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8. Europäische Regionalkonferenz von Rehabilitation International
8ste Europese Conferentie van Rehabilitation International
8e Conférence Régionale Européenne de Rehabilitation International

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Networking in Practice: Connecting Partners in Rehabilitation

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Abstractbook

Sous le Haut Patronage de Sa Majesté la Reine des Belges

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Sous le Haut Patronage de Son Altesse
Royal Prince Félix Luxembourg

Schirmherrschaft Dr. Wolfgang Clement

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CG-Raad

Chronisch zieken en Gehandicaptenraad Nederland



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Deutsche Vereinigung für die Rehabilitation Behinderter

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Deutscher Behindertenrat

In Zusammenarbeit mit



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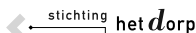


Info Handicap-

Conseil National des Personnes Handicapées a.s.b.l.



Fürst Donnersmarck-Stiftung zu Berlin



Stichting Het Dorp



Verband Deutscher Rentenversicherungsträger



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Abstractbook

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Networking in Practice: Connecting Partners in Rehabilitation

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Educations for all

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School & Education in Europe: Differences/Similarities in
Practice & Legislation

Working group I, Session 1

Education for All:

Inclusive Education /Education Towards Inclusion

Cooperation Between Schools and Common Projects

Kuhle, D.

Special school for children with a mental handicap, Zerbst/Zeppernick, Germany

My background is the work at a school for children with a mental handicap. "Education Towards Integration" is a good title for the working group session. I think it is a learning process for all people are working around or living with children with a special need for promotion.

I like to speak about cooperation forms of education.

Cooperation as a way between special schools and integration, integration "step by step": meetings, common activities, common projects - to opened the integrative education for more children with a mental handicap by a good quality of special educational promotion and therapy.

A special part of this cooperation are cooperative classes at regular schools. Cooperation can be a part into the conception of schools. Government and communes should make it one's business to plan location of schools on this background.

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Working group I, Session 1

Education for All: Some Reflections on the Inclusion Debate

Haskell, S.

University of Zurich, Institute for Special Education, Zurich, Switzerland

The demand for increasing the number of children with disabilities to receive their education side by side with their non-disabled peers is welcomed by all in the community. It reflects a general world wide trend towards equity and educational opportunity for such a minority group.

The conviction that all people have equal intrinsic value permeates the thinking and teaching of most individuals committed to promoting the well-being of people with disabilities.

If people are equally valued, then they have the "human right" and in many countries the "civil right" to be treated equally and to enjoy equal opportunity as others in the general community.

Today the recurring theme of "inclusion" has captured the attention of educationists. It has become the battle cry of political activists. Sadly it has led to a new form of orthodoxy and dogmatism in special education. The debate has degenerated into a struggle for ideological ascendancy.

However much of the research into the professional literature into the merits or demerits of inclusion lacks what might be described "cognitive perspective" and is equivocal. This paper will attempt to review the research evidence as to the efficacy of inclusive or special education placement for children with disabilities. Some comments will be offered for the capricious and idiosyncratic use of terminology, and nomenclature in the literature.

Working group I, Session 1

CBR Concept in Co-operation Between the Integrative School and In-patient Medical Rehabilitation Centre

Vetra Aivars, Alaine I., Karklina I., Kletniece I., Krumina Z., Vetra Anita

Riga Stradina University, National rehabilitation center "Vaivari", Latvia

The experience of integrative schools in Latvia is about 5 to 8 years. The integrative school "Vaivari" was founded in 1996 by the Rehabilitation Hospital (300 beds) and the local municipality. The major problems during the 5 year experience are:

- criteria for selecting children with special needs for school;
- relationship among the children at school;
- attitude of the school children and their parents towards the children with disabilities;
- lack of the professional staff;
- management of the teaching and educating process.

In the school year 2002 there were 160 children grades 1 to 9, 15 from them are with different disabilities (SCI, CP, Daun Syndrom, Celiachia) in the age groups 6 – 18.

This spring 7 children with disabilities participated in 3 months CBR program "YOU and ME". The aim of the programme was to facilitate the integration of the children with disabilities into the school of general education using the CBR concept and co-operation between the multidisciplinary medical team and teacher's staff. Before and after the rehabilitation programme the evaluation was carried out. All the activities were carried out in a pair – a child with disability and a healthy child (control group) 7 + 7.

Conclusions

1. Co-operation between the In-patient Rehabilitation Centre and integrative school is evaluated as very positive and needs future development.
2. Regular co-operation (once a week) between the medical team and the teaching staff in the process of rehabilitation:
 - gives the disabled child the motivation to attend the school, raises the child's self-awareness, self – esteem and confidence as well increases his/her parent's self – respect;
 - it shows to the healthy children that the children can be different, but they can learn and live together.

Working group I, Session 2

Young People with Disabilities in Mainstream Education (High Schools, Vocational Training Facilities, Academies)

Creating and Facilitating Networks in Higher Education of People With Disabilities - A Contribution of The Netherlands

Nagtegaal, J.

handicap + studie; the national expertise centre in the field of higher education and studying with restrictions, Utrecht, The Netherlands

The mission of handicap + studie is that more students with restrictions in the Netherlands can successfully follow the **higher education** calls of their own choice. handicap + studie works at this mission with 15 professional staff-members on a national level, acting from an independence position.

Issues as giving support to staff-members in institutions of higher education (**IHE's**) – and thus increase their expertise – and to **students** (helpdesk service), paying special attention to empowerment and image building, improving the information of all target groups and influencing **policy makers**, have a high priority in our work – which is done in deliberation with the national ministry of education.

We work together with partners in several networks. There are general and disability-related networks for students with restrictions and there is a unique/general student's organisation. There are also networks realised for the staff-members and student-counsellors at the IHE's. For the benefit of our activities, surveys, publications and conferences are important. As a result of a national **survey** we know that 8-10 % of the total student population experiences disadvantages from a disability during their studies. We now also know what their main problems are and which solutions are the most practical.

Insight in the actual situation of the support given to all the IHE's is presented in the **Annals** on Adapted Higher Education. It also gives an overview on the accessibility of the educational buildings.

In workshop I would like to tell more about our working method and its outcome and could report interesting results of our surveys, the likes of which should be available for every European country.

Therefore we appreciate every transnational opportunity to exchange knowledge and compare good practice on the level of the IHE's.

From my point of view, a European network on Higher Education must be realised, part of it being focussed on handicap access issues.

I hope that a serious discussion between students, employees from the IHE's, representatives from national councils, and politicians will create useful possibilities.

(Look also at: www.handicap-studie.nl)

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Working group I, Session 2

Inclusion - a Human Right in Different Fields of Life

Boban, I.

Halle (Saale), Germany

We have got to think about the difference between the concepts and practices of integration and inclusion in different fields of life of marginalised young people, especially those called people with disabilities. Their perspectives of their own future as adults have to lead us to certain strategies of organising the mainstream education. High schools, vocational training facilities and academies can orientate at the concepts of inclusive education and supported employment, which can be seen as parts of a paradigm of supported living and inclusion. Here person centered future planning and circles of support and friends have a key function.

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Combating Exclusion of Children with Disabilities: Developments in Switzerland

Hollenweger, J.

Zurich University of Applied Sciences, School of Education, Department of Research and Development, Switzerland

Disability is a major risk factor encountered by children in accessing the entire range of experiences in social, cultural and educational opportunities.

The Conference of Cantonal Ministers of Education has recently commissioned a prospective study about the status of education for children with disabilities in Switzerland. The author is a member of the advisory group and will highlight the critical issues identified and comment on the recent developments for children with disabilities. The aim is to seek ways and means to ensure that these children receive an adequate and high quality education in the most inclusive setting - and thereby ensuring equal opportunities in all relevant areas of social life.

My Education: My Experience in a Bulgarian Mainstream School

Tzvetkova, D.

Sofia, Bulgaria

The place from which you watch the world does matter - whether from a small window overlooking the backyard or from a window wide open to the wonderful world before you. Life does not offer plenty of alternatives to the handicapped for the realization of their personalities. Because of their physical disabilities, until recently children in unequal position had two opportunities of acquiring education - either to study at the specialized schools or to study privately at home.

The specialized schools in Bulgaria offered pedagogical methods and approaches giving education to the individual but not letting everyone develop one's abilities to a maximum. The closed environment and the isolation in which the handicapped used to fall, their impossibility for multiple and varied contacts, further hindered their social integration. After the educational system reforms in Bulgaria in conformity with the world and the European standards, a chance was given to all those who wished to attend the so called mass schools. The first ones who dared the attempt of studying at mass schools faced tremendous difficulties of various kinds, stumbling all the time into numerous problems to be overcome along the way by an attitude of tolerance and mutual assistance. The educational programme does not involve additional methods and approaches conformed with the specific possibilities and needs of the students with special problems.

On the other hand there is the great importance of everyday life barriers whose overcoming in the present conditions is possible only with the help of a permanent companion, and since schools have no available personnel to help the students with special needs and difficult movement, each handicapped student has to solve this problem on one's own. The number of differently disabled students in the mass schools is growing which provokes

Working group I, Session 2

an attitude of understanding of their needs. It is only now that some schools have introduced projects for improvement of the architectural environment conformed with the needs of the handicapped. The aim is to make schools accessible and more welcome to the disabled children, thus giving a chance to those who wish to enjoy attending their classes.

We can point out with satisfaction that there are more children now willing to attend the mass schools, and there are more and more schools opening their doors to the physically handicapped children. This will give a chance to more of them to get a look at the wide world and to live together with the others in it, to share both its joys and troubles, to obtain a possibility to find their own place and to prove themselves. This will contribute for a change in the character and the outlook of the people, as well as for the gradual social integration of the handicapped and for elimination of the existing barriers one by one.

Inclusion - An Education Policy and Pedagogical Perspective

Schnell, I.

GEW Working Group "Special Needs Education"

Children and youngsters with and without special needs can learn with and from each other successfully. Therefore, the Gewerkschaft Erziehung und Wissenschaft has been supporting joint learning, playing and living of handicapped and non-handicapped children and youngsters for many years. In their demands the integration movement has considered in particular physically and mentally impaired as well as sensorily affected children and youngsters. Now the big group of pupils with a disadvantaging background, who are among the pupils with poor school achievements resp. who (have to) attend special schools for the learning-disabled should receive more attention. Inclusive education offers a conceptional framework which needs to be concretised/substantiated.

Working group I, Session 3

New Information & Communication Tools in the Education of Special-Needs, Students

ICT for Children with Chronic Diseases

van den Steenhoven, J.

Knowledgeland Foundation, Amsterdam, The Netherlands

Joeri van den Steenhoven is co-founder of the Knowledgeland Foundation. This Dutch non-profit organisation initiates and supports innovative projects that help build a strong information society. Currently, one project is being carried out that stimulates the use of Information- and Communication Technology (ICT) for children with chronic diseases. These are children that regularly have to stay home or in hospitals because of their disease. In hospitals, schools and homes ICT can be an important tool to help improve the quality of life of children with chronic diseases, as several projects show. These projects help children to maintain a normal life as possible by using ICT for entertainment, education and peer to peer-contact. In this presentation Mr. Van den Steenhoven will focus on what opportunities ICT can and can not offer for these children, especially within the field of education. Two cases, Webschool and Digibeter, will be discussed in the workshop.

The Use of Computers in Inclusion; Making it Work

in 't Veld, Dorine A.

Nieuwerkerk aan den IJssel, The Netherlands

Mrs in 't Veld has been and is involved in several projects on implementation of the use of Information and Communication Technology (ICT) for visually impaired children. As board member of "I&I", the Association of teachers and ICT-coordinators in secondary education, she is involved in inclusion and ICT for Special Needs children. More on www.dvlop.nl.

The computer often is a "prosthesis" and more: it is enabling to communicate independently, thus giving privacy and emancipating. Examples will be given of how the computer can compensate for certain (aspects of) impairments and sometimes even stimulate certain functions. Inclusion is not the same as putting all children into mainstream schools; it is about meeting the needs and possibilities of children, allowing them

- to develop to their full potential, based on their talents and not on their impairment
- equal rights and possibilities
- to be different.

What do we need to make it work?

- Think in possibilities/challenges, dream
- Accessible software, sites and schoolbooks (!); technically and didactically
- The same if possible, special when necessary
- A whole range of practical points, from getting the right equipment, learning to work with it, to having useful programs
- Cooperation and networking.

Working group I, Session 3

Creating a University Without Barriers: Networking in Practice at the University of Dortmund

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University of Dortmund, Faculty of Rehabilitation Sciences, Dortmund Centre Handicap and Study, Dortmund, Germany

In the focus of interest stand the Dortmund Centre Handicap and Study (DoBuS) and the specific Dortmund approach: Barriers that become identified by individual support of students with disabilities are systematically removed by foundation of structural modules. By this a university that corresponds to the special needs of handicapped and chronically ill students will be created gradually. Central to this approach is that all students with disabilities must be given the opportunity to study any subject they want at any university they want independent of their impairment.

We will introduce three modules of DoBuS:

- The service of advise and support for handicapped and chronically ill students (BbS),
- the working place for students with special needs and the pool of electronic study aids (AfB),
- the service for adaptation of study material for visually impaired students (UD).

Finally we will present the need of reform which exists at German universities relating to equal opportunities for students with disabilities. We will name several starting points of realisation. It will become obvious that cooperating and networking are necessary principles for creating a university without barriers.

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New Information and Communication Technologies in Vocational Training of Young Adults with Disabilities

Brattig, V.

Berufsbildungswerk Annastift, Hannover, Germany

Vocational training centres, Berufsbildungswerke (BBW), are institutions for young people with multiple handicaps to prepare for or receive their initial vocational education. The disabilities of the young people may impair activities of learning and using of knowledge, mobility, self-care, interpersonal interactions and relations, or life coping generally. At a BBW, vocational trainers, teachers and educators as well as psychological and medical specialists are working together in interdisciplinary teams. Trainees are supported in many different ways in coping with physical disability or personal problems and in solving difficult social interactions and learning or work processes. These initial vocational trainings conclude with examinations before the appropriate institutions, i. e., the Chambers of Industry and Commerce or Crafts; disabled trainees hence acquire recognized vocational qualifications like any other apprentices.

At our centre we continually seek to verify and apply the potential of new information and communication technologies. Presented will be our new tele-learning concept, "virtual BBW", that is, very severely disabled trainees participate in vocational training via the Internet while continuing to live at home. Developed and practiced in cooperation with various other institutions, this concept is focussed on computer based training with the aid of a distance learning system (DLS). Learning processes occur in the framework of audio- and/or video-conferences in point-to-point as well as in multi-point settings, meaning that trainees interact with their vocational trainers and teachers either directly or in a group setting. DLS has proven to be a very promising tele-learning concept. Trainees are highly motivated to learn and to work, while being able to take a rest or receive care as needed individually.

Also, our various other uses of information and communication technologies will be mentioned, such as use of notebooks in a number of learning settings, or computer based memory and concentration trainings. Also, video based role-playing has been found a useful tool in practising social skills and building self-confidence in our young trainees.

Summarizing, new information and communication technologies are very useful in the initial vocational education of young people with multiple handicaps and/or learning disability. In this way occupational rehabilitation best prepares for integration and participation.

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Working group I, Session 4

Networking Opportunities for Parents in the Field of Inclusive Education / Education Towards Inclusion

Radical Change Through Small Circles of Friends

Smits, J.

Dutch Parental Organisation, The Netherlands

The official policy in the Netherlands on disability and education is that education should be more inclusive. Laws have been changed in the past decade to support that. Yet the Dutch educational system is one of the most exclusive in Europe and figures seems to grow worse.

It seems that in Holland official government policy was successfully influenced by the ones who want a more inclusive educational system. But teachers, school boards, parental organisations and local politicians are far from convinced that inclusive education is best for all. Official policy fails when active members in society are not made part of the policy change.

From a Dutch perspective it seems that radical change will have to come from small private networks. Whoever wants change, will have to become an active member of society and form a circle of likeminded friends.

Political changes within Europe make it foreseeable that such small circle of friends, dedicated to changing their immediate society, will get more opportunity to succeed. Political preferences within most European countries shift rapidly, as elections in several countries showed. National governments have a tendency to withdraw from all kinds of policy fields, including education and welfare. The retreat gives room to private organisations and private financing on this field. But then it gives also room for private networks of parents who can bring in their own good cause.

European law will give an extra push to this development. The new European regulation, which states that EU member states must have a law in which discrimination against disabled is forbidden, will give individuals the right to oppose a particular discriminative act. It can become an effective instrument, used by a small circle of friends wherever and whenever the situation calls.

In this shifting field, full of new opportunities and challenges, it is important to learn

- methods for empowerment of people,
- how circles of friends or personal networks can be formed,
- how these networks can work effectively and gain influence on all policy levels,
- how international cooperation between such networks can be established.

Networking Opportunities for Parents in the Field of Inclusive Education/ Education Towards Inclusion

Zelfel, R.C.

LERNEN FÖRDERN-Bundesverband zur Förderung von Menschen mit Lernbehinderungen, Köln, Germany

The "LERNEN FÖRDERN-Bundesverband" is the national association of parents and supporters for people with learning disabilities. This NGO has about 400 local groups all over Germany and chapters on federal state level.

In the presentation will be shown some examples of networking organized by a volunteer organization:

- Reinforcement, advice and guiding for parents with children with learning disabilities
- Local groups organizing networks for parents being confronted with the learning disability of their child
- Connecting and compensating a special school's work by organization of additional help for better inclusion into social life
- Networks created for the inclusion of children with learning disabilities within social groups, freetime activities, holidays and social events
- Coordination and supporting the transition from school to vocation preparation and vocational training
- Networks created to optimize the transition from school into vocational orientation and training
- Additional teaching support and personality stabilizing intervention toward vocational inclusion
- Networks for students with disabilities within vocational training organized by local groups
- Improving the cooperation of institutions toward vocational inclusion
- Networks created for the optimizing the process of vocational integration

Information about the work of the association and a information about vocational rehabilitation in Germany can be achieved in English language at the Internet page: www.lernen-foerdern.de.

Working group I, Session 4

The Important Role of Parents

Grooff, T.

President of Foundation for Inclusive Education, Almere, The Netherlands

As a mother of a daughter , now 12 years old, I was confronted with the problem how to get a school for her. In the Netherlands every school refused to give her education, let alone inclusive education. 5000 children don't get any education at all in the Netherlands. They spent their days at home , in daycare centers or in institutions. From other parents we got the information that the United States, Canada and Italy had some nice systems of education. We visited these countries to see if it would be really possible to educate my child in an inclusive school. After the visits I was convinced that inclusive education was the only way to get a good society with respect and love for diversity and to give my daughter maximum opportunities to develop her.

We started the Foundation for Inclusive Education to spread the idea and share the knowledge of experts with the schools, the parents, the politicians, the local/central government and organisations for people with a handicap. Seeing that inclusive education is possible will convince parents that it must be made legally possible. When you want inclusion you must start from the beginning , at kindergarten and schoolage .

As parents are the ones who are usually the most engaged and are experts in issues concerning their child, they should be the ones who play an important role in organisations, conferences educational institutions etc. To change an society as the Netherlands we need all the administrative help and money.

We call on this conference to accept a declaration that a school cannot refuse a child anymore and to give pressure on the Dutch government to give the child the right to visit the school he/she wishes without the possibility to be refused by the school.

The Role of Parents in the Movement for Inclusive Education in the UK

Goodey, C.

London, United Kingdom

In the UK, parents of disabled children were first given rights in 1981. However, this was simply a right to contribute to the child's assessment. It was not a right to inclusion. Since 1981 a number of parents' organisations have grown up nationally and locally. Some of these are concerned with assessment, others with inclusion. These latter, along with other parents not acting as a lobby group but as individual parents in strategic positions within the system (as teachers, politicians, administrators etc.) have succeeded in forcing some legislative changes. However, the government still does not give the disabled child a right to education with their peers.

Working group I, Session 5

School & Education in Europe: Differences/Similarities in Practice & Legislation

Situation in the Netherlands

Grooff, T.

Foundation for Inclusive Education, Almere, The Netherlands

In the Netherlands there still doesn't exist the human right to education.

The Dutch schoolsystem is hopelessly divided amongst public, religionbased and pedagogic system based, regular and specialschoools. And the special schools are divided in 16 different types following a medical model I call this "apartheid", the dutch disease. All these schools are fully payed by the government.

In such a selective system there are always children who don't fit in a categorie. This group of about 6000 children spent their days in a ortopedagogic daycentre, in an institution or at home.

Following European rules the Dutch goverment is trying for years to make a new law that the parents can freely choose the school for their disabled child. The financing will follow the child ;" the backpack".

The resistance of the schoolboards overwon the right of the child so regular and special schools can still refuse the child (also in the coming, endlessly postponed law), based on the abstract argument that they don't have enough knowledge or means to teach the child. We as the parent organisation for inclusive education struggled hard in the polder-sessions to give every child the right on education in the new law ,let alone the right on inclusive education. But it is still not sure, due to the resistance of the schools.

The only way to come to a right on inclusive education is to oblige by law every school, if requested, to accept every child in a regular classroom. We hope that this conference will accept such a statement and give pressure to the Dutch Government to realise this by law.

Inclusive Education in the UK: National Legislation, Local Initiatives

Goodey, C.

London, United Kingdom

The UK education system has some natural advantages that ought to favour inclusive education, namely a relatively decentralised system, creating room for local initiatives; the widespread acceptance of all-ability classes in mainstream schools; a child-centred approach to classroom teaching; and a strong emphasis on pastoral care as well as the curriculum. The overwhelming disadvantage is the failure of the UK government to legislate for inclusion nationally. However, a few local government areas with a desire for inclusion have been able to close special schools and create a fully inclusive system.

Working group I, Session 5

School Attendance of Handicapped Pupils in Italy

Dri, P.

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Since the late seventies, handicapped pupils have attended schools in ordinary classes. After an experience of over twenty-five years, integration has gained a good degree of social consensus and common instruction of all pupils is felt as the natural condition. Italian legislation refers to an integrated formative system in which school need to be flexible and well connected to the Health service and to the local authorities, therefore the situation is not uniform throughout the country.

Students with Learning Disabilities in German Mainstream Schools

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Only about 10 percent of students with learning disabilities are integrated in German mainstream schools. This paper intends to give a short overview about the situation of students with learning disabilities in mainstream schools in Germany and to discuss necessary changes in this area.

At first it seems vital to point out the German understanding of learning disabilities in school context. Then the paper describes the actual situation of students with learning disabilities in Germany. With the reference to low percentage of integration reasons for that situation are discussed. Necessary changes in mainstream and special education are proposed and conclusions for practically oriented research projects in this area made.

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Working group II

The Employability Concept

Session **1** (page 24 – 25)

Information Networking Between Employers and Placement Agencies

Session **2** (page 26 – 30)

Vocational Rehabilitation and the Employability Aim

Session **3** (page 31 – 35)

Access to Work and Employment (also for Disabled Women)

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Lifelong Learning combined with Occupational Rehabilitation

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Supported or Sheltered Work, Integration Companies / Social Firms

Working group II, Session 1

The Employability Concept

Information Networking Between Employers and Placement Agencies

Barrier-free Work Places: Adapted to People and Cost-efficient

Buhmann, K.

Verwaltungs-Berufsgenossenschaft, Hamburg/Germany

Attitudes of society towards handicapped people are changing in European countries. Changing from just taking care of handicapped people and deciding for them to giving them opportunities for being responsible and deciding for themselves as outlined in many documents, from the European Charter of Human Rights to individual country regulations, is a major challenge. This also affects health protection and safety at work.

Regulations for construction, protection at work and safety concepts do not take account of the specific needs of handicapped people. So far it is often difficult to employ them because it requires refurbishing of buildings and work places, as well as general changes to the working environment. In turn, this requires additional organisation and planning which might inhibit work processes in an enterprise and thus lead to additional costs, at the level of the enterprise as well as at the level of the overall economy.

The Verwaltungs-Berufsgenossenschaft (Association for Administrative Professions) has elaborated concepts for a barrier-free organisation of work processes which are based on an ergonomic definition that takes account of all aspects relating to people at work. These concepts do not only open up employment opportunities for handicapped people, they also facilitate work of non-handicapped persons.

The German Behindertengleichstellungsgesetz (Anti-discrimination Law) includes the provision that agreements between associations of handicapped people and employers should be negotiated with the aim of creating barrier-free work places. The Verwaltungs-Berufsgenossenschaft is a competent partner in establishing such agreements.

Working group II, Session 1

Co-operation Between the Job-Placement Agency "Outplacement-Büro" and Employers in Hamburg

Trommler, M.

Job placement consultant Outplacement-Büro Hamburg, Germany

The "Outplacement-Büro" is commissioned by the "Integrationsamt Hamburg" to place people with severe disabilities who are threatened with loss of employment.

There are many ways of making contact with companies in the private and public sector which are willing to employ job seekers with physical or sensory disabilities. The approaches mirror the circumstances on the job market and also the impact of political events and the level of social awareness (for example the reformation of SGB IX). The strategies are:

1. The access to companies by support of the representative bodies of disabled employees: Especially in the beginning eight years ago these workers representatives laid the foundations for good working relationships with the employers. The OPB still benefits today from the good contact which has been built up by using the OPB as a source of disabled employees. This is mirrored in the fact that they provide the placement agency with information about job vacancies.
2. "Gelbe Liste": The OPB has a so called Yellow List which is a list of 260 job applicants and their qualifications and skills offered to the employers on internet as well as leaflets send to 200 organisations.
3. Furthermore the OPB is working directly with the decision-makers concerning possibilities of employment. Successful job placement is evident in close co-operation with both – the managers and workers representatives.
4. Very important also is the approach to small companies without representative bodies: On behalf of the "Integrationsamt Hamburg) a call-centre undertook a telephone survey. 2800 companies were questioned, if they were interested in employing job seekers with severe disabilities. Secondly support was offered by an adviser in questions around financial and practical help. Also small enterprises and companies just starting up could be persuaded of the benefits.
5. Telephone-contacts: Initial contact is made with organisations by randomly telephoning them and also using the specialist job market in internet like "No Handicap" and "Jobline-Reha" (for visually impaired people). Furthermore the OPB support job seekers with hearing difficulties or less knowledge in German by making the initial telephone call for them.
6. Outreachwork: making use of the media is essential. This also means networking with other job placement and support agencies, participating in trade fairs and conferences.

The importance is not just to make new contacts to decision-makers concerning possibilities of placement but also to maintain the good and successful relationship with the existing pool of companies in the private and public sector.

Working group II, Session 2

Vocational Rehabilitation and the Employability Aim

WG II

A Life Span Orientated and Systemic Understanding of Employability - Consequences for Prevention and Vocational Rehabilitation

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What is it that makes an individual employable? In answering this question most of the definitions refer to individual knowledge, skills, attitudes and health. Recent concepts of employability particularly stress the crucial importance of the individual abilities to respond to the labour markets changing requirements and increasing competency. Presentation skills, self management, flexibility concerning branches, professions and localities as well as lifelong learning capacities are the additional new qualities of the today's employee. This "High Performance Employee" is his own career manager. He is responsible for a marketing strategy of his own capability profile.

This concept of employability is at risk of getting reduced to its individual dimension and thereby reduce the major responsibility for the adaptation to labour market developments, managing the structural changes and globalisation to the individual.

From this point of view it becomes evident, that employability implies a second social, situative or context dimension. In fact employability is a dynamic process of matching the individual capability profile with the work requirements. The consequence is, that there is a responsibility both on the side of the employee and of the employers/enterprises. Employability in this sense is part of the human and social capital of an enterprise. They are challenged to develop and maintain their human and social capital.

This challenge comprises a third dimension: employability is closely related to the individual life span. The promotion of employability has to orientate itself on the progression of the professional biography, aging and the dynamic state of health. Even the "High Performance Employee" does not deserve this title for his whole professional life. He might face health problems, his physical strength as well as the learning capacity will decrease by aging.

For enterprises it will be essential to develop strategies including the dynamic process of matching capability profiles with the work requirements and thus preserve the experience of the elder employee. For handling this dynamic process a pool of personnel-development resources has to be accessible for all different groups within the company. It is possible to take advantage of the integration of individual, social, cultural and age differences within the workforce (Diversity) and to provide respecting support to improve or maintain employability.

A life span orientated and systemic understanding of employability supports this process. The consequences, which result of such an understanding of employability will be shown exemplary on corporate approaches of intervention in prevention and rehabilitation in connection with a vocational re-training-centre (Berufsföderungswerk).

Working group II, Session 2

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Working group II, Session 2

New Approach for In-plant Integration: Agreements of Integration – Different Views of Responsible 'Actors'

Bernhard, D. (1), Schmal, A. (1), Niehaus, M. (2)

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The European anti-discrimination- and employment strategy is reflected in the political efforts of the German federal government. In July 2001, Book IX of Social Security Code was introduced, a revision of the Law to Combat Unemployment among Severely Disabled People. It contains a set of regulations, in particular new measures to promote employment. One new measure is the Agreement of Integration, aiming to develop more liable in-plant regulations for integration and rehabilitation. The partners who develop an Agreement of Integration are representative bodies for the disabled employees, the employers and members of the work councils.

The question is what consequences in regard to formulation respectively transformation of the integration agreement can be deduced due to those different views. This will also be discussed in perspective to disability management. The data is based on a study which shows the process of the formulation and transformation of the Agreement of Integration out of the actor's perspective. Responsible actors of 13 companies of the German Car industry participated in a written data collection (1. collection 07/2001: n=112; 2. 07/2002: n=103). In addition, interviews (N=18) and moderated group discussions were held in four plants. In the presentation the view of the participants will be emphasized. Differences in expectations and anticipated results of the Agreement of Integration will be set in contrast to the dependence of the representatives' position.

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Working group II, Session 2

Back to Work

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During the last ten years the Finnish employee pension companies have taken a more initiative role in organizing and financing vocational rehabilitation. The aim of the insurer-funded rehabilitation is to prevent disability to work and to improve income and earning opportunities. The insurer-funded rehabilitation comprises advisory services, workplace rehabilitation (trial work, job coaching), vocational training, business subsidies and examinations made to outline work capacity and rehabilitation possibilities.

