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II. International Conference of Steps

“Equal opportunities for people with learning disabilities”

in Rotterdam, 14th – 16th of November

SUMMARY OF THE DISCUSSIONS AND RESULTS

The **AIMS OF THE CONFERENCE** were defined as:

- What leads to discrimination? – practical experiences and knowledge about exclusion and discrimination/obstacles and traps on the way towards participation and solidarity
- Collection of practices and experiences

The Conference was subdivided in three main parts:

1. National working groups: factors of discrimination on the background of the national experiences
2. Mixed working groups: experiences concerning best practices and innovations to combat discrimination
3. Plenary Session: Reflection and examples

Michael Langhanky: Changing services towards human-rights-based services, we do not have to cope only with structural exclusion, a lack of opportunities in participation. We also have to cope with “social immunity”, the routine of non-contact as a result of separated milieus and living conditions for people with learning disabilities. And we have to cope with smooth or severe discrimination. We should continue the discussion about exclusion. But we should also face the fact of discrimination and social immunity and we should think on strategies to combat these too. (Please see Michael Langhanky’s Discussion Paper)

As **MAIN FACTORS OF DISCRIMINATION** the following items were discussed:

(Please see the results of the national working groups)

- Exclusion of the people with learning disabilities from the decision making process
- Exclusion from decision-making in the services, administration and politics, no influence on distribution of money
- Lack of assistance and methods of support concerning communication and self-advocacy
- Exclusion from economic flows and power. The people with learning disabilities are seen as not productive.
- Barriers in access to mental health and physical services, education, work and leisure, housing
- Specialised Services guarantee support but hinder at the same time the use of general welfare services (from childhood)
- Exclusion from the community
- Protective or paternalistic attitude to shelter the people – one of the main obstacles in combating discrimination? It limits full citizenship, self-determination and the fulfilment of fundamental rights.
- Poor trust in competence of the people
- Insufficient awareness of the diversity within people with learning disabilities. Despite the diversity they are defined as one group.
- Dominant cultural norms (double discrimination)

- Stigmatisation of Service Users
- Difficulties in accountability in the field of services for people with learning disabilities
- Fragmented Disability Politics
- Hierarchies of power and power imbalance inherent in the services, related professional structures and resources allocation and rationing process. The new devices of care management, direct payments, business management and contractualism bring their own hegemonies.
- Conflicts between individual rights and interests of the services (to maintain power and possession; economic interests)

DISCUSSION, QUESTIONS, DEMANDS

- Relationship to people with learning disabilities need to be based on equality.

DECISION MAKING

The needs and wishes of the people are individual. Effective and informed choice and control of lives are two important and inalienable human rights.

Therefore:

- Information and knowledge has to be free available, in an accessible and timely manner and above all has to be easily understood.
- The people need to experience possibilities and alternatives. (E.g. a person can only decide to leave a residential home if he/she has got an idea about living in the community and ambulant care.) Choices claim for possibilities.
- The people should have the possibility to negotiate and to complain about services.

Example from Sweden: Independent Living

In the US people with physical disabilities become entrepreneurs and hire their own employees. The US-concept for physically disabled is now being transformed to the Swedish context, also integrating people with learning disabilities. In the Swedish projects exist the people with learning disabilities can not become entrepreneurs but at least become members of the co-operative.

It effects improvement in the 'five matters'. That means that the person can choose and influence

1. WHERE you want to live - localization
2. The TYPE of housing you live in - what choice of house, villa, apartment, 2-store or ???
3. WHOM you live with, alone, with one or several friends - your housemates
4. The AMOUNT of support or personal assistance you need/wish for, how many hours, night?
5. WHO provides the support - the choice of staff, man/women, old/young etc.

Example from the Netherlands: Cafeteria Model

The user can choose between different products, can arrange their own care-plan. The outcome would not only be cheaper because the people get what they want. It would also guarantee more quality.

Question: How do the people learn about the alternatives? How informed choice could be guaranteed?

