



## **International Conference: Independent Living through direct payments**

**Expertise Centre Independent Living**

**European Network on Independent Living**

**3 June 2010, De Zwarte Doos-Gentbrugge**

### **The Independent Living philosophy by Jamie Bolling**

I think some of you are disappointed. I should have been Adolf Ratzka today and I'm not. I was asked to replace Adolf, but you can't replace Adolf. Adolf is Adolf. He's a fantastic guru. But I was asked if I could talk instead of him and I said "yes, I would do that gladly". But I don't have the 45 years experience that Adolf has. I only have 18 years experience in the Independent Living Movement and I don't have the experience of all that Adolf has done. He's a fantastic person, but I hope you won't be disappointed. I'll try to talk about the same things that he was supposed to talk about today. I need to start with saying "thanks" to the Expertise Centre that ENIL could be a part of this. I forgot to do that in the beginning. I was so excited! But anyway, we are happy that ENIL was able to be represented here today and to be a part of this conference. And Chris, I thought it was very important when you said that you want to look at the economical aspects of personal assistance. ENIL had a board meeting during last weekend. One of the things that were brought up was how in Germany, economic discrimination reigns with personal assistant and the way direct payments are working there. So that is something that is important for us to look at.

I'm going to talk about the history of the Independent Living. What is the Independent Living through direct payments? The speech is divided in three parts. The history of IL is interesting for me. I was



lucky when I was at the hospital and needed help. I had Adolf Ratzka's wife as my physiotherapist and she wasn't allowed to advertise STIL, but she whispered in my ear: "If you have problems with your life when you get home, there is an organization that can help you and it's called STIL." I didn't have any ideas concerning personal assistance, I was too much in my own body and my own things, I was not paying much attention. But when I got home, life didn't work so well. They don't come with a silver platter in Sweden and say: "Here, this is it. We will help you to have your life go on". You had to find out: "What do I have the right to, how can I make this life go on again and how can I become more independent?" You know, when I was depressed, because I wanted to do things and was locked in my flat, one person told me: "You just have to get used to not doing so much". And I thought: "That's not right, I can't do that, I like to do lots of things. This will kill me if I have to get used to not doing things." But that's what my psychotherapist told me, that was her advice. But I didn't like the advice so much, so I went to STIL instead. And there I found out: "Yes, you have rights, a right to personal assistance, to become active again and to lead the life you choose". This life is even a more exciting life than I lived before! You never know if you are going to fall out of a wheelchair or not. You never know if you get stuck in an elevator or not. You never know what's going to happen during the day. A day is full of excitement!

Anyway, the history. When I was with STIL, I was called on a Friday night by Helena Karnström, an activist in Sweden. She said: "Jamie, you owe me a favor." And I said: "Aha, why? What do you want me to do?" She said: "Well, on Monday I need you to hold a speech." I said: OK, I will do that." She said: "It is in English and that should be no problem for you." I said: "No, that's good. What is it about?" She said: "It's about Independent Living in STIL." I said: "OK, how long?" She said: "One hour." I said: "An hour!? I have to prepare a speech for an hour! It's Friday night and the speech is on Monday morning! How am I going to do that?" So I went to my library. I like books. I bought some books in the States that I hadn't have time to read yet. I pulled out a book called "No Pity". If you haven't read it, read it. It's a good book: "No Pity" by Joseph Shapiro, there he writes about the history of the Independent Living Movement, as well as about the conflict with charity and different things that are interesting for our movement. So there I read about Ed Roberts - unfortunately, I've never had the possibility of meeting him - and how he wanted to go to school in the United States. I'm an American, so I can get into his story: how he wanted to go to the university in California. Everybody was to have the right. But when he came, they said: "A wheelchair, an electrical ventilator? No, he doesn't get in!" So they said "no" to him, because they were prejudice and think that we can't think and we can't talk and we can't do things. So he had to fight. He had to contact the newspapers to say: "I have rights like anybody else. I want to go to university." He succeeded - through himself and three other guys that called themselves "The Rolling Quads", they got to the university. The next problem was: "how are we going to let them live there? We don't have accessible buildings". They had to turn the infirmary into a dormitory, so that these guys had some place to sleep, where they could get in and get out. "The Rolling Quads" were a part of the beginning of the centre of Independent Living in Berkeley, back in the sixties.