In November 2001 the labour market organizations reached an agreement on reforms of the legislation on the statutory earnings-related pensions. The aim is to increase the effective retirement age by 2 to 3 years and to create possibilities for a simplification and unification of the private-sector pension acts. The major part of the reforms will take effect from the beginning of the year 2005. According to the agreement, there will be a statutory right to vocational rehabilitation under the scheme when the persons work capacity is at risk due to illness. This improves the legal protection of a person who seeks rehabilitation provided by the scheme.

Varma-Sampo Mutual Pension Insurance Company is the largest private sector employment pension insurer in Finland. The main target of the company is to secure the employment pension cover of over 700 000 people. There are eight rehabilitation councillors working in our company with about 1000 rehabilitation customers every year.

My presentation reports on a project entitled Rehabilitation Service Project.

One aim of the project is to improve the co-operation in vocational rehabilitation between Varma-Sampo Mutual Insurance Pension Company and some of its major client companies in their efforts to help the ageing workers to stay at work or to return to work.

The project has started with 10 focus group interviews in our company. We examined our rehabilitation service processes; what happens when a person applies for rehabilitation, how customer oriented, flexible and transparent our processes are, what are the stumbling blocks and how do we manage to balance between varied expectations.

During the autumn 2002 we shall have focus group interviews in ten of our client companies. The participants of these interviews are representatives of companies' personnel management, superiors, occupational health care services and trustees. The topics are risks and problems of the working capacity of the personnel and the means of observing and taking action in these situations.

From the basis of the information gathered of our own rehabilitation processes and the experiences and expectations of our client companies we will develop new standards of activity and new rehabilitation services. What we would like to see developing in the future is:

- Services and policies that help people to return to work after a long absence.
- Flexible job coaching programs organized together with our client companies combining vocational training, mentoring and workplace learning.

Working group II, Session 2

Evaluation of the Reintegration Traject of Clients with Psychological Problems in the ICT-Domain

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In cooperation with the Federal Ministry of Labour and Social Affairs a project was started in 2001, in which the individual approach is stressed of the vocational reintegration of clients with psychological problems (borderline, schizophrenia, depression) into their former job in the ICT-domain. Operational management and actual execution of the project is done at the Vocational Training Center (Berufstrainingzentrum) in Cologne, that has a long tradition and experience with reintegration of clients with psychological problems. A formative and summative evaluation is being carried out by the Department of Vocational Rehabilitation of the Institute of Psychology of the Technical University Aachen. Implementation of the evaluation is based on the combination of the concepts of Donabedian (1966) and Kirkpatrick (1977). In this context instruments are developed which allow the evaluation of different training aspects for both clients and members of the training team at the following levels: Appraisal of structure, assessment of process and assessment of outcomes. The outcome level is further differentiated and encompasses four different aspects: Reaction, learning, behavior and results. For this purpose instruments, like interviews, questionnaires, psychological tests, skill training etc. are applied. Results of the first evaluation year will be presented.

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Working group II, Session 3

Access to Work and Employment (also for Disabled Women)

Disabled People and Employment in the European Union. Rights, Status and Remuneration. Report from the European Seminar (Luxemburg, 13-14 June 2002)

Ceccotto, R.

Fondation A.P.E.M.H., Bettange-sur-Mess, Luxembourg

The seminar covered an broad spectrum of issues concerning employment and disability in the European Union. While some of the issues are clear, often positive action fails. A presentation of the conference context will introduce the new law proposal on remuneration for disabled employees in Luxembourg and compare with other countries in the EU. Then will follow a commented overview of the major outcomes of the conference presentations and roundtable discussions:

- A central theme was the EU Directive on non-discrimination (1999).
- Another major concern was definition. Especially problematic are the definitions of work, handicap and rights. It is important that the terms are legally defined across the EU such that they are comparable.
- A further concern was the changing context of work. The rapidly changing nature of the economy throughout the Union currently plays an enormous role in what is reasonably achievable: business and governments must work closely together when planning to ensure that people with disabilities have the possibilities to achieve appropriate employment.
- The issue of support was raised frequently: Who supports whom, when and how? The evidence is that without appropriate support, disabled employees may not be able to achieve the relevant work standards expected of them. Another important issue – especially important in open employment – is representation in the unions or workers' councils.
- Finally, as always there remain the problems of special groups of people with disabilities and how they can fit into the workforce and what kinds of highly specialised support they do require.

Concluding statement

- No work without an appropriate salary
- Real choice for people with disabilities
- Not assistance but (person centred) strategies
- Well based scientific evaluations of support measures
- All in the context of citizens' rights

Working group II, Session 3

Development Project: Job for a Year; a Path Back to Work

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WG II

The project of development, Job for a Year of the Finnish Association for Mental Health, opens new viewpoints and produces information about unemployment as a life crisis. It provides means to cut off the circle of unemployment.

Having a job facilitates the crisis caused by the unemployment. The purpose of the different forms of activity in the project is to encourage and oblige the unemployed persons as well as to provide the participants of the project with tools for making choices for the future. The forms of activity of the project are: A paid employment; training days regarding rehabilitation; individual guidance and guiding support in the work. In the different places where the project is carried out the practices change but the basic idea of the rehabilitation is a unifying factor between the different implementations.

The central sphere of activities of the project is the cooperation between partners of the third sector, between public and third sector and networking with the employment authorities. This paper includes the experiences of the three central partners: the persons employed by the project, the advisors and the working places of the participants. The emphasis is in the rehabilitation.

The goal is to find common principles which make it possible to conclude what kind of an intervention works best and why it should be carried out while developing further the activity.

Working group II, Session 3

The New Legal Claim to Working Assistance - Working Assistance as a Method of Better Employability

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In the focus of this contribution stands the individual legal claim of working assistance (since October 2000/ July 2001), the method, its chances and its problems. This legal claim of working assistance gives severely handicapped and physically impaired people with a high need of personal aid the opportunity to do justice to the demands of their employment by getting a budget for engaging and paying people as individual working assistants.

The concept of working assistance is based on the model of personal assistance worked out by the political self-help movement of handicapped people. In a similar way handicapped students are managing their university studies by installing study assistance. The experiences with personal assistance and study assistance demonstrate the chances, but they also show the necessity of adequate information, training and probably service offers for people who start to work with working assistants. At the moment this legal claim seems to be known just by a few people and also to be presented to the potential users very hesitatedly by the "Integrationsämter". These experiences are supported by first results of a recent investigation.

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Working group II, Session 3

START-SERVICE – Vocational Training and Employment

for Disabled People. A Service from the Office of the German-Speaking Community of Belgium

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In the frame of vocational training and employment for disabled people the START-SERVICE works according to the principle "As normal as possible and only special when necessary". This principle implies at first to encourage the disabled person to make use of the services open to the community as a whole, for ex., the Labour office and their offers of vocational training and employment posts.

Only when these can neither respond to nor be adapted to the person's needs and abilities, the START-SERVICE turns to its own measures and institutions.

In the frame of vocational guidance and placement the START-SERVICE offers continuous accompanying on the person's individual and integral pathway to integration. The pathway to integration starts with vocational guidance followed by vocational training and ends up with the follow-up after a successful placement. Vocational guidance always takes into account the client's individual life situation.

In a first step, the START-SERVICE is always looking for training possibilities on the free Labour market in order to apply the measures "Orientation in a firm", "Training in a firm" or "Training stage". Those measures aim at employing a disabled person in a vocational field where the employer can best take advantage from her/him.

When the fitting between the person's abilities and the employer's requirements is lacking, the START-SERVICE turns to the measure "Employment in a firm" in order to compensate the discrepancy between abilities and requirements by means of a financial support.

Working group II, Session 3

Disabled People on the Labour Market - New Perspectives and Results on Employment Through Partnership of Disability Organisations and Public Agencies

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Background

The Marselisborg Centre is a unique partnership in rehabilitation, where Disability Organisations, Public Service Providers and Research Institutions have joined – with the aim to develop rehabilitation practice through cooperation across professional and sectorial boundaries.

Purpose

One of the areas where the Marselisborg Centre has developed new approaches is in integration of disabled people into the labour market. The paper presents both the methodology/approach and the practical results in this field. The purpose is to present the perspectives of synergetic cooperation and partnership.

Method and results

By combining, and taking the best from, the different knowledgebases, experiences and cultures that the Disability Organisations, Public Service Providers and Research Institutions each represent, a new and different method/approach to labour market integration has been developed. The approach is characterized by its immense emphasis on the individual persons own goals and wishes, participation and empowerment as a central goal, a holistic understanding of the individuals situation and competencies, securing coherent and interlocking rehabilitation-processes, so-called situation-specific multiprofessionalism, and a point of departure that is what the person can do (ressources), and not what the person can not do (limitations).

The approach has worked in practice. By using this approach since 1999 the Marselisborg Centre has been helping people with disabilities to get a job - people whom public agencies has seen as having no significant working capacity.

Discussion aspects and conclusion

The prospects of synergy will be discussed. What are the possibilities for synergetic cooperation (2+2=5) when combining public and private ressources and knowledge from Disability Organizations and Public Service Providers. What are the challenges and barriers in such partnership? Can the experiences be transferred to other areas of rehabilitation?

Working group II, Session 4

Lifelong Learning combined with Occupational Rehabilitation

German Experiences with Lifelong Learning in Occupational Rehabilitation

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The Training Academy of the German Economy, FAW, is active in several divisions, such as to train, to consult and to integrate people with special needs into the labour market. The integration of people with disabilities is one of its main tasks.

For working successfully in this area it is necessary to know and to understand the perspectives of people with disabilities and employers. The demands of both partners have to be brought into line. The concept of lifelong learning illustrates this in a very useful way.

For employers it is important to have workers who are motivated, efficient and able to learn. Small and medium sized enterprises have only few or no possibilities to support their employees with own resources. Especially soft skills like social competence (team working and communication) and method competence (organize learning) are getting more and more important.

People with disabilities need an occupation that fits into their abilities. Yet people often don't have the right qualification for this new occupation and need a special training that includes self organizing one's own learning. This will be useful in future settings.

Successful integration must connect both interests. Several examples will show the steps which have been found useful in practical work. Important points are close contact to every person and institution involved in this process, supportive instruction in modular form that compensates missing knowledge, and good coordination between different learning-places like training academy and place of work.

Promoting Work ability - Good Practice in Finnish Networking Rehabilitation Project

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Introduction

Maintaining work ability (MWA) and preventing work-related disability are issues of primary importance in the Finnish labour market. In Finland, the TESE-project (Prevention of Occupational and Social Exclusion, Unemployment, and Early Retirement) was launched by the Miina Sillanpää Foundation and carried out during 1998-2000. The ideas of project actions were based on a multi-targeted model of MWA, an integrated concept of work ability and preventive rehabilitation.

Working group II, Session 4

Objective

The aims were:

- to train "work communities" to understand the risk factors of work-related disability and to prevent employees being socially and occupationally excluded from worklife
- to enhance readiness of the enterprises to promote MWA-activities and support the workers' health, well-being, and achieve a better functioning of the overall work community.

Material and methods

The data for evaluation were collected by questionnaire and by interviews. Activities included e. g. improving of ergonomics, preventing stress and burn-out, and training of the middle management.

Results

The project employed a participatory and preventive approach in implementing side projects, and these succeeded fairly well in responding to the development needs of the work communities. The formation of various external and internal networks is important in improving the MWA.

Discussion and conclusion

The project improved the readiness of the project-engaged enterprises/companies, including various participants, for co-operating under the objectives of the MWA concept and increased the knowledge of systems connected to integrated work ability.

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Working group II, Session 4

Software Training for Sensory Impaired Employees

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Software Training for sensory impaired employees

DibS GmbH is a small company in Hamburg specializing in software training for sensory impaired employees. Since 1996 we have been educating handicapped people in the use of standard applications for office work and communication. Our students are under employment, but suffer from a variety of impairments – blind, visually handicapped, hard of hearing, deafness, and motor impaired. Our work takes the form of model projects funded by the European Social Fund and the labor department of the state of Hamburg. The general aim of all the different projects is to preserve the jobs of our students by helping them to adapt the changes of technology.

To date, we trained as much as 237 persons. 169 of our participants (more than 70 %) were blind or visually impaired 60 persons, (or 25 %) were deaf or hearing impaired, 4 persons were motor impaired. Our classes add up to a total of 24,125 training hours, providing an average 100 training hours to every student taking one or more courses.

By taking the example of our blind students, I would like to give you an impression of our objectives and activities.

The meaning of office work for blind and visually impaired people

The employment rate for blind and visually impaired people in Germany is about 20%. Office work is one of the very few opportunities for blind and visually impaired people to find a job commensurate with their education. –The term of office work, I take to include information processing, which is a common aspect to very different professions like typists, telephone operators, clerks, technical specialists, teachers, social workers, lawyers, and scientists.

As you all know, office work has changed completely since information and communication technologies have been developed, especially since personal computers came into use in the 80s. At first, the blind and visually impaired derived an advantage from the new technology. Technical aids like speech output, screen magnification and braille bars came up at an early stage, providing a host of new opportunities to access DOS computers. Blind and visually impaired typists and lawyers often were the first of their working group to adopt the new technology, and gained a reputation for their expertise role. The rehabilitation authorities played an important role in this process, giving generous financial support for technical equipment and training. Computers used to be a costly, but nonetheless effective means for integrating the blind and visually impaired into the workforce. This held true up to the time when graphical user interfaces, namely MacIntosh and Windows, were introduced.

The first screen readers for Windows made it to the market by 1994. Still of poor performance, they gave notice of the hard time that lay ahead for their prospective users. People of no or impaired sight encounter significant difficulties when learning graphical user interfaces. To them, the 3-dimensional, multitask windows environment, designed to be easily navigated by mouse click, turns out to be disorientating.

Working group II, Session 4

Braille bars and graphical user interfaces

Access technologies improved over time, offering a more and more intelligent preprocessing of screen content. Nevertheless it holds true that graphical user interfaces, designed to fit the rules of visual perception, are most of a challenge to the cognition of people with impaired vision.

It takes the mature intelligence of a grown-up screenreading software to break down the complexity of a graphical screen to the width of an 80-cell Braille bar, never losing track, ever giving an overview. On the other hand, it takes the professional help of a good software trainer when learning Windows from the narrow focus of a Braille display. Compared to sighted people, blind computer users need a more profound understanding in order to navigate graphical user interfaces.

Consequently, our target group needs adequate training facilities, if they are to cope with a constantly changing technical environment, without too much of a handicap compared to their more able bodied competitors on the labor market.

Our activities

With these considerations, we focus our work mainly on blind and visually impaired persons. They get about 110 hours of training per person, which is significantly more than our hearing impaired participants who get 82 hours in average.

Ahead of the training itself, we usually perform an assessment of the individual requirements. We investigate previous software skills, new job requirements and disability or technology related conditions. The assessment report serves as a guideline for the trainer where designing a training package and gives the measurement for quality controls.

A major outcome of our assessment activities are the consultancy which take place when investigating job requirements at the workplace. Outcomes of our training activities are skills in standard software, mainly Microsoft products of all versions.

Our teaching is designed for all levels of completion, starting from preparatory measures and simple basic skills, up to complex mathematical solutions, data base design, network administration, different programming languages, etc.

Especially for our blind and visually handicapped students with respective job requirements, we offer supporting measures to foster their social and communicational skills. Our classes cover customer relations, regulation of complaints, telephone training, conflict management, anti-stress training, and more.

Organization of training

Software training for blind and visually impaired students is usually conducted as single-participant training, with very few exceptions, and takes place at the clients workplace. Communication classes have up to 5 participants.

Our classes for deaf students have up to 15 participants, and are supported by 2 sign language interpreters.

Conclusion

The demand for our classes is ongoing – as is the further development of information and communication technologies. Looking ahead we can see a further need for supportive training measures for blind and visually impaired employees, if they are to overcome the danger of unemployment and find long-term secure jobs.

For more information see our website www.dibsgmbh.de.

Working group II, Session 5

Supported or Sheltered Work, Integration Companies / Social Firms

WG II

The Sheltered Workshop: a Phaseout Model or a Sustainable Concept? German Views

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When the new Social Code IX on the Rehabilitation of Disabled People came into effect on July 1st 2001 it had been welcomed as a milestone in the history of the German welfare state.

Especially disabled people employed in sheltered workshops seem to get the benefit of a wide range of improvements, such the introduction of a "professional education"-system instead of a "vocational training"-scheme. However, it still does not provide disabled entrants with a real apprenticeship.

The same holds true for the establishment of a "work promotion remuneration" which has the character of a pay rise. On the other side, the overall remuneration still remains on a very low level with an average of around 130 Euros.

Having in mind the most important European trends such as mainstreaming, anti-discrimination legislation and the strong accent on self-determination and individual rights for disabled people, German sheltered workshops seem to be obliged to adapt in order to avoid the danger to become a phaseout model in the European context.

The concept of sustainability for sheltered workshops must therefore tackle the following problems:

- 1) Are sheltered workshops ready to deal with self-confident employees who are aware of their needs?
- 2) Are sheltered workshops willing to support employees who want to leave the sheltered workshops for transition on the labour market?
- 3) Do sheltered workshops take participation rights seriously even if these rights might hit core decisions of the workshop management?

The Support Model for Workers Changing from the Rhineland Sheltered Workshops to the General Labor Market

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Disabled persons in Germany who wish to hold long-term jobs essentially have two options. The first option is constituted by general labor market jobs offered within the framework of the German social security system. Such participation in the general job market is usually funded by the Employment Office and the Integration Office.

The second option consists of employment in officially authorized sheltered workshops, i.e. facilities specially equipped for employment of these persons (protected labor market). As a rule, such employment does not occur within the labor market at large and is financed by the agencies charged with funding such programs (i.e. rehabilitation agencies).

The social services agency Landschaftsverband Rheinland estimates that a minimum of 0.5% (100–110 persons) of the approximately 22,000 persons employed in sheltered workshops in the Rhineland region could hold jobs offered in the general labor market.

In order to enable these persons to make the transition from a protected job to a job in the scope of the German social security system, the Department of Social Affairs and Integration of Landschaftsverband Rheinland has determined that the Rhineland Social Security Office and the Integration Office should pool their conceptual and financial resources within the framework of what is termed a "support model". This model sets out to promote an optimally smooth transition to the general labor market while enabling the relevant institutional actors (e.g. workshops, specialized integration services) to make a positive contribution to this process of integration.

- Every disabled person receives financial assistance enabling him or her to pursue a career in accordance with their abilities. The purpose of such funding is to enable disabled persons to be integrated into the general labor market.
- At least 0.5 % of the workers employed in sheltered workshops have the capacity to hold jobs that are available in the general labor market.
- Disabled persons can only make a successful transition from protected jobs to the general labor market if all relevant funding authorities (e.g. centralized social services agencies, the Integration Office) and institutions (e.g. workshops, specialized integration services) pool their resources and provide their services in a spirit of teamwork.

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From Sheltered to Open Employment - Practical Experiences from Luxembourg

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The main aims of the Ligue HMC Foundation in Luxembourg are to be active in promoting the rights and the inclusion of mentally disabled people in society. The foundation offers a housing structure and professional rehabilitation.

In the "Centre de Réadaptation" in Capellen, for each trainee, an individualized training plan is being developed and regularly evaluated. After the formation the trainees can find a job in a sheltered environment, where they can stay until pensioning.

As an alternative or a bridge to the open labour market, there are semi-sheltered jobs in co-operatives such as the Fruit co-operative, the Restaurant, Boutique and Bureau-Service, on a community level. The Restaurant is located outside the Centre in the middle of the town and is open to the public. A business for office needs where disabled persons can also work with new technologies such as bureau machines and computers offers our Bureau-Service. The Boutique is a little shop where the public can buy products delivered from the workshops of the Centre. In all those working places, the trainees have direct contact to society, and potential employers have the opportunity to recognize their capacities.

To achieve possibilities for transition into the labour market, probationary periods are organized in enterprises outside the Centre in order to integrate people with special needs in an economic environment. The strategy of Supported Employment was implemented in the last three years. As practical results there has been a significant increase of practical periods and new contracts for people working outside. To strengthen this cooperation with enterprises, a continuous support after placement is guaranteed for the employer and the disabled worker.

Beside several individual placements we follow the strategy to implement little groups, for example 2-3 persons, in a firm so they can support each other.

These strategies are part of an ESF project to increase the employment of mentally disabled persons. In the course of this project two subgroups were developed outside the centre, both on a community level. One of them works in a recycling centre and the other in the park of a village.

Working group III

Participation and civil Rights

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Empowerment and Participation as Main Aims for Full
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Policies & Practice

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Participation and civil Rights

Empowerment and Participation as Main Aims for Full Citizenship

Empowerment and Participation of People with Disabilities

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Assuming that participation is for the key stakeholders to have a say when their problems are discussed, it could be stated that the Bulgarian disabled are deprived of that. This definite statement is based on:

1. No access – physical, institutional, social for the disabled
2. No powerful and creative organizations to push for such access

Participation in this sense requires a two-way action: (a) empowerment of people with disabilities to stand for their interests and human rights, and (b) opening a process of consultations at all levels and different subjects in order to listen to all interested parties.

Empowerment of the disabled

Participation is a human right but also it is a responsibility. One should be clear about his/her interests, the interests of other stakeholders, possible though not infinite solutions to be applied and results achieved. It is obvious that this sort of activities usually are organised by NGOs of people with disabilities, which are supposed to represent their interests. At this moment more of the big disability NGOs are still in the charity paradigm – way behind the recent developments in the disability movement –, which presupposes passive behaviour of the target group and welfare strategies, oriented to survival rather than to development. Professionals, government agencies and donors of assistance dominate the policy drafting process, in which people with disabilities get the role of beneficiaries. This approach is justified by low level of education of the disabled population, poverty of individuals and families, lack of public money.

Children with disabilities seldom go to regular schools and acquire decent level of education. This predetermines their status of unemployed as adults. And further all their life follows the sequence of low-income, poor consumers of public resources. Then the next step is easy to make – looking for assistance to survive – starvation is not a companion to development at all. Thus, on average, people with disabilities themselves put pressure on their own organisations to look for charity support, leaving development for better times. This would never come, however, unless this "catch 22" is overcome.

For this reason empowerment activities should be given a priority. Mobilisation and self-organising efforts seem the most relevant under these circumstances in order to have a strong community of self-confident people with disabilities who would be skilful and creative to get involved in public processes and debates for social change. This should let them become a part of the mainstream society, which

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Access to the process

If the empowerment happens to be successful before politicians and policy-makers open up the policy process then the only result would be disappointment and frustration. It is hard to design a working consultative process in a diverse society, however it does produce better results. Such process requires organised constituency, relevant representation of interests and willingness on the part of the government to let others in and listen to them. Currently, there is legislation in Bulgaria that provides for participation of the Bulgarians with disabilities in the decision-making process. It does not work, however. Why? Representation is biased, organisation of the process does not work and disability NGOs are not interested enough to improve it.

WG III

Social Inclusion, The Economic Imperative

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Concentrating on employment, the purpose of this presentation is to demonstrate how micro and macro economic benefits would accrue across all of society if people with disabilities were included. It will argue that these benefits greatly outweigh the costs.

Three types of costs should be considered

- Opportunity Cost - cost of benefits foregone by doing nothing
- Capital cost - Once-off cost, normally of a structural nature
- Current cost - On-going cost, normally lower than Capital cost.

Opportunity costs are usually ignored. Capital and Current costs are typically lumped together. The benefits are rarely counted. a proper cost/Benefit analysis is required.

When one has no disposable income

- social support is required
- no direct and little indirect taxes are paid
- poor housing and poor nourishment are frequently suffered, thus an unnecessarily poor health condition often is the result
- interaction with the rest of society in social settings is lacked.

When one has disposable income, he or she

- requires fewer social support
- pays direct and indirect taxes
- normally enjoys better housing and nourishment, thus gains a better health status
- interacts with the rest of society in social settings
- contributes to society through the multiplier effect of being economically active
- influences industry to produce accessible products and services
- helps make funds available to improve services for those without meaningful employment.

Reviews of U. S. and British legislation show that workplace accommodations are rarely expensive.

Cost is frequently cited as a barrier preventing social inclusion. A proper cost/benefit analysis will show, however, that it is cheaper to include than to exclude. Indeed, people with disabilities and society in general all benefit.

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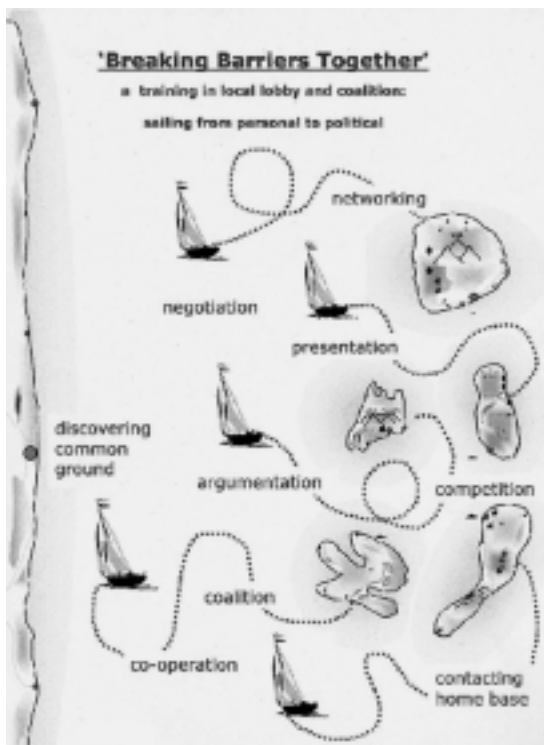
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- Trace Research Centre <http://www.trace.wisc.edu>

WG III

Breaking Barriers Together

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the 4 phases in the training

- | | |
|---|--|
| 1 | 2 |
| from personal and family problems to general solutions, political policies and concrete measures and facilities | preparing for action: inventory of strengths and weaknesses, opportunities and threats (SWOT-analysis) |
| 3 | 4 |
| negotiation: exchange of resources needed and resources to be offered, co-operation and coalitions | playing the game: the winning team will be the best prepared and most skilful in all commissions to be executed. |

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The Value of Experience-Based Competence in a Professional Setting

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In the U.N. resolution 4896 the rights and duties of people with an impairment have been established and this resolution is a valuable document for full participation in society, for people with an impairment.

In 1981, the International Year of people with a handicap was organised in the Netherlands with the following aim: to improve the government policy towards people with an impairment.

The government has put in place a variety of social welfare facilities for people with an impairment, but thanks to these measures, the initiative and involvement of people with an impairment, in drawing up and contributing to the content of this policy, has stagnated. Also how people with an impairment are seen by others and their actual involvement in work, relationships and in cultural activities, appears not to be realised through formal laws.

This is the reason that within the Council of the Chronically Ill and Handicapped people, two initiatives have been started, in which competent people, who have an impairment themselves, give educational training and information to professional people involved in service-oriented or healthcare sectors of society.

These two activities consist of:

1. Yearly around 150 informative educational sessions are given in courses or refresher courses to present and future professionals in the healthcare sector about what it means to live with an impairment.
2. Yearly about 80 training sessions are given to conductors and service personnel with the Dutch Railways (NS).

Both activities have the aim: to optimise the professional actions of people in service oriented jobs in such a way that people with impairments can fully participate in society.

The people with an impairment, who are involved, are recruited and selected on the basis of their professional competence or are specifically trained to carry out these informative educational sessions or training for various types of service personnel. These people with experience-based competence, working in a professional setting, indicate that preparing, carrying out and evaluating these activities, has a positive effect regarding their quality of life. Their self-confidence is enhanced, they obtain their own source of income and they widen the professional qualities of people working in service-oriented sectors.

More and more organisations approach the Council of the Chronically Ill and Handicapped people, asking to use their training modules, against commercial payment.

Working group III, Session 2

Role of Self-Help and Peer Counseling in Participation Policies & Practice

Methods for Information, Prevention, Policy and Recognising Sexual Abuse of People with a Disability or Chronicle Illness in Institutions – Experiences in Holland

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From 1985 we have developed and produced in the Netherlands various projects in the field of sexual abuse of people with a disability.

The first major project started in 1990 with the aim:

- To get insight into the sort and size;
- To get insight into the need for self-help;
- To stimulate professionalism by workers in institutions;
- To stimulate institutions to develop policy;
- To improve sex education
- To stimulate institutions and organisations, who challenge sexual abuse, to develop activities for people with a disability.

The following activities are developed:

- There have been published articles en leaflets with information and advice;
- There has been a research under managers and workers in institutions about their policy and their point of view of sexuality and sexual abuse;
- There has been a research under women with a disability or a chronicle illness to the specific nature of sexual abuse of women with a disability;
- There is been published a book about self-defence for professionals who are working with people with a disability
- There has been a course for social workers, the course has been published in a book;
- There has been made an exemplary policy document for managers in Institutions to help them to develop a point of view and policy of sexuality and sexual abuse.

At the end of this project there has been carried out more projects by The Dutch Council of the Chronically ill and the Disabled and other organisations. The most important are:

- An exemplary policy document to formulate a policy for intimacy, sexuality and sexual abuse;
- A telephone line, during three months, where people with a disability their experiences with aid after sexual abuse could tell;
- Project 'Regie in eigen handen' with a telephone line, companion contact and influencing policy;
- Convenant between employers, employees and customers organisations about actions to prevent sexual abuse from clients by employees in institutions.

During the workshop there will be given more information about the projects and the results. After that there shall be a discussion with the participants about the possibilities to start similar projects in other countries. We will also look on witch ways we can work together on this subject between the different countries.

Working group III, Session 2

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People with Disabilities in Romania

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Lacking enough financial resources, Government, Parliament, and local administration are seeing disabled persons as a social burden.

General perception is they are generally beggars and good-for-nothing citizens.

"They only ask for more" - they would say - "and give nothing in exchange for what they receive".

With few exceptions, media only publish and broadcast miserable aspects in poor families. Lately, the institutions are presented as the only solution for disabled people. According to a recent national poll on general perception of people with disabilities, almost two-thirds of the population see the place of adults with disability in institutions, while almost three-quarters of the population see children with disabilities only fit to institutions.

The sad part is that most of the disabled people have the same negative perception on themselves.

Who would hire me? Why should I try, when no one would understand me?

Family, specialists and policy makers use a paternalistic approach toward disabled people.

Family feels the burden of the situation, they try to solve it by their own means, but expect obedience and gratitude from their member in cause.

Lack of specific information for the families makes them depend on the only structure they know how to deal with, namely medical specialists. Families ask doctors for advice in all aspects of life: medical care, prosthetics, education, job, personal life of their members. The specialists, used to working in institutions, direct their patients to other institutions.