FUTURE PLANNING

“They listen to us but they don’t care what we say.”

Learn to listen: All people have different, individual needs and wishes.

“They remind us that listening is much more than passing strings of words from mouth to ear. Listening is resonating in body, in imagination and in spirit.” (Please see the speech of Joke Ellenkamp, PameijerKeerkring)

Example from Kensington/Chelsea: Person Centred Planning

“Person-centred planning is a powerful way to support positive change and promote a different way of working together. It is altogether a better way to listen and respond to people; it is important to recognise that it will be different for different people and to succeed it requires commitment, time and energy. PCP is yet another way of working towards inclusive communities.

It is a way of helping people make changes in their lives, and finding out what is important to a person, how they want their life to be and what help they need. It helps a person to take control of their own life as part of their community.

Person-centred planning is not a one-off event. It assumes that people can have positive futures and that their hopes will change and grow with their experiences. We do however have to recognise that the supports and services that we have now will not necessarily work tomorrow.

An aggregation of person-centred plans should provide a blueprint for needs-led services for the future. If the process of person-centred planning is properly embedded into strategic planning then it will be yet another way of ensuring that diversity and equality are regarded as important aspects of daily living. In the longer term effective person-centred planning will contribute to the enrichment of communities in which we all live.”

(Please see the paper from Hector Medora, Zenobia Nadirshaw, Paul Cambridge)

Example from Lidingö: Seasonal Meetings

“The working methods that we have been involved in developing based just on this: Where is the individual? Where is the person in the services? Can the wishes and desires of the person in their daily life, can that influence what happens in all the other circles instead of it just be a law influencing what happens at the other end? This means that the project has worked with everyday-life, the ordinary everyday-life. How do a person wants to be woken up in the morning, what sort of breakfast does he wants? Where does he want to eat his breakfast? With five other people or in their own apartment? We start with everyday-life. The work we are going to do with Lidingö will be a mixture of both, their housing situation and their daily activities... In Sweden we actually call it Seasonal Conversation. But that, we know, is very difficult to transfer internationally so we have said Seasonal Meeting. But it's not a meeting, it's a conversation, it's on a personal individual level.”

(Please see Patricia Ericcson's contribution in the record from the Saturday morning discussion, page 8)

Question:

How are Person Centred Planing and Seasonal Meetings integrated in the care process, the organisational and policy context? (Link to flows of money, service planning and brokerage, advocacy?)

Do the future planning methods lead to an increasing complexity of structures and additional overhead-staff?



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Example from the Netherlands: European Project “Circles of Support” (PameijerKeerkring, John O’Brien and “Circles Network”)

It was a very successful project about setting up circles of support: Four intellectual disabled people in Rotterdam created their own network and thus they were not dependent on the big providers.

The project had no follow up because it was impossible for the organisation to control what the worker were doing. It was only an organisational problem.

The results of the project are available on a CD.

SELF-ADVOCACY / ADVOCACY

The term Advocacy has different meanings in the five involved countries. This became clear at the Conference in Rotterdam and becomes clear again in this paper. We hope to resolve misunderstandings within the context of the ‘Comparative Framework’.

- To exercise self-advocacy the ability of speech is not necessarily needed.
- Independent advocacy is necessary but still missing. Advocacy should be independent from the administration and the service providers.
- Professional (paid?) and institutional advocacy is needed in order to overcome the discriminative paternalistic attitude and the asymmetry in communication and vice versa understanding.
- Advocacy should ensure legacy and equality. It should have a keen attention on the client’s personal integrity and to prevent damage of his dignity.
Specialised advocats are needed to support people to make informed choices in the complex field of care for people with learning disability.
- Professional advocats should have the ability to discuss, detect and research on these aspects in daily practice. They should be well educated in methods of

understanding, reading gestures and biographies, individual and self-determined future planning.

- User groups, advocacy groups, consultation groups should be integrated.
- Advocatoric structures in service providing institutions mean as well to democratise the structures around the person.