Judy Huemann lived on the other side of the States, on the East Coast in Brooklyn. She had had polio as a child and her parents made sure she got a good education. But when it was time to graduate, they said: "Oh, you can't graduate, you didn't do gym." I mean, *come on!* They can excuse us from gym if they want to or put some other kind of qualifications. But she managed to get that degree. Then she was to become a teacher and they said: "You can't become a teacher, you are a fire



hazard." So they weren't giving her that diploma either. She had to fight to become a teacher. And in the end, she is working with the US government with disability issues. She started the Centre of Independent Living on the east coast.

During the seventies, the Independent Living started spreading throughout the United States. And then we had somebody like Adolf Ratzka, who wanted to go to the university in Southern California, where he was able to get his education. He came to Sweden after that and when he did so, his lifestyle had to change. In the United States he had his grant from the German government, he had been able to have personal assistance and make his life function how he wanted it to: get up, study, have a party and go to bed when he wanted to. But when he came to Sweden, he had to get up at seven in the morning and go to bed at ten-o'clock at night, because that's when the people came to put you to bed and get you up. And he said to the Swedes: "Friends, you guys like this? You have to start living! I don't want to live like this." So then they formed the Stockholm Independent Living Group that proposed a pilot project to the Swedish government. They said: "We can take care of this, if you let us have a program with funding to have direct payments. You give us the money and we organize our assistance, we will have better quality." And it worked, and then they passed the legislation in 1993.

Adolf Ratzka was the guru in Sweden. I'm sure there are a lot of other gurus. I don't know all the histories in all the different countries here in Europe. But I do know the people on the board of ENIL. I know a bit about their stories. There is Kapka Panayotova from Bulgaria, who learned about Independent Living and started the CIL in Sofia. They are fighting and hopefully, this or next year, we will have a scheme for Independent Living there. We have John Evans and other people that fought in England. A lot of people have gone to the United States, got inspired, came back with the inspiration to Europe and started movements within their countries. Bente Skansgård from Norway, who is with us today, took her own car over to the United States, drove around and got inspired about Independent Living. Martin Naughton is our person in Ireland. These are only a few names; names I have taken from ENIL; the ones that are closest to me right now. But I know there is a history in each country where people had been involved. That people meet through peer support; we meet one another, and realize: "Yes, we can live a better life, we can have a better situation in our life."

What is Independent Living? It's a philosophy, but it's also a movement and it's also a basis for political action. The philosophy is - that we are the experts, we know how we want to live our life and we can organize it. Some of us may need support, but a lot of us can do it on our own. People with intellectual disability may need support, but they can also have personal assistants. They don't need to live in institutions. None of us need to live in institutions! The Independent Living Movement spread through ENIL. From the 80 people that were in Strasbourg in 1989, to the 400 of us that were there in 2009, and hopefully in two years I want us to be with at least 600! So come and bring your friends! Maybe we will 800, who knows?

Why is Independent living a basis for political action? Because in saying: that we are the experts and can organize services we need the political will and the funding to see that we have access to direct payments. We need access to community services in all EU countries! We can be there to organize these services, to say how the services should be organized and show that they work!

Everyday we are confronted with inaccessibility! Everyday there is a bus that passes in front of my house. I am active in the Green Party, and respect the environment. I prefer to ride that bus, but... the problem is - it is not accessible. Even though there is the EU bus directive and even though they said in Sweden: "by 2010 it should be accessible"! Now they are going to make the bus accessible by putting in a step climber. This is the solution after testing options, in cooperation with the disability movement. They had had a guy who was hard of hearing test this climber and he said it was OK. So they are going to order those, rather than putting in ramps. The climbers are cheaper but not accessible for all. I don't know the guy who was involved in the testing, but I think they should have used somebody who was a wheelchair user, who would have had another perspective. I have a feeling that when they actually put that step climber in my bus, it's going to take so much time and exclude many. It's not going to be something that people are going to choose to use. So we have the expertise that can be used as a basis for political action, whether it's personal assistance or whether it's accessibility.

The philosophy of Independent Living is about self-determination, self-confidence, self-responsibility and political and economical rights. Thanks to the way ideology is advancing, today our issues are issues of human rights! We now have the United Nations Convention on the rights of persons with disabilities. Even though the United Nations Convention contains no new rights, it's just all the "old" rights being accentuated. The philosophy of Independent Living is one of self-determination. We are the consumers and should have the sovereignty, we as consumers should be able to decide how the services should be organized. We shouldn't have people saying: "You get up at 7 in the morning and go to bed at 10 at night", as it was when Adolf came to Sweden. The disabled had services and it was the service deciding how they should organize their lives. They got up, went to university, went home and went to bed. I remember the times when they came to my house right after the accident. I also had what they called home help. I never knew what time they would come. I think somebody in the family had had a birthday and they came at ten o'clock. We had visitors and I didn't want to go to bed yet. I said: "Can you come back in an hour?" I had tried to call them. They said: "No, it's ten o'clock." They organized my life I had to go to bed when they came, instead of being able to organize my life in my own way.