Policy makers depend on the advice of specialists in institutional approach. Alternative approach is at the very beginning stage and does not constitute for policy makers a global solution to the problem. Global solutions are what policy-makers aim to.

A disabled person has to make a continuous balance between obedience, but receipt of a certain amount of money, versus fight for rights, with great chances of losing everything but gaining nothing. It applies when choosing the most suitable education, best medical treatment, finding a job, making a family.

Working group III, Session 2

Lack of accessibility in built environment and to information makes disabled people a practically invisible group. Their problems remain mainly in family. Lack of accessibility in physical environment denies access to mainstreaming education to many of the young people with disability. The above-mentioned pool reveals that only 1% of the people who know people with disability have met them in school, high school, or university.

Persons involved in policy making and law enforcement have the perception that they did practically everything for disabled people. When meeting a valid policy-maker, the first reaction of the latest is of pity and charity.

Many cases were reported when high ranked people declared they are astonished when hearing from a disabled person that he/she wants to be treated as a normal citizen, to have working opportunities, to fully imply in community life.

Only two organisations of disabled people (deaf and visually impaired) existed in 1989. They receive state subsidies from the centralised budget. Their plan of expenditure must be approved in advance by state bodies, from here their diminished independence of action.

From 1990 on, up to 300 NGOs of disabled people appeared, together with more than about 500 foundations acting for disabled people. At the moment there are active about 150 NGOs of disabled people. They act individually or in national associations of people with the same type of disability.

The only federation of organisations from all over the country and all types of disability is the National Organisation of Disabled People in Romania, ONPHR. ONPHR is full member of Disabled Peoples' International, as the only organisation of, for, and by disabled people. NGOs of disabled people are the only providers of de-institutionalised social services for their members.

Central and local administration lack experience of collaborating with civil society. Bureaucrats have the responsibility of using public money that comes from the centralised budget. According to law, civil society structures are excluded from using public money, except from very few specific projects.

Administration carries on the provisions of actual legislation. Very few legislative initiatives aim to de-centralising services to disabled people. When such an initiative appears, the approach is mainly paternalistic, declarative, and charity-oriented. The actual legislation, for example, provides the need to make the built environment accessible to persons with different disabilities. The act stipulates deadlines for making institutions, transportation, and other forms of infrastructure accessible for people with disabilities. A new act refers to banning discrimination, including that based on disability. The structures aiming to enforcing law are yet to become operational.

Actual concern of people with disabilities is the way the legislation on disability will be enforced. The ordinance of the govern from 1999 was taken into debate by the Parliament, and became recently a Law. Active lobby is made by the representatives of the National Council of the National Organization and other associations toward the representatives of the government to realize the implementing norms of the law in such a way to insure the respect of its letter and spirit.

Working group III, Session 2

User-run Projects in Mental Health Care

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The concept of user-run projects comes from the United States. In the Netherlands the first user-run projects started in the 1990ies. At this moment there are more than 165 projects all over the Netherlands and the number is still growing. Characteristic for user-run services is the presence of users on all levels of the project. This is a change in the traditional organization structure. A project starts because a user, or a group of users, has an idea, and not a professional. It is a real demand-control service. The projects are run by users, they form a juridical entity in order to obtain grants (more than 51% of board members have to be [ex-]users); they control the policy and budget, formulate the mission; they set the aims and goals; they decide whether to hire professionals or not, etc. etc.

The projects vary from: libraries, walk-in centres, activity centres, shops, restaurants, bicycle repair outfits, training programs, transport services, and support services. In the Netherlands there are a total of 6000 (ex-)users, voluntary or paid, working in these projects. The Dutch government subsidizes user-run projects.

The projects are not intended as a method of treatment and do not have a so-called "therapeutic character", but they are promoting and bettering the self-organising capabilities of the participants as a whole, letting them make their own choices (empowerment and self determination). The projects differ from the more traditional oriented rehabilitation programs, which are in general part of the mental health system.

Still there is a lot to learn about how these user-run projects should be organised. For this reason a group of (ex-)users of mental health services in the Netherlands started a European Network for User-Run Projects (URL: www.user-run-network.nl). They hope to develop the concept of user-run through exchange between user-run projects in Europe.

Working group III, Session 3

(Pre-)Conditions for Promoting Participation / Inclusion: Standards and Requirements

Empowerment of Disability Associations in Hungary

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The National Federation of Disabled Persons' Associations in Hungary considers disability to be a human rights issue.

In 1998, after several years of lobbying by the Hungarian disability movement an anti-discrimination act, i.e. the Act on Rights and Equal Opportunities for Persons with Disability, was established and it has been a milestone in Hungary in promoting the situation of disabled people in Hungary.

The act declares the rights of disabled people on a high level, defines the instruments for the exercise of these rights and regulates complex rehabilitation provided for people with disability. According to the act all these shall be done in such a way that equality of opportunity, independent life and active participation in the life of society for persons with disability be ensured.

In 2001, the Code of Civil Procedures was modified and authorized organizations representing the interests of people with disability to commence legal action in cases of violations of rights of disabled persons because of his/her disability.

With an anti-discrimination in force and a legal authorization of disability NGOs to advocate the right of disabled persons, establishment of an advocate system within our Federation became necessary.

Our Federation has 80 member associations. Interests of people with physical disability are represented all part of Hungary. Member associations' main task is to represent and advocate interests of not only their members but all people with physical disabilities in Hungary.

Recently advocate groups were established in the member associations of our Federation. Groups composed of advocate assistants of the associations are trained in the field of civil rights, civil procedure, act on municipalities, act on rights and equal opportunities for persons with disability, social insurance, rights of associations, etc. from the point of view of people with disabilities.

The advocate assistants are informed by individuals on alleged violation of human rights due to their disabilities. They make legal arrangements on local level to eliminate this discrimination. Should these arrangements fail cases are forwarded to the Federation.

An advocate office has been established in our Federation. This office is run by professional legal experts. Its aim is:

- to provide advocate groups run by member associations with legal expertise, coordinate and control their work;
- to advocate rights of people with disabilities in the court, if necessary, i.e. in case of violation of human, social, employments' rights due to his/her disability.

Advocate groups/office play an important role in empowering people with disabilities by making them aware of their rights, informing them that discrimination they face every day is not necessary and that they can use legal actions to eliminate them. This service enhances that anti-discrimination against people with disabilities declared by the law can be tangible in the real life.

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An Example in Partnership: the European Chromosome 11q Network - Co-operation between Parents, Researchers and Geneticists

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The European Chromosome 11q Network is a foundation all over Europe from and for families with a very rare disorder on chromosome 11. The network was set up, because it was understood that there would only be more knowledge, exchange of personal and medical experience and a better future for people with these disorders, if there would be a new way of peer counselling and cooperation.

The methods used were conferences, website, discussion-forum on the Internet, e-mail counselling, Newsletters and more usual ways of contacts: telephone, mail and personal meetings. The principal has been to bring together people with a disorder and then find medical information and support. So the families involved choose their own way from the beginning. Happily we met geneticists and researchers who also thought that this is the best way for progress. Due to the rare character of the chromosome disorder it has always been a European network.

Results are increased knowledge on disorders of 11q, close harmony to researchers and geneticists, intensive exchange about daily life and useful therapies between relatives and checklists for early recognition. Moreover the 11q Network is recognized as a good example of empowerment and self-help group, with international and well-based contacts. This is done despite the negative effects of national and European rules and habits. One of the main problems is that in practice it is not possible to register in 54 countries in Europe at once as a European Network. Nearly all funding and support is nationally organized. The financial support from the European Union is not for all Europe, but more important a small group does not fit all the time in the European objectives. Although we had support for the first conference, later we appeared to be too small to provide European added value. In this we don't agree with the European Union.

Conclusion

A small network can become a role model in cooperation with people involved, caretakers, researchers and medical staff.

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The Special Relation Between Access and Participation

Ten Years After the Adoption of the National Strategy on Disability Policy in Slovenia – The Right to Equal Access and Participation

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In March last year, there were ten years over since the National Assembly had adopted the Concept on the Development Strategy on Disability Policy in Slovenia, the first development document in the field of social policy in the independent Slovenia. The paper will present the document of 1991 from the professional public's viewpoint and assess its implementation in the light of the right to equal access and participation.

The document of 1991 was very important then and so is today. First of all, the state introduced through it a contemporary definition of disability. The Concept does not determine disability only as a (health) problem of an individual, but considers it a complex summary of circumstances or state, which is to a great extent conditioned by the societal environment. Besides the adoption of this definition, the Concept is particularly important for its entire and balanced approach to the solution of the disability problems. And finally, the document designing process was also interesting – the state representatives, professionals and persons with disabilities were actively involved in its preparation.

From the legal point of view it is necessary to stress that after 1992 there have been numerous regulations adopted in the fields of education, health care, employment, removal of physical obstacles in the environment, provision of financial aid for the most severely disabled persons; that the solutions included in individual fields of the national programmes are important for the life of persons with disabilities and that a specific government programme on promotion of training and employment of persons with disabilities was adopted. The law on associations of persons with disabilities, the law on vocational rehabilitation and employment of persons with disabilities and the law on equal access and equal consideration of persons with disabilities are also under preparation and – within the changes of the Constitution – the provision introducing a prohibition of discrimination on the basis of disability is drafted, too. Despite, numerous questions remained open. The first and the most important one is whether all these regulations and programmes really bring into effect the principle of formal and actual equality of persons with disabilities.

Moreover, during this period, the role and influence of the associations of persons with disabilities have increased. The Government, line ministries and key public institutions consult them – either through the Government Council for Persons with Disabilities, individual project groups or at »ad hoc« meetings – on all affairs important for the life of persons with disabilities (a different issue is, however, whether their opinion is actually taken into account or not).

Finally, it has to be pointed out that in 1997, under the investigation on the implementation of the UN Standardised Rules on the equalisation of the opportunities for persons with disabilities, persons with disabilities themselves were assessing the development in specific fields – among positive standards, family life and personal integrity, associations of persons

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with disabilities, rehabilitation, financial aid and social security and the health care were especially visible. Among negative findings, employment, the society's awareness level on persons with disabilities and the accessibility of the physical environment, information and communications were particularly emphasised.

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Accessibility – There are Other Obstacles Than Physical Ones

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In the sense of ICIDH/ICF handicaps can be understood as a misfit between a persons capacities and its environment. Whenever in rehabilitation questions of handicap and accessibility to different environments are discussed we find the focus of attention on physical barriers. But especially when we think about work environments, education or training settings the consideration of physical aspects is in many cases basic but not at all sufficient. We, too, have to take into account key qualifications in order to determine the match between person and environment and the extend of handicap.

Key qualifications are understood as cognitive and social capacities, capacities concerning work performance, psychomotor functions and basic educational skills. All of them are crucial requirements in for example work, education and training settings. Knowing a persons key qualifications is crucial in determining what job is suitable, in which way learning/education has to be organised for an individual and on which aspects training measurements have to concentrate. Especially for persons with severe physical limitations it is of importance to ensure accessibility by concentrating on their key qualifications.

Melba, an instrument dealing with key qualifications, will be introduced and discussed. Melba is a tool that allows the standardized description of a persons key qualifications and – in a

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compatible way – the standardized description of an environments requirements upon key qualifications. The comparison of both gives information about the quality of the match respectively the need of modifications.

Melba with its defined terms offers a "common language" for all different users and enables information networking of all concerned parties in a rehabilitation process. It is available in several languages and applied in a number of (European) countries such as Netherlands, Belgium, Lithuania etc. The areas and purposes of use vary. Beyond any questions of disability and rehabilitation BMW for instance does use this tool for primary prevention. Further aspects of Melba in networking will be discussed.

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Power and Domination vs Social Competence and Mutual Trust in the Design Process for Accessibility, a Case Study

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Legislation and regulations can only be developed and interpreted when they are tested in practice. I have tested current regulations in a number of case studies by studying the way in which the professionals involved in current projects have worked. The intention of the projects is to make buildings and environments that are worthy of preservation more accessible for people with activity limitations. Within the projects, representatives from organizations working with the preservation of cultural monuments and the disability movement have worked together with architects and experts in questions of safety.

The projects demonstrate that it is crucial from the point of view of quality that the various parties are able to build up a feeling of mutual trust for each other's competence and understanding for the various points of view that they represent. Besides providing valuable experience, the projects have also given valuable input to the authorities that develop norm systems and are in control of adaptation work. In my paper I use a number of case studies as the basis for the development of general practice.

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Campaign for Physical Access to Buildings for the Physically Disabled in the Republic of Macedonia: A Case Study on the Power of Ordinary People to Achieve Change

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Three lone wheelchairs mounted on concrete platforms, surrounded by chains and with placards highlighting their cause, were sited outside key inaccessible buildings in Skopje, Macedonia to mark 3rd December 2000. The result was unprecedented. It led directly to the main university complex being made accessible, big businesses installing ramps at their own expense and the locals of a bar in a remote village putting in a ramp "not for disabled people, it's for our friend..." And all this against a background of civil war and economic decline. How did we do it? We went out and asked each "man to do his duty". We presented the right of physical accessibility as a basic human right. We did not pay for a single ramp ourselves; we just presented our case and got back the most amazing response from citizens of a country where disability is perceived as shameful, possibly infectious and probably inherited; and in a time of economic decline and threatened civil war. The power of people, and we'd like to share how we did it with you.

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Information and Communication Technology for all

Barrier Free Internet – The German Approach

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With the new German legislation, Social Code book IX (SGB IX) and the law on the equalisation of opportunities for people with disabilities (Bundesbehindertengleichstellungsgesetz - BGG) the issue of barrier free access at the workplace and to public infrastructure has received a new emphasis in Germany. The definition of barrier free access for people with disabilities to human made infrastructure highlights three characteristics: the access needs to be possible in the usual way, without extra effort and basically without assistance. For the first time access to information technology was explicitly taken up in the BGG and particularly barrier free access to the Internet. On July 24, 2002 the decree on barrier-free information technology (Barrierefreie Informationstechnik Verordnung - BITV) according to § 11 BGG was officially published by the German Federal Government and entered into force. Legislation on the State level is under preparation in most of the States.

The content of the decree is based on W3C-WAI Content Guidelines 1.0. It outlines 14 "Anforderungen" (requirements) and a number of related "Bedingungen" (conditions) in two priorities PI and PII. PI is mandatory for all federal government sites, whereas PII is additionally requested for central portal entrance sites. Actually, fulfilling PI equals a WAI conformance of AA, whereas PI and PII equals a WAI conformance level AAA. Due to legal constraints the WAI guidelines have been taken as a basis but have been transferred into a suitable German legislative formulation. However, all 14 guidelines and all checkpoints have been considered, nothing was left out. The systematic and numbering is almost identical with the corresponding WAI numbering.

In order to support this development the "Alliance for barrier free information technology" (Aktionsbündnis barrierefreie Informationstechnik - Abl) headed by BAGH, an umbrella of German user organisations, has been started with support of the federal government (BMA). In cooperation with its partners Abl offers education, web-based information, etc., to support the implementation. One particular objective is to join forces in a harmonised approach and to assist public and private sector during the implementation. One important instrument will be the targeted agreements (Zielvereinbarungen) according to § 5 BGG.

Acknowledgement: This work is supported by a grant of the German Bundesministerium für Arbeit und Sozialordnung - BMA (Federal Ministry for Labour and Social Affairs).

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Working group **IV**

Quality as seen by the Users – a "Must" for Service Providers

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"Quality" Criteria for the Performance of Rehabilitation Services

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Self-Determination as a Rehabilitation Quality Issue /
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Quality Measurement / Quality Standards in the European Rehabilitation Discussion

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Quality as seen by the Users – a "Must" for Service Providers

"Quality" Criteria for the Performance of Rehabilitation Services

Quality From A Customer's Perspective

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Presented will be new developments in the working group (IV) topic like self determination as a rehabilitation quality issue, customer demand control, personal assistance and personal budget but also the impact of these developments on quality assurance and quality measurement in rehabilitation processes, systems and management.

The general introduction is looking for answers to questions such as:

- What is the strength of these developments?
- What can be described as the background of these new developments?
- How do we have to interpret "quality" from a customer's perspective?
- And is it possible to articulate "quality criteria"?

The customer's perspective is a widening concept in the world of patients, people with chronic illness or people with handicaps. The scope of the concept is concerning nearly all areas of personal and public life.

The concept has to be esteemed as today's result of emancipation, empowerment, an increasing degree of self-organisation. The concept has a breeding ground in the actual economic and political context, where the market is functioning as a metaphor for understanding and regulating relations, transactions of goods and services in our society.

The general introduction will present a characteristic of the concept of "customer's perspective". It will argue that this concept is both a reaction and an evaluation of the so called medical, social and political frames of understanding and explanation. It also is an alternative for sets of quality criteria of these frames.

Rehabilitation seen as part of a medical system uses the medical frame: rehabilitation as medical treatment. Rehabilitation is sometimes focused on the social frame: rehabilitation as socialization. It is also familiar with the political frame: rehabilitation as integration.

For rehabilitation, the customer's perspective can be a challenge in partnership with a consumer. It is a possibility to come in a vivid relation with modern self-organisations. Consumer's perspective has as implication that assurance companies are partner of a consumer in stead of partner of service providers.

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Quality of Life for People with Profound Multiple Disabilities – Results of the Project 'Quality of Life' at the University of Cologne

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In Germany economically justified amendments in the social-political sector have considerably affected the living conditions of people with profound mental disabilities and additional physical and/or sensory impairments. The Cologne Quality-of-Life-Study started to analyse the present situation by researching into everyday life of people with profound multiple disabilities in special homes or in nursing homes. A multidimensional concept of Quality of Life built the theoretical framework which integrates the objective conditions of life, subjective assessments of well-being and personal values and goals. In order to approach the specific point of view of people with profound mental disabilities the study used participant observations. Additional data are founded on interviews with the staff, document-analysis and a questionnaire concerning structural conditions.

Main results: The social services' principles are only insufficiently put into practice: Normalization is only realized within institutional structures, most of the people with profound multiple disabilities are not socially integrated, not even in community integrated housing settings. The well-being of people with profound multiple disabilities is severely restricted by the staff's lack of esteem and their refusing to open possibilities of communication, social relations, activities and self-determination as well as by lack of assistance in opening social and material experiences and by exclusion from participation in common life. Permanent deprivation and stress bring on challenging behavior.

The results of the study show clearly that institutions, responsible bodies, organisations for people with disabilities and social politics must take steps towards change. In order to evaluate the staff's daily work with people with profound mental and multiple disabilities we developed CHECKLISTS. They can help to raise the quality of life for people with profound multiple disabilities. The checklists will be shown in the workshop.

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Working group IV, Session 1

Vocational Rehabilitation of Adults in Transnationally Defined Occupational Education Networks

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Background

The Heidelberg Vocational Re-training Centre for adults, Ltd. (BFW Heidelberg), is affiliated to the SRH holding – a major group of facilities for rehabilitation, occupational education, vocational training, and worklife participation enhancement for persons with disabilities and chronic illness in Germany.

BFW Heidelberg is one of the founding members of the European Platform for Vocational Rehabilitation (EPVR), Brussels/Belgium.

Presentation contents

Based on the EPVR network of ten important rehabilitation facilities from 10 member countries of the European Union, and in close cooperation with a number of other occupational and academic education institutions specialised in offering re-orientation, assessment, qualification, further training, and health-oriented appropriation to adult persons with disability-related handicaps, a selected range of formal instructional courses for vocational education and personnel development is already taking place within a "European network" structure.

This network contains, among other things, opportunities for practice periods in neighbour countries, transnational exchange programmes for students and rehabilitees, joint international teach-and-study projects, and includes commonly developed "telelearning" sequences during the course of various studies.

Many of the curricula of these trades & professions have been considerably upgraded in this way and are expected to cause an improved overall career outlook for the graduates on the job markets not only in their home country. "Employment mobility", an increasingly important factor in a globalized economy, is improved or at least preconditions for employment mobility are strengthened. For example, a formal qualification named "European business merchant" or the "internationalised" version of the "multimedia information technician" today have its place in the offered educational range of the SRH professional academy (FH der SRH) in Heidelberg.

The lecture briefly outlines preconditions, advantages, contents, structures, but also problems – i. e. mainly in the domain of properly financing these education measures – in the new field of European cooperation within the vocational rehabilitation of adults

Working group IV, Session 2

Self-Determination as a Rehabilitation Quality Issue / Customer Demand Control

Subjectivity as a Starting Point for the Formulation of Quality Criteria

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Criteria for the quality of care are often formulated in a general way: preferences of users measured against performances of caregivers; quality from the perspective of users or patients. However we know that people differ individually in their preferences and perspectives; all too often the formulation of quality criteria assumes (implicitly) that 'we' all want the same, based on the principle of autonomy.

In my book *The Shaping of Identity in Illness. A study on chronic illness and subjectivity* I contend that, to do justice to individual differences, we should start paying attention to the different forms of subjectivity (narrative identities) of people with disabilities and/or chronic illnesses.

Starting from my own life with chronic illness I analysed ten biographical interviews with women with a chronic illness. I distinguished three plots or genres: a 'normal' life; an 'exceptional life': suffering; the difficulty of saying "I". There is no claim to be exhaustive. On the contrary, it is quite easy to imagine other plots one could find in other discursive circumstances or when interviewing people with different backgrounds.

But already these three genres show a variability in the shaping of identities which result in different perspectives concerning the quality of life and the quality of care. Autonomy turns out to be a complex concept and although important, not central in every genre. There is also the concept of recognition and the problem of the social construction of suffering.

It is my contention that we should base our quality criteria on a serious understanding of the stories people tell, on the (ever changing and continuing) shaping of their narrative identities.

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Working group IV, Session 2

An Event Orientated Patient Questionnaire – Patients Define their Criteria for Quality in Rehabilitation

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Since the advent of a consumer orientated medicine, the view of patients themselves becomes increasingly central as an indicator of quality. The patient as the user of the health care system should be able to evaluate his treatment, staff and the facility. Traditionally, patient satisfaction questionnaires are frequently used to get this information. Since the concept of patient satisfaction is often not clear and results demonstrate strong ceiling effects which partly contradict to results from other sources, a different approach should be able to get a more valid information. A measure which aims at concrete events concerning structures and processes of treatment and facility should be able to detect its quality from a patient's point of view.

This study is to develop a questionnaire which aims at indicators of quality of inpatient rehabilitation units by means of event orientated questions. To gather relevant events indicating quality, seven focus groups with patients, therapists and doctors were set up. Text analysis from 534 patient questionnaires provided additional information.

There are a number of concrete events concerning structures and processes of admission, therapy and discharge. The interaction with doctors, processes of communication and enlightenment were the most important issues where criteria were named.

The results demonstrate that patients, doctors and therapists were able to name concrete events which indicate qualitatively relevant criteria for inpatient rehabilitation from a patient's perspective. While evaluating quality of health care, patients should be more involved in the definition of relevant criteria.

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Working group IV, Session 2

FORTUNE, An Approach of Users' Influence

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Background

In the 90ies, user involvement consisted mostly of activities taking place in reference groups, without any payment. Users are asked to join in projects when the most important work already has been carried out and when the possibilities to influence are not that overwhelming anymore.

But then users wanted to play a more active role in projects and to become participants. Before they can be participants, the users had to be trained.

In 1997 the Forum of user-Organisations Training for Usability and Networking In Europe (FORTUNE) started as an EU sponsored project. The aim of the project was to train representatives from user-organisations to participate in Research & Development (R&D) based on the concept of true partnership.

Method

Participants should be trained to act in a professional way. The FORTUNE training consists of two parts,

- a training on national level and
- an international seminar with a group of 40 users with disabilities from 4 countries, Spain, Norway, Germany and The Netherlands.

The program of the training consists among other things of:

- Introduction to user involvement, experiences and possibilities for user participation
- Terminology used in European R & D projects
- Methods of user involvement
- FORTUNE concept of user participation

Results

After a start in 1997 with 10 enthusiastic representatives of organisations of disabled people, in 2002 we are a group of 6 users who are participants in projects of the Stichting voor Kwaliteits- en Bruikbaarheidsonderzoek van Hulpmiddelen voor gehandicapten en ouderen (KBOH), be members of committees from the Dutch Normalization Institute (NEN). One member is working internationally, she represent the users in a working party which is making up the revision of the wheelchair norm CEN / EN 12183 and 12184.

Conclusion

The FORTUNE concept describes the ideal model of user involvement, two of the seven principles are partnership and payment, and especially the latter one is the most difficult because the user's contribution is no longer to be had for free, it is no a volunteering activity so users should receive appropriate payment.

After 5 years we are proud to tell that we have signed up our first contract that is based on the FORTUNE concept. But we also became aware that it is going to take a long time before user participation in projects will be based on the FORTUNE concept.

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Working group IV, Session 2

On the Function of Professional Groups in Self-help after Brain Damage

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Background:

A question that deserves special attention is which professional groups can and should be involved in the support and promotion of self-help groups for patients suffering from acquired brain damage. In particular, this concerns the inclusion of professional groups from the area of medicine, who are able to contribute therapeutic knowledge to the self-help groups.

Method:

The co-operation between self-help groups and professionals is frequently still fraught with problems. On the one hand, it has appeared that professionals are often poorly informed on the local availability of self-help. On the other, their heavy work load has resulted in there being but little readiness to sacrifice their spare time to contributing to the supervision of a self-help group. In addition, the self-help groups fear that their autonomy will be reduced as a result of professionals taking part in their activities. An example of fruitful co-operation with professionals is the 25-member 'WIR' group, which provides help to patients suffering from strokes or brain injury.

Results:

During their 7-year co-operation with the medical facilities of the University of Cologne, this group has been primarily concerned with extending its counselling by providing regular advanced training courses as well as involving the rehabilitation consultation at the department of Neurosurgery, which has also been able to provide special support to the planning and the coordination of ambulant rehabilitative measures.

Main aspects of discussion/ conclusion:

In many regions, there is often no sufficient network of self-help groups available to people having suffered a stroke or skull-brain trauma. Yet for this patient group in particular, the care received in hospital and during rehabilitation, which frequently stretches over many months, needs to be supplemented by extensive help, counselling and attendance. Self-help groups are believed to be able to contribute substantially to the improvement of the ambulant care administered to patients suffering from acquired brain damage that has left them chronically ill and disabled.

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Working group IV, Session 3

Personal Assistance and Personal Budget – Quality Issues

"My Way" – Taking Part is not Everything, Quality of Life is More. Personal Budget as Control Mechanism for Participation

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According to the ideas of self-determination and participation a new guiding principle is growing in the German rehabilitation system. This effects the organisation of professional support systems for persons with handicap experience as the former idea of "living a life as normally as possible" (normalization principle) includes the tendency of obligating persons to an "average life" (one-size-fits-all principle). The realization that processes of evaluating quality of life are subjective contributes, however, to an individualization of services. These have to be seen as resources, which help developing own life styles and individual abilities and needs as well as promoting independent and self-determining action. The benchmark of quality of life becomes individual well-being and actual participation in living in the community.

On the basis of the concept of a research project "Person-centered Support and Quality of Life" ("Personenbezogene Unterstützung und Lebensqualität": PerLe) is set out how the break with a system that exempts persons from social tasks and delivers "all inclusive" provision can take place. Ways are seen in an orientation on existing or newly developing resources and needs of each individual and in the inclusion of persons with handicaps as co-producers in the developing process of the support-system.

This development will not only lead to a more concerted use of resources, but also to an increase of the users' quality of life, a pluralism of the support services and its linking with other fields of social work as youth welfare or services for migrants or the elderly.

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Working group IV, Session 3

A New Way to Improve the Quality of Life!

Kooij, B.

Per Saldo, Dutch association of personal budgetholders, Utrecht, The Netherlands

A personal budget (PGB) is a sum of money with which budgetholders can purchase their own care on their own conditions. In the Netherlands this system will be implemented in 2003 as one of the fundamentals in the healthcare system for people who require long-term care due to disability, chronic illness, psychological problems or old age.

From the perspective of the budgetholder we formulate the minimum conditions for a qualitatively good personal budget:

1. A realistic diagnosis of the need in relation to the insured care.
2. Enough budget to arrange the needs on care.
3. Enough freedom to spend the budget. The budget is spent inside the care domain, which extends beyond the restrictions of insured care.
4. Sufficient practical information and advice for budgetholders and those who have requested a PGB

We find it a principal quality issue that this budget in future is growing to an integrated budget, covering all costs of care, personal assistance, technical aids, adaptations in the house, transport, etc. We recommend the persons present aim at such an integrated budget, because this enables people to fulfill any social role they want to fulfill an any other person can do!

Personal Assistance. Local and International Networking as an Empowerment Tool

Janssens, H.

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Personal Assistance (PA) is a way to augment the autonomy and the freedom of choice of persons with a disability. A person with a disability engages someone who can assist him during daily activities. This way he is not dependent on an institution but decides himself by whom, when, where and how they are assisted. In some countries and regions, among which Flanders (Belgium), people with a disability can receive an assistance budget from the government.

Katholieke Vereniging Gehandicaptten (KVG) wants to support its members (persons with a disability) in acquiring and using such a budget.

One of our activities is the PA Helpdesk project (supported by the EU Leonardo programme). Our aim is to develop and organize a training for PA consultants. These are persons (preferably disabled themselves) who will supply information and support other PA users in solving practical problems concerning the organisation of their personal assistance (e.g. personnel management, administration, ...). It is also an objective to promote networking. This includes organizing Peer Support groups (PA users helping each other) as well as electronic networking between PA users, consultants and other parties involved.

In this project we work together with partners from Sweden, Germany and France.

Our presentation will be a case-study of the role of networking in the project PA Helpdesk. The public will be invited to participate in the evaluation and to give feedback.

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Quality the Way You Mean it. Or: A User Assigns Quality to a Product if it Adds Value to the Quality of His or Her Life

Staal, L.

KBOH – centre of expertise and information on technical aids for disabled and elderly persons, Woerden, The Netherlands

Quality of life can only be determined by the individual. He or she decides on the elements which make up this quality and the place that technical aids occupy in this.

The current flow of information in this area fails to take sufficient account of this perspective. Technical quality takes precedence, often in relationship to the costs.

KBOH produces information material which helps people to define the quality of life for themselves and the role a technical aid plays in this. KBOH works from a user-perspective and tries to match the ongoing classifications and standards with this user-perspective. The method used:

Orientation:

what is a specific device and what can it do, how can I use it to help my daily routine, how does it compare to other technical aids?

