

International Research Meeting for the Implementation of the ICF

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Summary

The ICF is a classification system developed by the WHO to describe health using the bio-psycho-social model.

In order to promote the clinical and research use of the ICF in Canada we received a CIHR Meeting Grant to start the discussion of the implementation of the ICF. Five international representatives from different areas of developmental care were invited to share their experience with participants from Canada and the USA over two days.

In professional education, interprofessional teaching by introducing the ICF to students or professionals from different areas at the same event could help to show the use of the ICF as a common language and establish interdisciplinary understanding and relationships. It was also felt that there is a need for knowledge transfer of the ICF outside the professional areas, especially for policy makers, consumers and funders of both services and research.

With regard to using the ICF in communication with professionals and patients it is important to focus on the concepts of the framework rather than on details. The ICF can be overwhelming when looked at it in detail as a classification system but the concept is compelling and can be the entry point to a change in attitudes on a professional and patient level.

To implement the ICF in Health Services, a first step might involve linking existing instruments (measurements, questionnaires) to the ICF. The use of the ICF might also be helpful in identifying needs of patients (e.g., could be used in managing waiting lists in different ways, as proposed by Heather Marrin, Erinoak). After using the ICF on a regular basis, it might also be a way to identify the need for new measures (what aspects of the ICF framework are not covered by instruments that we know and use now?).

Research questions related to the ICF in clinical practice should be related to the points above. It would be important to study if teams do work better when they apply the ICF to their work; whether the adoption of the ICF framework and concepts improves the parents' perception of care; and whether this approach improves outcomes (defining outcomes within the ICF framework). As there was an impression that funding is mostly directed toward questions that focus on changes in body functions and body structures, some of the participants started a study that

will look into paediatric clinical trials and analyze those regarding their outcome variables and how those relate to health components present in the ICF.

Participants

Participants were invited through direct contacts and via an email list (ICF-L@mcmaster.ca) established at McMaster University in 2009 to connect professionals and researchers of different areas throughout Canada interested in the ICF. A list of the participants and the institutions they are affiliated with is in the Appendix.

Introduction

According to the ICF, disability can be defined as a negative interaction between an individual with a health condition and the contextual factors surrounding the individual (Leonardi, 2006). This view results from the application of the bio-psycho-social model of health in the case of people with disabilities and chronic health conditions. In 2001 the World Health Organization (WHO) published the International Classification of Functioning, Disability and Health (ICF) based on this model, introducing the term “Functioning” to describe how health conditions are related to “Activities” and “Participation” (World Health Organization, 2001). A version for Children and Youth was launched in 2007 (World-Health-Organization, 2007).

The ICF can be employed as a research tool to measure outcomes on the different domains, not being restricted to “Body Functions” and “Body Structures”. One of the aims of this classification is to provide a common language for different health professionals and other specialists. This enables them to describe patients with chronic health conditions not only regarding the specific structural and functional disorders (diagnoses) of the body but also the resulting consequences and interactions regarding their activities and participation in societal life. The classification especially takes into account the influence of barriers and facilitators within that context. Therefore the ICF can be used as a tool to promote collaboration between professionals. It indicates and documents the needs of support on an individual, community and population level as well as the need for health advocacy by health professionals.

The aims of the ICF are to:

1. provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants;
2. establish a common language for describing health and health-related states in order to improve communication between different users such as health care workers, researchers, policy-makers and the public, including people with disabilities;
3. make possible comparison of data across countries, health care disciplines, services and time; and
4. provide a systematic coding scheme for health information systems.

The ICF-CY is already an established classification system developed by the WHO. It is relatively new (2007) and not well known among health care professionals. There is a need for targeted knowledge translation about this framework into clinical practice for various reasons. These include the need to implement a bio-psycho-social model of health care among health professionals; evaluate ICF-based approach of care in the future; and to create a necessary critical mass of professionals aware of and familiar with the ICF. This will make it possible to be able to develop assessment instruments based on the ICF to measure health according to the bio-psycho-social model, and based on these results hopefully influence health policies with new evidence.

