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Minutes General Meeting ECCE

April 24th – April 27th 2008

Friedel-Eder-Schule, Munich, Germany

Opening

Mrs. Adrienne Thier welcomes everyone and summarizes this meetings' program. She welcomes Mrs. Roelien Kort as the new secretary of ECCE. During this meeting we will have artistic breaks with 'Social Eurythmy', which Mrs. Alexandra Buijsman will conduct. There is a short introduction round.

Record of those present and excused: see appendix.

1. Draft minutes General Meeting ECCE, April 2007, Breitenfurt, Austria

- Mr. Manfred Trautwein: are the German and French translation of the ECCE statutes available? The ECCE office will contact the German and French members.
- Mr. Manfred Trautwein: point 3 – General Meeting twice a year: this will be discussed by point 11, "next meeting", of the agenda.
- Point 7: the abbreviation EMC stands for: Edith Maryon College.
- Mrs. Deborah Ingves: point 10 – top of page 6: 'learning disabilities' should be 'intellectual disabilities'.

The minutes are hereby approved of.

2. Election of Committee member

Mr. Michael Mullan, Breitenfurt Austria, has been proposed by the Committee as a new Committee member. He has accepted the proposal and introduces himself by telling us his biography.

There follows a discussion, from which some remarks:

Mrs. Maria Hasford has resigned as a Committee member. She is a representative of a parents' organization. Mr. Michael Mullan represents an institutional organization.

Since Mr. Heldt and Mr. Fulgosi represent training organizations, there is a lack of representatives of institutes, although Mr. Heldt himself is also a parent.

What is the strategic/rules of ECCE about this representation? In how far do we, as a full member of EDF, stuck to their rule that 51% of our members should be parents' organizations? The statutes of EDF are clear, shouldn't we follow that? Up till now, ECCE's policy has been: priority is our own balance, second is: EDF full membership, we also can be an ordinary EDF member.

Our rules can be steered into the directions of EDF. Should we also have - as a full member of EDF - a 51% parent attendance also in the steering Committees? Mr. Bernard Heldt: EDF never asked us to state this.

At the moment the constellation of the Committee is: 3 parents, 2 representatives of training organizations and 1 professional. There is need of a representative of an institutional organization. The Committee proposes there is also place for another parent to make out the 'full member of EDF' balance, to be able to participate as much as possible in the discussion on a European level. The German parents' association is asked to propose a Committee member who can informally co-operate in the Committee already. The General Meeting of 2009 will decide.

The members agree on this procedure. Everyone agrees on Mr. Michael Mullan as a new Committee member. On behalf of everyone present, Mrs. Adrienne Thier welcomes him as such.

3. Finances

3.1. Annual report 2007

We need a professional accountant to make a financial report, because participating in European Union programs demands such a report. Also funds like f.i. Software AG, which gives funds to the congress 'The tide is turning', 24th – 27th of October 2008 in The Hague, will ask for a report.

Page 4, pt. 1.6: Mr. Bernard Heldt mentions a new point in the report about the description of voluntary work. Up till now on this point only subsistence costs, like travel costs etc. were mentioned. Estimation of the voluntary work in figures is arbitrary.

The Committee will take this back to their next meeting for discussion.

Page 11: Cashflow statement for 2007: can anything be said about the projects mentioned?

Bernard explains the CESTE-NET project: the auditor controlled the figures to reality and a declaration about this is taken up in the financial report. ECCE has a contract with the European Union, according to which the concerning EU-department controls.

How can there be open payments of members over 2002?

Bernard: there are non paying members. The Committee will have to discuss whether these members have to be excluded or not. There was also a mistake in the administration of one of the members, which will be solved; this will make a difference in the report 2008.

Mr. Manfred Trautwein: we have probably to expect a loss in 2009, because members are not paying contribution. This should come into the draft report, we have to book them out.

Page 15: the auditor costs is the payment in 2006, but this concerns the costs of 2005.

The annual report 2007 is hereby agreed on and adopted.

3.2. Draft budget 2008

The Committee proposes to the General Meeting, to increase the contribution 2008 with 5%. But there is also asked for information about the financial situation of the members. The current contribution key is deducted from the key of the Council for Curative Education in Dornach, but needs improvement.

It is decided not to raise the contribution 2008, with regard to 2007. The Committee will set up an improved key, which will be presented in the General Meeting 2009.