Stimulation:

recognition of the personal situation.

Choice:

which aspects are relevant to the personal situation, what is my set of quality requirements?

Evaluation:

have I got what I wanted?

This is an interactive programme developed on the basis of requirements defined by users and supplemented by safety requirements.

The result is that potential users of a device are better informed and prepared at the assessment stage and, as a result, receive aids which are more appropriate to their needs. Our intention is to develop increasingly such information for all categories of equipment, in cooperation with partners and interest groups. We hope that user requirements, prescription methods and classifications can be better integrated.

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Quality Assurance Strategies and Quality Management Systems in Rehabilitation

Using Evaluations to Improve Quality of Life

Nossin, M.

Perspectief, Utrecht, The Netherlands

The Netherlands is looking at strategies to change the system of service for people with disabilities towards broadening options in the community. People with disabilities have the right of self determination and participation in the community.

But often services have the interests of the institution at heart rather than the interests of the individuals. This has led to a system of segregation rather than social networks and community inclusion. Perspectief wants to focus on the improvement of quality of services offered to people with an intellectual disability through external evaluation.

Perspectief, established as a charitable organisation in 1999 by the Dutch Federation of Parent Associations, is a consumer and family controlled trust. We operate in partnership with service providers on the basis of voluntary and agreed standards.

This presentation will focus on strategies of change that were successful and explain how this has led to our current national organisation. We have now trained 250 people and work with them in external teams that include people with disabilities, families and professionals.

Perspectief is mainly funded by Government and is an important player in the field of improving lives of people.

Quality Evaluations by Clients

ter Avest, M. J.

Landelijk Steunpunt cliëntenRaden voorzieningscentra gehandicapten (LSR),
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Background of authors' work/cooperation

The LSR is a national organization, which was established in 1993. In cooperation with the CG-Raad the LSR supports physically disabled people who are living in sheltered housings. The LSR wants to achieve a situation in which people with a physical handicap can live like any other citizen in Holland. They should have the same rights and possibilities to participate in this society so they can decide by themselves about all the aspects of their life, such as the way of living, the support, the care and treatment they need, their free time and their work. They should have enough options to achieve independence and control about their lives.

The LSR supports councils of clients. We offer them information, advice, training and support. With the councils of clients the LSR evaluate the quality of living in sheltered housings.

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Purpose

The purpose of the quality evaluations is clients to become more conscious about their wishes, needs, rights and possibilities. We stimulate them to discuss with the management about necessary and desirable improvement and innovation. In this speech we want to give information about two methods of quality evaluation. We will explain our methods step by step.

Results and conclusions

The result is to explain the purpose and the step-by-step procedure of two different methods of Quality Evaluations. We want to make clear that Quality evaluations, connected with a procedure of training, advise and support, are a good way to stimulate empowerment, improvement and innovation. The process of innovation should always be based on the dialogue with the clients. Because its about their life, their future and their quality of living. Finally, it is up to the clients to define how they want to live.

Aspects of discussion

- Is it important to give the council of clients of main role by quality evaluations?
- Is empowerment a result of quality evaluations?

Dimensions of Quality Control in Vocational Rehabilitation

Greve, J.(1), Jochheim, K.-A.(2), Kaiser, H.(1), Kluge, G.(1), Schian, H.-M.(1), G. Neuhäuser, G.(3)

(1) IQPR-Köln, (2) DVfR, Heidelberg, (3) vorm. Sozialpädiatrisches Zentrum UNI Giessen

New German legal Context of Participation for persons with handicaps (SGB IX) considers the international classificatory context of functioning (ICF). ICF, on the other hand contains extended dimensions of participation in multifactorial issues including interaction with various environmental conditions. These aspects touch all levels of "coping" with daily life problems as well as the handicap creation process. Therefore different socio-ecological systemic aspects are analysed and presented.

To assure quality in the process of participation by vocational rehabilitation all these dimensions are to be respected, which until now is not done neither in out-come-documentation nor in any evaluation. The following proposals for theoretical, methodical and practical dimensions are developed to assure participation and especially sustainable vocational integration: (1) IPI as Integration-Prognosis-Index to account levels and social-systemic dimension; (2) IMBA as global-profile levels for documenting work-place conditions within an interactive-system; (3) KODI as communication-diagnosis assessment documenting behavioural items of interaction to assure attention, endurance and empathic reactions (beside MELBA); (4) a scoring based also on FIM gives hints toward a severity-algorithm in analogy to DRG/FRG-systems. These screening instruments provide a necessary "Minimal-Standard" to assure quality of vocational rehabilitation within the dimensions of ICF. These basic data and scoring allow epidemiological, rehabilitative aid adjustment as

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well as inter-institutional comparisons to provide social equality for severely "handicapped" persons. They should be enlarged and deepened for special aid and socio-therapeutic aspects in rehabilitation.

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Uncomplete Networks of Persons with Disability and Professionals in Central and Eastern Europe

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During last 14 years fast development happened in countries of Central and Eastern Europe (CEE), which influenced also situation of persons with disability (PwD), their organisations and service providers. Author describes his own experience in development of international relations in Czech Republic and in other CEE countries. First network described is Rehabilitation International. Together 27 countries belong to RI region of Europe and only 7 have active member organisation of RI. Advantages and limitations of RI membership are described. Occupational therapist represent very active network in Europe. European organisation of OT schools (ENOTHE) organised meeting of OT representatives from CEE countries. In several CEE countries started OT education, e.g. Czech Republic, where number of OTs doubled during last five years. The last network is Abilympics. It is contest of vocational and leisure time activities of PwD. During last ten years Abilympics became popular in several countries of Central Europe. 5th International Abilympics was held in 2000 in Prague, Czech Republic with 738 participants from 29 countries. It is described how these networks could influence each other and how to build stable network in CEE and with the rest of Europe.

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Working group IV, Session 5

Quality Measurement / Quality Standards in the European Rehabilitation Discussion

European Quality Standards for Best Practice in Rehabilitation

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The European Quality in Rehabilitation Mark

Providing quality of services for all customers, service-users, stakeholders, funders and employers, is an obligation of all service providers. Transparency and meeting standards of good practice are important criteria in the provision of these services.

The European Platform for Rehabilitation (EPR) has taken the initiative to launch the European Quality in Rehabilitation Mark (EQRМ). With the EQRМ the EPR wants to encourage transparency and quality of service delivery and to establish best practice in the field of rehabilitation.

The process

Recognition of achievement in best practice in Rehabilitation is based on the EQRМ nine Principles of Excellence, which offers applicants the benefits of a structured approach to identify organisational strengths and areas for improvement. The organisation will be required to prepare an application and a self-evaluation document. A team of qualified assessors will review the application, the self-evaluation document, carry out a Site Visit and provide a feedback report. Applicants whose score is confirmed at 540 or more points will be nominated for the EQRМ. Organisations of people with disabilities, service providers, employers and funding agencies on the European level are represented in a Quality Committee that will award the applicant with the EQRМ.

What do I gain from the EQRМ?

The achievement of meeting the EQRМ Principles of Excellence provides a recognition at a European level in addition to the National Accreditation in the field of Rehabilitation. The assessment methodology provides organisations validating their current level of performance using an experienced team of independent assessors. Consultancy will be provided in the process of self-evaluation. The process provides a benchmark for learning and improvement and an analysis of the gap between current state and best practice in the field of Rehabilitation.

Workshop description

In this workshop the participant will be informed of the European Quality in Rehabilitation Mark. The workshop will emphasise the involvement of service-users (People with a disability and employers) in the EQRМ Principles of Excellence. The participant will learn how these EQRМ Principles of Excellence will be assessed.

The results of participant's assessment based on service-user criteria will be reviewed and discussed. This review process may give the participant the opportunity to calibrate the perspective of the assessment for service-user involvement in the EQRМ Principles of Excellence.

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Customers'/Employees' Satisfaction Surveys - an Important Instrument of Quality Measurement in Health Care

Messner, T.

German research group "Metrik", Landau, Germany

There are no easy solutions to the problem of improving the quality of care. The identification of methods for assessing the views of customers on health care has only developed over the last decades. The use of customers' views to improve health care development requires valid and reliable measurement methods.

You will get an answer to the question, how you can create an effective and efficient customer satisfaction management in your organization. In addition, you will see the requirements of a valid and reliable instrument to measure customers'/employees' satisfaction in health care.

A specified well-defined framework makes it possible to assess and control the improvements in your organization continuously. You will get a further possibility that allows you to react directly, instead of acting blindly.

WG IV

The Circle of Requirements Toward User Involvement in Assistive Technology

Treffers, B.

Dutch Council of the Chronically Ill and the Disabled - CG-Raad, Utrecht, The Netherlands

In the field of research and development, design and production, standardisation and quality assessment and the provision of Assistive Technology (A.T.) the role of user has to be improved and completed. They contribute to dissemination of ideas and solutions on an individual level, found in e.g. rehabilitation centers and research institutes by and in interaction with potential users, service providers and experts. Would stimulate research, development and design (for all) with the aim to imply these solutions into the mainstream. Therefore the inclusion of representatives of organizations of disabled people in quality (and usability) assessment is a 'conditio sine qua non'. It would improve the expertise of disabled people and deliver incentives to participation of organizations of disabled people in national and European standardization processes. To combat inequality, substantial funding such as national and EU funding are necessary to facilitate organizations of disabled people to materialize their targets towards user involvement, to train their members and to coordinate their policies. The inclusion in this work of the UN Standard Rules and other disability specific declarations and conventions into legislative frameworks on a European level; freedom of movement of disabled people should be realized as an example of equality and non-discrimination in this particular field.

Working group V

Social Security for People with Disabilities – Time-Tested Systems Face new Challenges

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Paradigm Change and Emerging New Target Groups in Rehabilitation: Their Impact on the Social Security System

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Social Security for People with Disabilities – Time-Tested Systems Face new Challenges

Paradigm Change and Emerging New Target Groups in Rehabilitation: Their Impact on the Social Security System

Without Care no Community – Policy on People with Disabilities: A Matter of Dialectics?

Blaas, J.

Dutch association for care and support concerning people with a handicap (Vereniging Gehandicaptenzorg Nederland), Utrecht, The Netherlands

This lecture will concentrate on actual policy matters in The Netherlands concerning people with disabilities. Two tracks will be walked on:

- One track contains a system analysis of changes in the provision of (health)care in our country. Focal point is the overturn of the (health)care system in the direction of demand domination: preferences of clients are decisive in the way (health)care will be provided in terms of what?, when?, how?, by whom?
- The other track contains an analysis of how views concerning people with disabilities have changed over the years, including government policy. Attention will be paid to the paradigm-evolution starting with sheltering of handicapped people and discharging in full-fledged citizenship (community care).

The lecture will be build up to the Big Challenge: What contributes to an effective/efficient way - in terms of legislation, financing and distribution of responsibilities - to do justice to preferences of clients (including empowerment) on the one hand and securing a ground-level of care and support provisions on the other (in terms of availability, accessibility, pay-ability and quality).

In policy concerning people with a handicap a balance has to be reached on several levels:

- a balance between market and solidarity;
- a balance between shelter and independence;
- a balance between professional standards and client preferences.

This balancing starts with the formulation of rights of citizens with a handicap, the safeguarding of skills needed to provide support and care to these citizens (a matter of quantity and quality) and – last but not least – the provision of legislative and financial means to secure the link between both. In the lecture these three elements will be presented as a necessary policy-triptych concerning care and support for people with a handicap.

This whole will be presented against the background of ongoing European integration, dominated by economic principles. What will be the consequences for social security in the European area, especially the provision of (health)care and support?

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Common Servicepoints For Rehabilitation

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Federal Rehabilitation Council, Frankfurt am Main, Germany

The German system of social protection reflects historical development, and rehabilitation therefore does not come under one single but seven different agencies. Therefore often several rehabilitation carriers are competent for the multitude of medical, vocational, social und supplementary services and benefits. Such a system has as well advantages as disadvantages: the colleagues of many institutions work together with much knowledge and engagement for a more comfortable life of disabled people - on the other side such a system means many competences, many partners to address, much bureaucracy.

Successful rehabilitation often requires services of different rehabilitation carriers. Already at the access to rehabilitation preliminary decisions are made about the course and success of the whole measure and its single steps. The persons concerned have to find a contact, where they are advised completely and reliable.

The establishment of common servicepoints for rehabilitation therefore is one of the most important novelties of the SGB IX. According to the SGB IX the rehabilitation agencies guarantee, that common servicepoints for rehabilitation exist in all rural districts and all cities outside these districts, which means the construction of at least 440 common servicepoints. At these servicepoints disabled people as well as their intimate friends receive advice and support quickly and unbureaucratic. The common servicepoints for example inform about the principles and services of the institutions providing benefits, find out the competent rehabilitation agency, clear up the personal need of rehabilitative measures possibly so complete, that the rehabilitation carrier can decide immediately and give support in making a claim for rehabilitation. Support by the common servicepoints is also to be granted during the benefits itselfs and during short interruptions of the benefits.

WG V

Return to Work and Rehabilitation Legislation in the Netherlands

De Vos E.L.

TNO Work and Employment, Hoofddorp, The Netherlands

The share of the working age population that is not working because of a disability is twice as high in the Netherlands as the European Union (EU) average.

Ten years ago prime-minister Lubbers concluded that 'The Netherlands is sick', because more than one out of eight persons between 18 and 64 years old was receiving temporary or permanent disability benefits. Despite a rise in jobs and} some policy measures this situation has not been improved.

This presentation gives an impression of labour market policies for disabled. In particular, attention is paid to new policies on return to work and rehabilitation of people with disabilities. The government introduced the Rehabilitation Act (WREA) on July 1st 1998. The

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implementation and effects were evaluated by TNO Work and Employment. The aim of WREA is to improve procedures and the results of rehabilitation activities. However these effects are not demonstrated in the evaluation study. This is due to difficulties introducing the new legislation and discrepancies in interpretation. Despite changes in legislation the regulations are still complex. Furthermore the agencies that are responsible for implementation suffer from organizational and staffing problems. New initiatives in 2002 may lead to better results.

From Integration to Inclusion - Rehabilitation Services in a Changing Society

Wansing, G.

Universität Dortmund, Rehabilitationssoziologie

Participation in society is the stated objective of European policy for persons with disabilities. Main issues are equal opportunities and the full recognition of their civil rights. However, the implementation of this guiding principle has to take into account the changing conditions of participation in modern society. Persons are not as a whole integrated in a social system but they participate partly and from time to time in social functional systems (economy, education, health, legislation, policy etc.). In this context inclusion stands for the free and equal access of all citizens to function specific achievements of society. This demands the development from the idea of integration of persons with disabilities in the sense of adaptation towards a "society for all" that reflects the different prerequisites of all citizens from the beginning. Inclusion as task of rehabilitation means a fundamental re-organisation from institution-based to person-centred services. The care and support in "special worlds" lead to institutionally moulded biographies of persons with disabilities and endanger strongly their chances of participation in central areas of life. Inclusion as access to individually important function systems requires the alignment of all support services to the life style of the individual person and its needs and desires. Essential are the person-centred control of financial resources (personal budget) and an organisation and planning of support that is oriented on the individual person and its available resources (case management and community care).

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European Social Legislation Regarding Disability Provision: Are Client "Protection" and "~Activation" Sensibly Balanced?

Strengths and Weaknesses of Social Legislation Regarding Disability Provision

Wright, P. H.

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The balance between the rights and duties of individuals and their governments changed, as state goods and services funded by law replaced charity and the right of citizens to succeed or fail. There is an implied 'social contract'; the successful give up some of their good fortune to those who fail, through an intermediary state.

Most agree that those who cannot work and support themselves deserve state benefits, though less about the income level that this implies. Most agree that the disabled should receive free health care and rehabilitation. Fewer that returning people to work takes priority over helping those who could never support themselves.

An approach based on human rights and the social model of disability can be seen as demanding all possible help for every disabled person without considering costs, and so to extend beyond any current political consensus. It blurs the traditional picture of a disabled person deserving of sympathy and help.

Social solidarity links donors and recipients within a fluid political process that is local, national and international. It inevitably stereotypes both.

The views set out are those of the author and do not necessarily reflect the views of the UK government.

Client Participation in Return to Work Programs: Benefits and Requirements

Cremer, R.

TNO Work & Employment, Hoofddorp, the Netherlands

Three levels of client participation are distinguished. On the micro level direct needs of clients of RtW programs are the issue. In other words do clients get the services that they require? On the meso level collective needs of clients are defended in organisations such as employers, public organizations responsible for assignments and in organizations providing the RtW programs. On the macro level representatives of clients advice on legislation and policy making.

In this presentation direct needs of clients are emphasized and the importance of their active participation. In recent adaptations in social laws clients of RtW programs are encouraged to take a more active part in their reintegration than in earlier periods. The expected outcome is a higher motivated and satisfied client. Moreover, the law enforcer expects more clients to return to work with lasting results.

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Neo-Liberal Visions, Cost-Containment Aims, Commercialization/Privatization Trends – and the Principle of Solidarity

(Re)integration in the Netherlands and the Role of Client Organisations

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A short description will be given of the Dutch legislation that exist to increase the (re)integration of handicapped people in work:

- The **Wet verbetering Poortwachter** promotes that an employee with a chronically illness or handicap should be able to stay at work at his employer or another employer. The employer is financially responsible for this reintegration. The employer has to pay a high bounty if the reintegration fails. Employer and employee can both make an appeal on the Wet Rea.
- The Wet **(Re)integratie arbeidsgehandicapten (Rea)** knows compensations for the many forms of reintegration services that persons may need such as: education, admittance, mediation, coaching on the workplace, labour costs aid, etc. The credit facilities come from revenues. The regulation is accessible for everybody. A national public organ with decentralised settlements does the appreciation for this kind of provision. The supply of reintegration services has recently been privatised.
- De **Wet Sociale Werkvoorziening (WSW)** acknowledges compensations for work under sheltered circumstances.

The clientorganisations in the Netherlands (CG-Raad and allies) want more demand-controle in these regulations. The person with a handicap should have more control over his/hers reintegrationproces.

Therefore several activity will be unfold.

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Cooperation in the Border Region Netherlands - Germany

Ybeles Smit, P.

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The 'Regional Patients en Consumer Federation South Gelderland', a summit-organisation from 250 elderly, handicapped and ill people and patient-organisations in the region Nijmegen, Netherlands, near the German border, works since a year in close coöperation with the Kreisgruppe Kleve from the Paritaetische Wohlfahrtsverband in the German land Nordrhein- Westphalen.

The purpose of this close coöperation is the forming of a cross- border network of users of care, for information, use of the health care facilities on both sides of the border and political lobbying for the patients and consumers of care. The German and the Dutch side bring in their specific possibilities.

We don't plan to form an separate organisation. The work is done in the framework of both the RPCF on the Dutch side, and the Kreisgruppe Kleve on the German side.

As member of the board of the RPCF South Gelderland I work in close coöperation with my German counterpart on the shaping of this project. Today I want to share with you some of the challenges and possibilities, from the perspective of the person who is dependent on forms of care. Especially from the political perspective.

It seems so easy

In the border region Nijmegen- Kleve cross- boundary- cooperation is completely normal. The former frontier is still a barrier for a lot of 'official' business, but in practice the inhabitants of the region form traditionally one community from the Dutch and the German side. By example, in Kleve, the nearest German city, the local dialect which people speak is in fact a kind of Dutch.

Many organisations have already met their German counterpart. So by example the health-insurance- companies and the huge conglomerations which offer care on the Dutch or German side. Since a year it is by example possible to get a German dentist, when you live on the Dutch side, because there's a lack of dentists on the Dutch side. Or German people go for some medical operations to the nearest university hospital which is in Nijmegen. In this framework the German and Dutch organisations of patients, of elderly and of handicapped people felt that they had to establish also cross- border contacts. The situation on each side of the border gave reason to look for a kind of support from the other side. By example the budget for health care from the German land is 30 % bigger than the health- budget from the Dutch government. I must explain here that the Netherlands and the German land have about the same amount of inhabitants, about 16 million, and the situation on both sides of the border are in many respect quite similar. Since 20 years however, the Dutch government has used the heath care as a kind of organge, to press all the juice out, and cut expenses. These politics results in big shortages in the care. On the other side, the political work which do Dutch patients and other people dependent on care already since 20 years, is virtually unknown on the German side. There the political work of patients is badly needed, but almost not there. So German people came to us and asked: can you learn us how to do that ?

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The practice is complicated

In practice all is not that simple. The health insurance companies in the already existing cross-border framework, the Euregio Rijn/Waal, were not pleased with our initiative. The insurance companies claim that they are the voice of the people who are dependent on care. They don't want to talk about their own institutional interests, which are not necessarily the interests of the individual patient or group of patients. For our Dutch ears the discussion in the Euregio sounds as if the clock has been put backwards 20 years. And the companies who give care on either side of the border are on their turn afraid of the level of care on their side, and make a lot of problems when patients can be helped better on the other side of the border. The most absurd example of their attitude was the statement recently by the chief chairman of the medical university in Maastricht, which is close to Belgium and Germany. He claimed that he would sue every patient who would go for a treatment to Belgium or Germany. The fact that, because of the failing Dutch health-care politics, there are endless waitinglists for patients for all kinds of cure and care, didn't interest him. That patients are allowed by EU-regulations to go to elsewhere in the EU to be treated, didn't interest him either.

In general there is a lack on information about the possibilities of treatment or care on the other side of the border, and this lack of information is not by accident. Only pressure by patients can help to get the information one needs.

In short: for themselves the health insurance companies and care offering companies are eager for cross-border contacts, but when organisations of patients and consumers want these contacts, they are felt as a threat to the existing positions of power. Real care and cure depending on what the good informed patient or consumer wants, is equal threatening.

Successes

Of course we cherish our successes. We are not afraid to confront the existing positions of power and monopolies. We go our own way, and are sure we have strong political support, from the Dutch and the German side. We have now als patients and consumers two official seats in the existing cross-boundary body, the Euregio. Our political support is on the Dutch and German side translated in financial support, which is quite remarkable in these times of 'uitgavenstops' and 'haushaltsperrren'. The German land even says that we are the only project of this kind (so of patients and consumers of care) in the whole EU. Why the politicians do support us, has many grounds. For us most important is that the reasons why politicians do support us, go very well with our own plans.. And we have said to each other: even when the manipulations of the health-insurance-companies go as far as that the politicians would take away the financial support, we would continue anyhow. Then we will show how strong we are in spite of lack of official funding.

First tasks

The first tasks ahead of us are making visible the many patient or consumer-related organisations on both side of the border, to make relations between these organisations possible (by example patients with Parkinsons disease from the Dutch side meet Parkinson-patients from the German side), make a flyer with basic information about who is who, making a website etc. And support groups who want to share activities.

Working group V, Session 3

Poverty and social exclusion

What has all this to do with combatting poverty and social exclusion? Well, on both sides of the border we have people with a very low income, especially patients, handicapped and elderly persons and other people dependent on care. Many do not work for a salary any more, because of their health condition or age. These people live mostly on welfare, and their possibilities to participate in society are often very limited. By example: As consequence of the 1994 law on care for handicapped and elderly people in the Netherland, the possibilities for support and the level of care which they can get have sunken since 1994 nationwide with 70 %. And in Germany also poor people have to pay for the days when they are in a hospital. And go get 'carec' help at home is in Germany very difficult and very expensive.

When we run this project, many more examples will show up. A part of our role then can be supporting poor people, so that they can get the rights they are officially entitled to, but in many cases don't get because they are poor.

We hope to inform you in a year again about this unique project.

The Right on Income in the Netherlands

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Great changes are taking place in the Dutch system of social security: The insurance for income guarantees for people who can not work (full-time) because of their disability will be partial privatised. The roll of the insurance companies is increasing.

Formerly the Dutch knew a system that contained a sharing of costs for the income guarantees by employers and employed. This system existed next to a tax-paid regulation for disabled people without a record of previous employment.

Under the cloak of the great worries of the amount of people who aren't able to work because of a disability, a great privatisation takes place. Unions have an indistinct part in that development. Client-organisations like the Dutch Council of the Chronically ill and the disabled are hardly being heard.

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Working group V, Session 4

The Need for Efficiency and Effectiveness in Rehabilitation Service and Disability Administration: Examples of Good Practice

Efficiency of Rehabilitation by Comprehensive Responsibility of Suppliers – Life-Long Care for Spinal Cord Injured Persons by the German Workmen’s Compensation Insurance System

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Purpose of the presentation is to demonstrate the effectiveness of comprehensive care of spinal cord injured (SCI) patients in one hand as performed by the Workmen’s compensation insurance system in Germany.

Responsibility is not ending when patients are discharged from the hospital. Life-long control is done in view of prevention and specialized treatment in case of typical complications. Control includes social and vocational aspects.

Results: The share of persons in the responsibility of the Workmen’s compensation system within recent cases is about 18% per year. Within the readmissions it increases up to 30%, in Hamburg up to 45%. Controlling for typical complications such as neuro-urological diseases or pressure sores in the sense of prevention or treatment is much better. Concerning life-expectancy we found in our study that it nowadays is situated around 60 years.

Discussion: The German health insurance system in respect of cost coverage, is structured into different agencies. In case of severe injuries like SCI, this changing of responsibilities induces disadvantages especially in view of follow-along rehabilitation.

Conclusion: There is a lack of comparable groups of different suppliers. Nevertheless we note severe differences in the rehabilitation process and the results. Treatment under only a single, comprehensive responsibility is better and more effective.

Rehabilitation/Case Management and Networking out of the Rehabilitation Clinic

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Background and Purpose

This plan is directed at national insurers, private accident insurance companies, professional educational institutions and companies. It gives them assistance for decisions in the rehabilitation management concerning persons with complicated course of a disease, complex severe injury or handicap.

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Methods

The point is to lead the rehabilitation/case management out of the rehabilitation clinic and to work in a flexible network using existing regional structures. An interdisciplinary analysis of the situation is drawn up and the potential for rehabilitation is found out. Afterwards, under taking the positive and negative performance-description into consideration, an – independent – recommendation is given to put further measures to practice, keeping an eye on orientation towards getting solutions in networking.

Results and Discussion

Described is the 6 and 12 months follow-up of 30 cases with complex consequences of an accident, most of them with head injury. The persons were in the mean 37 years old, had had the accident 5 years ago, about half of them were unemployed when they came to the clinic and they were in the mean 37 months unfit to work.

In each case a concrete instruction for the way of acting was given, with suggestions to medical, social and vocational measures. For example one young person, who lived in an old people's home, could immediately been taken in for a specialized in-patient development programme, in other cases nursing could be optimised or concrete suitable occupational qualification could be determined and introduced without losing any time.

Conclusion

This rehabilitation/case management opens in networking – co-ordinated with all persons involved – rapidly the way that offers a performance-oriented participation in the working life and in the society and is economically tenable for all persons involved.

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Working group V, Session 4

Business and Political Economic Potentials of Cost Savings Because of Intervention and Networking in Plant

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Because of increasingly globalised strategies in management and business, automation- and changing technologies in production of companies aiming at the maintainance of the ability to compete in strongly competitive markets, human beings in the work process are considered often as second choice.

For the personal Manager the accounts have priority, their workers are just means to an end, have the purpose to function. Workers, especially older workers have been victimised quite frequently already by changes in the world of work.

Illness, time of absence caused by working conditions, augmented measures of rehabilitation, early retirement or notice are often the consequence. But it has to be kept in mind, that the workers are the companies capital, which has to be used adequately to the advantage of all participants, which are involved in the corporate process.

The company carries a social responsibility for the workers and adding to this the duty to provide an adequate equipment adjusted to the abilities of the worker. It is not a new perception that ergonomical considerations at an early stage can not only save costs for the company, but are also the base for business economical and to a high degree as well national economical benefit.

Next to the company all responsible social bodies profit of an arrangement which leads to an augmentation of work related contentment as well as the health of workers. At the end of the chain we'll find again the worker, who closes the circle with his contributions or opens it up once more.

Respecting data security ,an forum of information has to provide for transparency, costs can be avoided through aimful measures orientated on workplace as well as by the reduction of waiting time in the rehabilitation process.

This presentation will give examples for potential of the companies, networks in medical, social and vocational rehabilitation and their effects on integration and effectivity will be shown.

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Working group V, Session 5

Legal Framework Aspects for Quality Performance (Regarding "Rehabilitation Before Disability Pension", "Before Chronification of Illness", "Before Longterm Care")

Full Participation from the Perspective of the Persons Concerned

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On the basis of Article 13 of the Amsterdam Treaty, a number of legal measures have been taken, which – considering different starting points, legal framework and citizens' attitudes – aim for equal opportunities for people with disabilities and/or chronic illnesses and therefore full participation in work and society.

Organisations of and for persons concerned are campaigning at European and national level for a legal framework which either prevents the rise of chronic illnesses or helps to reduce/avoid their consequences, permitting the effective use of rehabilitation measures. So people would no longer be forced to leave work at an early stage and would not be in need of permanent care, but of temporary aids at best.

This requires rehabilitation measures to be offered at an early stage. However, prevention measures at different levels would have to come first.

In some European countries, people take advantage of the measures on offer much more frequently than in others. To start rehabilitation measures at an early stage will in practice improve the full participation of the persons concerned.

Measures of prevention and rehabilitation must be available for everyone and organisations must help ensure that offers are actually taken up. So far, there are still deficits of varying degrees.

Efficiency in this field also depends on networking structures including all responsible partners. Doctors, paediatricians, schools, employers, representatives from companies and staff associations, disability organisations, authorities responsible for prevention and rehabilitation must all work together.

The objective is to provide any person concerned with any service he needs in his special case; and to ensure that his active participation in the measures and in the decisions that are taken on them is secured.

Therefore, regarding the legal basis, it has to be a pre-requisite that the persons working for those systems will offer a guaranteed Quality Performance. This comprises professional qualifications including regular further education and advanced vocational training, in special cases an extensive social medical assessment and the immediate availability of the combined services and benefits applicable to that special case.

Working group V, Session 5

Diagnostic Related Groups Challenge the Social and Healthcare Opportunities of Handicapped People

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DRGs and their implications for handicapped people

Diagnosis Related Groups (DRGs) mean that fixed prices are charged for complex hospital services based on certain case groups. DRGs have been introduced in many countries but their scope in terms of settlement of accounts varies greatly. In Germany plans are under-way for coverage of almost all inpatient treatment services, but initially only the hospitals with DRGs will plan, manage and account for their services.