In order to facilitate the clinical and research use of the ICF in Canada we received a CIHR Meeting Grant to discuss the international experience with using the ICF. Five representatives from different areas were invited to share their experience. Those were, in order of appearance:

- *Liane Simon*, clinical director of an early intervention centre near Hamburg, Germany that was pioneer in the use of the ICF. She is also a lecturer at the Course for Special Education at the University of Hamburg.
- *Nicole Habenicht*, study nurse and coordinator of the use of the ICF in the Neurorehabilitative Hospital Affoltern of the University of Zurich, Switzerland.
- *Judith Hollenweger*, professor for education, one of the collaborators in the development of the ICF-CY and in charge of developing an ICF-based system to determine the eligibility of students for special education in Switzerland.
- *Carla Sabariego*, researcher at the Ludwig-Maximilian-University in Munich, Germany, project leader on applying the ICF to patient teaching at the ICF-research branch of the WHO Collaborating Center in Munich, Germany.
- *Armin Sohns*, professor for pedagogy at the Universities of Applied Sciences Nordhausen and Gera, Germany. He implemented teaching of the ICF into the curricula for social workers and early intervention specialists.

Presentation summaries (see copies of presentations in Appendix)

Liane Simon

Early Intervention Center Norderstedt, Germany

Liane described briefly the nation-wide program of early intervention for children from birth to age of six years in Germany. A great part of the interventions is home-based. The program is free of charge, paid by public funds (municipalities). In Germany there are approximately 1200 Early Intervention Centres, serving around 80.000 children.

The approach of the work is resource-oriented, family-centred and the teams are interdisciplinary. The clients are families and children with disabilities and at risk

for developmental delays. Clients can self-refer but if an intervention is seen to be indicated, the municipality has the final decision whether the intervention will be funded.

In 2004, a group composed by Marijke Kaffka-Backmann, Olaf Kraus de Camargo, Jürgen Kühl and Liane Simon developed a checklist for Early Intervention Services in order to better describe the complex needs of the population served in Early Intervention Centers and make the indications for funding more transparent and understandable (Kraus de Camargo, 2007). Until then, the main criterion for funding was the establishment of a medical diagnosis, which meant that children without a formal diagnosis had difficulties accessing those services.

The checklist was introduced as a pilot project in the Early Intervention Centers of Lübeck and Norderstedt and the feasibility was assessed with a questionnaire distributed to 80 early intervention professionals. The professionals used the checklist to document their findings and discuss them with their colleagues from other disciplines to establish common intervention goals. In that process it was appreciated that the checklist offered a common language for all professionals involved on the team, that it required team interaction to be used and that it reached beyond the medical view. It was also seen as an instrument that made parents feel appreciated and promoted education for professionals. On the downside, it was felt that the checklist lacked depth because it was not detailed enough, that it was not very helpful if used only by one professional alone and that the additional effort and work were not being honored or funded by the agencies involved. During the last couple of years the checklist has been adopted by an increasing number of Early Intervention Centers as it helps to delineate intervention goals in a transparent way to the funding agencies. An updated version of the checklist is expected as soon as the German translation of the ICF-CY has been released by WHO. This checklist will be available in English and German.

Discussion

A discussion followed the presentation about the use of the checklist. Regarding the choice of goals it was explained that the early intervention team tries to limit the number of goals to a maximum of 6. The discussion process takes about 30 minutes per child with case presentation (usually with video from the home visit) and establishing the goals. The younger children usually receive more goals in the area of body functions while with increasing age the goals become more activities and participation focused. It was felt by the participants that although the establishment of goals with the ICF seems very useful, it should be followed by a measurement process of outcomes. The qualifiers of the ICF alone are not sufficient to determine the changes in functioning and need to be based on assessments that would need to be linked to ICF items or even need to be created, especially if we look at participation and contextual goals.

Nicole Habenicht

University Children's Hospital, Zürich, Switzerland

Nicole is working as a research nurse at the University Children's Hospital in the Neurorehabilitation Clinic, Affoltern. The clinic has 48 beds distributed in 3 units. The rehab team includes a school and kindergarten, as some children stay at the facility for months until the time of discharge.

The ICF is an integrated part of the electronic health chart and all the chapters are represented but only with regard to the framework. The relevant items are identified and entered as free text and not coded. The purpose of the use of the ICF is to have a view of the individual needs of the child. On day 1 of admission there is a multidisciplinary meeting with the parents (child) and the questions addressed are basically about how life after discharge will be, what are the hopes, expectations and possible restrictions. In addition to the ICF-based information other data are gathered, like the diagnosis, the degree of independence using the WeeFIM, the score in the Glasgow Coma Scale and a description of life before the admission. It is acknowledged that the goals and expectations of the persons involved might be different and these differences of goals/expectations (patient, parents, referring physician) are also documented in the chart. The Rehab Team organizes and structures the goals according to ICF dimensions (A/P, BF, Context) and takes into account the resources available (patient, family/social network).