We will have an expected loss in 2008 of € 1.000,-. This is not too bad. Can we agree on this? Herewith the meeting agrees on the draft budget 2008.

ACESTA started in 2006 as a professional organization, after the first free year as an observer they started off with a contribution of € 325,- for 2007, which can raise till 2009; because ACESTA is a growing organization this agreement has been made.

The German parents are paying for 2 parent organizations (Bundes ElternVereinigung and Freundeskreis Camphill).

There should be a distinction in the report between kinds of members.

4. Membership issues

4.1. *Italy:* The Bruno Marchesin School which Leonardo Fulgosi is representing, has been accepted by the Committee as an observer ECCE for 2008.

Mr. Rüdiger Grimm explains that the training has been represented for quite a number of years. We don't know how it is at the moment. The school is established and has pupils.

4.2. *Greece and Georgia:* Application for the status of observer ECCE of Estia Agios Nikolaos in Galaxidi, Greece, and the Association for People in Need of Special Care in Georgia, Mrs. Marina Bulia are honoured by the Committee. They are not able to participate in this meeting.

Mr. Bernd Keicher would like an actualized overview of all the members of ECCE, divided in parents / organizations / trainingcentres etc.

5. European politics and organizations

5.1. Membership EASPD

For the ECCE section of service providers the Committee decided to become a member of EASPD. The Secretary General Mr. Luk Zelderloo will give a contribution in the mini-conference next Saturday.

5.2. De-institutionalization and community living

The paper: Key Elements of a System for Supported Decision-Making, the position paper of Inclusion Europe is handed out.

How do we position ourselves as ECCE concerning this paper. Inclusion Europe has a very one-sided look at de-institutionalization, they emphasize the numbers and don't underline the care quality. ECCE works in the opposite way: the quality of life of people with intellectual disabilities and their freedom of choice to live their own way of living is the most important thing for ECCE.

The needs of the disabled people should be expressed in a stronger manner.

Mrs. Katharina Karlsson explains the situation in Sweden.

5.3. Participation of ECCE members in meetings with colleague NGO's

Mrs. Adrienne Thier has been to the General Meeting of the EASPD recently.

She points out that it becomes a strain for her to participate in the conferences which are organized and are of interest to ECCE. Therefore she asks for support.

There will be a EASPD conference on 'The Importance of Values, Religion and Faith in Service Provision for Persons with Disabilities' from November 27th –29th 2008 in Berlin. Adrienne Thier and Bernard Heldt will attend this meeting, but maybe someone from the German members can go too? Who could speak on behalf of the ECCE on that conference? Dr. Rüdiger Grimm has taken this into consideration.

This will be an interesting conference (also for parents) with different points of view, mainly concerning philosophy of life and religion. Information about this conference can be obtained at www.easpd.eu

5.4. European Congress for people with dependency needs 'The tide is turning', October 24th – 27th The Hague, Netherlands

Call for participation for this event. Bernard Heldt is the chairman of the organizing group and does also the fundraising. He would like to receive addresses for fundraising in the different countries and asks who can be the 'carrier' for the fundraising in that countries.

5.5. ECCE Congress 2009

This event is delayed due to the above mentioned congress in October 2008. Preparations for a next conference (2010) will be picked up again.

5.6. Additional agenda point: ELIANT

At this moment 370.000 signatures are being collected and there is a call for more in order to reach the goal of 1.000.000. The best way is to make a direct approach towards people to get their interest. ECCE represents 25.000 people with a handicap; together they might be able to come up with 50.000 signatures!

Most of the signatures were collected in Germany and the Netherlands. A link on the website of ECCE members to www.eliant.eu would be a good idea.

6. Office

6.1. *Information sheet ECCE members.* After the office has collected all the data, it will be put on the ECCE website. For those who have not yet send their data, please send it to Roelien Kort in the office.

7. Policy paper ECCE

7.1. Friday – first session (see for 2nd and 3rd session annex 1): reaction of the members and collecting themes for discussion.

Points of discussion:

- The policy paper is meant for ourselves, for relations with whom we work and for relations we are in contact with (insiders and outsiders).
- Through our relationship with Inclusion Europe and EASPD we can collaborate on a political level with this policy paper.
- It is a rather substantial document. We should determine the size of it. The policy paper of Inclusion Europe has 5 pages, ours has 8. It should come to main points: easy and quick to read.

