

INDEPENDENT LIVING INSTITUTE'S MATCH WITH INTERNATIONAL INITIATIVE FOR DISABILITY LEADERSHIP

Notes from "[Match](#)" May 28 and 29 2018 in Stockholm

Introduction by Jamie Bolling

Jamie Bolling, director of Independent Living Institute, opened the workshop and welcomed participants representing ILI and a multitude of other disability organisations from countries as diverse as Canada and Australia. The participants' expected to:

- find collaborative strategies between countries,
- meet useful networking partners,
- get an update on recent legislative changes and cases that can be useful in the struggle for disability rights,
- fill the slogan "Nothing about us without us" with a new meaning and find new power that can strengthen our movement,
- receive news and discuss the Australian insurance model, NDIS and the recent activities in Canada influenced by this.

It was decided to use the open space during the afternoon of the 28th to discuss insurance schemes. During the two days, participants also made personal presentations of themselves in the form of Pecha Kucha, presentations made by 20 seconds talk to 20 pictures (maximum 6 minutes 40 seconds). Time management, as well as technical issues, was sometimes present during these. Only Pecha Kucha-content relevant to the subject of discussions is part of this documentation.

Adolf Ratzka on Independent Living and its implications

Independent Living and personal assistance are enshrined in article 19 UNCRPD. This is now more closely defined in the general comment number five under the convention. However, independent Living is a concept that has been around since the 1970's. It is a philosophy and a civil rights movement, and now with the new convention living independently and being included in the community is also a human right.

The philosophy, what we are working for is that we demand the same choices and control in our lives as our non-disabled brothers and sisters, neighbours and friends take for granted in theirs. Since we are the experts on our requirements we must be responsible for showing the solutions we want, take charge of our lives, think and speak for ourselves. Therefore, we need to support and love each other, organise and achieve legal protection for our civil and human rights. The Independent living philosophy is built on some basic principles: We are

against discrimination of disabled people and for more personal and political power. One of our goals is to have legislation in place in all countries to protect our civil and human rights (**anti-discrimination**), as disabled people as a group are disadvantaged within all major community areas.

We must change the view of us as deviants from the normal, people that are labelled sick and marginalised from duties and rights connected with ordinary lives. People labelled sick will meet little understanding for demands to live in the ordinary housing stock and not in institutions. Therefore, we must change the view of us as sick that exists both among the community and within ourselves (**de-medicalisation**). We have to fight being shut away in institutions where we will be cared for. One of the goals of the Independent Living movement is to shut down the specials - the special housing, special schools, special transportations etcetera – and force our way into the mainstream of society (**de-institutionalisation**).

Because we are seen as sick, needing special things, we are seen as needing care from and being rehabilitated by people in white coats. In this way, society has handed over control over us to the professionals, and the more power we give to the professionals the less we believe in our own strength. We have to reverse this (de-professionalisation) and speak up for ourselves as the best experts on our needs and aspirations (**self-representation**). The same self-representation is also needed in our movement, an organisation of disabled people fighting for our own rights and staffed with disabled people. Non-disabled people can be allies supporting our struggle without taking the front positions.

Independent living is basic, applied psychology. The most important change is change within ourselves. When we look at ourselves differently, other people will look at us differently too. When we respect ourselves, it will be easier to achieve respect and equality. To change the perception of oneself can be difficult without role-models, people that are or have been in the same situation and through whom we can get guidance (**peer support**). Peer support means to share the fruit of our experience.

If we do not want to be the victims, we have to take the initiative. This is what we try to do at the Independent Living Institute.

(You can read about this here – link <https://www.independentliving.org/about.html>)

Comments and discussion

How do we achieve this paradigm shift from talking about care to support? It is hard, for example on the EU level everyone talks about vulnerable people and care (SWE/J).