The use of DRGs in hospitals raises the issue of the links to preceding and subsequent forms of care in the healthcare and social services. If the overall economic goal is to combat rising costs, then only a sector-overlapping approach to care will actually prove effective. This will thus bring about the following desirable developments:

- Creation of integrated forms of care with a common per-case budget or a per-person budget, comprising the services of all sectors within the framework of a single care case
- Fixed prices for almost all forms of care, hence also for rehabilitation, nursing and other ancillary services
- An increased interest from the service providers' perspective in providing services on an outpatient basis, thus ensuring consistent implementation of the principle "inpatient before outpatient".

What does this mean for handicapped people?

Per-case prices = standardization

As far as finances are concerned, DRGs will usher in a growing trend away from individual help planning towards standardization of services. The system of help-requirement groups with corresponding allowances, which is in the process of being introduced in Germany, is one such example. However, it has been noted (in hospitals, too) that this system does not function with four or five price groups (help-requirement groups). Rather, what is needed is a clearer distinction which, however, has its own limitations. Otherwise there would be no point in drawing up price groups, in particular as far as planning and managing services are concerned. On the whole, the handicapped person will be assigned by all service providers to one price category and will receive an increasingly more standardized service, which as far as possible will be tailored to this person's individual needs (80 per cent solution).

At first glance this may appear frightening, but on the other hand it provides handicapped people with an important security. This is because the price catalog also entails an obligation to provide a service; this obligation can be verified and compared. In turn, this exerts greater pressure on the service providers to provide high quality service at a competitive price. (§ 93 German Federal Social Security Act).

Efforts to create personal budgets for the handicapped are still in their infancy in Germany. In the last analysis, these are the only solution to this dilemma posed by fixed prices, on the one hand, and individual structuring of help measures on the other. This will help to reinforce the sense of self-responsibility of the individual concerned.

Working group V, Session 5

Increased use of the outpatient setting = Mobility

Increasing price pressure as well as the growing trend in sector-overlapping networking in integrated care will result in increased use of outpatient services. This is accompanied by two developments:

- Growing supply of mobile rehabilitation facilities
- Increased need for handicapped people to be mobile in order to make use of outpatient services

As a result of economic pressure, the handicapped person will have to be more integrated in his/her social environment to avoid hospitalization. While at present this may be a mere political statement, it will become reality as a result of how funding is managed. But here it must absolutely be ensured that in addition to providing technical 'rehabilitation', the social welfare of handicapped people should not be neglected or this should not give rise to a situation where they are isolated within the confines of their own living spaces.

Politically, it is desirable that the hospitals should be opened up for outpatient services. This would mean that the hospital would enter the domain of the medical specialists practicing from their own surgeries (2nd pillar), thus competing with them. In parallel, the proportion of cases warranting unavoidable and paid hospital stays would decline accordingly. In Australia 50% of all cases are being treated in the meantime on a one-day basis. But since the treatment process is not completed after 24 h, the patient will have to attend the outpatient department of the hospital for further treatment or follow-up services. The patient will thus be compelled to become more mobile. In general, handicapped people are less mobile and thus for the time being constitute an obstacle to the hospital treatment processes. Moreover, the issue of mobility costs and of who can bear them is raised. In particular handicapped people, who statistically account for a higher treatment density in hospitals, will have to adapt to marked changes because of this development. Without integrated care matters will tend to get more complicated than simple.

Danger of being passed on

But as long as integrated care has not been implemented, the use of per-case prices poses an enormous danger of patients being simply passed on. With separate budgets all service providers have a considerable interest in assigning the individual concerned as quickly as possible to another service category. This line will end with the patient being in the care of one service provider or not being treated at all. Thus this can result in inadequate care being provided in some sectors and in a decline in the quality of care. Hence there is also less likelihood of being able to integrate the person concerned.

Conclusion

If per-case prices are employed, sector-overlapping networking will be needed not only where the service providers are concerned. Rather, the individual budgets will have to be changed in the context of integrated care to per-person budgets, at least for subsectors of the healthcare and social services. An investigation must absolutely be conducted to establish how the individuality of the handicapped person can be adequately taken into account in these price systems, for example by consistently introducing personal budgets. In this context, the aims of individual measures must be discussed in order to be able to engage in realistic planning. Similar planning systems are in place in programs to help the handicapped, but these must not be degraded to an accounting system.

Working group V, Session 5

"Case Management with the Aim of Preserving Jobs and Job Training Programmes for Persons with Disabilities" (CMB) – Situational Report on the Federal Republic of Germany

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The Bundesarbeitsgemeinschaft für Rehabilitation (BAR) in cooperation with the organisations responsible for the provision of rehabilitation within the classified social security of the Federal Republic of Germany, has developed a case management system aimed at preserving jobs and job training programme participation by the disabled and other persons suffering from long-term, health-related work disabilities. In concrete terms, measures to help these persons participate in occupational life are to be initiated as early as possible and are to focus on individual situations more than was heretofore the case. On the basis of a differentiated analysis of skills and job requirements, the system aims at continuation or resumption of a person's former position, another suitable job or training at the former place of employment, and aims at getting this done quickly, efficiently and economically.

The stated objective of this model initiative is to determine the framework conditions under which case management can be optimized. Scientific experts are accompanying the project. The results obtained from this model project are to form the legal basis for future institutional support of the case management method.

The General Agreement on Trade in Services (GATS) and its Meaning for Social Services

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The GATS, inaugurated in 1995, is a multilateral treaty of the WTO, which sets up a legal framework of principles and rules for the worldwide trade in services. Currently, 144 nations are member of GATS, including all EU countries.

Main objectives of the GATS are the promotion of economic growth and the economic development of the developing countries by expansion of the international trade in services through progressive liberalization of national service markets.

Therefore GATS sets up a legal framework for all measures of national governments affecting trade in services with the focus to remove barriers for trade in services and to open up the national service markets for all GATS members on a mutual basis.

The scope of the GATS is very wide and covers all types of services, including also human services, such as education, health care, rehabilitation and other social services, which in many countries are part of the public domain. Therefore the critics of the GATS, particularly trade unions and civil society groups fear an erosion of public services.

The author presents objectives, scope and mechanisms of the GATS, its presumptive effects for social services and the pros and cons of the GATS as they are discussed by the WTO and the critics.

Working group **VI**

Disability Prevention – A Key to the Future

Session **1** (page 92 – 93)

Disability Prevention in Europe: a Discussion of Examples

Session **2** (page 94 – 95)

Disability Prevention in the World of Work –
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Childhood-related Prevention Issues Regarding
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Programmes for Adults Aiming at Prevention:
Risk Group Oriented Health Strategies & Disease
Management Issues

Working group VI, Session 1

Disability Prevention - a Key to the Future

Disability Prevention in Europe: a Discussion of Examples

Health promotion in Europe – A General Introduction

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The working group VI has the title "Prevention – A Key to the Future". For three days, congress participants (persons with disabilities, representatives of their organizations, helpers, and professionals) will discuss approaches to prevention and – in a more general way – to health promotion in different settings, such as families, schools, working world, community, and leisure, but also in facilities caring for those who suffer from diseases and disabilities. The aims of my introductory remarks are:

- to give an overview of the development of health promotion and prevention in Europe since the mid-eighties (Ottawa charta);
- to present the essentials of the current discussion in Germany concerning an introduction of a "Health Promotion Act".

Focusing on the more specific concept – that of prevention – I will show, that prevention has two meanings in rehabilitation services:

- As a strategy to avoid stress and burnout of the professional staff, prevention becomes increasingly important. However, certain groups of staff (e. g. assistants without formal qualification) benefit from such strategies as an exception only.
- As a new approach to the clients' problems. In this context the dividing lines between "prevention" (and health promotion) on the one hand, and the rehabilitation on the other hand efface step by step. It is the "outcomes" that count – at least for the future. However, the development and implementation of assessment instruments needed to measure and to prove the effectiveness and outcomes of preventive work and of health promotion are only the first task of many which have to be done urgently.

Working group VI, Session 1

ICIDH in Sociomedical Assessment – a Report from the MDK

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Everybody talks about ICIDH (International Classification of Impairments, Disabilities and Handicaps) and the following classification ICF (International Classification of Functioning, Disabilities and Health). In Germany, some people indeed applied the ICIDH. In 1999 the MDK (German medical service of health insurances) made preparations for using the ICIDH in sociomedical assessment.

Purpose

With the increase of treatable chronic diseases and of the number of elderly persons in our society, rehabilitation and social services for compensating disabilities are getting more and more important. At the same time, today social security systems have to control health care costs and to justify their services. Against this background instruments are necessary to present e.g. rehabilitation needs in a comprehensible way. ICIDH is such an instrument. Therefore it is applied in sociomedical assessment of the MDK Berlin-Brandenburg since 2000.

Results

The experts of the MDK Berlin-Brandenburg have been taught to apply the ICIDH when asked questions concerning rehabilitation. For this application the ICIDH has been adapted. For practical reasons we use a checklist of the ICIDH. Codification is not obligatory. Thus, our training was successful. The conceptional model of the ICIDH leads to expertises which are more precise and convincing.

Conclusion

The experience of the MDK Berlin-Brandenburg shows: Applying the ICIDH in sociomedical assessment is possible. It is important and – finally – unavoidable, if rehabilitation is conceptionally clearly distincted from cure.

Working group VI, Session 2

Disability Prevention in the World of Work – A Discussion of Examples

Ability Orientated Disability Management

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International versions of Disability Management were presented in Vancouver, Canada in May 2002, which all referred to the "Code of Practice on Managing Disabilities in the Workplace" of the International Labour Organization. Comparisons are however problematical as social and legal general frameworks differ widely, and in particular because the financial incentive systems underlying Anglo-American developments appear not to be practicable in Germany. At the moment, the Code is however seen as a means of support for the necessary better coordination among the actors involved in the process of rehabilitation, an objective obviously required as well in the SGB IX (social code Book 9 on rehabilitation and participation of people with disabilities).

Because of this discussion, many fail to notice the preventive approaches of the Code, in analogy to the ones obviously contained in the SGB IX with its strong emphasis on priority of prevention.

In Germany, an ability orientated approach lends itself for these purposes, along the lines already discernible in several corporate models. Consequent health promotion which not only is managed relative to the person but includes thorough consideration of working conditions, will contribute to maintaining employability, no matter what an employee's functional health (ICF) is.

Needed as an indispensable basis is an early warning system capable of showing both changes in abilities and changes in the working conditions, putting the right signals for early intervention.

Corporate concepts to this effect deserve appreciation. Financial incentives should however not merely be aimed at acquisition of subsidies and reducing absence from work but should be targeted at supporting employees' abilities, enabling them to react in a flexible and motivated way to ever-changing working conditions.

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Working group VI, Session 2

Disability Management by Ability Management. The Experience of a New Concept to Integrate Handicapped Employees

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Cost comparison of different European production plants resulted in a careful consideration of employees whose productivity was limited due to disabilities. The task was to maintain employment for about 500 people whose medical problems, age and chronic diseases, had lead to disability and to integrate them in normal productive workplaces. The history of these people and their way into unproductiveness was influenced and described by medical restrictions. A new positive approach (including ergonomic improvements of the new lines as matter of course) with IMBA (Integration von **M**enschen mit **B**ehinderungen in die **A**rbeitswelt) resulted into a success story. The cooperation with IQPR and the import of their experience was a very important support. The comparison of abilities of employees and of job requirements helped to reintegrate about 300 handicapped people with normal, productive jobs. About 90 are working on re-insourced easy jobs.

The calculated cost-savings caused a mind-change within management thinking and into a paradigm shift: "Handicapped and disabled employees have an important and productive business impact!" In consequence the intervention project lead to an early prevention concept, which reflects the new social laws in Germany. Ability Management is a business task! With the implementation of a new organisation with the position of an Integration Manager within Ford is an important investment into the future.

Working group VI, Session 3

Childhood-related Prevention Issues Regarding Disability and Social Exclusion Risks (Including the Role of Parents)

Prevention and Rehabilitation of Locomotor Disability in Children

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It is necessary to program:

Premarital prevention

- Premarital Health Teaching Institutions.
- Diagnostic studies: blood incompatibilities, contagious, hereditary and drug risks.
- Premarital studies of the genital canal: narrowness, scoliosis.
- Precocious diagnosis of the risk - mothers.

Gestation prevention

- Avoid unnecessary X-rays and medicaments.
- Controls and echographies.

Childbirth prevention

- Asepsis and training of the medical staff.
 - Avoid premature, hypermature and prolonged deliveries.
 - Avoid anomalous presentations (shoulder, buttock).
 - Avoid hypoxic childbirth.
- It is advisable, early preventive caesarean than a dangerous childbirth.

Prevention in newborn and sucklings

- Immediate postdelivery medical revision (specially risk-children).
- Precocious exploration of head, spine and extremities: preventive application of orthosis (abduction of hips, feeds deformities): monthly revision. To apply polypragmasia
- Vaccinate according to laws of each country.
- Provide good vision from all angles and enough crawling room: prevention of deformities.
- Avoid forced bipedestation and deambulation: let Nature do its work.

Prevention before schooling

Annual revision.

- Early diagnosis of disabilities and precocious adequate therapy.
- Control weight and height: gymnastics and diets avoiding obesity and anorexia.

School prevention

- Annual revision ,according to the development laws.
- Health and hygienic teaching (avoid drugs, contagious possibilities, sex).
- Children back – school.
- Adequate sports.

Working group VI, Session 3

The Hungarian Conductive Education in Cerebral Palsy

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Conductive education (CE) is a centre-based, systematically applied, pedagogical, holistic approach for children with cerebral palsy (CP) and other movement disorders.

There are characteristics, principles and important elements of the system and the method of CE practiced by on BA level trained conductor-teachers.

The well developed Hungarian CE system offers

- organised screening for the very early aged premature babies in loco (hospitals and clinics)
- for high risk infants and babies and
- screening of motor delayed children
- systemic, free of charge assessments and advise for every Hungarian children at every ages with suspicion for CP or other motor dysfunction
- optional admission for CE in the central institute (the Petö Institute, Budapest) out-patient departments, kindergarten or school or in the Hungarian network according to the professional (and parental!) decision, without any other limitations.

The centre-based practice of CE can be applied session wise, intermittently, half-day or whole-day and residential basis. The interval-type CE will be offered and its methodology was developed for those, who can't or won't stay for longer periods at any cause. It is an important form from theoretical point of view also.

The main goal of the first counselling in CE is not the evaluation of the child, but the appropriateness of CE itself and the suit form should be assessed for any given child. The unfinished diagnostics does not mean a hindrance, because the children will and should return to their own physicians in all cases.

The CE methodology serves the early, general development. As any early rehabilitation CE become preventionThe programme of the motor development is included into the integrated, many folded, age appropriate, regular kindergarten and school curricula.

The various CP forms (spastics and dystonic/dyskinetic forms) answer mostly with the benefits of minus signs of CP (somatomotor neglect, lack of motor patterns and dynamic stereotypes, absent of body scheme). Hungarian experiences show that indication of long term CE can be suggested for very young children with tetrapalsy and to those with dystonic/dyskinetic forms at any ages. Short term CE has the place in caring of diplegics and hemiplegics.

The earliest success seems to be the start of speech, the improvement of the visuo-motor coordination, the equalisation of the unfavourable side to the most palsied one in the asymmetric tetrapalsies. The long term CE produces relative permanent changes in the behaviour and intelligence. 17% of the twenties people educated conductively produce off-spring. Hard scientific evidences are still missing.

The fact that CP is a status-like disorder, not really preventable and not really curable, means a huge problem for families, societies, education and healthcare. Our common task to search new initiatives, to develop and refine traditional methods, find other, alternative ways like CE, as a method of rehabilitation of tertier degree for children with CP.

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Early Integrated Assistance

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Motor and/or mental delay disorders in very young children can sometimes be foreseen at birth, but may also become evident in the course of the first two years of their life. Therefore the recognition trajectory is dual in the Netherlands. With disorders that can be foreseen and severe handicaps children and their parents will meet medical specialists immediately. The paediatrician considers it his task to pay attention to restrictions and disorders in other areas as well, in addition to medical aspects, and can refer to institutions with specific expertise.

If the disorder does not become evident until the course of the first two years, parents and child follow the standard trajectory. In the Netherlands, parents of young children will visit child health clinics. These clinics focus on the monitoring of the physical, cognitive and socio-emotional development of children from immediately after birth until the fourth year. Physicians and district nurses cooperate here. If a child's development is not satisfactory, parents will usually mention this at the child health clinic first. Then the child health clinic may refer, often through the general practitioner. In many cases this will be to a paediatrician who will examine the child medically.

For the treatment of delay and functional restrictions children and parents may turn to two different assistance circuits: the circuit for physically handicapped children or the circuit for mentally handicapped children.

Both circuits have different expertise. The rehabilitation centres, that focus on physically handicapped children in particular, are mainly specialized in the provision of integrated paramedical and medical care and diagnostic processes. In the circuit for mentally handicapped children the Social Services for the Learning Disabled and the day care centres for mentally retarded children focus primarily on parenting support in the home, on stimulating cognitive and socio-emotional development of children and they help the parents in their coping process. According to the parents, the care organisation results in a number of bottlenecks, that they made known to the Ministry of Public Health, Welfare and Culture. These were the origins of the project Integrated Early Assistance.

The essence of this project is to generate cooperation between the expertise, developed by various fields and institutions, with the objective of being able to provide integrated, demand-oriented assistance, that is given at the right moment.

On the basis of the target group's assessed bottlenecks and characteristics the solution as developed in the project Integrated Early Assistance is described. In addition, the results of an evaluation study among parents and social workers in the five pilot regions after completing the project, will be presented. Finally there will be a description of how to proceed with Integrated Early Assistance.

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Health Promotion for Children and Teenagers in General Practice

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Introduction

Many children and teenagers react to too much strain in school, family and leisure time with psychosomatic, functional and chronic illness. Therefore preventive research refers increasingly to the development of programs for the reduction of teenagers harmful health behavior.

Method

We asked general practitioners and paediatricians to what extent they speak in their offices with children and teenagers about health promotion topics and we asked them about their interest in a cooperation with schools to promote prevention. A standardized questionnaire was sent to 110 general practitioners and paediatricians.

Results

General practitioners and paediatricians from the area of Hannover sent back 51 of 110 questionnaires. 80% of the physicians estimated parents and pupils knowledge about health promotion as average or modest. More than 95% of the physicians showed interest in a cooperation with schools to improve the health education. On the other hand most physicians indicated talking little with children and teenagers about health promotion in the past.

Summary

General practitioners estimate children and teenagers knowledge about health promotion as modest. Simultaneously exists a high interest in a cooperation with schools to develop a program for health education.

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Programmes for Adults Aiming at Prevention: Risk Group Oriented Health Strategies & Disease Management Issues

Structured Treatment Programme for Type 2 Diabetes Mellitus

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Despite steadily rising costs in the health service, the number of heart attacks and strokes are still high and at the same time they are the most common cause of the dramatic increase of mortality and morbidity of diabetic patients. This is, as before, the unsolved main problem of the diabetes therapy today. In Germany, women with diabetes have a six times higher risk of having a heart attack in comparison with non-diabetics, the heart attack death-rate is also six times higher. In men with diabetes these risks, in comparison to non-diabetics, are about four times higher. Despite the increase of expenditures for the prevention and treatment of heart disease, it has not yet been possible to reduce this higher rate of cardiovascular complications. On the opposite, some examinations have even shown the trend over the past twenty years to be increasing. The rate of amputations in diabetes patients in Germany is in comparison to the non-diabetics ten times higher. These high numbers of amputations have not decreased in Germany in the past twenty years.

A critical analysis of the mismanagement of diabetic patients in Germany defines three main causes for the failure of medicine in the undertaken trials over the years to reduce the higher cardiovascular risk of diabetic patients:

1. Wrong therapy goals.
2. Too seldom use of proven useful interventions.
3. Too often use of uncertain medicines.

To improve the prognosis, i.e. the reduction of the high morbidity and mortality of diabetes patients, it is urgently necessary to make a nationwide change of the therapy strategy. These interventions should include:

1. Introduction of a structured treatment programme to accomplish the known useful interventions.
2. A consequential use of the methods of evidence-based medicine in practice.
3. Patient-orientated, concrete and independent information for practitioners.

Networking in Practice

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In 2002 legislation introduced disease management programs in the German health system. The first two programs cover diabetes mellitus type II and breast cancer. The disease management programs are combined with financial transfers between the health insurance companies to set impulses for improving the medical care for chronic diseases by insurance companies. The programs start at the point of clinical diagnosis of illness and require an inscription of the patient. Primary Prevention is not part of the disease management

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programs, but will probably be added step-by-step by the health insurances themselves. The programs base on medical guidelines following the principles of evidence based medicine, a profound impact of quality improvement is expected. The programs contain further impulses to improve the quality of medical care by elements of quality management as e.g. regular and standardized documentation of key parameters by the doctor, feedback-reports to the doctor basing on these documentations, support of informed decision making by the patients, improving the responsibility of the patients for secondary and tertiary prevention and improving their compliance. Finally the legal settings require, first time after 3 years, evaluation of the disease-management-programs.

The Significance of the Amputee Initiative (Amputierten-Initiative e.V.) within the Interdisciplinary Competence Network for the Elimination of the Current Care Deficits of Angiopathic Leg Amputees

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An amputation of the limbs causes most significant complications for blood circulation in the lower limbs. Every year approximately 40,000 to 60,000 leg amputations are carried out in Germany, although one of two amputations could be prevented by diagnosing in time and offering sufficient therapy.

In retrospective, structural deficiencies have been found which resulted in amputations of the lower limbs for patients with peripheral arterial disease (PAD). According to the findings, family physicians would hardly refer their patients to specialists, i.e. angiologists or vascular surgeons, that is, physicians might withhold sufficient, interventional, preserving and operative therapy from their patients.

Referral to a nearby hospital often happens at a progressive stage of the disease when urgent treatment is needed, a hospital where only a general surgeons department is available. General surgeons amputate higher at the leg than vascular surgeons do. In comparison to an expert's treatment amputated patients treated by general surgeons have to stay 2,8 times longer in a hospital.

The Amputierten-Initiative e.V. tries to help reduce those structural deficiencies in many ways depending on the objectives of the different patients needs.

1. Cooperation with medical specialists and their specialists representations
2. Cooperation with the Associations of physicians such as Kassenärztliche Vereinigung and die Ärztekammer
3. Lectures at medical symposiums or congresses
4. Information and public relations work for amputees and people who might face an amputation
5. Referrals to vascular specialists especially before amputations

Objectives, which are increasingly implemented successfully, are:

1. Reduction of the number of secondary amputations
2. Cut-back of the number of amputations of the second leg
3. Benefit of quality of life for amputees and a better life expectancy
4. Decreasing the amount of limb amputations.

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Evolving Healthcare Through Internet Disease Management and Shared Care

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In the last 2 years NetDoktor has transferred its consumer facing experience to clinical applications. The development of a system capable of supporting disease management and shared care has transformed NetDoktor's business and is assisting in the evolution of healthcare from a disjointed process with little patient involvement to a coordinated system where the patient plays a key role.

The first implementation of the system has been to manage asthma in Northern Denmark. There, NetDoktor has worked with the clinical teams to configure an application for the following functionality:

- Patient education through e-learning initiatives
- Remote monitoring and surveillance of asthma
- Creation of a strong peer support network
- Sharing of clinical data between disparate clinical teams and the patient.

This has enabled patients to become fully engaged in their own care by facilitating self-management. Measurable outcomes from the study include: medication usage, frequency of asthma symptoms, number of acute asthma attacks and patient satisfaction.

Future applications for the system include coronary heart disease, diabetes and hypertension. The presentation describes the functionality and issues surrounding the implementation and assessment of the system of asthma management in Northern Denmark and its extension to other conditions.

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Elderly People with Disabilities

Geriatric and Gerontopsychiatric Rehabilitation – its Contributions and Successes

Evaluation and Empowering of Motivation in the Geriatric Rehabilitation – Contents and Goals

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The continuous dialogue between therapists and patients is part of our understanding of rehabilitation.

Therefore the patient's ability and readiness for cooperation is necessary, which is based on motivation. This is the cause that one of the most important tasks of rehabilitation is the promotion of motivation.

We have analysed the motivational level of geriatric patients in the beginning of a special rehabilitation after different acute diseases.

The motivational situation was measured by a special questionnaire.

64 of the 96 patients with an average age of 77.9 years were female, 29 patients suffered a stroke, and 51 patients had fractures mostly of the femur near the hip. Further 18 could not take part because of aphasia, demential syndromes or affect incontinence.

The reasons for motivation having impact on the process and arrangement of rehabilitation were individually different.

A lack of motivation may be presumed only if psychic and psycho nervous disorders can be excluded. Therefore patients with endogenous depressions, neglect syndromes and primary and secondary psycho organic disorders were not of this investigation.

We have found a lack of motivation in 17 patients. Certain formulations gave concrete hints on motivational problems. They are of three different kinds:

1. Individual problems of the patient, e.g. in concerns of education, profession or character
2. Problems linked to the professional staff
3. Problems occurring because of certain circumstances of the rehabilitation as other patients, contacts to relatives or material equipment.

We would have a very good chance of promoting motivation, if we can solve these problems and signalise that we are able to understand the patient by being empathic. Taking all points into account it can be concluded that geriatric patients could achieve a good rehabilitation level even if they had a bad motivational level in the beginning of the rehabilitation.

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Elderly Citizens and the Challenge of Protection from Avoidable Care Dependence

Perfectly Unhappy - Issues of Mental Health and Residential Living for Elderly Women with Intellectual Disabilities

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There are men and women with disabilities, the issue "gender" as life determining factor, however, is easily ignored. Simultaneously, the number of elderly women with disabilities in Germany is continually increasing. Female seniors with intellectual disabilities are particularly found in residential homes. Their life stories and circumstances differ considerably from the "so-called" normal biography as to the basic dimensions of life management (self-esteem by being appreciated, social orientation in familiar contexts social backing in a self-chosen surrounding, normality as to the ability to act). Their chances as to education and supportive measures, their individual life-style as well as their wishes and worries are analysed on the basis of interviews. Thereby it becomes apparent that in fact in the special context of a not self-determined life "typical female" behavioural patterns can be observed, however, a "typical female" biography cannot be lived. The effects of always having been exempted from social duties as well as the lacking availability of traditional roles is discussed from a gender specific point of view.

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On Self-Helping Groups in the Process of Coping with Aphasia – a Report from Germany

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The West-German self-helping union for aphasia "Bundesverband für die Rehabilitation der Aphasiker" was founded 20 odd years ago in Bonn. The federal political structure of the country is mirrored in regional organisations on the level of the states of the German federation. My home organisation is called "Landesverband Aphasie und Schlaganfall Baden-Württemberg" (Stuttgart). We are following an expanded, "systemic" conception that brings together (1) Aphasics, (2) Relevant others/their partners/family, and (3) rehabilitation professionals with a special interest in self-helping as an aspect of coping with stroke and partial language loss.

We choose four forms of self-help activities to illustrate the contents of our regional work:

- (1) "Begegnung"/meeting others with a similar problem
 - Club Aphasia
 - "talking cure" for spouses
- (2) "family seminar"
- (3) PC language training for aphasics
- (4) Rehabilitation sport groups after stroke

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Occupational Therapy (Ergotherapie) as Connecting Partner in Rehabilitation – a Report from Germany

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Occupational Therapists are working in a variety of medical fields and in different settings. They are engaged in hospitals, day-care institutions and in private practices as well. This way they are the ideal connection for ongoing therapy after the patient has left the hospital.

In **Paediatrics** the overruling goal is to achieve competence of behaviour as best possible. Thus even children with disabilities in concentration and endurance can be treated to be able to attend regular schooling at the age of 6.

In **Orthopaedics** one of the fields of OT is the manufacturing and training of splints before or after hand surgery. Also prevention and protection of the joints especially for patients with rheumatic diseases are aims.

In **Psychiatry** the main goals are development, improvement and upkeep of psychic basic functions like self-confidence, motivation, endurance and flexibility.

Vocational Therapy (Work Therapy) is a field of OT, where a working situation is anticipated. In the beginning the patients have to regain endurance, concentration, day- and time-structure and to gain more motor and vocational skills for a job to take.

Patients in **Neurology** are mostly suffering from traumata of the brain, apoplex, multiple sclerosis or M.Parkinson. Here not only pathological ways of movement are treated but also neuro-psychological disabilities.

In **Geriatrics** patients show multi morbidity in older age, in addition often combined with dementia. Here the OTs goal must be to activate the functional ability for movement and skills for activities of daily living.

Two examples of cases will be given: (1) Treatment of early stroke, (2) Children with learning disabilities.

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Barrier-Free Living Conditions and Disability-oriented Policies for Elderly Citizens

Is There a Common Ground?

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The conjunction of the Second World Assembly on Aging calling for equal rights for the world's elderly, and the United Nations' decision to explore the need for an international treaty on the human rights of people with disabilities, has brought to light a parallel situation:

- People with disabilities are enjoying greater life-spans than ever before, often attaining old age;
- More and more aging people are developing age-related disabilities.

Both groups of older people, those with life-long disabilities as well as those with late-life disabilities, are demographically significant and will be even greater in number as time goes on. Members of both groups may confront handicapping attitudes and policies in their respective societies. Disability, old age and poverty are closely intertwined. Thus the life experiences of these two groups may be similar. But are they compatible?

To counteract double discrimination, should older persons' federations and disabled peoples' organizations join forces?

The Realisation of a Barrier Free Living Environment for Senior Citizens in the Netherlands

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Demographic factors underline the need of an impulse in the realization of new living arrangements of seniors. R&D efforts are directed towards the development of accessible housing arrangements and the realisation of new care arrangements. This involves the reconstruction of existing housing arrangements and the realisation of new buildings. The role of technology at home is becoming more prominent, not only in preventing physical barriers or dissolving existing ones but also by giving support to services and care delivered at home. This can be done by technology installed in the house (domotics) supplemented with a services and care support organisation. A characteristic of present Dutch policy is the ambition to strengthen client involvement in all areas related towards independent living of seniors. At present senior citizens are highly unfamiliar with the possibilities and potentials of technology at home. A series of stimulatory measures have been developed to correct this situation. Also initiatives have been developed to gather user related experiences with these technologies and services. Based upon own experience in contract research in the area of implementation of domotics technology this presentation will cover recent developments related to the creation of a barrier free living environment for senior citizens in the Netherlands.