Suggestion: start with content, summary and conclusions.

It almost seems impossible to make the paper shorter. The explanation of the identity of ECCE can be shortened.

- May the paper contain the same points as other organizations; in any case ECCE has to make a difference and find her own special profile. We should study the policy papers of other organizations.

No other organization has used the term 'Sustainable Inclusion' in a specific way. We do; also in the advertisement in the MEP Magazine.

From the paper the summary on page 9, nr. 1, is read out loud.

This should be one of the discussion points.

- Does ECCE have a point of view about abortion of disabled children and by disabled women? No, each member may have her or his own point of view, but ECCE as an organization, has not.

- What is the human vision of Rudolf Steiner about the situation of disabled people? Should this be in the paper? We could make a preamble about how we think about ethical issues, put in a few sentences, however no quotations from Rudolf Steiner.

The summary should stand on itself, explaining the most important issues, in order to be able to use the summary on itself.

The paper need to be more specific, some sentences are too common, we need to confront more.

We should emphasize what we want: sustainable inclusion, but how? Certainly not a one-sided opinion.

Mrs. Katharina Karlsson points out that the name of the parents organization in Sweden means 'individual life within togetherness'. With this term one can go either way you want.

- Saluto genesis should be taken up in the paper.
- Be careful of getting pulled into the language of other organizations. We have to keep our own style.
- When is the policy paper due for printing? After the General Meeting 2009.
- Should ECCE invite villagers/users to discuss these issues? Maybe there can be a working group during the conference in The Hague? There have been discussions with villagers/users, notes thereof have been made by Mrs. Claudia Hackert and Mr. Jack Reed, we could also use these.
- We have to show that ECCE points of view comply with The Declaration of The Charter of Fundamental Rights of the European Union.
- Is 'Human rights, with the Inclusion Europe policy paper in mind', a topic for a working group?

The meeting is split up in three groups in order to go through the policy paper point by point.

Three issues came out of the above inventory:

- 1) Sustainable inclusion (with Inclusion Europe position paper in mind).
- 2) Basic values in social therapy and curative education.
- 3) United Nation Convention on Human Rights (art. 12) and how we work with it.

Outcome working groups, main points of discussion:

- 1) How do we co-operate with other organizations?
- 2) How can we improve the specific co-operation within our own organization?

3) What is work?

4) Legitimacy.

How is self advocacy constructed within ECCE and how will this be developed?

Start the policy paper with legitimacy to speak on behalf of people with complex dependency needs and also use that term.

General conclusions working groups:

- Each country does research about de-institutionalization, preferably on university level; bring the results back to the next General Meeting ECCE; then publish booklet
- The policy paper should be a short paper, with concrete issues: position of ECCE on a political level; translation should be made available.
- The working group on the policy paper will come with a new draft.
- Discussions should be held in each country about the ECCE policy paper.

8. Training issues

8.1. The CESTE-NET project

This project is finished, the results are printed in a brochure of 400 pages in English and German. Copies can be obtained at www.ceste-net.org (€ 45,-; postage included). The report is also available in a summary on the CESTE-NET website, in an English and French version. Also Seelenpflege has published a small summary.

The following people asked to receive a report:

Manfred Trautwein, Paulamaria Blaxland de Lange, Alfred Leuthold, Maria Hasford, Bart Vanmechelen, Helle Hansen and Béatrice Cussac. Can you please order the report via the CESTE-NET website?

9. Mini-conference: De-institutionalization and human dignity

Contributions and conclusions: see annex 2

10. PR and public affairs

10.1. Brochure ECCE

We are through the brochure. We could print the current one, it is still up to date. If we do so, we can use it for the EASPD conference in Berlin in November next. In general this brochure is meant for members, parents and politicians (Brussels).

Suggestions:

- renew layout and pictures (get rid of the 'Kindergarten-look')
- don't use too much colours; keep it simple; give it a title; mention all therapies
- use not too much text; keep in mind the cultural differences of each country, the brochure should be attractive to politicians (Brussels) too
- put in a map on which is mentioned the locations of institutions and figures about how many people live there and how many parents are involved
- costs for a new brochure isn't taken up in the budget of 2008
- the layout of the website should be the same as the brochure
- Manfred Trautwein can provide photographs

The Committee will work out these suggestions.

10.2. Website ECCE

The website has been recently updated.