Norwegian example: when Norway finally legislated the right to personal assistance they positioned the right within the health care legislation. This means that the concept of care and the medical model contaminates the legal right to personal assistance, and the right gets limited to hours for basic needs excluding hours for community activities. There are also a lot of health care standards applied to personal assistance which are not the standards we must set for it. At the moment, the struggle in Norway is to get the right to personal assistance out of the health care legislation and into the equality legislation. Surprisingly or not, one of the main problems is that a lot of disabled people themselves are scared of

moving outside the health care legislation and sector; especially concerning disabled children and people with intellectual impairments (NOR/V).

One of the most toxic consequences of the medical model is the effect of the medical culture. The medical professions are one of the most hierarchical ones, where the doctor is always at the top. Within this culture, we will always end up at the bottom. We cannot talk about the quality of personal assistance within the medical framework. The model for healthcare is built on caring for the unconscious patient (SWE/A).

You are far ahead of the Canadian situation which is almost solely focused on accessibility. So much energy and expense go into this discussion that there is hardly anything left for issues surrounding support such as personal assistance. The discussion is also pushed by some well-resourced individuals who have access to personal assistance and other necessary support (CAN/B).

We are far behind in the Central and Eastern European countries, and unfortunately, the social system has the same culture and flaws as the medical system. When we now start to talk about personal assistance, it is a service placed within the social service system. This means that it continues to be a service controlled by professionals. The social systems within the countries in Eastern Europe are also very controlling of the client. Unless we get personal assistance within a human rights perspective, this will always be the case (BUL/K).

This is the same struggle as in Norway. We also have the traditional disability NGOs against us. They have totally missed that personal assistance is about power (NOR/V).

The trend on the European level is the same. A decade ago disability issues belonged within the justice directorate but after the election when Thyssén became the minister of social affairs, she demanded the disability issues should be moved to her jurisdiction (EU/J).

When personal assistance was introduced in the 1980's in Sweden, it was also met with resistance from the established disability organisations. They had worked hard for semi-institutionalised solutions, so there was a lot of prestige connected to the issue. Also, they could not understand that what we were missing was power, and power comes with money instead of in-kind-services (SWE/A).

Something we never discuss openly is the culture of bullying in the sector. Where people are afraid of lobbying for a new solution because of the risk of losing the services they have. A representative for a big traditional organisation actually phoned up and said: talk about the problem, not the insurance solution (CAN/B).

We have the same problem in Bulgaria. The issue is that Independent Living takes courage. Some disabled people do not go for it, and they are unprepared, lack social skills and often needed education. That is why I have to ask: who are us in the slogan "nothing about us without us"? Politicians use this division as an excuse to not decide on reforms (BUL/K). That is why you have to have flexibility and solutions on different levels (CAN/B). Of course and that is why we need to talk about this and formulate strategies on how to handle it (BUL/K).

This subject of difference in power is very evident in the transition ongoing in Australia. Resources are allocated for the service sector to enable it to transfer from the old care-based system to the new insurance based. However, there are no resources allocated to support disabled people to make the transition, and we are now seeing some problems

connected to this. There is also some fear with all the power currently being with one stakeholder (AUS/M).

Service providers have also been around for decades and have well-established channels with the political sphere, and people move back and forth between the two sectors. See for example Belgium where the minister of social services has come directly from the charity Caritas since the end of the second world war (SWE/A).

When Sweden de-institutionalised around the year 2000, it was by law, so there was no other choice. The de-institutionalisation for people with intellectual impairments was well planned, and you could see that even the people whom, very few thought would be able to live well outside the institutions, got much more independent and had better life quality. However, the group homes with approximately 6 people soon became mini-institutions where the staff have power over you (SWE/R-L).

The good thing is that now we have an operational definition within the general comment number five on what is an institution. The definition even states that any service where you share staff is to be viewed as an institution (SWE/A).

Emil Erdtman and Ola Linder on using the law as a tool

Emil introduced himself and Independent Living Institute's project "Law as a tool". The independent living movement was inspired by the case of *Brown v Board of Education of Topeka, 1954* which set the legal precedent that separate schools for black and white students are inherently unequal.