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Hospital Social Services as an Advisory Centre for Appropriate Living Conditions for Elderly People with Disabilities

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The hospital social services are faced with a complex system of services and insurance-related tasks when caring for elderly multimorbid persons after discharge from hospital. These are enshrined in Books V, IX und XI of the German Code of Social Law, the Federal Social Welfare Act as well as in regulations at Länder level.

The social worker, in cooperation with the hospital physicians, must ensure that e.g. rehabilitation facilities for the elderly are applied for and implemented.

He/she must find a solution with the person concerned (patient). In doing so, relatives and the immediate social environment must be taken into consideration, the desires of both parties taken into account and a consensus reached.

In addition, optimal use should be made of the right to the services and benefits from the different paying authorities. Often protest procedures are needed because, at a time when financial resources are scarce, these authorities take a restrictive approach. A further aspect is that hospital stays are becoming increasingly shorter, and this puts the person concerned under enormous pressure when having to make decisions.

Only with good discharge management on the part of the hospital social services can the quality of life of elderly people with disabilities be assured and their extensive independence preserved, based on self-determination.

Residential Needs and Residential Planning for Elderly Persons with Mental Handicap in Germany

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Getting old has become natural. Today, in the western world the period of retirement amounts to roughly a third of the adult life. But no until the past decade real attention has been given to persons with mental handicap in Germany. This is doubtless also due to the fact that a demographic gap makes this group of senior citizens barely recognizable. This gap arose in the 40s of this century, when the National Socialists systematically killed between 70,000 and 100,000 persons with handicap, considering them as "useless eaters" and "burdening characters". Thus it is the post war generation of persons with mental handicap which becomes significantly discernible as a future cohort of "elderly people".

In Germany adult persons with mental handicap in older age predominantly live in special (in-patient) facilities. The death of their parents at the latest as well as the non-existence of a personal social net make a life in private households, outside special facilities almost impossible.

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Residential facilities who in principle acknowledge to accommodate people to the end of their days are increasingly concerned with the question of creating adequate general conditions for the elderly residents. As prerequisites for a successful aging they name architectural changes (17.4%), changes within staff (32.6%), structural changes (47.8%) as well as the use of technical aid (2.2%).

An improvement of the living situation of persons with mental handicap requires an orientation towards an aim and a concept according to which changes are possible. It is primarily a change towards a view which combines the individual needs of the residents and their living situation. If old age is no longer seen as a stage independent from all earlier stages and with specific rules, it is not enough for the special facilities to divide the residents into groups according to their age, or to think out adequate services after considering the need for care.

Of course, opportunities which have not been offered by society can normally not be made up for by special arrangements. However, this is no reason to let go in the attempt to find adequate services for the German pioneers of old age among the persons with mental handicap. One method of quality securing and developing, which can be conducted through a permanent exchange between facilities, staff and elderly residents is the so-called Five-I-Program.

Based on the Five-I-Program we might succeed to discover the residential needs of elderly persons with mental handicap and improve their happiness.

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The Market of "Intelligent Products" for People of an Advanced Age with Disabilities

Why Did we Overestimate Market Potential of Senior Applied Products? Old and New Product Visions for Senior Households

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Our society places high value on the ability of individuals to design their lives on their own terms, especially to maintain an own household. In old age, however, physical and mental limitations can make it difficult or even impossible to live independently at home.

Household appliances specially suited to older people can help us meet our everyday needs at home for years to come. Despite its (growing) demographic significance there has been fairly little market success. Indeed common appliances for seniors tend to encounter rejection because they are stigmatized as products which stem from rehabilitation technology or have been developed as technical aids for the handi-capped.

The paper identifies four main reasons for the relative small market penetration and presents new concepts and visions of senior applied technology with a brighter market future.

The main hypothesis is that in this context the development of new technological facilities could be the key issue but that some preconditions with regard to technical and social criteria have to be fulfilled.

These new products and services can improve the quality of life and independent lifestyle of elderly people.

The paper will focus on results of the Sentha research group at the Technical University Berlin.

Improving the Quality of Life of Elderly Invalids Through Use of Rehabilitation Aids

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The basic document defining Russia's official policy on invalids is a law adopted in 1995 on "social safeguards" for invalids. The law states that invalids in Russia have a right to a dignified and full life and stipulates the creation of conditions that would eliminate any barriers that might exist between invalids and others. In the wake of the law, there has developed in Russia in recent years an industry devoted to the development and manufacture of mechanical and other devices for rehabilitation purposes. These include automotive devices, wheelchairs, crutches, walkers, devices for home and work situations, specially legible types for the vision-impaired and prosthetic-orthopedic devices. Experience has shown that those most in need of aids (wheelchairs, crutches, walkers, canes, and so on) are invalids with impaired ambulatory function. Invalids with impaired hearing or impaired vision and

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the like also need special aids. Currently, in the largest cities and regions of Russia, Technical Rehabilitation Centers are being created whose basic mission includes finding those who need technical aids and providing them with them.

For elderly invalids, rehabilitation principally focuses on work-related, mass culture-related, home- and community-related and social-psychological measures. All this requires the careful selection of aids and their individual adjustment. The current social-economic situation makes the development of a technical rehabilitation industry all the more urgent. Patient-appropriate work and social activity, made possible by rehabilitation aids, do more than stimulate the development of compensatory mechanisms and prolong life. They also mean income and financial support, vital in the new market conditions in Russia.

Our work is aimed at determining which technical rehabilitation aids are needed by elderly invalids of a variety of kinds.

We have had 10 years' experience at the Federal Rehabilitation Center working with invalids of various age groups, including pre-pensioners and pensioners in the age range of 50 to 65 years. Russian law, it should be said, stipulates age 55 for women to go on pension and age 60 for men. For our study, we have selected 200 invalids, ages 50 to 65, of whom 120 are women and 80 are men.

In terms of age, 170 of the 200 were between 50 and 60 years of age, which means that they had real chances to live full lives for a considerable time. The basic pathology underlying their invalid condition involves problems in the functioning of the heart/circulatory, respiratory and endocrine systems; the body's support-ambulatory apparatus; vision problems, and hearing problems. It is not unusual for vision and hearing problems to be found in patients who have had amputations or breakdowns of some other bodily system. We have determined that 80% of our group suffered from problems of the support-ambulatory apparatus to one degree or another. The pathology presented itself in the form of illnesses of the central nervous system (strokes, brain injuries), the spinal cord (osteochondrosis, Bechterev's disease), illnesses of the upper and lower limbs (peripheral paresis, post-amputation problems). Of the group, 75% showed an accompanying pathology; thus, for example, spinal cord illnesses were accompanied by heart and lung diseases, while those with post-amputation problems of the limbs suffered from endocrine pathologies or diseases of the inner organs. Of our group, 45% showed a combination of arterial hypertension, ischemic heart disease and strongly marked malfunctioning of the support-ambulatory apparatus. It is thus quite clear that ambulatory system breakdowns with consequent decline in mobility have a negative effect on the operation of the heart and lungs and lead, over time, to heightened arterial pressure. This condition, in turn, leads to the limitation of physical activity – in effect, a vicious circle.

We analyzed our patients' needs for rehabilitation apparatus. We found that the majority of patients of this age group (86%) needed some form of rehabilitation aid. We conceive of aids as falling into three groups: (1) devices to improve mobility (wheelchairs, crutches, walkers, canes); (2) devices needed for everyday functioning (special fittings to ease functioning in bathroom, kitchen and with telephone, for personal hygiene and so on); (3) devices for work – as carpenter, metalworker, artist, user of computer, and so on. We conducted a separate survey of needs for specially configured automobiles.

We took particular note of invalids with impaired functioning of the support/ambulatory apparatus. We found an approximately 20% need for wheelchairs among this group of invalids, of which 8% might be considered a temporary need for patients awaiting lower-limb

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prostheses. More than a third (38%) of this group used crutches and walkers of various modifications (with rollers and without). Forty-two percent used canes for balance while walking or to favor injured limbs. We found that instruction in the use of canes was not always correct. Lengths were not always properly designated, nor the correct end for putting to the surface, which sometimes undermined the development of compensatory mechanisms. About 40% of the patients were found to need devices for taking care of their own needs and for operating in their everyday environments. Overall, these are devices for the bathroom, kitchen and garden. Invalids who have lost both upper limbs needed individually configured devices to eat, take care of personal hygiene and to dress. These devices included an attachment for removing shoes and socks, for working with a knife, scissors, pencil, pen, and so on. Much work was done with patients who wanted to return to work but were unable to carry out the necessary operations because of limitations in the functioning of the upper limbs. Among the pre-pensioners and pensioners, this contingent made up 27% of the total. Of the 27%, only 12% returned to their workplaces as such, with the remaining 15% finding it possible to work with the help of rehabilitation devices in a home workshop or home garden plot. These devices include a set of attachments for working with keys, chisels, hammers, sewing machines, typewriters, computers, and so on.

All the patients were provided with suitable rehabilitation aids. The devices for domestic and work functions were created in the Rehabilitation Center's experimental laboratory or obtained by the patient on our recommendation from another institution. We found that 13% of the patients needed cars with hand controls and a special attachment for the steering wheel.

A retrospective analysis has shown that rehabilitation devices helped our patients to use their potential more widely and more fully to upgrade the quality of their lives. They felt greater confidence in themselves, and many were able to continue doing work they love, bringing benefit to themselves and their families.

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Developing Intelligent Products for Senior Households – A Multidisciplinary Challenge at the Intersection of Product Developers and Product Users: New Methodological Foci from the Senthä Project

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Since 1997 the research group 'senthä – Seniorengerechte Technik im häuslichen Alltag' (Everyday Technology for Senior Households) has concerned itself with the development of intelligent products for senior households. The multidisciplinary group is coordinated by the Centre for Technology and Society at Berlin University of Technology. The purpose of this presentation is to summarize the most important results concerning participative and co-operative product development in a multidisciplinary context.

Developing intelligent products for seniors is a focus group oriented task in that it has to address the special demands of a specified target group. Only if the products developed meet the demands of that target group can the market of intelligent products for seniors be adequately exploited. In this context, the senthä group worked out an approach that relies on three operational dimensions for target group specific product development: (i) the development process has to take inputs from various academic disciplines into account (co-operative dimension), (ii) it has to involve potential users (participative dimension), and (iii) the product developers have to actively use their experience with the target group concerned (empathic dimension). Integrating various inputs from all of these dimensions, therefore, is the crucial challenge to successfully manage the product development process. The main point of discussion is to relate the benefits of such an approach to the costs.

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Rehabilitation Science and Disability Research

The Perspective of Disabled People: Priority Focus for Science & Research Programming

Programming and prioritising research. Perspectives of people with disabilities – a report from the Dutch mountains

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Healthcare is not a goal in itself. Healthcare is just the means to an end: offering a system to promote or keep up health. But healthcare should also provide assistance to people, who have a chronically disease or have a disability, in preserving or regaining an optimum quality of life. This goal is sadly enough not easy to reach with the current system of healthcare.

Therefore the healthcare system has to change. Which is easier said than done. Knowledge about ways to realise these kind of changes are hardly available.

One could picture 'knowledge' as a kind of multilevel building; but some of its floors are hardly habituated. Theoretical knowledge, the knowledge of policy (policy-problems, policy-choices, implementing a chosen policy, etc.), the knowledge of professionals working in the field of health and healthcare occupy their floors vividly. These floors are often richly endowed with worldly goods as research money, researchers and a facilitating infrastructure as part and parcel of these floors.

But the floors, where one should expect to find identifying and developing experiential knowledge of consumers of healthcare of patients, are empty. Bearers of this kind of knowledge are at best merely asked to re-act on someone else's findings, or more common seen as research objects – as data carriers. It means that their research-questions are never fully articulated and hardly ever researched. This unbalanced habituation of the House of Knowledge demeans the building, the entire building.

Certified changing knowledge is missing. Knowledge about changing the healthcare systems, about enlarging the systems effectiveness in supporting life and living conditions of people with disabilities or chronically diseases.

Empty floors and lack of knowledge do not equal. However filling the empty floor with new ideas and worldly goods will deliver the new knowledge, the new kinds of know-how's that are sought after in exploring new ways of having a good life, also with a disability or a chronically disease.

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Rehabilitation-needs of Patients in General Practice

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Introduction

Doctors are playing a key role controlling the access of patients to rehabilitation. Doctors in practice, especially general practitioners are caring their patients regularly and for a long time. The general practitioner very often is the first professional to be contacted if patients want to take part in rehabilitation-procedures.

Question

The main aim of the non-representative study was to find out the need of rehabilitation of patients in general practice. On the one hand part of the patient presumably has no need for rehabilitation and on the other hand there are probably many patients in each practice who are in a state of undetected need for rehabilitation.

Methods

Within a sample were made surveys with an questionnaire about the subjective condition of patients older than 29 years in three German GP offices during ten working days. Also necessary was the personal contact with a doctor because general practitioner doctor should give make a simultaneous evaluation of the patient. Chosen as a suitable instrument asking the patients was an instrument frequently used in German rehabilitation-clinics ("Indikatoren des Reha- Status (IRES)" from N. Gerdes and W.H. Jäckel). It was developed to provide an extensive instrument imaging the most important current aspects of the rehabilitation-status of the patients. The rehabilitation-status encloses the patients somatic, functional und den psychosocial status. At the same time take place an evaluation of the patients filling in the IRES-questionnaire by the general practitioner not knowing the patients anweres for which was developed an own questionnaire.

Results

Altogether at the study take part 181 patients. The rehabilitation-status according to IRES was "serious" at 31% of the patients, "exceptional" at 34% and "normal" at 35%. General practioners found a rehabilitation-procedure to be "suitable" in 38% of the patients, "rather suitable" in 25%, "rather not suitable" in 13% and "not suitable" in 24%. In 65% of the cases the results of the questionnaire and the doctors' ratings are corresponding. In some cases the patients felt completely healthy although the results of the questionnaire and the doctors' statements rated them being in need for rehabilitation. Other patients in need for rehabilitation rejected it for other than health-related reasons.

Conclusion

The results of the study give evidence to general practitioners' key role for patients' access to rehabilitation. Discrepancies between the patients needs and demands for rehabilitation could be showed and solved in a better way by a standardized screening.

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Research on Self-Help Initiatives in Germany - an Overview

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Health related self-help groups and organisations receive increasingly financial support by the German social security system and become more and more part of the health care system. Thus, the Federal Ministry of Health finances this expertise regarding the research in Germany in this field.

The foundation of this expertise is an inventory of all research projects on self-help initiatives. A questionnaire was sent to all relevant faculties and departments of universities, universities of applied sciences, private research institutes and to self-help organisations (n= 800).

The results of this review show, that health related self-help initiatives make an important contribution to the German health care system. Especially self-help groups increase mutual aid and social support, knowledge about the disease and its consequences as well as possibilities for changing attitudes of the group members and their social environment. They disburden the primary social networks and families of the afflicted persons and reinforce the 'intelligent' utilisation of the professional services of the health care system. There has been almost no systematic investigation of the activities of self-help organisations yet, except from counselling services.

In order to involve greater parts of the chronically ill and handicapped in self-help activities, an intensified co-operation of self-help initiatives and rehabilitation facilities is suggested.

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The Evaluation of the Activities and the Participation of disabled With Disturbances of Biosocial Functions

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The aim of the study - to evaluate the disturbances of activities and participation of the disabled with determined III functional class by New York Heart Association Functional classification (NYHA) and compare with the disabled of the II functional class by NYHA.

The contingent - 135 disabled due to cardiovascular disorders, average 51,8 years, who were examined in our scientific and practical laboratory of the rehabilitation of the disabled. After clinical examination and carrying out ECG and stress tests we determined that 51 patient belongs to III functional class by NYHA and 84 – to II functional class by NYHA. The activities and participation were evaluated in accordance with the International Classification of Functioning, Disability and Health (ICF, WHO, 2001).

The study showed the remarkable disturbances of the mobility (walking, moving, using transportation), domestic life (household tasks and assisting others), major life areas (work and employment). Less disturbed – general tasks and demands (undertaking single or multiple tasks, carrying out daily routine, handling stresses), learning and applying knowledge, impersonal interaction and relationships, community, social and civic life and entirely undisturbed communication and self care activities. The disabled of the III functional class by NYHA were determined to have severe or complete difficulty of activities, meantime the disabled of the II class were determined to have moderate or mild difficulty of activities and participation. (ICF, WHO, 2001) Results lead to conclusion that the activities and the participation of disabled due to cardiovascular should be carefully evaluated while organizing rehabilitation team and treatment.

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Accessibility and Assistive Technology as Subjects of Rehabilitation and Disability Research

Accessibility and Assistive Technology as Subjects of Rehabilitation Sciences and Disability Research

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In our European context technology is present almost everywhere we go. Technology has a great impact on our life and an enormous potential to support us. In relation to rehabilitation and disability technology plays an ambiguous role, first facilitating and supporting second raising new barriers and excluding people. The function of rehabilitation sciences and research related to technology is therefore on one hand to identify and use the positive potential on the other hand to monitor threats, avoid or remove barriers. The underlying targets are to facilitate full participation and improve the quality of life within the given constraints of technological feasibility, social economics and user acceptance.

With the paradigm change of understanding disability from a medical to a social model (ICIDH, ICF) and the omnipresence of technology the concept of accessibility became also subject of change. Traditionally, it was the complement of rehabilitation technology in the built environment, like ramp and wheelchair. Today we consider concepts like "design-for-all" or "universal design" (UD) or "barrier free design" in relation with accessibility complementing assistive technology (AT). The concept change is twofold: the range of consideration is broader from the traditional accessibility subjects to access to information and communication technologies and related services (e-learning, e-shopping, e-...); it is further identified that the benefit of access measures for all can be so important, that it is no longer considered as a social accessibility action but as a market and profit oriented improvement of products and services for everyone. UD as a market concept will only be implemented if it actually meets the needs and wishes of a considerable market at a commercially profitable price. This connects our research field to general usability research and market research. Beyond this general market we have to come back to accessibility and assistive technology as socially induced special measures. This kind of accessibility can therefore be understood as compatibility with AT. The current understanding of AT is also a much broader than traditional rehabilitation technology. It covers all aspects of life and crosses sometimes the boarder to mainstream products. Much of the current accessibility and AT research in the EU and US deals with flexible, adaptable or adaptive user interfaces through modern information and communication technology. This is often combined with new outpatient service applications. In the research methodology itself concepts of user centred or even user driven research have been added to the conventional approaches.

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Accidents – ‘The Scourge of Europe’, how Planning and Design Can Reduce Costs and Frequency

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Background

Falls are a major cause of mortality and morbidity, especially in the older population, and a growing socio-economic concern. Resulting injuries produce personal pain and suffering as well as enormous costs to health and social care. Falls account for two thirds of home accidents and are the sixth leading cause of death in the over 65's. In 1990 the estimated number of hip fractures world-wide was 1.66 million (1). Accidents may be caused by poor health and fitness, inappropriate footwear, poor amenities, poor lighting, but frequently by bad design of environment, buildings and transport, including slip / trip hazards. WHO, ECOSA, EU, have set targets for reductions in numbers of deaths from accidents (2,3,). There is no agreed prevention strategy and effectiveness of prevention measures.

Method

This paper cites specific research and proposes good practice guidelines for accident prevention. This includes a review by the USA and UK Geriatric Societies (4) and a randomised controlled clinical study in older community dwellers, aged 65 and over, resulting in reduction of secondary falls by over 50% (5).

Discussion and conclusions

Assessments, including Daily Living Scales, Falls Handicap Inventory, and Environmental Hazards Checklist, highlight statistics for hazards, need for improved design and finish of walkways and footwear, as well as use of good practice methods as in accident prevention to benefit individuals, their families and socio - economic factors, in extending independent active life.

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Impact of the World Health Organization's ICF in the Rehabilitation Sciences

ICF: the German View

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Introduction

"Disability" is a health-related term. That means the disability process begins with a health problem, for example a disease, disorder, injury, or trauma. Independent of the health problem an individual may then experience disability as a phenomenon in its own right, which hinders him or her in performing activities he or she wants to do, or in living an independent life, and the disability process may develop a momentum of its own. For this reason, "disability" is a phenomenon which is to be regarded over and above any existing bio-medical health problem.

In 2001 the World Health Organization (WHO) published the International Classification of Functioning, Disability and Health (ICF). It has replaced the ICIDH (International Classification of Impairments, disabilities and Handicaps) of 1980. The most important differences of both classifications are as follows: (1) The ICF is based on a comprehensive bio-psycho-social model including contextual factors, (2) it conceptualizes the term "functional health", (3) it regards both, resources and deficits. For these reasons it can fruitfully be applied in all fields of rehabilitation and social medicine evaluation.

When the second German translation of the ICIDH was published in 1995, the revision of the classification was already underway - a process in which Germany took part. A German ICIDH Working Group has been established which includes associations of people with disabilities, social security institutions, as well as societies and ministries in the fields of rehabilitation. A large group of professionals translated the so called Beta-1 version, Beta-2 version, and the final version of the ICF without royalty. The Department of Rehabilitation Sciences of VDR co-ordinated the revision work between Austria, Switzerland and Germany. The German Version of the ICF is now ready for publication.

Applications of ICIDH and ICF in Germany

The ICIDH or ICF respectively has been taken in account in the following areas:

1. ICF plays an important role in the training for the medical field "Physical Medicine and Rehabilitation".
2. The ICF is also included in the curricula of the medical specializations "Social medicine", and "Rehabilitation".
1. In 1996 the Federal Ministry of Education and Research and the German Pension Insurance initiated the joint research programme "Rehabilitation Sciences". The programme has an overall budget of 40 Million Euro. The programme includes some projects dealing with the ICF. One project aims at the development of disease specific ICF check lists.
2. The model of consequences of diseases (ICIDH) is part of the rehab quality insurance programme of the German Pension Insurance.

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5. The German Health Insurance applies codes of the ICDH when granting both the prolongation of rehabilitation measures, and Caring Insurance benefits.
6. We are planning to develop a German adaptation of the ICF which meets the special needs of Rehabilitation in Germany (e.g., cardiac or oncological rehabilitation) and of social medicine evaluation (e.g., earning capacity).

The new German Social Code No. IX (SGB IX) – Rehabilitation and Participation of People with Disabilities – was developed during the revision process of the ICDH. It is based on the bio-psycho-social model of the ICF, and it explicitly uses the word "participation". However, the historically rooted special features are also taken into account, for instance, individuals who are threatened by disability have the same social rights as individuals with disabilities. Moreover, the new German Anti-discrimination Act (March 2002) explicitly refer to environmental factors in the sense of barriers and facilitators.

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Putting the ICF into Practice. Development in Switzerland

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This paper will offer a brief description of the development of the ICF in Switzerland. Some account will be given of development towards implementing the classification as well as of initiatives and projects undertaken in various areas concerning adults and children. Two examples of implementation will be provided. The first is related to the re-organisation of a rehabilitation unit, the second is the application of the ICF framework in regular schools, aimed at identifying the special needs of children - and their environment.

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Facilitating Participation. The ICF as Guideline to New Ways in Rehabilitation

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The shift from a medical to a social model of disabilities demonstrates the importance of the environment in which a disabled person lives. Not physical impairments but the interactions between a person and its environment are decisive for the experience of disabilities and the needs for rehabilitation. Accordingly the life situations of persons with disabilities are different in different environmental settings. The question is, whether certain characteristics of a person are seen as disability or gift, whether they support or prevent personal development and whether they enable or disable persons to participation.

One approach to examine the bio-psycho-social life situation of a person is the ICF (International Classification of Functioning) (WHO 2001). In difference to the former ICIDH the ICF takes the environment of an individual into account. The analysis of environmental factors in interaction with individual life situations points to the process of disablement and resulting rehabilitation needs as well as to the use of resources in a specific social-cultural context. A high degree of participation indicates a good fit between an individual and its environment and goes along with the availability of sufficient personal and social resources. In view of this participation is start and aim of resource-centred rehabilitation.

Against this background first results of a cross-cultural project that is conducted at the Universität Dortmund are presented.

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Methodical Procedure in Diagnosis Against the Background of ICF

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According to the ICF approach diagnostic and assessment can be consequently classified into three dimensions: diagnostic of functions and structures, diagnostic of activities and diagnostic of participation (WHO 2002). Complementary it is necessary to consider the environmental and personal factors.

The differences of those three dimensions will be described with respect to the characteristics: units of analysis, mode of performance provocation, parameters for judgment, and methodical procedures (Nellessen 2002).

By means of different examples it will be demonstrated which approach should be chosen for evaluation in the rehabilitation process. In this context current recommendations for diagnostics in medical rehabilitation (BAR 2001) and social-medical evaluation will be reflected. Further consequences for research in the field of rehabilitation will be pointed out.

Beyond this the differentiation between the terms "capacity" and "performance" set up by the WHO will be discussed. Performance describes what an individual does in his current environment (it considers the involvement of a person in life areas). Capacity describes an individual's ability to execute a task or an action in a uniform environment (neutral, standard and universal). Capacity means the highest possible level, which a person can avail in a domain of activity. How far it is possible to measure "capacity" will be discussed against the background of the general situation- and task-specified measuring of performance.

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The "Market" for Rehabilitation Research in Europe: Initiators, (Paying) Principals, Clients, and Target Areas

Consumer Involvement in Research

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During the last decade health research policy has been changing. Both patient organisations and governments increasingly plead for the involvement of health care consumers in the identification and priority setting of health research topics, the design and management of research projects, and the interpretation and dissemination of research results.

Several recent governmental and institutional initiatives aim at stimulating consumer involvement in health research processes. For example, in the Netherlands, consumers are members of committees or councils that establish or advice on national or institutional priorities for health research. Attempts have also been made to stimulate research from the consumers' perspective by the formulation and implementation of specific research funding programmes. In the UK, a special advisory group has been established in order to stimulate and facilitate consumer involvement in all stages of health research.

However, in spite of these initiatives, the actual involvement of consumers in health research is still in its infancy. Little research from consumers' perspectives has been conducted so far, and consumers themselves often do not recognise their priorities in research projects.

One of the reasons for this is that ideas and expectations on how to involve consumers in research successfully differ widely. While some professionals prefer to involve consumers in research by only informing them about research results or at best consulting them about research priorities, consumers prefer to be involved in decision-making processes themselves and want to be heard and respected. A structural methodology for the implementation of consumer involvement in research is lacking.

In this presentation I reflect on some strategies for consumer involvement in research. Referring to the specific knowledge and experiences consumers could bring in the research process, I will propose a more structural participation strategy that focuses on the integration of consumers' knowledge and experiences in the research process.

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The German Research Funding Programme "Rehabilitation Sciences" – Results and Implementation

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The German Federal Ministry of Education and Research and the German pension insurance set up a special funding programme for medical rehabilitation research. Eight regional research networks with about 150 projects receive funds for two three year periods (1998-2001, 2002-2005). In these networks medical and social scientists from universities and other research units cooperate with rehabilitation centres and pension insurance institutes. The programme aims at improving the research structures and at tackling the major challenges of medical rehabilitation research. The following subjects represent the main fields of the ongoing research: a) etiology, course and prognosis of chronic diseases and their consequences to rehabilitation, b) diagnostics in rehabilitation, c) evaluation and improvement of rehabilitation therapy, d) the patient's perspective in rehabilitation and e) rehabilitation system research. Support of the networks in the second period is based on the results of a thorough evaluation of the progress of their research in the first period and their structural perspective.

The German pension insurance is responsible not just for financing medical and vocational rehabilitation, but also for developing rehabilitation concepts, for decisions about form, duration and site of rehabilitation measures and for quality management. As implementation of research results is not guaranteed by their publication alone or by incorporation in clinical guidelines the German pension insurance implements research findings in a stepwise manner:

1. Publication and dissemination,
2. Models of best practice,
3. Introduction into concepts and guidelines,
4. Monitoring by quality management programme.

Compared to research results about special interventions and their efficacy/effect-tiveness, implementing research findings dealing with the rehabilitation system is much more difficult because several institutions with sometimes conflicting interests and traditions must join in a common effort.

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Involving People with Disabilities in Rehabilitation Research

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Organisations of people with disabilities or chronic illnesses are not universally convinced of the value of research. Sometimes, past experiences have given rise to a sense of mistrust: a feeling that researchers are actually exploiting people for their own career-goals. There are also some more complicated issues. The questions researchers pose may derive from a different understanding of disability, or from different values, than those held by people who themselves live with chronic illnesses or disabilities. The result can be that new provisions (eg drugs, assistive technologies) are evaluated in ways that don't reflect the needs of those who are supposed to profit. Or it may be a problem of 'research style'. Researchers may be inclined to treat the people with (on?) whom they are working as 'sets of symptoms' rather than as knowledgeable and reflexive collaborators. If 'knowledge is power', research can be an important resource for patient/consumer organisations. But only if we can escape from old prejudices and structures and build new bridges. In this lecture I will stress the importance of two initiatives that can be taken. First, we need forums that cut across the many divisions separating patient/consumer organisations from the world of research, and within that world inhibiting dialogue between the various scientific disciplines (medical, social and humanistic). We need forums in which mutual trust and mutual understanding can slowly be built. (Innovia, a Foundation I have recently helped establish, is trying to take a few steps in this direction.) Second, new ways have to be found of involving people with chronic illnesses and disabilities with the research process itself: ways that respect the unique insights they have to offer on the basis of lived experience.

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Co-morbidity Research from the Patient View

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Co-morbidity can be described as the occurrence of several diseases in one person. When the underlying diseases have chronic features, co-morbidity can be a serious problem.

In the Netherlands, several Health Funds in co-operation with the Dutch Council of the Chronically Ill and the Disabled, have chosen for a unique project to show their common surplus value: co-morbidity seen from the perspective of patients.

Therefore they have asked a group of patients and scientists to draft a report with concrete recommendations for a research programme regarding co-morbidity. In this report an overview will be presented with respect to co-morbidity in general, the consequences of co-morbidity for the quality of life of these patients and the quality of care. A literature-search has been done, and patients, scientists as well as other experts have been questioned about this theme.

When getting more illnesses, patients memorised three kinds of consequences for their quality of life:

- physical consequences of co-morbidity: "you will become more dependent from others in daily practices"
- psychic consequences of co-morbidity: "you cannot trust your own body and mind anymore"
- and especially the social consequences: "you will loose your job; you will loose friends; your partner becomes a nurse."