During the rehab process the discharge goals are broken down to short-term goals and each week all the charts of all children are reviewed. When needed, longer multidisciplinary meetings are scheduled for an individual child, especially if changes in the goals or in the approach seem to be necessary. Every 4 to 6 weeks the process is reviewed with the parents (child) and new goals are established.

Discharge occurs when the goals have been reached or a maximum level of participation/independence has been reached. The family has to feel comfortable about going home and all the necessary resources at home have to have been organized. This could occur up to one year after the start of the rehabilitation process.

With the introduction of the ICF a change occurred in the focus towards participation and important life areas occurred. The goal setting process became more multidisciplinary as well as a feeling of a more democratic process among the staff members, especially the nurses.

Discussion

The main question was how effectiveness is being measured and how this is presented in organizational reports. This is mainly being addressed using the WeeFIM and in the Swiss experience there is a good compatibility between the ICF and the WeeFIM. It was also discussed whether the added time necessary for the frequent multidisciplinary meetings has been shown to improve outcome or patient satisfaction. Although the incorporation of the parents' and patients' views can be

overwhelming at the beginning and time consuming, it is felt that this improves rehabilitation, as it allows the family to adapt to the process from the beginning and feel involved and in charge.

The software used for the electronic health chart is produced by Parametrix (Phoenix) (<http://www.parametrix.ch/ws/de/phoenix/>). The WeeFIM data are being shared on a proprietary database (<http://www.weefim.org/>) (UDS) and will be used for future benchmarking.

Judith Hollenweger

School of Pedagogics, Zürich, Switzerland

Judith is a teacher and professor of education. She was involved in the development of the ICF-CY and is one of the coordinators of the translation of the ICF-CY into German.

Judith coordinates the development of a new system to determine eligibility for special education services for students with special needs in Switzerland. Due to changes in legislation a reform of the traditional diagnosis-based processes was necessary and the ICF was used as a framework and documentation system to assess students with special needs. The process to develop this new approach involved all relevant stakeholders, a procedure called “middle-up-down”. Based on the consultations, the ICF was expanded to integrate aspects that focus on goals and needs and are therefore located in the future. A data collection exercise was undertaken to understand the practice to establish eligibility. The objective was to identify the determinants of “need” and “requirements”. The rationale for selection of ICF items was based on the explanatory power to differentiate “levels of need” or “requirement for adaptations”. The methodology applied to develop the list included exploratory regression analysis (identify items with high explanatory value), factor analysis (represent items with highest loadings from relevant components), cluster analysis (represent important constellations), frequencies (selection of most commonly used items), correlations between ICF items and “needs and requirements” added to item selection process. The resulting item list bridges clinical practice (description of functioning & disability) with educational practice (planning interventions to reach goals in participation).

In a further step, this list was implemented into a nationwide database to collect data about the students with special needs, and professionals were trained also on a nationwide basis. The database is web-accessible but highly protected (www.sav-pes.ch).

Discussion

It was appreciated that this is one of the first nation-wide projects to make use of the ICF in children with special needs (Hollenweger & Lienhard, 2008). This project is a good example of how it is necessary to combine teaching of the ICF on a broad level and at the same time provide an Information Technology (IT) infrastructure in order to make good use of the collected data (not duplicating assessments, and offering the students the support they need on an individualized basis).

Carla Sabariego

Ludwigs-Maximilian-University, Munich, Germany

Carla is a psychologist by training and works as a researcher together with a group led by Alarcos Cieza at the ICF-Collaboration Center in Munich. She presented a study that used and adapted the ICF core-set developed for patients with stroke for a patient education module (www.forschung-patientenorientierung.de). The selected items of the core-set were written on cards and had on the backside of the cards a description of the item in lay language. Those cards were used for patients that had suffered a stroke and were starting a patient education program, to describe their level of functioning, the facilitators and barriers they were encountering or expecting to meet. Based on the selection of items by the patients, the patient education module was adapted to the specific needs of the patients in order to customize the education part and allow people to use the time spent more efficiently. A randomized controlled study is in progress, comparing this approach with a standardized patient education module, which is the same for all patients.

Discussion

It was discussed whether the use of the core set of items would not focus too much on problems in the intervention and if there was also room to talk about what was going well during the education session? One of the outcome criteria was the increased use of services when the patients need them (find out by telephone interview) and the question was how does self-efficacy translate into getting the necessary support.