Adolf Ratzka talked about his personal experience of spending eight years in California, studying at the University of California in Los Angeles. The legal tradition in the Anglo-Saxon countries is different from the legal culture developed in a system based on case law. It is interesting to look at the case law system and what can be the result of this, for example, the Americans with Disabilities Act, ADA. The sentiment in Europe is that we do not want this legalisation of individual lawsuits here. Here we say that we have the laws and it is a problem of the police and administrations that do not follow them. The difference is that here we pass laws, but in the US laws are used. The potential of this system where you can take issues to court and thereby create social change attracts me a lot. Therefore, we have this project on how to use the law as a tool.

Emil told about the legal situation in Sweden where recently legal reform was enacted making it an obligation to eliminate easily remedied obstacles, and also an addition to the anti-discrimination act prohibiting discrimination due to lack of reasonable accommodations. As Adolf said, we do not have a culture of lawsuits at all in Sweden maybe because we have a high level of trust in the government and think the state will do good. For those of you interested, in effect a strong welfare state allied with the civil society can have on anti-discrimination legislation, I recommend reading the article "The development of legal protection against discrimination" by Csilla Gradwohl. (länk - <https://www.independentliving.org/files/DiscriminationLegislationEnglishShorter.pdf>) The project is based on the idea that it is useful for us to learn from other legal cultures. Another

background to the project is the fact that the current Equality Ombudsman tasked with monitoring discrimination is not performing this task very well in our opinion. So the background of the project is lack of legal resources, enforcement and remedies. And the project aims to strengthen the use of law by increasing the complaints, disseminate knowledge and strengthen the disabled people and the disability organisations.

The project is connected to an NGO with the same name. This is because the National Heritage Fund does not fund litigation so while they fund the project we can take cases to court with the help of the NGO. You can read more about the project and the NGO Law as a tool here (länk - <https://www.independentliving.org/law-as-a-tool>).

Ola Linder: I came in contact with the project through an interest in human rights and how to implement legal rights through strategic litigation. Of course, since the limitations put down by the Heritage Fund in how we are slowed to use their money, we have to work our way around this and use our NGO. We also have a sibling project called "From talk to action", which is about the CRPD and how this can be used within a national legal perspective. I want to challenge the perception that we in Sweden do not use the law as a tool. We do this but only in certain areas, for example within labour relations.

The situation is changing, and we are getting more and better laws in Sweden. The issue is how are they implemented. This is where it gets more tricky since the laws regulating support for legal fees etcetera have not been updated. This means that it is hard for individuals experiencing discrimination to take their case to court as they cannot afford legal representation. Sweden also does not allow contingency fees as this promotes behaviours such as ambulance chasing. Contingency fees are an agreement between client and lawyer that the fee will be a certain percentage of the awarded damages. Participants representing countries where contingency fees are allowed agreed that this was not the best system as it: clogged up the system, risk driving cases in an unfavourable direction for the client, etcetera.

Some issues of Ola Linder's talk about using the law as a tool in connection with CRPD article 19 and the general comment number five was also included in the discussion below.

The participants in the workshop decided to move this subject forward from the morning of the 29th during the discussion, as this already had started to touch issues within this subject area.

Discussion and comments

Do you have any experience of taking cases to court on the ground of the UNCRPD? Does the convention have direct legal effect in Sweden, and have you tried any cases under it? (BUL/K)

The short answer is that it is probably possible to do it successfully, but it is better to do it if you connect it to the European convention, ECHR and national legislation than applying it directly because the Swedish courts are not used to this method of reasoning (OL).

Is this not because the ECHR has been ratified in a different way while the CRPD has been ratified in the loosest way possible?

The issue is complicated as it is not just a case of making a convention into Swedish law (as in the case if the ECHR. The ECHR was used in Swedish courts before it became a part of

Swedish legislation. This just show that the way international norms become national hard laws is complicated. There are both pros and cons of making the CRPD into Swedish law (OL).