Patients also indicated the problems of co-morbidity in the care-setting:

- "medical doctors don't agree about medicines; they are just familiar with their own speciality, diabetes mellitus for instance. But what if you also get an coronary heart disease?"

Scientists and experts discussed the same topics, this time from a scientific point of view.

In this presentation the final conclusions from patients, scientists and experts will be given and research recommendations will be discussed.

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Research into the Challenges of the EU Enlargement: Free Exchange, Confluence of Ideas, Pressures to Adapt/Adjust

Research in Rehabilitation in Hungary – with Regard to Enlargement of the European Union

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Conditions for research have been changed basically parallel with the political changes in 1989-90. State owned research institutions and overall financing were decentralized. At present most research activities are financed by grants. Researchers have to compete for obtaining grants. Shortage of personnel in rehabilitation is a special challenge.

Grants for researchers in rehabilitation are available from the government through the Széchenyi plan managed by the Ministry of Education, through other ministries within their speciality field (e.g. Ministry of Health, Social and Family Affairs), from the Public Fund for Equal Opportunities of Persons with Disabilities, from private funds, (e.g. Soros Foundation) and also by the European Union (EU) 5th Framework Programme. The presentation will give examples of research projects within the different listed structures. The two present EU supported projects in rehabilitation with Hungarian participation are development of a robot for physiotherapy of the spastic upper extremity and development of an international quality of life assessment tool for elderly people.

Networking of researchers is helped by regular conferences and periodicals. "Rehabilitáció" is primarily a medical journal with possibility for interdisciplinary publications. Other journals like 'Social Work' or 'Special Education Review' are offering possibilities for publications on results of research in rehabilitation. Finally more and more institutions use web pages as well as interactive communication channels – at present primarily in Hungarian language. The weakened communication of researchers within central-eastern European countries may be a consequence of difficulties in co-operation with other European countries in earlier years.

Concluding: the EU membership is seen in a positive way by most researchers, expecting wider communication possibilities and increasing resources. On the other hand there is a fear of increasing brain drain that is a real and already existing challenge, especially in a field with serious shortage of personnel.

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Rehabilitation and Disability Research From the EU Candidate Country Perspective

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There is not much difference in demographic changes in the EU candidate countries of Central Europe, comparing to official 15 EU countries. Populations are "graying" and disabilities related problems have much in common. However, recognizing that disability is a product of an interaction between characteristics of the individual and characteristics of the environment, the differences in the environment in the countries concerned are much more obvious and evident than those of the individual persons. The issue will be considered from the experience in Slovenia.

Since four years Slovenia has been participating in EU research as full partner country in the 5th Framework program. For the FP 5 calls in 2000 there were 102 successful participants in 97 projects with 29% success rate regarding the number of participants and 28% regarding the number of projects. The sixth biennial European Conference for the Advancement of Assistive Technology in Europe was the first one organized outside EU. It has been great input to the disabled and research community in the region, bringing together researchers from almost all EU and EU candidate countries. After such successful professional events, networking have been easier as one third of the participants (more than 100) were from EU candidate countries.

Typical examples of research activities, extremely beneficial for EU candidate countries are CONSENSUS (Assessing driving ability of persons with special needs through common methodologies and normative tools) and COST 219 ter (Accessibility for All to services and terminals for next generation networks). Successful example of networking with Slovenia is the European Platform for Rehabilitation (EPR), which is a network of leading European service providers to people with disabilities and other disadvantaged persons.

Advanced technology is going to have great impact in the candidate countries, and issues like availability and accessibility have to be carefully considered. Another characteristic issue is the implementation of ICF, which is to be translated soon. Expectations from legislators and disabled persons are great, but ICF is not magic stick which will solve all social condition problems from the past and for the future. ICIDH was translated to Slovenian also, but accepted mainly as a tool to improve health terminology.

Next important international scientific conference in Slovenia will be **8th Congress of European Federation for Research in Rehabilitation, Ljubljana, 13 – 17 June 2004**. Welcome!

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Current Issues of Demography and Disability in Russia

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Since the nineties of the last century a growing demographic crisis is observed in Russia. Most regions of the Russian Federation demonstrate constant long-term decline in population. For the last decade 1,7 million of deaths are registered. In 1999, the total Russian population decreased by 768 000, in 2000 by 740 000. In 2000, natural decline in population was 6,6 per 1 000. In the beginning of 2002, the Russian population comes to 144, 9 millions. Life duration averages at 65 years: 58,9 – in men, 72,4 – in women. Birth rate is extremely low and averages 8,7-9,1 per 1 000, while death rate is 14,9-15,7 per 1000. For 2016, approximately 134 millions of inhabitants are forecasted for Russia. Hand in hand with this development, the number (and percentage!) of people with disabilities tends to grow. Now, it is 10,5 millions, in 1992 it had been only 3,98 millions.

The increasing number of disabled children triggers special concern. The percentage of people with disabilities in work age is 8-9% of the total.

In all Russia, there are only 40 specialized vocational schools for the disabled where just 72 000 students are trained. The list of vocations available for the disabled is very limited, many of these occupational fields/trades are out-of-date and uncalled-for in today's labor market. Disabled people do not demonstrate enough motivation for training or for work; that has to be discussed. Disability in Russia now is a problem "in transfer" from just a social issue into the category of a national security threat. Against this crucial facts of our demographic background, new cardinal governmental measures targeted at the prevention of disability, at discontinuance of the persisting pensioning policy and at the stimulation of motivation for rehabilitative and integrative effort in the disabled people themselves are very urgently required.

Disability ~ Towards a Common European Technical Agenda

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The 2001 World Health Organization's **International Classification of Functioning, Disability and Health (ICF)** signals not only a dramatic change in the language and philosophy of 'disability' - which is both positive and liberating - but the potential of forging a more tangible and interactive relationship with mainstream society.

For **people with activity limitations**, however, the reality of present day Europe is far from ideal. Notwithstanding the fact that different types of European Union legislation have existed for many years which require that buildings and places of work be accessible, the naked absence of political will on the part of European politicians and controlling authorities at national, regional and local levels has ensured that, even today, countless barriers to that accessibility are still being erected in the 'built' environment. Furthermore, a lack of comprehensive technical guidance on protection from fire in buildings has resulted in the creation of a far more pervasive form of physical restriction on the full participation of people

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with activity limitations in the social, economic, cultural, and political life of the general community.

And just now resulting from a bizarre combination of ignorance and indifference to the issues of **Social Justice and Inclusion**, a new generation of participation restrictions is being engineered into the development of the fledgling European 'virtual' environment. In the context of **Sustainable Human and Social Development**, however, it is possible to outline a basis for a Common Technical Agenda which is tailor-made for the Region of Europe ; and it would comprise the following elements

1. A coherent **Policy and Action Programme**, initially covering the short term up to the year 2010 ;
2. A multi-lingual, **Harmonized E.U. Vocabulary** of 'disability' ;
3. A reliable, **Harmonized E.U. Database** of 'disability' related statistics ;
4. **'Person-Centred' Research and Demonstration** which answers the 'real' participation needs of people with activity limitations, and the practical demands of those who plan, design, construct and manage for accessibility in the European 'built' and 'virtual' environments ;
5. A comprehensive array of 'disability' related **Performance Indicators** ;
6. Incorporation of accessibility requirements into the definition and implementation of all E.U. policies and actions, i.e. **Accessibility Proofing**, in particular with a view to promoting social justice and inclusion (refer to Article 6 / ex Article 3c in the TEC) ;
7. Delegation of responsibility for the inter / intra **E.U. Institutional Co-ordination** of policies and actions concerning social justice and inclusion to the Secretary-General of a re-organized European Commission ;
8. An effective E.U. regime of **Performance Monitoring and Technical Control**.

Working group **IX**

Sustainable Developments for Groups of Especially Dependent People with Disabilities

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Raising Awareness in Society for the Concerns of People With High Care Dependence

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Sustainable Developments for Groups of Especially Dependent People with Disabilities

Forms and Concepts of Support for Very Severely Handicapped People

Developmental Aspects of Rehabilitation

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Social deprivation or hospitalism seems to play no role for individuals with mental retardation or intellectual limits of capacities any more. However, segregating specialized education has the consequence of restricted institutional and inter-personal participation. Therefore people with mental retardation are separated and may experience direct or indirect violence. Because of eugenic-selective tendencies in actual ethical discussions it should be considered that development is determined by genetic as well as epigenetic factors. Multifactorial interactionistic-systemic approaches are necessary for all measures of rehabilitation, which has to be discussed around ICF-implication because of its normative taxonomic basics. ("Deviation" has to be taken as an integral part of structuring "individuality" as one part of other systemic constituents, without this part the whole is unthinkable. In reality "normative" compounds are not sustainable without widespread functional interactions.)

Rehabilitation has to be based on a developmental approach as a dynamic interaction process: Individual peculiarities are understandable only if the learning history in a given environment is considered.

Neurophysiological and neuropsychological studies resulted in important basic knowledge, about the development of the central nervous system and its dependencies of environmental circumstances and its own capacity of plasticity. This has consequences for all measures of rehabilitation.

A newly designed scheme documenting the communicative state in relations to behavioural items is presented (in analogy to the KODI-modul to perform computer assisted-communication by CAS-aids and assuring possible vocational integration by IMBA-items, s. Schian, Greve et al, this ER-Conference). The marked items will give a reliable picture of the individual participative potential in rehabilitation. An example from integrative work shows that persons with "severe mental handicap" need special care to provide participation.

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Personal Assistance as a Method for Independent Living in a World That Handicaps People

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Independent living is often denied to handicapped people because they depend on others' assistance, which they cannot determine in its extent, place and time course. The concept of Personal Assistance sets a form of help against the traditional handicapped aid, which was developed by handicapped people themselves and offers the persons concerned an independent lifestyle. After the model of Personal Assistance handicapped people become employers of Personal Assistants. Thus they have all competencies to shape their life. The realisation of Personal Assistance however also involves certain requirements for those who take and give assistance. Since April 2002, MOBILE – Independent living of the handicapped e.V. has therefore been offering trainings for both groups. From the background of the practical experience collected so far we will derive the idea and history of Personal Assistance as well as questions concerning the criteria for designing support and training offers as well as their quality control.

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"Social Networking" as a Strategy for Adequate Long-Term Care and Participation of Severely Brain Injured "Apallic" People and Their Families – a Report from Germany

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Background

Severe brain injuries often occur in young adults who nowadays can survive for several decades due to modern medical and nursing rehabilitation technologies. In the past 15 years experiences with an integrated care system (i.e. intensive medical care, early rehabilitation, long-term care and social participation) have been made with more thousand severely disabled "apallic" people and their families in Germany.

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Purpose and method

Development of data-based, obligatory guidelines for qualified long-term care and social participation of severely disabled and "apallic" people and their families who require lifelong complete assistance.

Results

With the help of adequate instruction of family members and early participation of all relevant partners only 30% of the people were integrated into special nursing homes. However, 70% can be reintegrated into their families when sufficient nurses, doctors, therapists as well as emotional, psychosocial, and financial support were provided.

Discussion

Proceeding from "coma to community" both kinds of long-term care (home or family; i.e. phase "F" of neurologic rehabilitation, in Germany) can be successfully managed even in "worst" cases. Therefore, "social networking" within the local community is the most adequate social strategy for long-term-care, reintegration, and social participation as well as to protect the human rights of these people.

Conclusion

Obligatory guidelines for constructing and connecting "little social networks" for severely disabled brain injured people and their families are an imperative humanistic demand on European modern societies.

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Who Shall be There to Assist? Answers to the Future Lack Care Personnel: Issues of Recruitment, Assistive Technology, and Sustainable Housing

Who Shall be There to Assist?

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Due to the demographic change of our society more and more people will need professional nursing care in the future.

The change of the paradigm in nursing in Germany raises new questions and demands to nurses and other health professionals. In the past nurses mainly considered humans as being a 'patient', an ill person. This is changing to a more holistic view - the healthy, the ill, people needing long term care, as well as people with many different kinds of disabilities, in different age groups and with a different cultural background. It is not anymore only nursing care in hospitals and 'nursing homes'. This will shift, due to many reasons, especially to economic ones, to more community nursing, more care by relatives as well to more self help activities.

Approximately 8 million people with quite different physical and psychological disabilities/ conditions are living in Germany and most of them depend on professional help.

Disabilities until now were not really considered to be a domain of nursing. Along with the above mentioned changes there is a change towards more concepts in nursing and activities of nurses for and with disabled people.

Who shall be there to assist is the important question to deal with right now. However, the future of professional nursing does not look positive in many respects. Already now we have a shortage and nurses stay in their profession not more than 5 years on average.

There are a range of important areas for immediate action by politicians. Governments will have to implement new strategies to meet the need of the population.

DBfK (Deutscher Berufsverband für Pflegeberufe e.V., Bundesverband) the biggest nursing association in Germany, will present some guidelines in order to prevent 'bottle neck' situations for people with severe disabilities in the future. Nurses will have to develop nursing assessment instruments for the needs of people with all kinds of health requirements; new concepts in family nursing and other fields, like 'Case-management' etc.

Working group IX, Session 2

Telerehabilitation, a New Approach in Long Term Rehabilitation and Aftercare – Experiences from Pilot Studies in Different Fields of Neuro-Rehabilitation

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Background

In Germany, inpatient rehabilitation programmes following acute hospital treatment or surgical interventions are well established. But good functional outcome after rehabilitation decreases in the long term course of the disability due to deficits in aftercare and long term rehabilitation.

Telerehabilitation development

Therefore, together with Siemens Medical Solutions and Dr. Hein GmbH (formerly Evosoft Tele Care) we developed a system software package for telerehabilitation in the different fields of neuro-rehabilitation. It includes:

- Different cognitive training software being available on the market
- Files for the prescription and monitoring the patients' performance and results by the therapists
- Tools for subjective assessments and e-mail exchange between patients and therapists
- A statistical package for training effects and evaluation (can be sent to cost bearers like social health insurances).

Patients and their therapists can do their work completely independent in time due to a server and LAN based solution meeting any data safety requirements.

Results from pilot studies

1) Neuropsychology:

A randomised controlled intervention study was performed in n=60 patients with chronic cognitive disturbances after stroke or traumatic brain injury. In a matched pair design they had been treated with cognitive training, mainly attentional functions, over 11 weeks. Once a week they had got an additive face-to-face contact with the therapists supervising their PC assisted training. By examinations before and after they had not only improved on attentional functions but also showed lower depressed mood, better mobility (less spasticity and faster gait velocity) and less burden for the caregiving relatives.

2) Neurolinguistic:

The tool hat yet been developed, including training modalities for speech comprehension, reading and writing. First experiences in an open trial show good acceptance by the patients if they have good introduction or assistance. The system can rise the training frequency in addition to a classic speech therapy approach. A randomised controlled intervention study is about to be started.

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3) Severe cognitive impairment/vascular dementia:

The "Entertrainer", developed in an EU research project, which allows to present emotional relevant contents in form of images, texts and musical pieces, was tested in an open trial in 13 patients. The training showed significant short term improvements of vigilance, psychomotor activity, mood and reminiscence capability.

4) Others:

Open and controlled trials are also performed with the telerehabilitation approach in cardiology and orthopedics.

Conclusion

Telerehabilitation may be a promising approach for the challenges in long term rehabilitation and aftercare. But it needs to be closely guided by specialised therapists.

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Disability ~ Fire Engineering Research in Europe ?

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On Friday, 26th February 1993, an explosion ripped through an underground car park in New York's World Trade Center (WTC) Complex, immediately killing 6 people and injuring 1042 others. The most prominent types of injury were severe exposure to smoke and, with some evacuation times well in excess of 9 hours, exhaustion. Approximately 30 pregnant women were rescued and evaluated by medical personnel, and 20 people were treated for cardiac stress. Not all of the information relating to evacuation of people with activity limitations has yet been made public.

On Tuesday, 11th September 2001, more than 3,300 people were killed in the collapse of the WTC Twin Towers, including 2,830 building occupants, 157 airline crew and passengers, and 343 firefighter, police, medical and other first responder personnel ; the remains of many have never been found. An unknown number of people escaped that day, in spite of evacuation procedures at the Complex. Following the 9-11 Incident, some media reports appeared concerning individual cases of people with activity limitations who managed, with assistance, to reach 'safety'. The recent WTC Fire & Investigation Report (FEMA 403, May 2002) was inadequate. A reliable study on the long term survival quality of direct participants and close eyewitnesses should be carried out.

Health can no longer be described as the absence of disease or infirmity, but as a state of physical, mental, psychological, social, cultural and economic wellbeing. The word 'safe' on the other hand, meaning simply un-injured or out of danger, when used in the context of protection of people from fire in buildings, is entirely inadequate to properly describe the correct fire safety design objective, i.e. that during and after the process of independent evacuation to a 'place of safety', or partial evacuation to a 'place of relative safety', or protection in place, the health of those people involved (including first responders) should be assured.

The lack of comprehensive and harmonized technical guidelines in Europe on fire protection in buildings for **people with activity limitations** is not just an important issue of public health and social justice - it continues to result in the creation of a pervasive and deep-rooted form of physical restriction on participation in the economic, social and cultural life of the general community.

Progress will be reported in this paper on a **European Fire Research Project (2000-2003)**, under the auspices of the EUropean Concept for Accessibility Network, which involves Belgium, Italy, Sweden and Ireland. The aim of the Project is to produce a harmonized **Technical Guidance Document (TGD)** which is linked to, and underpinned by, European Union legislation. The TGD will have widespread application throughout Europe. For the first time, an emphasis is being placed on mental, cognitive and psychological impairment. Also explained will be the necessary evolution of a more coherent fire engineering philosophy, based on first principles, and derived from meaningful consultation with building users and the observation of 'real' building fire performance, e.g. at both WTC Incidents. Improved fire safety design concepts are essential in order to assure - for people with activity limitations, and ultimately first responders - a proper level of health protection, in or near buildings, during and after a fire.

Working group IX, Session 3

New Trends in Personal Assistance for People with Very Severe Handicaps

The Chance of Empowerment for Mental Health Users by Their Own Organisations

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As a represent of the European Network of Users and Survivors of Psychiatry (ENUSP) there will be first an shortly explanation of the network. The ENUSP is an user organsation with about 46 member organisations in 26 countries of Europe. Our aims are to support and improve the rights of users to take their own decisions, to give a chance to communicate between users , to avoid discrimination against psychiatric patients and to have influence on the policy makers in the field of mental health within Europe.

This speech however will have the subject on the Dutch situation in mental health.

The influence of the user and survivor movement in the Netherlands on the empowerment of the Mental Health users and survivors.

In the Netherlands we have for e period of 35 years user organisations in mental health. They've got good ideas about patient rights and the public opinion as well as the lawyers were in favor of them. We have as a result of that patient movement (others patients with other illnesses organised themselves as well) in the present some very good laws for the rights of the patients. So now we have the chance to empowerment with the law on our site.

We'll give several examples how empowerment came out of the user movement.

Transnational Remote Assistance for Employment Integration

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Aljjscha Tallaj from Orscha near Minsk was only 16 when he stepped on a World War 2 landmine. By this accident he lost both his legs and his arms. He spent 10 months in Germany for rehabilitation while he got artificial limbs (legs and arms) and learned the German language.

Back in Russia he lives in Minsk in an orphan and old people's home with rehabilitation facilities.

The "Berufsbildungswerk im Oberlinhaus (BBW)", a vocational training centre for disabled students, took the part of giving him the opportunity to learn a profession. Due to the distance between Potsdam and Minsk, we use our 3 years of experience in long distance learning and training via Internet and Telephone.

The presentation explains how the BBW tries to achieve this goal and explains the technology used especially with regard to the severe disablement of this young man.

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Supported Communication in Education, Vocational Training, Worklife, Selfhelp, and Everyday Care

E-Learning for Vocational Training in the Context of Rehabilitation

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Background, Purpose of Presentation

Since 1997 young people in Germany are getting vocational training to work in IT jobs. In the IT area the speed of innovation is very high therefore the official German developing plans (curricula) for IT education and training (defined by the institute Bundesinstitut für Berufsbildung BiBB) is very flexible.

Web technologies are becoming more and more important. Physically handicapt young people being educated in the area of web technologies are getting excellent possibilities to find a regular job.

Method used

The combination of the web technologies HTML, PHP and MySQL are covering important areas of the official curricula. The methodology of this new way of education is based on selfpaced and project-based learning.

Results

To reach this objective the rehabilitation center for handicapt young people ALBBW Berlin is developing complex training and working scenarios which are project-based. The development of this new educational concepts are financed by the German Federal Ministry of Labour and Social Affairs (BMA).

The webserver script language PHP is an object-oriented programming language (OOP). To learn an OOP language is an important part of the curricula. PHP and MySQL, which are both based on free open source, are an excellent combination of web technologies to create products for E-Learning and E-Business.

Main Aspects of Discussion

- Changes of the role of teachers and educators to coach, teletutoring and advise the project-based learning process in combination with self-paced E-Learning
- Concepts, Examples, experiences, consequences

Conclusion

Feedback from companies proofs that the new educational concept of complex training and working scenarios (Lern- und Arbeitsaufgaben) which are project-based provides an excellent possibility to qualify handicapt young people for IT jobs.

Examples

- E-Learning Linkmatrix + HTML/PHP/MySQL Workshops: www.albbw.de
- in cooperation with educational company PPS Salzgitter GmbH: www.mv-livia.de
- web catalog traveling agency
- in progress: Internet boutique, web-shop

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Interlocking of Medical and Vocational Rehabilitation in Germany

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Background and Purpose

In Germany, a better interlocking of medical rehabilitation with other fields of the health system is demanded frequently [1, 2, 3]. The aim of our study was to clarify, whether a patients vocational reintegration could be improved through a systematic co-operation between rehabilitation physician and company physician.

Methods

Within the framework of prospective study with a historical control group employees of the AUDI AG which stated a problem concerning return to previous employment were included in an intervention program (treatment group: N = 40). The treatment group was compared with suitable individuals which had finished an in-patient rehabilitation between 1993 and 1998 without a special treatment regarding return to work (control group: N = 56). The main target points were duration until return to work and days of disablement within 12 months following discharge from the rehabilitation clinic.

Results

The results show a significant between group difference in days of disablement within 12 months after discharge, favoring the intervention group.

Conclusion

In conclusion, the intervention program is superior in decreasing temporary as well as permanent disablement. Because the described results concerning effectiveness are so clear, the program is recommended for transfer in routine co-operation between rehabilitation clinic and company physicians.

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Working group IX, Session 4

Employment through Work Assistance

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BAG UB's current project "Employment through work assistance" was launched in March 2001. The aim of the project is to implement the new "personal" entitlement to work assistance in order to support and accompany the "affected" person.

The entitlement offers handicapped people the potential of choosing from a wider range of professions on the job market and of strengthening their capacity to make their own decisions. Both are central aims to the Code of Social Law IX (Sozialgesetzbuch SGB IX).

However, implementing the practicalities of this entitlement is met with insecurity about the financial and legal framework from all sides – from those receiving work assistance, from employers, sponsors and advisors:

- Who decides to which extent work assistance is necessary?
- Who covers my costs?
- Can I finance my work assistance with the lump sum contributions?
- Which tasks and responsibilities do I, as an employer, have towards work assistants?
- How do I come into contact with work assistants?

Our project's aim is to find the answers to these questions. We intend to achieve this through:

- Creation of a help-line and information centre
- Public relations, publicising information about the entitlement
- Survey of the practical implementations
- Assemblage of case studies, nation-wide documentation
- Development and implementation of qualifications.

The objective of our project is then, inter alia, to make personal entitlement to work assistance available to all handicapped people. Also, a lump sum contribution may contradict the individual's requirements for the necessary work assistance.

Reference

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Impulse Nr. 19, 20, 21 and 22 (BAG UB specialist journal)

Working group IX, Session 4

Experience with Integrated Study at Universities in Košice

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Authors present work on the project "Integrated university education system for disabled". The project objective was - Development and implementation of the integrated university educational system for disabled students. The main output was to establish the Access Centre at the Technical University. It happened in July 2000 and its main roles are assessment, advise and technical support for the incoming students with disabilities at the Technical University of Košice and two others participating Universities in Košice. The centre offers information for the public about whole procedure of assessment and study conditions at the selected University. The Access centre offers to accepted students proper equipment, methodical materials and training for necessary preparation before entering the university and during study. Access centre administrative and technical team have been retrained by EU project partners' experts from University of Bristol and Fondazione don Carlo Gnocchi, ONLUS, SIVA Milan, who are experienced in teaching methods, which respect a contact with disabled students and provide equal access to the curriculum. The Access Centre plays an important role in University environment supporting students with severe disabilities. It improves quality of life not only for students with disabilities but for able bodies students and teachers too.

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Working group IX, Session 5

Session 5: Raising Awareness in Society for the Concerns of People With High Care Dependence

Connecting - About Language in Networks and the Assessment Tool IMBA

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The connecting of partners in rehabilitation demands useful tools. One of these tools – IMBA - and its fields of applications will be presented.

IMBA is a documentation system that allows the standardized description of a persons functional capacities as well as the standardized description of an environments requirements, both in regard to physical items and key qualifications. Both descriptions are compatible and can be compared in order to ensure the best possible match of person and environment. With this IMBA represents the basic concept of ICF, especially in the context of employability. IMBA allows a number of answers to relevant questions in rehabilitation and integration. The comparison of functional capacities and functional requirements carried out on an individuals or on a group level may show the need of modification of environment, for instance by reengineering a work place, or the need of modification of capacities, for instance by training or by personal assistance may be shown. A number of other possible aims in the use of the tool will be explained.

Crucial to IMBA is the question of "common language". Connecting partners in a network requires adequate means of communication. This refers to national partners and teams, as for instance in occupational rehabilitation, as well as to international networking. For all different users with different professional backgrounds and contexts IMBA provides a "common language" with standardized and defined terms, that can easily be "learned". For all different users from different (European) countries IMBA can be translated - and in fact already is translated for instance into English and Lithuanian - and though enable the building of networks across borders.

IMBA is used in a number of institutions for vocational training and education, in rehabilitation centres, in counselling etc. and part of the quality assurance and management system of many of them.

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Working group **X**

Inclusion in Culture & Arts, Travel & Tourism and in Sports

Session **1** (page 150 – 151)

The Barrier Free Concept in Culture & Arts, Travel & Tourism and in Sports

Session **2**

Inclusion of People with Disabilities in Mainstream-Travel and Tourism from Consumer Perspective

Session **3** (page 152)

Inclusion of People with Disabilities in Culture & Arts; Education, Media Attention, Awareness-raising

Session **4** (page 153 – 158)

Sports and Physical Education for People with Disabilities: Inclusion or Exclusion, Inclusive or Special

Working group X, Session 1

Inclusion in Culture & Arts, Travel & Tourism and in Sports

The Barrier Free Concept in Culture & Arts, Travel & Tourism and in Sports

Art Therapy in Rehabilitation after Brain Injury

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Background:

Ever since Antiquity, the contemplation of works of art has been used for therapeutic purposes, usually by means of confrontations with representations of divinities. In both Christianity and the other world religions, sacral representations are believed to be invested with healing powers.

Method:

Only few facilities have implemented art therapy in rehabilitation after brain-injury. We use art therapy in daily individual therapy, making it an integral part of the early rehabilitative treatment of 50 patients suffering from severe brain injury.

Results:

The experience gathered from this therapy indicates that art therapy could become an integral part of early rehabilitative treatment. The sculptural works that are created in art therapy express de patients' search for a new hold and orientation during a time of illness and upheaval, which often leads to drastic changes in many areas of daily life.

Conclusion: In contemplating the sculptural works made by the patients, only secondary importance will be attributed to the formal beauty and the quality of the representations, whereas both the immediate expressive power of the colours used and the manner in which the image area has been shaped are considered to be of crucial importance, reflecting as they do different neurological deficits and individual diversity.

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Working group X, Session 1

"Health, Sports, Experience" – Network Organization in the Rehabilitation of Drug Dependent Patients

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Background

Physical activities and sports are integrated parts of rehabilitation programs for drug dependent patients. In most clinics this approach is used for the following therapeutical functions:

- improvement of physical fitness and well-being
- improvement of social behaviour and competence
- improvement of body- and self-concept
- development of leisure-time activities.

Unfortunately most patients don't continue these activities after leaving the clinic. Mostly they don't find any specialised offers for them in the community or they are not informed about these facilities. On the other side many drug dependent people need emotional and social support to stabilize their new learned behaviour in community.

Conception and results

The presented conception "Health, Sports, Experience" will demonstrate some organizational and informal ways to coordinate different sport facilities for drug dependent patients in community. The main intention of this network is to create an attractive lifestyle without drug-addiction. A clients' survey was taken (n = 22); the results indicate a high acceptance of the different facilities. The results will be presented and discussed in detail.

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Working group X, Session 3

Inclusion of People with Disabilities in Culture & Arts;
Education, Media Attention, Awareness-raising

The Project "Museum of Psychiatry" - History of Psychiatry from a User Point of View

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There is a long tradition of the exclusion of outsiders in our society. Because of that the dealing with the history of psychiatry is an important possibility, to reflect the present situation of users and to change it in the future.

Durchblick e.V., a self-help organisation in Leipzig, is already founding a museum of the Saxon history of psychiatry.

The museum shows the history of psychiatry from a user point of view. The focus of interest are biographies of users. Another priority is set up the description of the everyday life in psychiatric institutions. The museum is independent.

On the basis of selected biographies and the development of psychiatric institutions in Saxony the museum shows the two faces of the psychiatry: on one hand the claim of cure and care and on the other hand the order of social control, which led to the euthanasia in the Third Reich.

With the medium of a museum it is possible to succeed, to interest the majority of public for the taboo psychiatry and to overcome the fear of the unknown against psychiatry. The museum is a place of meeting and communication. With events and specific offers, for instance for pupils, we like to come in touch with a lot of people and contribute to overcoming of prejudices.

The museum will include the job creation for users.