Members' information will be put on as soon as the information is received by the office. Roelien Kort will ask Vincenzo Ruisi for an overview of all access codes and login codes, please contact her in case you've lost your codes. For those who have the codes available, the member page on the website is accessible.

Suggestions:

- make a link on the members' area about activities, an agenda. Links to websites of members have already been put on.
- find out how many 'hits' the site has
- ask members to put info on the site or in the Link

- short messages or articles can be put on, preferably with a photo. Also for the public area of the site?
- make a link to the website of the Council for Curative Education and Social Therapy (www.khsdornach.org)

10.3. ECCE Link

We need someone to edit the Link on the website. Also messages from EDF, Inclusion Europe etc. Who can and want to take this on voluntarily?

For the last Link there was not enough input from the countries.

We should have an inventory round of reports from the different countries, at the beginning of each General Meeting. We can use a theme, which would make it easier, it otherwise can become a summing up of. The need for members to share and talk about their difficulties is great.

11. Next Meetings

11.1 (informal) General Meeting 2008:

The International Conference for Curative Education and Social Therapy will be held from October 8th – 12th 2008 in Dornach, CH. We schedule the 2nd (informal) General Meeting on Sunday the 12th (afternoon) and Monday the 13th (morning, till 12.00h) next, at the office of the Konferenz für Heilpädagogik und Sozialtherapie, Ruchti-weg 9, Dornach.

This will be a (non-decisional) meeting.

Advise to participants: make reservations for B&B at an early time.

11.2 General Meeting 2009:

The next General Meeting ECCE will be held: 7th – 10th of May 2009, at the Iona Institute, Nieuwe Bevelsesteenweg 66, B-2508 KESSEL, Belgium.

Romania has been mentioned as an option, but withheld due to high costs for members to go there and because we are not sure they can have us (moneywise). Romania will stay an option for in the future, the same for Denmark and Ireland.

Closure of the meeting

ECCE history

Bernard Heldt realized during the meeting that ECCE is developing. Leonardo Fulgosi and Bernard are from the beginning the pioneers of ECCE. We have to start writing the history before it has faded away. Relevant documents should be collected and archived.

European conference for parents

Michael Mullan suggests a conference, organized by ECCE, for 300/400 parents (maybe in 2 years time), for exchange of thoughts and ideas, lectures and issues which are parent related. It should be a large conference, somewhere in an European city. This has been done before. The parents can voice their experiences on such a conference. Michael would be willing to set things in motion.

Béatrice Cussac points out that the numbers within the parents organization in France are getting less and less. She feels the need for feedback from professionals.

L' Arche (very catholic) organizes meetings for grandmothers, sisters and brothers, but not for mothers, Béatrice would be interested in such a meeting.

Mrs. Adrienne Thier closes the meeting at 12.00h. She wishes everyone a safe travel homewards.

She especially gives thanks to Mr. Peter Keuschnigg, principal of the Friedel-Eder-Schule, for hospitably and generously hosting the ECCE General Meeting this year.

Appendix

Present and excused members General Meeting ECCE, April 24th – 27th 2008 Friedel-Eder-Schule, Munich, Germany

Guest: Mr. Luk Zelderloo, Secretary General EASPD (mini-conference April 26th 2008)

Present

Austria

- Herta Feichtinger
- Renate Chwatal
- Michael Mullan

Belgium

- Adrienne Thier
- Ann Naeyaert

Denmark

- Helle Hansen

France

- Béatrice Cussac

Germany

- Daniela Steinel
- Michael Dackweiler
- Bernd Keicher
- Manfred Trautwein
- Maria Hasford

Netherlands

- Alexandra Buijsman
- Bernard Heldt

Sweden

- Katharina Karlsson (SE, DK, NO, FI)
- Deborah Ingves

Switzerland

- Susanne Frey
- Erika Volery
- Rüdiger Grimm
- Christian Gaegauf
- Brigitte Kaldenberg

United Kingdom

- Paulamaria Blaxland de Lange

Minutes: Roelien Kort, Netherlands

Notified absences

Czech Republic

- Anezka Janatová

France

- Bernadette Bernier

Italy

- Margaretha Fulgosi
- Leonardo Fulgosi
- Vincenzo Ruisi

Netherlands

- Chris van Teeseling
- Adri Benschop
- Walter Bosch
- Freya Steffelaer

Romania

- Roxanna Byrde
- John Byrde
- Adrian Pinte

Observers

- Thomas Pranger (Greece)
- Marina Bulia (Georgia)

Absences

United Kingdom

Representatives of Families and Friends of Camphill

Annex 1 Policy paper ECCE

7.2. + 7.3. Friday – (second & third session): discussing the themes in working groups; plenary discussion on the outcome of the working groups.