It's important that we can formulate our own needs and our personal preferences. How do we want to live in the community? Some people want to live in a collective. I have a lot of friends in the north of Sweden who live in collectives - people with disabilities and people without disabilities. They like to live together, so they might buy a big house or rent a big house and then live there with ten people. Maybe we would like to live like that. But then again maybe we want to live alone with a husband, with a girlfriend, with kids or whoever. It's important that we should be able to choose how we want to live and not be put in institutions. Self-confidence is confidence in our selves. That we know we have our own resources and our own competence. We are capable of developing strategies to be able to succeed; we are able to organize our own lives. We want responsibility. We want the services, allowing us to take our responsibilities.

When I moved to the north of Sweden, about five years ago, I was a little bit afraid they might not like the idea I was coming, they might check and change my life and see I didn't get the same scheme for personal assistance. They left me alone, maybe because I was a politician! I didn't talk to anybody, I just moved there. But I wasn't a burden to the society, because I worked, I paid taxes. I

have four personal assistants who would all probably be unemployed today if they did not have employment with me. This because I live in an area where there is high unemployment. One guy is a refugee from Africa. He would definitely be unemployed because I think he is one of the only refugees in his group who has a job in that area. There are advantages for the government having people employed as personal assistants rather than being unemployed.

With personal assistance we can assume our responsibilities as citizens. By being a politician, I myself am active with the greens. I work in the church. We should be able to do whatever it is we want to choose to do. Being as active as I am or being just as active as one chooses. Taking care of our kids, dog sitting our friend's dog or whatever it is that we want to do to be active in society.

I will give you a short definition of Independent Living: independent living means to have the same range of options and the same degree of self-determination that non-disabled people take for granted. This is a quote from Adolf Ratzka. This is as close as you can get to him today! It's a question of having choice, control, participation and inclusion. We want to choose how we want to live and who we want to live with, where we want to live. How we want to organize our personal assistance, with control, so that we decide when they should come and how they are to work. We want to participate in society in the way we choose with inclusion in society. We want to be counted on as someone participating in society, someone that can be counted upon.

What aims do we have - ENIL and CIL's? Promoting Independent Living philosophy; developing the concept, principles and definition of Independent Living; promoting the development of Centres of Independent Living; carrying out training and awareness raising activities at the European level. To this, I add the adoption of a EU Independent Living Directive. This is something that we need to talk about within the movement; that we need to develop. It's at a very early stage, but how should this directive be formulated? What strategies do we have to get it passed? We are going to have to do a lot of lobby work at all levels for such a directive.

This power point is a cartoon from one of my favorite cartoonists, John Callahan, who also had an accident and is a wheelchair user. He wrote a good book. Another good book to read if you haven't read it yet, "Don't worry, he won't get far on foot". He wrote about his life and how he ended up in the Independent Living Movement. This one, if you see, there is an empty wheelchair and next to it a guy in the fountain, taking a shower. Another guy is coming up and is saying: "As manager of the hotel, I promise I will personally find you a room with an accessible bathroom!" This may be not as common in all countries today, but there are still a lot of inaccessible hotels everywhere.

How can we gain Independent Living through direct payments? Direct payments are high on many agendas today. If we are going to get direct payments, the UN convention is one of the major tools to use. A lot of countries have them and it is now a question of keeping them. In Sweden they are trying to change the legislation all the time and try to take it away. In Germany users consider their system as economic discrimination. I'm learning the situations of all the countries, but I don't know them all as yet. But I know that there are countries that don't have personal assistance or community services. As per the United Nations Convention article 19. – we have the right to Independent Living. The convention was adopted in 2006 by the General Assembly. It has 50 articles. The purpose of it is to insure that disabled people have full access to their human rights. There are no new rights. It's the rights from the Human Rights declaration, but as we needed a women's convention and a children's



convention, we needed the convention for people with disabilities. This, as rights are not respected! And the United Nations estimates that 10 percent of the world's population, are people with disabilities and we need this convention in order to fight for our rights!