Self-efficacy is a means to an end, finding the solution is more important. In fact some people were upset after the intervention, because they understood more about their problems (and evaluating their own situation was not easy for them).

Armin Sohns

University of Applied Sciences of Nordhausen and University of Applied Sciences Gera, Germany

Armin is a professor of special pedagogics and presented data about the changing requirements of training clinicians who will work in early intervention as well as social workers. He presented results from a German national survey (KiGGS 2006/2007 http://www.kiggs.de/experten/erste_ergebnisse/English_Articles/index.4ml) that found an increase of multiaxial exacerbating factors (single parent, conflicts between parents, disaffection of the parents etc.) that result in an excessive demand on parenting. The difficulty of coping with these demands puts children at particular risks during infancy. Children with regulatory disorders (e.g. excessive screaming that has - in interdependency - an impact on the parent-child relationship) have considerable problems. While the study indicates that nearly 50% of children in Germany have at least one health problem, 90% of parents identify their children as being very healthy. This might indicate a change in perception with a reduced ability

to recognize health and developmental risks. After describing the situation of the children, Armin showed how the actual functioning of the early intervention system tends to be not well coordinated and not responding to the shifts of needs in society (*"The system of ECI is inclined to show itself as an uncoordinated coexistence of support with vague professional requirements, high bureaucratic obstacles and few concepts considering the environment and parties involved."*) To change this situation it is necessary to facilitate the collaboration between families, clinicians and funding agencies. The ICF could be useful as a common language to achieve this.

In the graduate courses that Armin teaches the ICF has been included in the curricula to prepare future professionals adequately. Nonetheless many issues with the practical use of the ICF need to be resolved, such as whether coding of single items will be done or if checklists (like one that already exists for early intervention in German) will be implemented or revised to use on a larger scale. To work in these questions, Armin recently submitted a research proposal in Germany.

Discussion

It was discussed how the ICF knowledge could be best taught. Is it a common curriculum to all professionals or should it be tailored according to the professional background of the learners? The high numbers of children needing early intervention in Germany were also a point of discussion. The use of the ICF in this context could help to identify better which kind of support is needed, as this does not always seem to be 'therapeutic' in the sense of OT, PT and SPL.

Workshop Group Discussions

Participants were divided into two groups and joined discussions with the following themes (the discussions were held twice over the course of the workshop):

- A. The ICF and Professional Education
- B. The ICF and Health Services
- C. The ICF and Communication with Professionals and Parents
- D. The ICF in Clinical Research

The workshops were each facilitated by two researchers from McMaster University and one transcriptionist took notes in each of the workshops. The groups switched themes, so each topic was discussed twice. On the second day, a plenum discussion was held and perspectives for further work developed.

A - The ICF and Professional Education

Ideas were collected regarding the contents for teaching, methods of learning and new ideas among the participants. We discussed the classic paradigm that teaches and organizes professionals into specialties according to impairment categories. Introducing the ICF means also introducing a new philosophy of how professionals

see themselves in a multiprofessional team or network. The content would need to focus on training to recognize activities and participation as important parameters that need to be assessed. This could be taught by case examples and also by performing linking exercises of different instruments to the ICF. The introduction of the ICF into the curricula would allow for more interdisciplinary experience during education. Especially in medical education the ICF fits quite well within the different roles that compose the CanMEDS Physician Competency Framework of the Royal College of Physicians and Surgeons of Canada (<http://rcpsc.medical.org/canmeds/>).

Relevant issues were identified in how well the ICF will be adopted just by exposure to students. It will need a broader acceptance of the ICF into current practice. Therefore it became clear that we need to educate students who can implement these ideas into their clinical practice. Benefits of using the ICF must become clear to clinicians and that will need to be addressed by research. Opportunities for education could be in

- staff education, interprofessional teaching, and
- by including ICF in regular curriculum (might be difficult)

There is a need to learn from clinical settings where ICF concepts are actually applied and new staff are coming and learning about it.

Another important aspect of educating about the ICF is the Knowledge Translation directed at non-clinical people:

- Board members, sponsors, politicians, people who decide about how services are being organised
- Parent organisations, parents
- Patients

It will also be necessary that the application of the ICF in clinical practice be tailored to each particular purpose. This means not all settings must use it to the same level of detail. It should also be considered how the ICF will become part of evidence-based practice, for example by defining outcome criteria according to the ICF.