Points of discussion:

The themes of discussion for the next working groups are:

1. co-operation with others and within our organization
2. which are our basic values?
3. sustainable inclusion

Outcome of the three working groups:

Group 1) Basic values ECCE

Freedom (the 'I')

Individual (person-centred), cultural, religious, educational

Interdependence (astral)

Relationships

Normality (etherical)

Freedom of choice, movement, true normal rhythms of life

Environment (ethical, aesthetic, healing) – (physical)

Conclusion: How can we in the policy paper show that it is an act. Who do we address with the policy paper? It didn't become clear, for whom we do it for.

We should take the draft paper back to our countries and start discussing it.

Group 2) Co-operation with others within our organisation

Co-operation with relevant actors on a European level to achieve our aims and objectives.

- membership in an organisation / NGO on an European level
 - same field of disabilities
 - follow the same aims and interests (EDF, EASPD, Inclusion Europe, ELIANT)
- networking on an European level
 - get information
 - have influence in decision-making processes
- support of other initiatives
 - be part of networks and projects
 - ECCE – professionals (service providers / training centres)
 - ECCE-members – parents / representatives user organization

Conclusion: It would be helpful to design a 'slide' first. Membership can be withdrawn when ECCE is going into another direction. Necessity to be part of networks like EDF etc. The paper itself is not the most important, we should meet also to work and exchange about it, in order to be heard by other organizations. Start the paper with half a page on the basic values.

Group 3) Sustainable inclusion

- support families in the education
- giving good practices
- the concept of open community building, focused upon developing the individual through:
- being able to go in and out; work in and out; live in and out; the community as mediator to support the individual to find inclusive connections to societal subsystems
- develop a cultural atmosphere in which the individual can develop
- different schooling possibilities for children
- creating sheltered spaces
- the open community gives the opportunity to the individual to contribute to the well being of the community
- lobbying and influencing political parties on a national and EU level and force them to put 'disability politics' in their program – 'pluralistic issues'

- 'free choice in a pluralistic society' as attitude for all actors in the social-political field
- show the children in school, let people be visible in society

Conclusion: What is sustainable inclusion. Is it the right term? It is the balance situation within society, as a societal enduring system. But: then we have to change the attitude and that takes ages. But this might be necessary. How do we reach this?

Micro-level: local area where the institution is located. One has to look for good examples. Examples of the concept of open community building. Focussed on development of individuals. To be able to work and/or live inside or outside an institution. To help the individuals develop cultural strength. There must be a cultural atmosphere to develop...

An example is given of very autistic persons who can't survive in an open community.

Macro-level: in Germany every political party has to include a program for disabled people.

Annex 2 Mini-conference, Saturday April 26th 2008

Introduction on the theme: the secretary of the international council for curative education and social therapy, Dr. Rüdiger Grimm, *secretary of the international Council for Curative Education and Social Therapy in Dornach (CH)* kindly took over from Mr. Leonardo Fulgosi, who is not present due to illness.

In 1957, Karl König talked about 'What has taken place in the process of working in a community of people disabled and not disabled'. At that time everyone contributed what for that person was possible. Community came about. A lot of what was envisaged then, was fulfilled. Main question was to help the individual who was in need of special care. That they could have a biography, was something quite new at the time.

Rüdiger glimpses on a few areas on which it is necessary to work on:

- 1) contact with each other, as person to person: with all the aspects of illnesses of the disabled person which express the illness of the time. The individual may not be touched by others, or just seen as something outer in a pure, only social sense. Meeting between individualities have to take place. This cannot be institutionalized, no one can be forced about this.
- 2) he is convinced that our communities are important between the different settings or structures of which our society is made of. We are part of the society because we use our rights, f.i. circles of friends and circles of common interest. Our people cannot link between the different circles of our society.
- 3) inclusion should not be misunderstood. The individual has the right to choose, how he wants to live within society. Individual right of choice is the first thing within society, is a hereditary of European history, this has brought us the understanding of the individual within the society. He doesn't know what integration is. The individual must integrate within their own biographical development.