Article 19 is on living independently and being included in the community. It states that a state should recognize the equal right of disabled people to live in the community with choices equal to others. It states that states shall take effective and appropriate measures to facilitate disabled people's full enjoyment of this right and full inclusion and participation in the community. It says "full inclusion". This doesn't mean having to accept that you can't become active as this lady told me 20 years ago.

What are direct payments? Schemes to carry out personal assistance. Money from the City, County or National Government levels to disabled person in need of personal assistance. I can take you through the Swedish example. That's the one I know the best. In Sweden it's the combination of the city and the government responsible for direct payments. To start the person in need contacts the local social worker. They will negotiate their need of hours based upon the personal and social needs needed to live their life. Some people who have communication disability and mobility disability can have double assistance, or up to 48 hours or maybe 36 hours during one day. Or somebody else might only have 3 or 4 hours per day. Depending on needs, there are different legislations that back them. We have the legislation on special support for people with certain disabilities. This gives us the right to personal assistance as well as other rights. For example services where somebody takes you to the cinema. There are also the services that enable you to live in a certain kind of housing. But I'm just going to explain the personal assistance service. If your needs are over 20 hours a week, then it becomes a question for the government. So then you would go from this social worker to the government agency and restart your negotiation - based on the first negotiation, talk with them and confirm your hours needed. The city pays for the first 20 hours and above that the national government pays for the rest. You can organize it through the municipality - today there is still a majority of people getting their services from the municipality. They do call it personal assistance. Even though many people within the movement would not say it's personal assistance if they don't organize it themselves. But there is a majority organizing their assistance through the municipality and they do decide whom they want to employ. But this solution may not have the same freedom of choice, which for example would be the case if someone organizes the service oneself. You as an individual can receive the direct payment to your bank account and you are responsible for paying the salaries, paying the insurances, paying all the costs around the responsibility of this person that you have hired. And you are expected to respect for example the employment legislations, which you need to understand. It's a question of how many hours one can work in a week and when they have to have off and other regulations. Or you can choose a cooperative. For example, I chose STIL, the organization I am a member of since 1993, before we had the legislation for personal assistance in Sweden. STIL is the formal employer. I sign a contract with them. They get the money that I'm eligible for to their account and then I have my account with STIL. I organize my assistance through them. I then can put an advertisement in the paper, which I don't usually do. I usually go mouth-to-mouth. I find people and I try them out. They either like the work or they don't like the work. I decide when they are going to work, how they are going to work and what are the kinds of people I need to make my life go round. So STIL is the formal employer, and I'm the work leader. Or one can choose a company to organize personal assistance. The amount of companies is growing and this is something



we'll talk about further on. With the different kinds of choices, there is more competition, and it also is a mean in assuring a better quality for our personal assistance. But we have had companies in Sweden that caused some problems. Some companies for example try to bribe people to come to them and promise money in return. This isn't legal, so now the government is going in with hawk eyes, saying: "Ha, is there some extra money here? We need to draw down!" And they are looking at the situation, the legislation. So we are waiting for a new adaptation to the law, which should come in a few months. So there are four possibilities to organize personal assistance: through the city, personally, through a cooperative or a company.

Now a short definition of Personal Assistance: Personal Assistance means to be able to customize services to your unique individual needs by either employing your assistants and deciding who works with what, how, when and where, or by buying services choosing freely among many competing service providers. I buy my service through STIL, a cooperative. All countries are having their special legislations. For example in Sweden there are some issues I think we have in common when working with personal assistance, and that is: are we allowed or are we not allowed, should we or should we not employ relatives, people from the family, mothers, fathers, daughters, sons, etcetera. In Sweden in the Independent Living movement we say that you feel free and more independent if you are not dependent on your family. But there are people who want to choose family members to work a certain amount of hours. The legislation in Sweden limits you, if you have your own company you are not allowed to employ your family members. So then people may use STIL for these employments. They have their own company and hire their assistants, but then they would have a certain amount of the hours they have that they would administrate through STIL, who would then hire and pay the family members as they are not allowed to do this themselves.