The background to the question is that the Bulgarian constitution stipulates that any ratified convention immediately become Bulgarian law. When we went into it through a case, it turns out that the convention is not applicable as it is too vague. It does not work at all, and especially article 19. There is no way beyond the national legal system. Bulgaria has not ratified the optional protocol. This example is probably a good starting point for a discussion on how we can strengthen the convention and make it applicable as a piece of law (BUL/K).

While the CRPD is vague, the general comment number five is more detailed. Is the general comment to be viewed as part of the law? (SWE/A)

I can only speak on the subject as I understand it from the point of Swedish law and working with the document in different ways trying to find the best legal approaches. Important here is that the state has ratified the convention. It has not ratified the general comment, so the argument that they are part of the convention is not very viable. A more credible way is to use the general comment in the actual arguments of the case and explain why this is an authoritative text and its status within international law. You create a chain where you connect your arguments to the national legislation, this to the ECHR and CRPD, and after that to the general comment. There is case law to the ECHR that state that the ECHR should be interpreted in the light of CRPD (OL).

From later during the discussion: it is easier, at least from a Swedish perspective, to get the norms within the CRPD recognised in the European court than in the Swedish national courts. The European court is better at international law than the national courts, in a similar way to a federal court as it can make decisions on whether human rights have been breached or not. Sweden does not have a constitutional court (OL).

Can you compare it to the explanatory notes to national law?

Not probable, because the explanatory notes are written before the law is enacted, the general comments after. The general comments are not law, but we should not see them as useless. If you take the analogy with money. Money has the value we give it. The reason the ECHR is as strong as it is in Sweden is because of legal activism. Complaints and lawyers willing to push the boundaries. The same must be done with the CRPD. Even if it becomes Swedish law, you will still have to find the cases and argue them. There are no remedies in the convention. (OL).

A clause prohibiting public employees to discriminate against disabled people with bad attitudes and mistreatment in the Swedish anti-discrimination act was discussed. It has not been tested yet.

In a follow up from the earlier session, an issue concerning personal assistance legislation was introduced. Can personal assistance rights be codified within human rights legislation without being diminished by problems connected with this, for example, the vagueness often associated with written norms on human rights and the application of the principle of proportionality?

This is something that has been discussed between the lawyers in projects Law as a tool and Från snack till verkstad. There is a need for mapping of the European case law which is

something we could discuss in a broader context. Maybe resources can be found as this would be something not only useful from a Swedish context but also for other European countries. This exchange of knowledge could be much better (OL).

The very first case under the Bulgarian anti-discrimination law was argued using the ECHR. This was before the CRPD was ratified. The decision was that the state discriminated against disabled pupils due to the fact that no money was budgeted for their needs (BUL/K).

A similar case is one of the first Canadian anti-discrimination cases concerning discrimination of first nation pupils where they received as little as half the budgetary resources per student.

At the moment there is an interesting case in Queensland concerning access to transportation. Trains for 4 million AUD\$ have been contracted out and built in India not following Australian access standards. The Australian discrimination tribunal refused to grant an exemption, but the trains are already running on the tracks. So there are a number of individuals contemplating legal action.

The issue of whether omission can constitute discrimination at procurement is something I want to try against Swedish anti-discrimination legislation. There are many places in Sweden where this is an issue in transportation (OL).

A recent court case of interest presented by Ola Linder

This case was the first decision under the recent legal reform classifying lack of accessibility as discrimination. A student complained that access to his school, especially concerning ramps which was not only lacking but posed a risk of injury for the student. The case involved lack of access since the date when the legal reform was enacted, though the access issues were present long before this. Interesting is that several other legal norms were used, such as the laws regulation schools and workplaces, not only the anti-discrimination act. The fact that the lack of access had caused injuries and risk for severe injuries was brought up. They won. The fact that the student who is a teenager had a father who also is a wheelchair user and helped write up the complaint was probably a definitive cause that the case got to court. The complaint was sent to the Equality ombudsman at the time when they were looking for a case on this issue, which shows the random chance of getting a complaint tried through the ombudsman.