Mr. Luk Zelderloo, secretary general of EASPD, speaks about *De-institutionalization and human dignity*. Will also talk about the UN Convention on the Rights of Persons with Disabilities, on impact on services for PWD (Persons With Disabilities), European network, scene setting documents in Europe and sharing ideas on what the impact is of these documents within the work with the disabled.

Are we doing things right? Are we doing the right things? Effectiveness, vision. Development of activism. Fundamental questions should be asked. ECCE is think-tank whom is concerned with the philosophical approach. Monolithic thinking is dangerous.

EASPD's three I's: 1) Information – 2) Impact – 3) Innovation.

- 1) Information: Service provision to members: networking, offer exchange possibilities to members at an European, nation/regional and local level.
- 2) Impact: Policy influencing: offering service providers a voice in Europe.

3) Innovation: Research and Development as basis for innovation and improvement of service provision.

EASPD Key issues: - Quality of Services; - Staff: training, lifelong learning, availability; - De-institutionalization; - Employment of persons with disabilities (2,5 million); - Position of service providers in EU.

Items of lobbying in Brussels: availability of services: waiting lists are enormous; accessibility of society: no transport available; affordability of services and support: quality services are required; adaptability: social services should be able to adapt themselves to the need of the disabled.

Scene setting documents:

A. UN Convention 2006

The purpose of the present Convention is to promote, protect and ensure the full and equal and fundamental freedoms of persons with disabilities.

B. Council of Europe Action Plan on disabilities 2006-2015

C. EU action Plan 2004-2010

Key messages from the 3 scene setting documents:

1) shift in paradigm: medical -> human rights approach. We have to shift in thinking and shift towards a medical approach and human rights approach. This has a major impact on how we work with our people.

2) full citizenship and inclusion: mainstreaming.

People with disabilities should be part of society. Mainstreaming is important: disability perspective, employment, providing substances.

3) focus on employment, education ...

4) empowerment, self-determination, participation.

Additional challenges:

5) market mechanism: penetrate in our sector. Authorities withdraw.

6) demographic change: extra services for 25 million people; staff.

7) new technologies: opportunities and risks.

The services of the future should respect individuality and protect the most vulnerable, opportunities should be offered. All this should lead to a quality of life.

De-institutionalization in Sweden 20 years later; Mrs. Katharina Karlsson, *Nordiska Förbundet för Läkepedagogik och Socialterapi* in Järna, Sweden and Mrs. Deborah Ingves, parents' association *Individuellt Liv i Gemenskap*.

Mrs. Katharina Karlsson:

In Sweden there is a good schoolsystem. 34% of your salary disappears to taxes etc. But people are anyway satisfied. The law is meant for everyone, for non-disabled and disabled people. In 1988 a new law was the start of the development we are still in; the process is not finished yet. There still is a lot of work to do.

Grunewald prepared a new law in about 1988, for special support for disabled people. A group of parents from anthroposophical institutions, thought this law could be a difficult thing for the disabled people. So they then started a parents' organization: *Individuellt Liv i Gemenskap*.

Three years ago a working group from the government came to the institute for social therapy in Järna where Katharina Karlsson is working, to see their way of working in social therapy. How the free choice possibility and citizenship is practised.

What is the law exactly?

A building with apartments for handicapped people and a social area on the base floor where they can socialize. But this didn't really work. People used to stay in their own apartment and the base floor was only used by co-workers. The people with disabilities went shopping in a fast-food store, etc. This was supposedly the ideal situation according to the government.

Fully equipped apartments had to be built, but this is not totally used anymore, some kitchens and bathrooms are being shared.

There are lots of small initiatives, ca. 70. Consisting of ca. 5 – 7 people.

Big institutions still exists, but built up in small units. The administrations are big but the units are small.

A theatre play in Stockholm, a musical, done by handicapped people was a big success. But in the papers the question was raised why it is so nice to look at handicapped people? Other people said it was a joy to watch.

Where is Sweden in the way of this process? Small units need more effort.

Looking at the society, how do we fit in etc. Basic values are important and must not be forgotten. The struggle is still going on.

It was concluded that co-operation with parents is very important. This was being realized in social therapy, but parents had to get accustomed to this. Now there is a functional co-operation between co-workers and parents.