Quantity and quality of your Personal Assistance services (and thus quality of life) are determined by three things: your country's policy, the market and yourself. For example, if there is no personal assistance schemes in the country, then people are organized either through family, friends or through volunteers. From a lot of people I know, they have tried to find volunteers who can do their personal assistance. When you get a scheme in your country, I know that some schemes are limited to only having assistance at home. Sweden is going in this direction, trying to limit personal assistance to the home only. One of the suggestions has been to change personal assistance to a home service, so persons with lesser needs would have 40 hours home service. This hasn't gone through, but it was one of the suggestions from the politicians. If this had gone through, I guess what we would have had to do was to get another scheme. If working, then you would probably have been able to get more assistance hours through your employment. But those who don't have employment would probably start a life being more at home than outside. I know that there are countries for example where maybe the maximum for personal assistance is 20 hours a week. So you have to decide how to use these 20 hours a week. And then, how do you find the support that you need for the other hours needed? Is it through the institution where you live or is it through your family and friends? So the countries policies of course are very important. How does means testing work? If you have worked hard and you have to pay all your savings for services what is the result? In Germany they are saying that the personal assistance schemes are keeping people very poor. So there is the question of dependence on family members and there is the question of the results of means testing. The next thing is the market. If you do get personal assistance, how are you going to administrate it? How has the country policy allowed for the administration? Is it a free market or is it only for



example a government administration? But it depends also on us, and how we organize ourselves. What kind of ambitions do we have? Unfortunately, we still have a lot of special schools for people with disabilities. I visited some young kids at a special school we were going to talk about development cooperation. There were 6 young kids sitting in wheelchairs and a few other kids with other disabilities. Talking to this group I realized that there was not much expectation on them. The expectations of these kids were lower than the expectation would have been in another classroom. And that's a problem. Another problem is that we are educated into norms, that we are to accept that we are some sort of B-class citizens and that we really should not want to do much with our lives. When raised in the United States, you believe anybody can become president like Obama! He succeeded. And any of us can do anything we want to do. We are just need try and we get there. But this is hard when the whole system goes against you in so many different ways. But it does depend on ourselves.

It's we who can influence the quality of our services. We have to know what we want in life, we have to know what we want to do. Do we want to go to the university? Do we want to work in some sort of apprenticeship of something that we want to learn? One guy who was blind said: "There is a job I can't do. I can't pilot an airplane." That's the kind of way we need to think. We have to know what we can and cannot do and our assistance needs. We have to know our personal strengths and weaknesses. You learn a lot about yourself through having personal assistance. 20 years now I have personal assistants. I'm not always the best working leader. I have my faults, I have my weaknesses, I have my strengths. Sometimes I realize: "Oh, I should have taken that conflict a little bit earlier. I should have based the expectation a little bit higher." You have to learn that there are different things, even in the personal assistant relationship. There is the relationship of power. When is the assistant taking over? When do I take over and dominate? Rather than having an equal relationship as we are working together as partners in this work that we do. So knowing strengths and knowing weaknesses is important. You have to learn how to express your needs and how to delegate. How to delegate as much as possible and do as much as you can do yourself, because you want to be as active and as independent as others. But you need to know what you need to delegate and how to delegate it. And that is not always so easy. In Sweden there are questions like: can you ask somebody to wash your windows or can you not? There are always the practical issues of the house. What does the legislation stop? Within the Independent Living Movement we say: What would I have done if I had not been sitting in my wheelchair? Maybe I would have been painting my house every couple of years, because I like to change colors or what it is that I would like to do. Working, is it being able to travel? How do I want to live my life? Choosing your assistants. My assistants are not allowed to smoke. Smoke drives me crazy. I have a daughter, she gets too nervous, when we are traveling we always have to stop for cigarettes. I ain't got time to stop for cigarettes! So my assistants have to be non-smokers. I hire people who like dogs. My girls have dogs. I don't want to have a dog myself, because I'm not at home enough, but I like to take care of my kids' dogs. So my assistants need to be somebody that is not allergic to dogs for example. We all are different kinds of people. I love The Blues. I had an assistant, she hated The Blues. I went to The Blues once a week. "Do we have to go to The Blues tonight?" she would say. "Yes, we are going." "But you heard them last week!" "That doesn't matter, I want to listen to them again." So I learnt that I had to find out what kind of things assistants want to do. I like to go fishing. I love to fish. I fish in the summertime. I realized it did not work when someone could not help me to fish. I realized I had to think about so many things. Do people know how to swim? Do they know how to hop on a boat? Can they work in a boat? I take it



for granted. People can do this kind of things. But this is not always the case. Do they like to fish? Can they take the fish of the hook? Or are they against killing the fish, like those who are vegetarians or vegans? They are not going to kill the fish. I'm a Christian. I go to a church. That can be difficult if I have a Muslim who is working for me. But then again on Christmas, it was great because the Muslims would go with me to church they would work on Christmas. Others wanted to be off on Christmas. Unfortunately, my father died and the girl who was working for me, who just started, she was Jewish. So she went with me to the United States. And I didn't realize that Jews should never see a dead body. So this was also a problem. Knowing the cultural differences is important! All of a sudden you can find yourself in different and difficult situations. Things just happen and it is not always easy, the different conflicts.