To be mentioned in this context:

- The family is an important pressure group which has been involved for a long time in building services. This includes a possible conflict: Who represents the person? Do they get their own representative or is he/she represented by the families?
(See for example the Spanish experiences: the contradiction between the families as responsible bodies for the services and representatives of the people with learning disabilities)

Questions:

- How to come to an operative advocatoric system?
- Who could be a spokesperson? (Function, competence?)
- How could they receive and maintain influence and power?

Example from Barcelona: Guardianship

The law of guardianship came into force in 1983. It makes it possible to take persons, who cannot manage their own lives, under an adequate guardianship of physical or legal persons. In 1995 the Spanish Association of Guardianship Foundations was created to achieve a better co-ordination of actions and activities within the foundations, which have been established throughout the country to cover the necessity of guardianship and so far the experience has been quite positive.

The Fundació Catalana Tutelar Aspanias from Barcelona is member of the STEPS-network. Josep Tresserras is kindly ask to share some of his experiences at the Conference in Lidingö.

HUMAN RIGHTS/ANTI-DISCRIMINATION POLICY

Example from Barcelona: Office per non-Discrimination

On the occasion of the 50th anniversary of the United Nations Universal Declaration of Human Rights, mayors of 41 European cities assembled in Barcelona to sign, on 17 October 1998, a Commitment of the Cities for Human Rights. The Commitment should be a starting point to work on the drafting of a Charter of Human Rights in the Cities in collaboration with the Council of Europe and the United Nations.

In this context the Office for Non-Discrimination (OND) was established. It is an orientation service for the defence of the rights of persons in general, with special attention to groups who are discriminated against for reasons of gender, cultural identity, physical and mental health, and age in the city of Barcelona.

What does the OND do?

- Inform, educate and raise awareness concerning all matters related to the equality of rights.
- Exercise the mediatory function in complaints regarding discrimination.
- Offer legal advice for the lodging of complaints regarding discrimination.

People with disabilities turn to the OND for example with the following complaints:

- barriers in public transport / accessibility
- insufficient integration in school
- discrimination in the Media

(Please see Maria T. Sans contribution on Saturday Morning, page 2)

Example from Sweden: The office of the disability Ombudsman

The Office of the Disability Ombudsman (Handikappombudsmannen) was established in 1994 to monitor issues relating to the rights and interests of persons with disabilities. The Ombudsman works to achieve the general objectives of disability policy-full participation and

equality for people with disabilities. The Ombudsman's activity is regulated in a special statute.

The Ombudsman seeks to remedy legislative deficiencies and to raise the issue of statutory amendments, etc. Advice about legal issues accordingly constitutes the core of the work of the Disability Ombudsman, and emphasis has been placed on the importance of having qualified legal expertise within the organisation.

In addition to telephone service and correspondence, the Ombudsman offers basic legal advice on its website. In this way it is hoped that increasing numbers of persons with disabilities will be able to look after their own rights and interests.

One of the Ombudsman's central tasks is to evaluate and disseminate information about the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the United Nations in 1993.

Cooperation with organisations representing and run by persons with disabilities is fundamental to the work of the Ombudsman. Each organisation of this kind which is entitled to a state subsidy accordingly meets the Ombudsman twice a year.

In May 1999 a new law came into force which outlaws discrimination against people with disabilities in working life. The law protects employees and job-seekers against discrimination on the part of employers. The Ombudsman shall ensure that this law is voluntarily observed by employers. The Ombudsman has the right to represent individuals in court if their union organisations choose not to do so.

The National Ombudsman will held the introductory speech at the Conference in Lidingö.

(See as well the "Study on antidiscrimination bodies (May 2002)"

http://europa.eu.int/comm/employment_social/fundamental_rights/publi/pubs_en.htm)

ATTITUDE

- A shift in culture is necessary in the service providing organisations and in the wider community as well.