Working group X, Session 4

Sports and Physical Education for People with Disabilities: Inclusion or Exclusion, Inclusive or Special

Sports for People with Disabilities in Germany: Development – Aims – Social Dimensions – Future

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German Sports Federation for People with disabilities (DBS)

The German Sports Federation for people with disabilities was founded by veterans of World War II who were for the most part active sport participants prior to injuries sustained during conflict. In Germany, as in many other nations in the world at that time, the youth had incurred impairments resulting from the war. These young active people were not deterred by a disability but were eager to put their abilities to use in the great field of sport. Through the efforts of DBS (German Sports Federation for people with disabilities – Deutscher Behindertensportverband), legislation was enacted which provides benefits to athletes with a disability in Germany through the health care system. In the 1950's a law was established that resulted in significant financial assistance to the veterans with a disability in their quest for active living through sport. A variety of sports clubs sprung up throughout the country to support these athletes who had clearly demonstrated the need for organized training and competition opportunities.

As DBS continued their relentless pursuit of support for the athletes with a disability they were able to prove to the health care system the worth and benefit of offering rehabilitation sport programmes, which have become the foundation of the German disability sports movement.

Today DBS is one of the largest national sport organisations in the world with over 340.000 members organized within 17 regional associations and 3.400 sports clubs throughout Germany.

The aim of the presentation is to point out the development of sports for people with disabilities, the development of legislation in the field of sports in the process of rehabilitation, the worth of sports for people with disabilities in the field of health and social dimensions. It will be shown, what activities people with disabilities put into the field of sports to explore new areas for leisure time activities etc. Finally the future role of sports for people with disabilities, the future aims of DBS and visions for development in the necessary network process with the relevant social and organizational partners will be presented.

Working group X, Session 4

The Paralympic Youth Camp of the German Disabled Youth Association – Youth work: Sporty, Fit and Committed

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The German Disabled Sports Youth, the youth organisation of the German Disabled Sports Association, is concerned with covering all areas starting with rehabilitation means, leisure time sports, to high performance sports for children and teenagers.

Similar as to non-disabled children, sports has a high and important status in the lives of disabled children and youth. But getting access to offers in sports is generally accompanied by various problems which non-disabled children do not have to face.

Unfortunately even less than 10% of that specific group is organized in sports organizations. In comparison to that figure stands the number of members in sports clubs of non-disabled children of the same age . 50% of them are organized in sports clubs and associations! To increase the interest of disabled children and teenagers to participate in sports the paralympic youth camp was founded in Barcelona in 1992. This was the first time an event like that took place for disabled while the Olympic youth camp for non-disabled can look back to a long tradition.

Besides offering the chance to watch the competitions and games of high-performance disabled athletes, and arouse the interest to join the sports actively, it was also aimed to enthuse those teens for various work in their sports clubs at home and in the national head organisation. Therefore the Paralympic Youth Camp was not a single isolated event, but was followed by various seminars covering topics concerned with youth work in sports clubs, as well as public speaking.

Our interest is not restricted to future high-performance athletes. We pay the same amount of attention to those with social talent, who participate in the various fields of work in the sports clubs and in the head organisation.

This way, which started in Barcelona and lead from Atlanta to Sydney, proved to be a successful path in mobilizing disabled children and teens. The success becomes evident in numerous examples: One of the most successful athletes during the paralympic games of Nagano and Salt Lake City was a former participant of a paralympic youth camp.

Also a great number of new and young members could be enrolled for the work in sports clubs and in the head organization thanks to measures such as the Paralympic Youth Camps and seminars.

Working group X, Session 4

Structures of Sport for the Disabled in Europe – Focus on Networking

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The organised sport for the disabled on international European level is a complex and differentiated system of sport organisations. Most of them are specialised in certain disabilities and/or single sports, some of them are cooperating, most of them are member of the International Paralympic Committee (IPC). The purpose of the presentation is to show off the prevailing structures of sport for the disabled in Europe by introducing the different organisations offering sport for the disabled and to point out links, cooperations and networking amongst them. Another focus is directed to the involvement of lobbying organisations of the sport world and disabled field like European Disability Forum (EDF) and European Non Governmental Sport Organisation (ENGSO). The presentation focuses as well on the involvement of the EU (Commission) and the Council of Europe (COE). After analysing the structures of sport for the disabled it becomes obvious that there are not many networking-activities among the sport organisations for disabled. The result of the discussion about the necessity of networking in sport for the disabled in Europe leads to the conclusion that a network of one collaborating movement of sport for the disabled raises the chances to get the legitimate and necessary public and political awareness for sport for the disabled. The "European Year of People with Disabilities 2003" builds a chance and "stage" for this.

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Working group X, Session 4

20 Years of Standstill? – The Situation of Physical Education at Special Schools in Germany

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Background

At school the child and its individual needs and abilities are in the centre of education. The importance of motor activity regarding the integral development is indisputable. Support can only be successful if context factors (ICF) are appropriate. Physical exercise can influence the development of the individual across the disciplines in classes in a positive way. Although these aspect have been discussed for a long time reality at schools looks different. Teachers are not educated adequately, therefore physical education and the encouragement of movement has an inferior role at school.

Method

Over the past 20 years, research has been done by using questionnaires in different German states to examine and compare the situation of physical education and movement at special schools.

Results

In the 1970ies, more than 50% of the teachers at special schools teaching physical education in Germany were not educated and qualified in any way for this subject.

20 years later the situation is the same. Up to 68% of the teachers are still teaching without adequate qualification. However, the external conditions like gyms and equipment have improved.

Discussion

Due to increasing heterogeneity and degree of disabilities, the demand of motoric development becomes more and more important at special schools. Consequently the qualification of the teacher has to improve. Since the "principle of class teacher" is widely practiced, the required motoric development can only be reached up to a certain limit.

Conclusions

In order to solve the still unsatisfying situation of sports and encouragement of movement for disabled students we ask for:

- differentiated, student - orientated sports programs;
- integration of movement and physical education into all classes;
- qualification of teachers as obligation.

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Working group X, Session 4

Handbiking and Inlineskating as an Integrative Training-Program

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Background

The idea of this project was to create and evaluate an innovative fitness-program with the intention of realizing an integrative opportunity, reducing injuries and practicing an individual training program for well being in health. The project was organized in three parts:

1. Beginner-Course for Handbiking and Inlineskating, 2. Training-Program, Handbiker and Inlineskater together. The Beginner-Course contained the basics of exercise technical realization and the Training-Program took into account a training with instructors.

Method Used

The sampling was based on 13 wheelchair users and one person without a handicap, 10 men and 3 women, aged 37.4 ± 6.72 . The group of Inlineskaters included 488 aged 16-68 years ($x 41.4 \pm 11.6$), 160 men, 328 women. 40% of the participants had a chronic disease. The main focus of the research was to register changes in endurance capacity and metabolic effects after 5 month of activity. The experiment was done in a panel-design. The examination method included Field-Tests with Handbikes and Inlineskates controlled by lactate, heart rate and Borg-Scale.

Results

36% of the Inlineskating and 60% of the Handbiking sampling participated in the Marathon. The integrative Training-Program was organized in training groups based by different velocities. The results support a significant increase of the speed and a significant reduction of heart rate provable by 2 and 4 mmol/lactate.

Main aspects of discussion

- Innovative organization-forms of integrative fitness-programs
- Quality Management of integrative fitness-programs
- Problems of Drop Out (activities for mobilizing)

Conclusion

Inlineskating and Handbiking have a positive influence of physiological effects and are a possibility for sport-beginners. The results can be the basis for further integrative practical applications.

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Working group **XI**

Living in the Community: Serving People with Disabilities at Lokal and Family Levels

Session **1** (page 160 – 161)

Promoting Integration Through Support of Family Networking

Session **2** (page 162 – 163)

Informal Networks and Disability Access Issues in Local Communities – Developing Empowerment and Awareness

Session **3** (page 164 – 169)

The Role of Professionals in Local Disability Services and GBR Concepts

Session **4** (page 170 – 171)

Strengthening Self-Help Initiatives: Cooperation Tasks of Local Politicians & Support Groups

Session **5** (page 172 – 175)

Disability-related roles and Needs of Women in the Community

Working group XI, Session 1

Living in the Community: Serving People with Disabilities at Lokal and Family Levels

Promoting Integration Through Support of Family Networking

Promoting Participation in the Rehabilitation of Children With Special Needs Through Family Support in Finland

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The background of my doctoral dissertation (Mattus, 2001b) was my own experience as a mother of identical twins with disabilities. When my twins were toddlers, legislation was passed in Finland for disabled people (1987) and rehabilitation (1991). Theoretical background was ecocultural theory besides family systems theories and social network models (Dunst et al., 1988; Mattus 1994).

In Finland there is a growing interest of supporting families with different challenges (Mattus 2001a). During my study, a family-centred instrument called "Interview as intervention" was developed and evaluated. The process of interviews of families of multiply disabled children carried out by professionals was analysed with qualitative family research methods. Main results were as follows: 1) professional helping behaviour does not always function as family support, 2) promoting family/customer participation demands that family cultures and different roles of family members are taken into consideration, and 3) shared expertise between families, professionals, and public authorities may give a useful policy to the service system on an affluent society.

Discussion:

It is a relatively new way of thinking that co-operation between parents and professionals is mutually beneficial and advantageous not only to both parties but to the child who is taken care of. Instead of asking how parents feel the professionals could ask: "How can we help you to live your daily life?"

Conclusions:

The professional role can be transformed from one of controlling to another of partnerships.

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Integrationsvereinbarungen (Agreement of Integration) and its Influence on Networking

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The poster presents selected results about the contents of "Integrationsvereinbarungen" (agreements of integration) and its influence on in-plant and external networking and exchange of information in the course of the disability management. The data was collected within the scope of a study and is based on questionnaire at several occasions, on interviews in outlets of various companies and group discussions in task forces. The data will be supplemented by statements of representatives of the Federal Employment Office and the central Agency for the Disabled and other relevant experts.

In October 2000, the "Law to Combat Unemployment among Severely Disabled People" came into force. That act includes a new employment measure to increase job opportunities for (severely) disabled people, called the "Integrationsvereinbarung" (agreement of integration). With this measure, more liable in-plant regulations for the integration and rehabilitation of (severely) disabled have to be developed and brought to a conclusion.

The main purpose of this study is to research the implementation and acceptance of this agreement on the example of the German car industry. Furthermore, it shall be studied how these measures are handled and which possibilities as well as limits will occur.

The study is financed by the Federal Ministry of Labour and Social Affairs.

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Working group XI, Session 2

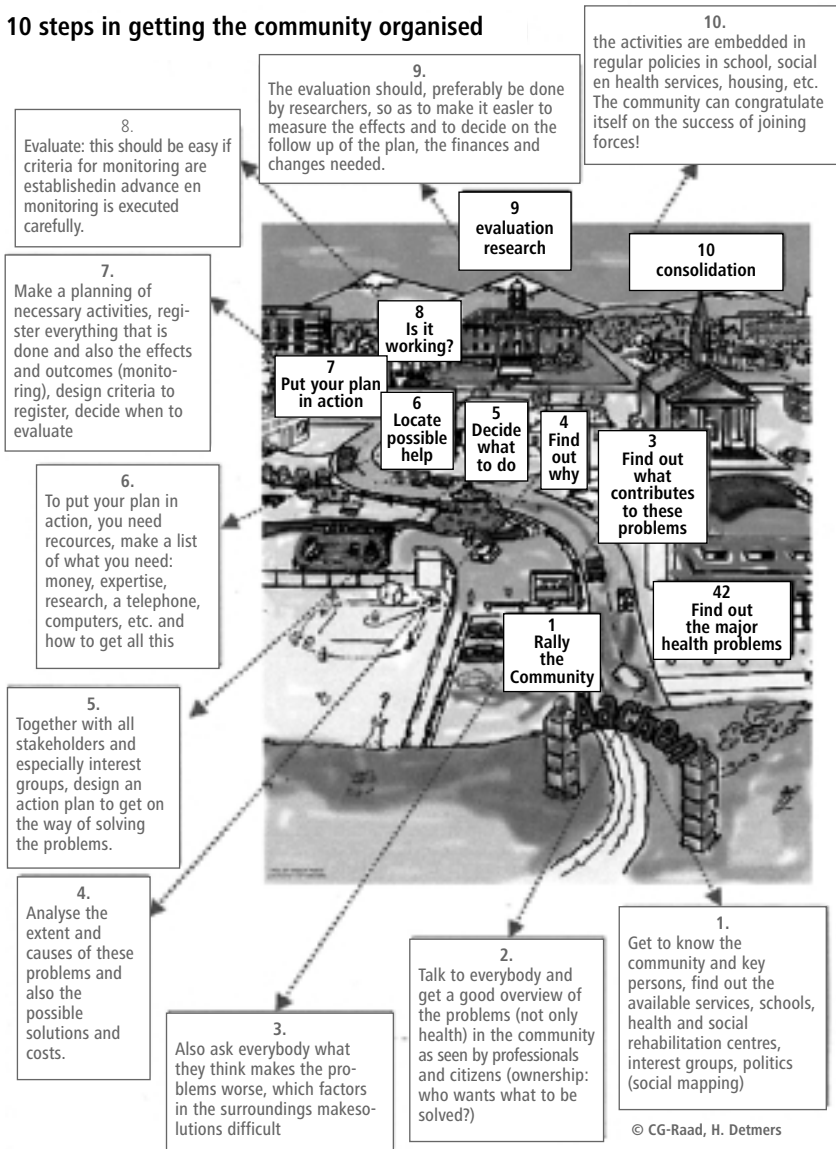
Informal Networks and Disability Access Issues in Local Communities – Developing Empowerment and Awareness

10 Steps to Get the Community Organised

Detmers, H.

Dutch Council of the Chronically ill and the Disabled (CG-Raad)

10 steps in getting the community organised



© CG-Raad, H. Detmers

Working group XI, Session 2

Assisted Living – The Advantages of a Centralized Financial Management

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The fact that the demographic development of the disabled population in Germany differs from that of the general population is a consequence of Nazi extermination policy. Due to this development, as well as due to significantly improved conceptions in care and medical attendance the number of disabled persons requiring outside assistance is expected to rise substantially over the next decade. In 2001 alone, the trans-regional social services agency Landschaftsverband Rheinland provided € 0.6 billion for the care of persons living in homes for the disabled. Non-residential services are financed by municipalities.

The expansion of non-residential integration assistance services at the expense of residential programmes is a useful and necessary step not only in light of the substantial financial burdens involved but above all for reasons of expertise. One of the main features of the policy paradigm shift that has been occurring since the early 1990s is the expansion of the rights of disabled persons. This shift has found expression in key laws, most notably changes made in Article 3 of the German constitution, in Social Code Book IX (rehabilitation and participation of disabled people) and in a law currently being debated that guarantees equal rights to people with disabilities. The time has definitely come to begin regarding disabled people as Service delivery agreement partners, rather than as "objects" whose provision is defined exclusively by others.

A great deal of expansion potential exists for the model of assisted living at both the individual and structural levels. This undeniable potential must be tapped in such a way as to vitalize the paradigm shift we are now witnessing. But this can only be achieved if responsibility for the financing of support services for disabled persons in assisted living settings is pooled in one central agency.

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The Role of Professionals in Local Disability Services and GBR Concepts

Community Development: No Citizen Excluded

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Background

For four years now, there has been a policy in the Netherlands to stimulate the independent living of people with disabilities. It is called Community Care. That policy concerns people with mental, physical, psychic disabilities.

In the Netherlands there was and still is the culture to provide care for disabled people in rather large continuing care units, residential accommodations. These centres were financed out of the Health Care security system. At the same time there are in the Netherlands very serious problems in the health care and cure. There are big waiting-lists for nearly all the care and cure and the macrobudget for health care increases ever higher.

In the Netherlands there is no explicit legislation for equal rights and possibilities for disabled people as in the USA and a lot of other countries in the world. Recently a law was passed that gives equal rights to people with disabilities or chronic diseases in the sector of labour and vocational education/training and in the accessibility in public transport.

In the Netherlands a lot of highly qualified provisions for the disabled and elderly have developed in history. The solidarity was incorporated in the health care and social security system. The care has developed well, but independence and empowerment of people with disabilities have got less attention.

In the presentation the two lines for a successful independent life in the community for disabled people will be emphasised.

(1) Dick Cochius will give attention to the conditions which have resulted from his residential living to his independent living in the society.

Conditions for independent living

It is well known that people with physical or mental disabilities are in a disadvantageous position in regard of social life. Therefore the principle of equivalence needs a special accent. This principle is the central starting point for creating conditions for disabled people to participate in a fully equivalent way in social life.

In this regard you can distinguish external and internal conditions:

External conditions: Residential care, adapted housing, accessibility in different ways, education and vocational training; creating a possibility for living in a full independent way.

Internal conditions: In this context I will remark that also disabled people do not only have rights but also duties!

- Full social participation includes to make choices; note: you can't make choices without risks!

I'll tell in this regard about my own experience.

- Learn how to deal with disappointments
- Interdependency and professional support

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- Care by those directly involved (parents, partner, friends) and volunteers
- Social network

(2) Anthony Fennis will outline the conditions to facilitate independent living by the most important actors in society: the municipal government and council, the welfare and social services, community (development) work, housing associations.

The basic assumptions

- The resident is not in the first place an object of care but a citizen as others.
- That person plays different roles.
- There has to be reciprocity and equivalence.
- Necessary is an adequate budget and a sufficiently bearing surface in the community.

Conditions

- Working on a positive image building in the community.
- Working on the accessibility and usefulness and safety of the provisions in society for people with disabilities in all circumstances.
- Working on accessible and adequate information and communication processes for all people with disabilities.
- Adequate provision of technical resources and technical provisions.
- Working on close partnerships with allies.
- Internal coordination in the municipality and clear processes in the community
- Working on instruments and methods

Every time the municipality government and the service providers have to be invited to give answers on the demands and create the conditions for citizenship in all sectors of the society. They do not need to react to purpose groups.

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Role of Professional and NGO Services for Persons with Disability in the Czech Republic

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During last 14 years many changes happened in services for persons with disability (PwD) in the Czech Republic and other countries of Central and Eastern Europe (CEE). They were influenced both by general developments in each country and partially by examples coming from developed countries, especially from the EU. It is important to say that economic, organisational and cultural differences between separate CEE countries are large and closer contacts between them are not general but derived mainly from similar language and/or tradition of friendly relations. I mainly describe the situation in the Czech Republic, which has good relations with Slovakia and partial contacts with other countries of Visegrad groups and with some countries of former Yugoslavia. In the Czech Republic a Governmental Committee for PwD was established and a National Plan for Development of PwD services was approved and it has been regularly checked. Many new organisations of and for PwD were founded and they closely collaborate with professionals. They are responsible for counselling, organisation of courses, personal assistance and some other social services. Fast development of occupational therapy improved programmes of medical rehabilitation for PwD. Offers of school programmes for PwD have enlarged. Tradition of Abilympics developed, which advertise employment of PwD but vocational rehabilitation of PwD is not so far included as one system and has not appropriately educated professionals. Approaching of the Czech Republic and other CEE countries to EU should bring influence and help also in development of services for PwD in these countries.

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Evaluating Resources for Independent Living – Improving Chances by Improved Advice

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The amendment of the Social Law Book IX in Germany prompts supplementary activities of local services for disabled people to contribute to the paradigmatic change towards participation in social life. As one basis for participation is given by a most independent living in an own flat, it is indicated to improve the chances for disabled people to live this way even if there is a need of extensive care.

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Dealing with this matter is mainly founded on FTB's many years' experiences relating to housing consulting service and independent living training.

FTB's housing consulting service is frequently requested by people with disabilities in need of care, or their relatives respectively, because of uncertainty to decide between living stationary or at home with outpatient care. These problems interdepend with strain of the client and his/ her relatives concerning an outpatient care situation. The necessity to identify the individual personal resources as well as needs for outpatient care and technical solutions usually overstrains the means of consultation.

In this context FTB's independent living training project, including a two to four weeks training period in a smart home shows more problem sensitivity. The training accompanied by an interdisciplinary team and following a rehabilitation plan improves the participants self-evaluation of personal abilities in terms of occupational performance. Needs for medical and social care as well as for technical devices are assessed problem based and systematically. Participants have been encouraged to live in their own home. Despite these promising project results it turns out that these additional training measures are too extended and complex to be cost-effective.

A combination of advice and training with an interdisciplinary, client centred approach seems to be successful and should be advanced to a standardised evaluation of independent living resources.

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Working group XI, Session 3

From Institution-Based to Community-Based Rehabilitation: Person-Centred Support as Challenge for the German Rehabilitation System

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Self-determination and participation have become main issues of rehabilitation legislation in Germany. However, up to now for many persons with disabilities the possibilities of self-determined living and participation in society are still limited. Rehabilitation in specialised institutions as "all inclusive" care prevents the realisation of individual ideas of living and therefore increases tendencies of exclusion.

Alongside to the changing conceptualisation of disability as lacking fit between an individual and its environment the development from an institution-based to a person-centred support is necessary. A substantial step towards this direction is to be found in a reorganisation of financial structures. A Personal Budget enables persons with disabilities to buy and organise support according to the own needs and desires. An organisation of support that is individualised and close to the particular life situation requires focussing on personal activities and competences as well as the building up of a network of social and environmental resources within the community. Necessary professional services are to be offered outpatient and community-based.

Against this background a concept of a Personal Budget has been developed at the University of Dortmund in the course of the three-year research project "PerLe – Person-Centred Support and Quality of Life". At present the concept is put into action in pilot experiments.

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Working group XI, Session 3

Rehabilitative Approach to Psychosexual Problems of the Mentally III

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The moral code in the pre-reform Russia depreciated the importance of the intimate life. It was declared that the Soviet people have no sexual problems. The official attitude to the sexuality of the mentally ill bore a repressive character.

The ideas of rehabilitation filled with a humanistic sense formed a different approach to a person with the mental illness as a representative of the gender. The patients' psychosexual sphere had to be investigated with the aim of contributing to their integration into the society and restoration of their personal and social status.

196 patients with mean age of 27 years were investigated. The significance of this problem is evidenced by the fact that sexual relations are regarded as a very important component of life respectively by 100 % male and 67,7 % female patients with affective disorders, 57,1 % males and 72,6 % females with schizophrenia, and 55,6 % males and 45,5 % females with schizotypic disorders.

At the same time, 60 % males and about 57 % females from all diagnostic groups are dissatisfied at their relations with the persons of opposite sex. 80 % males and females with a diagnosis of schizophrenic spectrum and 65 % males and females suffering from affective disorders are dissatisfied at sexual relations.

In addition to lowering the quality of life, such situation creates conditions of heightened vulnerability and eventual aggravation of the disease. Disharmony of psychosexual sphere is characteristic of these contingents of patients, which influences the communication and represents a significant factor underlying the dissatisfaction (Alekseyev B.Ye., 2001).

Secondary and tertiary prophylaxis of heterosexual communication disorders and associated negative feelings are directed at harmonization of the sex role behaviour and gender identification, at self-acceptance.

Rehabilitative measures are carried out successively in hospital and outpatient settings. Instruments of influence employed in the hospital include department's therapeutic milieu with the contingent of patients of both sexes, behavioural training, group and family psychotherapy. In outpatient settings those include participation in the club of former patients, educative and psychotherapeutic assistance within the framework of a public organization "Community of families with mental patients (disabled)" aimed at understanding and acceptance by parents of sexual life of their children as well as at harmonization of interpersonal relations in partner couples.

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Working group **XI**, Session **4**

Strengthening Self-Help Initiatives: Cooperation Tasks of Local Politicians & Support Groups

Independent Living and Personal Assistance as Good Practice for Best Value and Quality Management

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What is Independent Living and Personal Assistance

- Definitions of Independent Living and Personal Assistance
- How it has transformed the lives of disabled people in many ways
- Moving from the Medical Model to the Social Model

Self Determination

- Enabling more control and choice in disabled peoples lives
- Shift from being passive recipients dependent on services to becoming employers of personal assistants and running own businesses
- Widening the opportunities for participation

How Control of Personal Assistance Services Enable Full Participation

- Enabling more freedom of choice and ways of living
- Helping to provide more opportunities for employment. How many personal assistance users have been able to move into full time employment.
- Increasing more social and vocational mobility.

Importance of Personal Budgets

- Enabling more control over how one organises one's lifestyle
- Allowing disabled people to become more responsible and accountable through using personal budgets
- Empowering disabled people to develop better management and financial skills

Independent Living and Citizenship

- How Independent Living and personal assistance has contributed to enabling disabled people to take up more roles and responsibilities in their local communities
- How Independent Living has emancipated and politicalized disabled people

Good Practice of Best Value

- Examples of how personal assistance schemes demonstrate good practice and best value for money
- How Independent Living is one of the best value examples of good economic sense

Improvement of Quality of Life and Health

How people running their own personal assistance schemes have improved their quality of life and health. This has enabled them to avoid going into hospital and hence a good economic saving for the State. This also includes people with mental health as well as disabled people and other impairment groups

Working group XI, Session 4

Overcoming Social Exclusion

Examples of how Independent Living is an effective way of overcoming social exclusion.

Independent Living and the Future

- How Independent Living is the ideal way forward for the future.
- How Independent Living has influenced social policy in many other
- European Countries, and how it is enabling many disabled people and older people to live in their own homes and help them to avoid ending up in Institutions.

Health Related Self-Help Organisations and Quality Management – The German "Rheuma-Liga"

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Increasing public financial support and integration in the health care system cause higher requirements of services and activities of self-help organisations. Thus, the "Rheuma-Liga" and the Pension Insurance Agency for Workers in "Baden-Wuerttemberg" support and finance a systematic investigation of quality in the work of this self-help organisation in patients with different rheumatological diagnoses.

Standardised questionnaires asking about the quantity and quality-indicators of several services and activities were sent to all leaders of the 79 local units, 200 counsellors, 100 leaders and 1.000 members of self-help groups, 800 volunteers, 500 therapists and 2.000 participants of gymnastic groups and 2.000 participants of information meetings. The average response rate was nearly 50 %.

Preliminary results show on one hand, that many people suffering from rheumatism, can be reached in the community. On the other hand, the results indicate, that the quality of the activities and services varies much between different regions and units.

The conclusions are twofold: The results show clearly the necessity of quality management also in self-help organisations. Beyond the question of quality it is clear, that the number of persons reached by this self help organisation, can by no means be reached from the professional health care system, especially regarding gymnastic groups and counselling.

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Working group XI, Session 5

Disability-related roles and Needs of Women in the Community

Sexuality, Physical Disability and Chronic Illness: a Private Matter?

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Sex is a part of human life. At the same time, it means something different for each individual. In many ways, cultural influences determine what people do in sex and how they experience it. The present widespread media attention for sexuality (at least in the Netherlands) gives many people the false impression that there are no longer any sexual taboos. In Western Europe, in spite of seemingly open and free ideas and moral standards about sexuality, most people remain traditional in their behavior, norms and opinions concerning their sexuality. Though, when things get too personal or sex is a problem the openness disappears rather quickly.

When one considers sexuality in combination with a physical disability and/or a chronic illness things do not seem so natural or easy going. Most people can only imagine worries and problems. Many studies show a high prevalence of sexual difficulties among people with different somatic problems such as: diabetes, multiple sclerosis, rheumatoid arthritis, heart and kidney diseases, spinal chord injury, spina bifida, cerebral vascular accidents. With percentages ranging between 50 and 80% it is amazing that in 2002 the taboo remains. Youth with physical disabilities and chronic illnesses are also confronted with a taboo in the area of sexuality. They especially experience problems in discovering their sexuality and starting relationships.

In this workshop, we want to have an open discussion examining the sensitive area of sexuality. How do we look at sexuality and what are the ideas and prejudices when considering the sexuality of people with a physical disability or a chronic illness? We will present a summary of the Dutch research in this area and will be interested to hear how other European countries compare in these areas. Above all, we will examine with the participants which aspects of sexuality in relation to physical disabilities and chronic illnesses are of importance to the individual, the interest groups and policy makers.

This workshop is intended for people with a physical disability or a chronic illness (and their partners), representatives of patient interest groups, policy makers, politicians and professionals working in this field.

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Women with a Disability, Relationship, Sexuality and Motherhood- Items for an European Approach?

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In February 2002 a research was been published by the Verwey-Jonker Institution. In order of the Department of Public Health, Welfare and Sport they investigated the living conditions of women with a disability or a chronicle illness. They interviewed 51 women. During the interviews they were detailed questioned about there life history and the current situation. Experiences, bottlenecks and wishes for changes in the various subjects.

Relationship, sexuality and motherhood were three from the subjects who were discussed.

Bottlenecks in relationship were:

- Dependence and inequality of power between the partners;
- Social pressure on the partner without a disability;
- Self-image;
- Ways to make contacts.

Bottlenecks in sexuality were:

- Lack of sex education;
- Reactions of the environment;
- Sexual abuse;
- Problems with communication especially for blind and deaf women;
- Obstacles by sexual activities.

Bottlenecks in motherhood were:

- Problems to organise assistant and facilities;
- Reactions of the environment;
- Restrictive regulation for adoptive parents or foster parents with a disability.

During the workshop the bottlenecks will be more explained. After that we inventory the bottlenecks in other countries. At the end we discuss with bottlenecks ask for an European approach and in which way women with a disability or a chronicle illness can organise themselves on these items.

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Disabled Women's Needs in the Community and in the Family

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At one of the largest conferences of disabled women, in Washington D.C. 1997, about 650 women from 80 countries identified five main areas of concern: (1) education; (2) economic empowerment; (3) ending violence against women; (4) access to health services, and (5) access to family life. The author will outline disabled women's needs in these five areas and then focus on the subject of violence against women. The problem will be described and prevention methods will be discussed. An innovative legal approach to the issue can be found in the new German Rehabilitation Code of 2001. The new rehabilitation benefit for disabled women in Germany will be discussed as a model for other countries.

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Non Segregation Andragogy as an Instrument for Implementing Community Living of People with Learning Difficulties

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In this paper I set out andragogical principles for the development of community-based environments for people with learning difficulties which facilitate community membership and participation. The starting point of my argument is that, without a more holistic approach, "ordinary" dwellings for people with learning difficulties are much in danger of becoming "mini institutions" with institutional structures and similar exclusionary consequences.

A simple change of the spatial situation is not sufficient in itself if the objective is real inclusion in society for people with learning difficulties. The danger is to develop mini institutions with their institutionalised culture in the community. A reality we can see and experience in lots of so-called community-oriented housing situations for marginalised groups.

That is to say: Community care is more than just housing, it involves, for people with learning difficulties, their whole living situations of everyday life without segregation. This desegregation then has a ripple effect for neighbourhood structure, staff training and for all actors involved.

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