How to motivate assistants can be another issue. I never really thought about this. This is also a slide that I borrowed from Adolf, one that he had in a speech at Strasbourg. Since I was asked only a week ago to take over, I didn't have the time to develop all my own slides and I was to talk about his issues. So I looked through his last speech and I took three or four of his slides. I thought they were quite good. He delivered a good speech in Strasbourg last year and I thought: "Gosh, I don't think enough about how I motivate my assistants!" How do I motivate my assistants? I guess the way I do it, yet I'm not sure, I have to interview my assistant Annika later, but I try to choose the right person for the right situation. I don't choose somebody who can't sit still to come with me to a conference for example, because they are going to climb the walls. So I try to choose and motivate them. I split my travelling so that everybody gets to travel. For the housework, it's not always the same poor guy that has to clean my toilet. You try to change things. You try to motivate so that the job is as interesting as possible. The first thing I do every month, before planning the month's work, I ask: "When can't you work next month?" Because somebody may have a birthday or a party they want to go to or there may be a concert. OK, Annika can't work this day, this day and this day. And Katia can't work this day, this day and this day. Then I try to put together the puzzle. And the puzzle is not always easy to put together, but that's a sort of a way of motivating people. They work when they want to work, so that they think it's fun to do this together.

How to defend your interests? That's another question I haven't thought about. I have a pretty strong character, so I defend my interests. I do what I want to do. I live my life in a full way. So I haven't really thought about this question so much either. But it is food for thought. Think about it and maybe tell me afterwards. But then the next question is: how can our movement assist the individual in this process? The Expertise Centre with their research, STIL in Stockholm, JAG in Stockholm or BOL-BUDIV, how can we as an organization together grow to peer support, strengthen one another and get access to the personal assistance that we need? Those are the questions that maybe we will even have up later today as we are talking. The research results and meeting and talking to one another are a sharing and peer support, a sharing of our relationships and the experience that we have.

I always have to show this slide. I think I got it from Bente a long time ago. "Mobility in freedom". I come from the States, where the statue of liberty is an important symbol. Free, what do we need to be free? I need a bus in front of my house that I can enter. I need access to my personal assistance. These days I don't go to the movies anymore. I loved to go to the cinema. I moved to a little town in the north of Sweden, 500 kilometers north of Stockholm, and the cinema is not accessible. So I had

to put in a sound system in my bedroom, so I can watch my movies and FEEL like I go to the cinema. But I would prefer to GO to the cinema. I would prefer to be with people. That's part of the experience. But how are we going to get that accessibility? In Sweden they had the march, on the 29th of May. I was traveling and haven't read so much about how it went. I know 31 towns had a march on Saturday. The march in Sweden is being used to promote legislation where inaccessibility is considered discrimination. We don't have such legislation as of that yet. There is a law in England, Norway and some other countries, but we don't have such a law in Sweden. Though they keep talking about it. I don't know how long they will keep talking about it. Probably until I'm dead and gone!

In Adolf's speech he gave a link if one wants to read more read for the "Model National Personal Assistance Policy", a paper that he wrote for the project European Center for Excellence in Personal Assistance. You can find it on the Independent Living homepage: <http://www.independentliving.org/docs6/razzka200410a.html>

If anybody wants to ask questions or if there is any point you want to make as far as problems that you realize that you have in your country – you are very welcome!

## Questions:

### **Jakob Putz from Austria:**

For me it would be interesting to know what kind of interpretation there is for personal assistance. I'm asking this, because in Austria we do not have one single law for personal assistance. It's kind of regional law. So we have nine different laws, but not nine laws. Only one law and eight kinds of this laws. And they divide living, spare time and work. So if you need assistance in the spare time and living, you have to apply for it, and if you need assistance for the work, you also have to apply for it. My personal experience is: when does the spare time start and when does the spare time stop? And when does living start and when does it stop? If you go to the shop: do I buy in the spare time or do I buy in the living time? And so on, and so on. So for me it would be interesting: do they accept to interpret, you are at home independently of spare time and living time?