The difference between the new anti-discrimination law and other laws, regulating rights to education and health and safety in the workplace, is that the new norm provides a remedy.

There was a discussion on different types of remedies: damages in the form of money and/or a demand to rectify the situation.

Discussions on national insurance schemes

The subject chosen for the open space was national insurance schemes based on the experiences of Australia's NDIS presented by Michelle Moss. However, the participants

decided to let Bill Cowie present the thoughts of the Canadian organisation, Every Canadian Counts Coalition sees in the scheme, and why they are advocating for a similar one in Canada.

Every Canadian Counts is an organisation aiming to introduce an Australian type insurance scheme in Canada. The Canadian initiative came from a board member of a service organisation providing a range of services to some 12000 persons with intellectual impairments. The impetus behind the Australian scheme, NDIS can be found in the DIG report (Disability Investment Group) from 2009 which showed that the existing system was inefficient, dysfunctional and unsustainable.

The DIG report advocated for an insurance solution. Every Australian Counts Coalition was formed by three national organisations representing agencies and service providers, parents and caregivers, and disabled people to advocate for the insurance solution. A five year, five million AUD campaign was brilliant mostly using social media, highlighting the current inefficiencies and proposing the insurance solution. Political support was vital and came in the form of the minister for social affairs (labour). Every Australian Counts Coalition stipulated ten non-negotiable features of the scheme, for example, mobility, needs-based, for your lifetime, etcetera. In Canada, the problems are lack of strong disability organisations and political support at the federal level. This is changing.

The NDIS is a program designed to provide disabled people with the support they need through their lifetime as an entitlement. It is funded through a surtax on health income based. A discussion on whether it really is an insurance program as this does not constitute an insurance premium. An argument was made that it is built on an insurance model as it is distributing risk and work on aggregate even if it is funded through a tax. The average tax was app. 370 AUD per year. One of the problems with a scheme like this is the size and needing a new bureaucracy to handle a program of this size. A referendum gave the program 86% support. If you sell it as insurance required by everybody people understand what they are paying for. On the revenue side it is a tax, on the expenditure side it is an insurance. It is insurance like Medicare.

Comments and discussion

This phase of the NDIS consists in working out some of the issues found after rolling out the scheme. Every Australian Counts Coalition closely monitors the scheme and its campaign Fund it and fix it aims to solve these.

In the **discussion on insurance schemes**, different types of insurances, details of the schemes, obligatory participation etcetera was addressed. The scheme has stimulated innovation and is moving away from the medical model. It is a direct payment system with funds available for modifications, equipment, and/or core or direct support. There some flexibility to move between the types if fun but mainly you have to stay within each bracket. The scheme pushes funding towards investment instead of core support.

The **data collection provides possibilities** to analyse the effectiveness of support and what works or not.

Australian taxes are paid to the federal government. You enter the system before 65 years of age.

More facts can be found at NSIS' webpage www.ndis.gov.au The scheme has been described as an aeroplane being built in the air while it is flying, so there are issues which have to be addressed as for example in the Fund it and fix it campaign.

The relation between private insurance and publicly funded insurance, does the Australian schemes allow both, i.e. allow people to supplement, or does it deduct? This question was raised as interesting but did not carry on in the discussion.

Effect on the view on disability. Every Australian Counts campaign shifted the rhetoric around disability and the cultural values connected with this, so the same discussion of disabled people as costly was not present. Instead, the views that people had equal rights and it is an entitlement was promoted. Also, the productivity commissions evaluations killed the economic arguments because the old system was so much inefficient that they could not continue as it would bankrupt the system. This argument came from the ministry of finance.