Example Sweden: The Citizen Perspective/Human Rights Perspective

If we see persons with an intellectual disability as citizens, members of society, we expect them to belong and to be part of society and to be able to, with assistance from their representatives, participate in community life like others. They do not need to prove their competence for this participation, as it is a consequence of their right as a citizen. This perspective can be called a citizen perspective or a (human) rights perspective.

When we from a citizen perspective expect full community participation for persons but see how this does not become a reality, because it is sometimes naively hindered or consciously thwarted, we find that these persons are discriminated against. Actions towards emancipation, participation and solidarity becomes three potent avenues to raise their citizenship and thereby to better their lives.

This citizen perspective is a recognized one as regards disability support. The UN standard rules for equalization of opportunities of 1993 is based on this perspective as it talks about “equal rights and obligations” for persons with a disability. When you trace the background to this document you find its roots in the UN position of human rights of 1948.

(Please see Kent Ericsson’s discussion paper)

- Support and assistance for people with learning disabilities should not start from the limitations but from the abilities of the people.
- Carers should begin to understand the cultural context within disabled people live their lives. Only on this basis services are able to have an effective dialogue with carers concerning rights, choices and abilities.

COMMUNITY LIVING, COMMUNITY DEVELOPMENT, PARTNERSHIP BUILDING

An inclusive society has the following characteristics:

1. *It offers the possibility to take part in living with different people.*
2. *It offers access to social networks.*
3. *In the society is a positive attitude towards people with intellectual disabilities.*
4. *There is access to regular services.*
5. *Law and regulations are flexible so that they really facilitate life in the community.*

(See the speech of Joke Ellenkamp)

- Cultural Competence: Paid workers should be educated about cultures and communities, about the aspirations of disabled people and the values and ethics of services. They should work in the community.
- To meet the needs and to identify unmet needs in the community: Accurate information are required about the communities and the needs of the disabled people within those communities.

Questions:

- Limits of integration/inclusion: Could friendship be organised?
- Solitude of people living in the community
- Risk management: Could people with challenging behaviour live in the community?

MAINSTREAMING SERVICES VS. SPECIALISED SERVICES

Possible developments

- Specialist workers (and appropriate resources) will be integrated in general services.
- Advocates will be educated and work as paid professionals.
- Specialised services will be opened to the public.
- Specialised and general services will be offered in one house

Essentially, it is a question of attitude and education: most problems (e.g. health) can be solved and treated by general services (by general health services)

But:

On the one hand Mainstream Services haven't the detailed knowledge to work with people with learning disabilities and the staff is not prepared to take care of people with learning disabilities. It is a challenge to co-ordinate the different services, for example education, health and care. It needs more time and effort.

On the other hand specialised services for people with learning disabilities are not prepared to provide for example necessary mental health care.

Netherlands: Professional Mental health advocates

WORK

- In order to be accepted the people need a role in society.
- Work is the most important tool for integration.

Questions:

- How can people with a disability contribute meaningful work in our knowledge society? What we can do to enable them to obtain the necessary competence?
(See the speech of Jos Elbers)
- How "work" could be defined? (conceptual and linguistic)
- Payment?

Example from Rotterdam: Co-operation PameijerKeerkring and OMIJ

Peter van Loon is kindly ask to make available his speech at the Conference.



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“LAST WORDS” AT THE CONFERENCE BY KENT ERICSSON, SWEDEN

“I think we should congratulate ourselves that we got the project. This is an achievement. It was hard competition, but we got the project. And I said this in Hamburg and I say it again: It is an important project. This is the one aspect. The other aspect I want to say is: Not every project finishes in the nice way it starts. We must handle the project in the right way. This is not a European championship about intellectual disability. This is not a competition. We are different countries, we have different contacts, with different experiences and we must respect each other for all our experiences. But the point is that we put things together and something will grow, which is better than what exists in the single countries. This is important.

It was a pleasure to meet you all, I looked forward to the next Conference. You are most welcome to Sweden in Spring!”