### **Jamie Bolling:**

In Sweden you mean? In Sweden they take your life as a whole. So what are your needs to live your life as a whole? But as I was saying, there was a suggestion that they were going to limit assistance to 40 hours only in the home. And then we would be in the situation where they would take the home living versus the employment living. When I lived in Stockholm, I was meeting people all the time. I had time, to go to The Blues, I was working as a politician, I worked in different jobs. My work within the United Nations Association was my spare time. Almost all my life is considered as spare time! I'm doing research at the university. Is that spare time or is it work? I'm not paid for it, I have to finance it personally. So they can consider that as spare time or they can consider that as work. As you say, the



definition could be difficult. Because I'm not hired as a researcher but doing it on my own, they could actually consider my research as spare time. Though I would not do so. I work for ENIL half time and I'm doing a doctorate at the university in Sweden on inclusion of people with immigrant background and disability my other part time, so that could be considered as spare time. That's another interesting problem we have: living, spare time and working, the division that countries try to make. When you say there is one law and eight, is this the way all the different provinces or counties interpret it?

**Jakob Putz from Austria:**

We do not have a single law. We have nine regions and in eight regions they are kind of willing to do something. In the region where I come from, we have a fixed law which says you get a personal assistance divided into living, spare time and work. We in Austria say: "the worst law is better than no law". And it's our experience that our law in Stiermarken is awful, but it isn't as awful than it is in other regions.

**Jamie Bolling:**

But all the regions have this division between living, spare time and work?

**Jakob Putz from Austria:**

It depends on the politicians' opinion. The politicians in Stiermarken say: "We have to divide the time in living, spare time and work." So there isn't just one political opinion.

**Jamie Bolling:**

Anyone else who wants to share their experience from their country, or any problems that you see?

**Andreas Vega from Germany:**

Maybe a solution for this problem is to support the United Nations Convention. I think this is very important. I think it's a German way for politicians to think so, to make differences in lifestyle. If I go to work I need another social affaire government and for working I need money from another government. So I think we have to support the United Nations Convention. The article 19 is clear.

**Jamie Bolling:**

I agree with that, thank you. Anybody else who has something to say?

**Cor Van Damme from Belgium, BOL-BUDIV:**

We have been talking about the pioneers with the ideas like 20 or 30 years ago. Freedom and self-determination for people with disabilities. But now of course this is 20 to 30 years ago and my question is: do you feel that there is a new generation of people with disabilities taking over throughout Europe? Is this something that is OK, or is this something that could be a problem?

**Jamie Bolling:**

You mean taking over the organizations?

**Cor Van Damme:**

Taking over organizations and also the lobby work. Just the idea of fighting for freedom. Or is it the pioneers still who are mainly active?

**Jamie Bolling:**

You bring up a good point, Cor. When I look here today, I'm quite happy. It's a mixed group with more young people than older people. I remember when I got active in the movement, I was 40 years old and people thought I was young. It was like: "Hey man, I am not young!" Where are the young people? There is a problem. I think it is a problem of empowerment of younger people. But then today we also have the problem throughout Europe as well as the United States. There is also another book I can recommend, called "Bowling Alone". I can't remember the authors name, but he looked at the NGO world and their growth and actually how membership is going down. People don't join organizations as much as they used to. And so it's a problem. The young people I think who are out there are maybe not as organized as people were 20 years ago. We are trying and through ENIL we want younger people to become more active. There should be a mixture within the board, there should be a mixture in all of our organizations. It is something we have on the agenda, we are not there yet but we need to get there somewhere in the near future. So you bring up a good point. Then the question is how to get people involved. We have the social networks through the internet like Facebook. A lot of younger people are active there, they don't join organizations, pay membership fees. It is sort of an archaic way of organizing oneself. How do we get around this, just when we are expected to be able to say we have so many members in so many countries? If you are going to get financing from the EU commission for example, you need to have this membership and people with members to show that you really are represented. So yes, it's sort of a problem right now. These two go against one another. I have met younger people who were in there 30's or 40's that are active in different countries. But it is something to be aware, that older people should become mentors and mentor the younger people, so that they can take over so that we become stronger.

**Viviane Sorée from Belgium:**

Do you have an idea in how many countries the right to personal assistance really exist?

**Jamie Bolling:**

Right now, I don't have that. That is something that we need to do. I know there are several laws under the way, but how many countries actually have laws, I don't know that right now. I did before, but I'm not up-to-date as of yet with my new job as director of ENIL. So I need to know. We need to get somebody to do that for us. That would be something for the Expertise Centre to do. That could be a project, for example to know which countries have legislation and to know what are the problems we are facing, whether it is economic discrimination or whether it is the division between spare time and living time. What are the things which are hindering us from living full participation in society?