Ola Linder about using the law as a tool in connection with article 19 CRPD and general comment no 5.

The previous session on the law as a tool developed into a mix of issues concerning CRPD and the session's originally intended subject of Swedish case law. Many issues concerning CRPD had therefore already been initiated at the expense of examples of case law. To cater to both subject areas this session would continue to be a mix of both. Ola summarised the previous session which touched upon CRPD, particularly article 19 and the recent general comment to this. The European Convention on Human Rights, ECHR was also discussed, and this would be something revisited during this session which focussed on common legal strategies.

Discussion: The views differed on ***the usability of CRPD and particularly article 19*** from toothless to useful from a policy perspective. The question of whether the crisis in housing posed a new and different challenge to implementing a right to independent living, was raised. The fact that de-institutionalisation so far very often has meant moving disabled people out of big institutions and into smaller group homes added to this problem area. What if all the inhabitant in these group homes, defined as institutions by the general comment, were to demand independent living in an environment where there is no housing available. The young generation also has other expectations. They do not want to live in group homes.

Ola Linder: This discussion takes us back to general comment number five and some key aspects of independent living which Adolf raised at the beginning of the workshop. If, the general population have trouble finding, for example, housing, do we talk about equal right to choices? The general comment is quite detailed and really interesting is its definition of institutions and what personal assistance is. Institutions are defined not just as collective living arrangement but service organisation generating lack of control and choice for the service user.

Discussion: Many factors can lead to lack of control and must be viewed as institutions: different types of service combined through economic agreements in public tender or

contracts; lack of empowerment and therefore individuals unable to take control of their own lives; restricting environment, for example, family members. There is a strong resistance against not allowing family members to work as assistants.

Ola Linder – ***a legal case on the right to decide where to live***: A disabled person had been living at this group home (a farm) for more than twenty years. He liked his home, and the services functioned well for him. Suddenly, the municipality for no specific reason decided to move him to another group home. The sibling project - Från Snack till Verkstad – argued this case on behalf of the person using article 19, CRPD as supporting an argument to the social right under the Swedish law. The administrative court of appeal decided against the municipality, and the person was allowed to stay. The court did not refer to the CRPD in its decision. This is one way to use the CRPD, as supporting argument to how the national law is to be interpreted.

Conventions become Estonian law when they are ratified, but the problem with the CRPD is that its wordings are quite vague and the Estonian standards of proof are high. You never quite manage to get enough proof to reach the necessary standard. That is why the general comment could be so good if it could be used.

The issue, ***whom are we talking about and can everyone move out and live independently*** without loss of social ties and control, was raised.

Discussion and comments: The implementation of the general comment is flexible as not to force people to change who do not want to. If you want to stay in an institution, you can, but the state is not allowed to build new institutions (OL). Other views during a quite animated discussion:

- The question is not if someone wants to stay in an institution but if they have had the possibility to know what an alternative is. How can we be sure that it is really the disabled person deciding to stay in an institution?
- Well, of course, we cannot take someone out of an institution just like that. It is always a process, but we must start somewhere.
- And how do we make sure that it is an equal voluntary option of choice? If you have the choice to go out with limited resources, of course, you want to stay in the institution where they get twice as much money to provide assistance.
- There is a concept called institutional injury which afflicts many people. It can be caused by extended hospital stays, residential institutions, prison and other kinds of institutions. We are not keeping non-disabled people in prisons if they want to stay there because of institutional injuries, we are not keeping non-disabled people in hospital if they want to stay there because of institutional injuries. And I do not think we should keep disabled people in residential institutions because of institutional injuries.
- We have to create a social fabric around people because there is a crisis of loneliness in our society not only affecting disabled people.
- We also need to acknowledge that institutions are not really safe places, even if people can think so.

Kapka Panayotova, CIL Sofia on legislation and Independent Living in Bulgaria

The question is really de- or re-institutionalisation. The centre of Independent Living is the only organisation promoting independent living actively.

