange. There are two streets with the same name as her, one in Örebro and one outside Örebro where she lives. Taxi drivers have been wrong before so this time she tells him that she lives outside Örebro to make sure he took her to the right place.

It's pretty far from Gothenburg to Örebro so he had to fill up the gas on the way. He told Isabell this so when he drove to central Örebro she assumed that he was looking for a gas station. But all of a sudden he stopped and started to take Isabell out of the car. She looked out the window and saw that she wasn't at her house so she told the driver: I don't live here! To her surprise the driver answered: Yes you do, this is your address.

But of course Isabell knows where she lives. She told him: my house is brown and white, this house is yellow! The driver said: how long have you been away? Maybe they repainted the house while you were gone. Now Isabell started to panic: but this house has steps and I'm in a wheelchair. My house has a wheelchair ramp! The driver's answer to that was: well if you've been away for a long time maybe they've moved it.

Isabell was going crazy! What ever she said the driver wouldn't believe her. Finally after arguing a lot the driver asked someone who was outside the house if they were expecting an Isabell. Of course they weren't and then he started to believe her. Isabell told him that if the car was outside her house her parents would be able to see it from the window. So the driver called her parents and asked them if they could see the car. When they couldn't he finally believed Isabell and her parents also told him the right way to their house. Then at last he drove her home!

This is a typical example of how Färdtjänst work. They don't believe you and after fights you might get your way, if you are lucky!