**Viviane Sorée:**

I think there is a difference between a law and a right. Because in Flanders we have the law, but we don't have the right.

**Jamie Bolling:**

That's another problem: the law and the implementation. Laws can also be very confining as long as they are not a good law. It can confine us rather than help us move forward. So you are right there as well. Plus, even if you have a good law, what's the implementation? Where do you make a division? For example, in Sweden people who are deaf and blind can't get personal assistance. They are excluded through the legislation, which is a problem.

**Jakob Putz from Austria:**

Which kind of handicap is included and which is excluded?

**Jamie Bolling:**

I should know it, but I'm somebody who's getting older and don't remember things of the top of my head. Could you help me, Davy?

**Davy Gaeremynck, from Sweden, Independent Living Institute:**

There are 3 different categories. First there is autism and similar conditions. Then there is intellectual impairments at adult age, due to physical disease or an external blow. And then we have a third category for physical impairments which are not caused by normal aging and which cause severe needs for external assistance and support. When you are included in one of these three categories, you need to have five basic needs to be able to get personal assistance. Those needs are eating, personal hygiene, communication, getting dressed and undressed. And the fifth basic need is permanent assistance by somebody who has deep knowledge about how to assist the person in case. This last one is for people with intellectual disabilities. So you need to be included in one of the three categories and you need to have one of these five basic needs for at least 20 hours a week.

**Jamie Bolling:**

Thank you, Davy. Anybody else?

**Patrick Vandelanotte from Belgium, GRIP:**

First of all I want to thank you for meeting you here. I'm not involved in this movement as long as you are. I'm working for GRIP for two years now. GRIP is a movement in Flanders for equal rights for persons with disabilities. You mentioned the United Nations Convention and as you pointed it out, they talk about assistance, but there is no link to direct payments. Could you clarify this? Because when we want to use the United Nations Convention for direct payments, we need some tools and they are not mentioned in the United Nations Convention.

**Jamie Bolling:**

Maybe this is something we can discuss when we have some more time, because I think through article 19 they say that you are supposed to be able to buy community services. But then that's an interpretation. What are community services? The definitions are important, and it's going to be about lobby work and how to define what we mean by direct services. This is one of the things that we are planning to do for the MEP-meeting that we are going to have in September this year. What kind of services do we want? There is nothing mentioned about direct payments, but we feel that direct payments really are what we need to have. So we lobby for this.

**Peter Lambrechts from Belgium:**

Thank you, Jamie. Dominiek from Belgium has one last question. I am going to give him the opportunity to ask that question, but many specific things like "how it is in Sweden?", we are going to be able to see them in detail in the panel discussion and in the workshops. So there will be a lot of opportunity to ask very specific questions and to get the answer to them. So after Dominiek has made his last question, I propose we go to lunch. The tables are ready, outside in the sun, and there is also the possibility to go to the toilet outside. And afterwards we can go on with the program of the afternoon. One very important thing though. We have that stand by the people from GRIP, the organization of Patrick. You can go there to discuss and explain what your view is on what Independent Living should do in the future. Also - What the Expertise Centre should do in the future? Maybe suggestions to ENIL, because we really want to get a good input from you. We want to hear what your opinions are. So on that stand manned by GRIP, you have the opportunity to share your views, your experiences, your advise to us. And now, the last question.

**Dominiek Porreye from Belgium:**

Is there in Sweden also an EEP, a peer counseling system? Do they in Sweden also use this technique of gathering people with handicaps to do peer counseling?

**Jamie Bolling:**

Yes, through the Independent Living Movement, we have peer counseling and peer support. You have it through STIL, JAG and GIL. It's not as wide spread as I think it should be. STIL has 200 users, Jag has 400 users and GIL has I'm not sure how many members today. But the people within these organizations would have the opportunity to meet and to have peer support and peer counseling.

So that was the last question. I forgot one thing. Today we are going to consider as the official release of the DVD for the Freedom Drive. I forgot where, I haven't seen Maja yet, but somewhere there are DVD's which each of you are welcome to take a copy. Watch the Freedom Drive from last year and please spread the DVD, you can make copies and try to get people to come to the Freedom Drive next year! Thank you.

**Peter Lambrechts:**

Thank you very much.