This [showing slide with image] is an institution for people with physical impairments, people who only need a wheelchair, an adapted flat or housing. There is a legal case of a woman approximately forty years old who has lived her whole life in an institution. She needs a place to live to move out from the institution but because she needs to adapt her flat no landlords agree to rent to her. So she is stuck in the institutions even though she has wanted to move out for at least ten years. She applied for social housing but was declined due to too high income - at the level of 3 Euros. There have been a couple of unsuccessful court cases.

A BBC documentary called *The Abandoned Children of Bulgaria* was made by Kate Blewett in 2007. It showed, appalling situations with nine to ten-year-old children, almost dying, weighing no more than 30 kilos. Kate Blewett came after a tip-off from human rights activists. She was let into the institutions because they expected donations. After this EU funding became available which the government used to close down large institutions and build up smaller ones. CIL Sofia kept pointing out that this is bad and not de-institutionalisation. The response we got was that this is what the disabled people wanted. This is an example of why it is important who asks the questions and what they ask.

When we asked we got the answer from one woman that it was better in the old large institutions because there she had friends and the ten people she shared the new group home with was not someone she had chosen. Her friends were sent somewhere else. The building is new, but the social relationships are bad, and the staff controls everything. Even though they were put in a smaller place, their situation was worse. This is the situation in Bulgaria, a lot of money is spent on making things worse. One example is the program for personal assistance providing such low allowance, so it is impossible to hire somebody on the market, so the family got the job. Extra money was coming to the family, but nothing in the disabled person's situation changed. It ruined the relationships within the families.

The view of disability is entirely medical. This is why group homes are built in the backyard of big institutions, and disabled people are viewed as unable to work. The whole set up in Bulgaria is set up to meet the vested interest of those working in the disability sector. The evidence of that is the institutionalisation: contractors and building workers earned money building the group homes, local administrations get their services solved, the staff get salaries and control, and the government get to look good and fulfil EU demands. They have now included something called ex-ante conditionality that the Bulgarian government needed a clear strategy based on inclusion before receiving more money, but the money keeps flowing.

What can we do about the issue of de-institutionalisation?

A case before the European Court of Human Rights: Stannow successfully sued the government of Bulgaria on account of them forcefully detaining him within a psychiatric institution. He was let out with compensation, but he did not get any support. He died of

poverty on the streets of Sofia because of the lack of support. Now the government use this case as an argument that disabled people cannot be let out of institutions.

EU money should not be allowed to use to build up institutions. It should be invested in mainstream services.

We need to stop it together in solidarity. But I have no answer as to how. We thought ENIL would be the key but now the EU has not granted ENIL any funding. How do we work together on the issue of de-institutionalisation?

Discussion and comments

Funding going to the personal assistance program does not go to assistance because the definition of personal assistance is too vague. Now the general comment to article 19 defines personal assistance in more detail but what is the status of the general comment?

When someone dies while in care In Queensland a review of 75 cases of death while in care found that 55 per cent of them were preventable deaths. Have other countries done any work on this? In Sweden, there have been a couple of high profile cases: one woman who was denied more assistance hours that fell in a public toilet, got stuck and died, and a child who died unsupervised in the bathtub while in respite care. The Australian review was more systematic, and it has resulted in 23 recommendations and regulation that every death while in care must go through the coroner's office. The information also has to be presented in parliament. When Canada started to investigate the consequences of sending native children off to school institutions, one of the issues found was a lot of unreported deaths.

There was a rather long and complicated discussion on economics and/or vested interests as incentives for social change of different types. It included issues of differing organisation of services moving costs from one budget to another, how service organised through public tender mean possibilities to plan service provision while funding to individuals create a less secure market for providers.

Final words: I am looking for solidarity but not on the grounds of disability but on the grounds of human rights.

During the last quarter of an hour of the open space, Vibeke Melroy Melström raised the importance of language and calling for the use of disabled people to make it clear that it is the society that disables us. There were also participants talking against the concept of people-first-language.