Mrs. Deborah Ingves: tells about her daughter. Ordinary family life was too difficult for her. It took Mrs. Ingves about 2 years before other people could work with her daughter just as well as she could. At the age of 11 her daughter moved to an institution in Järna. She lived there until she was 19 years old. She then moved to her own apartment. This was actually a dangerous situation because she is a very outgoing person. Somebody had to support her, but this didn't really work, Mrs. Ingves wanted her daughter to learn to look after herself.

Mrs. Ingves looked for a place like Camphill to live but this was not easy to find. In the end she found a place: Valmatorp, which is like a halfway house, where you go to get training, one can't live there one's whole life. It gives her daughter a chance to see whether she once will be able to live by herself. Her daughter got a chance, a small 2-room apartment with a kitchenette and a bathroom, it is like a student housing, in a former school for agricultural training. Five apartments in one corridor. There is staff on the premises.

This is a step by step training towards a little apartment in the middle of town. She isn't really expecting that her daughter can live there in the future, but maybe

Daily life: making breakfast. Helping out with cleaning and making food, also learn to make some money with household work.

One day a week she is supported by a co-worker, with doing laundry and shopping etc. It is a constant learning situation. Deborah is surprised to find that her daughter can do all these things, she wasn't expecting this at all. She is grateful her daughter is able to find out all these developments about herself.

Plenary discussion

Mr. Bernard Heldt summarizes very shortly the contributions of this morning and leads the discussion.

Mr. Bernd Keicher: asks whether it would be worthwhile translating Grunewalds dream in German.

Mrs. Karlsson advices to translate the last two chapters, in which everything has been summarized and concluded.

Mr. Heldt: Siebesma looked especially to how the system worked out. He supports the vision behind the Swedish law. So he interviewed clients, co-workers and parents.

Mr. Bernd Keicher asks about co-operation with EASPD, why they have so less German members?

Mr. Zelderloo: for EASPD partnership is crucial. Different stakeholders have different understanding about issues. Co-operation with other organizations in Europe has become more important. Different groups are concerned with different issues, one can join these groups as ECCE when wanted.

Important is to understand diversity, to value diversity. He gives as an example the situation of Jewish people in Antwerp, they live in a quarter of 2 or 3 streets, they are a part of society, they live together to keep their own identity, we should respect that. Value diversity.

The bigger the country, the harder to convince organizations to work together with EASPD. The Germans are becoming more and more interested in the European level, that level decides over 70% of your legislation.

He hands out a draft paper of EASPD: The UN Convention on the Rights of People with disabilities – from words to reality? Strategies facilitating the development of community based settings and person Centred Services.

Mr. Zelderloo: everywhere in the EU we are struggling with the individual needs of people with disabilities. The larger the organization the more difficult it becomes to individualize. We have to go back to community based services. No more than 30 people? It becomes risky! Smaller units like in Sweden are not a guarantee for a good quality of life, but probably there are more chances. EASPD sees huge difficulties but the work has to continue.

Independent living is difficult in a setting of about 700 people, as in the east European new EU members .

We have to develop small rudders to move the bigger rudders.

Mrs. Hansen: in Denmark we can do what we like, single flats for the handicapped or big institutions; they are still allowed. She speaks for the anthroposophical institutions. Self-determination within the institution. Has worked with a very handicapped person (foster child) who will never be able to live by herself.

An institution of 500 people with big sleeping dorms, has now been taken back to 250 people in little units. In such a big institution people can swim, drink coffee etc. That they can't do when they live integrated within a normal living environment like a town. In Denmark they will close all the big organizations! Which is in this sense ridiculous.

Mrs. Blaxland-de Lange: In the UK there is no community within society. 'We are in business because we want to make money'. A lot of money is being spend on closing places. Social services only want to deal with the bigger institutions because the smaller ones are too difficult to deal with. Auction off of organizations.

Conclusion:

There will always be a group of disabled persons who will need special settings.

The number of inhabitants in a community based service is not interesting, it seems ideological. It makes parents afraid.

ECCE does not agree with Inclusion EU on this point. This has been already communicated on several occasions.

EASPD is willing to intensify this discussion with ECCE.

Mrs. Adrienne Thier closes the mini-conference with a thank you to Mr. Grimm, Mr. Zelderloo, Mrs. Karlsson and Mrs. Ingves with a symbolic present from Brussels.