Vibeke Melroy Melström on personal assistance and children

ULOBA's aim is a world in which disabled people have the freedom to develop a fully independent life and participate in all areas of society.

Personal assistance is a model for empowerment, securing human rights, equality and participation in society. The transition is from care to equality, it is support not care. In Norway, the number of people granted personal assistance is rising more slowly after the legislation granting this as a right. Approximately 3.240 disabled individuals have assistance,

and 300-400 of these are children. We know that approximately 6.000 children are fully or partially raised in institutional settings such as group homes. It is also quite common to send a child away for shorter periods to such institutions. We have the same problem of parents thinking this is a good situation as was presented during the last session from Bulgaria.

ULOBA have 909 children (out of 1.200 members) who have assistance through them, and the number is increasing. It is important to remember that, according to the Convention of the Right if the Child, disabled children have the same rights as all other children to grow up with their parents,

What are the most crucial differences between a nanny or a child carer and a personal assistant?

First and foremost the intention: a nanny plans the schedule, leads and guides the child, a personal assistant guides the child, depending on age and development, in a process with the aim of the child growing t be self-determined. Decision-making is gradually transferred as the child gains empowerment. Nannies are until the child grows up, personal assistance is for life so should allow children to grow up and become independent from their parents.

Is the training for personal assistants of children different from training for personal assistants of adults?

It is important for parents or guardians of children with personal assistance, to supervise and guide the personal assistants, to empower the children. We try to teach and make parents aware of ways to empower their children through dialogue. In ULOBA everybody is assigned their own peer supporter who is a disabled person and work leader for their own assistants. When a child has personal assistance through ULOBA, they are assigned two peer supporters, one for the child and one for the parents. The parents or others functioning as an “acting work leader” for a child or a member with cognitive impairments also have to attend the introductory education of ULOBA.

It is important growing up to be allowed to make mistakes, make mischief and learn from this. But this is hard when there are parents, school staff and viewing the assistant as having a controlling function. It is all about the transferring of control and power, so there is a need to find warning signals when the child's control and empowerment are breached in the wrong way. Adults are obliged to take responsibility for their actions children are not from a legal perspective.

The important thing is that these issues are made clear beforehand, so the assistant knows what to do and not. Obviously, illegal activities cannot be part of the work requirements. It is important to discuss issues around ethics, morality and personal boundaries and it is important that the child also takes part in the discussions gradually.

Summary of group discussions on the way forward and joint strategies

Build a network through which we can share knowledge of useful court cases. Unity is important when deciding on which are the right cases. The issue of financing court cases was discussed but not resolved.

The CRPD is not being implemented, and we need to go at it through court processes. Funding is a problem in most countries. Use the examples of other countries as a role model or guide for advocacy. Learn from each other.

In the third group, the discussion focussed on more local issues in a Swedish context (a group of all Swedes) for example support groups through the churches, mentors and role models brought in.

- Build networks.
- Find allies.
- Recruit volunteers.

Evaluation

Good things:

- The dynamic way of moderating and allowing the agenda to change, so the really burning questions got space, i.e. changing the agenda according to the needs of the group.
- See the above, also an appreciation for the possibility to introduce a subject on the agenda from the beginning.
- Good to exchange problems and issues with participants from a wide group of countries and let the discussions go where they needed to go or where we wanted to go.
- The group was a good size and the atmosphere informal enabling us to discuss freely.
- The mix with participants from such diverse countries was really interesting.

Things to better:

- There were so many ideas and issues during some discussions that the time was not enough. It would be good if we could leave issue and ideas in written form somewhere when this happens, so the moderators can pick them up.
- If we had time to unpack some of the legal cases and delve a bit deeper into these.
- Maybe we could have gathered and disseminated more information before the workshop to make sure everyone had the same level of knowledge available.
- The issue of leadership is important, and we could maybe have been introduced already during the workshop.