B - The ICF and Health Services

Health Service delivery based only on diagnosis will not meet the needs of families adequately. From the experiences of some of the participants it was inferred that it is important to have an individualized assessment of needs of families, especially families with children with disabilities, to be able to serve them well. The kind of impairments, content of therapy and environmental conditions can be communicated in a common framework/language.

The ICF was considered to be an excellent tool for linking health services and measuring outcome measures, allowing teams to identify needs of children and family and allocate resources.

The need to spread the idea of the ICF more amongst families, communities, peers, and resources was identified.

Two (unpublished) studies were described by Marilyn Wright and Jan Willem Gorter (Siebes et al., 2007). Both focussed on how the services provided were matching the needs of families and found that, for example, in a group described as “hard to serve families” the needs of those families were much more dependant on individual issues related to environmental factors such as family dynamics, transportation access, etc. In a study about therapy contents and goals of the family in the Netherlands it was also shown that the agreement between them was not high.

Examples/Ideas from the group:

The main focus was on the possibility of using the ICF to share information. This could be across agencies, between in-patient and out-patient services, as well as trans-institutional.

Another focus was in using the ICF to empower patients and families to improve their participation, make information understandable, respect the views and goals of the patients and making the goals more relevant to them.

It was argued that probably the role of a lead therapist or case-manager could facilitate the transfer of the information between the different professionals, agencies and the patients, based on the ICF.

On the critical side it was discussed that the increase in exchange of information also has the risk of misuse by agencies, as there might be threshold and gate-keeper issues to access services and the patients themselves might feel overwhelmed by identifying a series of ‘problems’ and ‘restrictions’. It will be important that the patients as well as the professionals be trained in the proper use of the ICF.

Implementation ideas:

- Link with patient groups (parents organisations) to promote the ICF
- Start with awareness activities
- There is a need to show that the use of the ICF improves care (research needed, see below!)
- Offer new services based on ICF profiles and participation goals
- ICF and Outcome measures:
 - Linking ICF to existing measurements
 - Need for new measures
 - Identify needs, resource allocation
- Spreading ICF between different professions, professional societies, parents, patients
 - Use the framework to:
 - present results in research
 - talk to parents and patients
 - show that it is feasible and relevant

C - The ICF and Communication with Professionals and Parents

Experiences of the group – What has been done?

The participants report that after starting to use the ICF there is a shift of focus to activities and participation and quality of life (ability to participate as the main problem) when assessing patients. It was discussed that it is sometimes difficult to explain this shift to patients, especially as parents are frequently focussed on 'fixing' the underlying biomedical cause of a health problem. The ICF framework was presented in newsletters and articles, as well as using it in the everyday conversation with parents, focussing on participation and quality of life by some members of the group. Some clinicians use the ICF in Health Records and written documentation. It was identified that parents often do not know how to ask different things than the "medical" questions. There is a need for parent education about the ICF and the meaning of health in this framework.

Potential problems with teaching or implementing the ICF were identified:

It was found, that the ICF can be overwhelming at first sight and the terminology can be difficult for different professions, depending on their background. The attempt to code everything might seem daunting and time consuming. It was also felt, that especially the specific interaction between mother and child (dyadic relationship) was difficult to represent with the ICF and it was discussed whether the level of granularity with a 4-level classification would be really clinically useful and meaningful.

Implementation ideas:

Despite nearly all participants working in interdisciplinary teams, it was felt that there is not a good working language that can be applied across all sectors between professionals and patients. Although the ICF offers a common language, from the perspective of knowledge translation there need to be more examples to illustrate that using the ICF is well suited for this purpose and enhances meaningful communication between disciplines and parents. This could be obtained, for example, by creating consolidated reports that are structured according to the ICF and no longer according to disciplines as it is the rule currently.

Families may play a role in forcing professionals to change the way they are communicating once they have a better knowledge of the framework of the ICF.

From a research perspective there is a need to explore whether and how this approach is better than others, and how this would improve patient care, family-centredness and outcomes (see below).

D - The ICF in Clinical Research

The discussion started about how the ICF is being used in research by the participants or what they are aware of. Some apply the ICF in order to describe where the outcomes they are measuring are found in the ICF. Some research is

looking at psychosocial difficulties in persons with various mental/brain problems (PARADISE Study, Munich, <http://paradiseproject.eu/partners/lmu/>). It was also discussed that frequently studies that are looking into effectiveness of interventions, despite being well funded, fail to organize the outcomes in terms of functioning. These studies rather use health utilisation as an outcome measure. This leads to a circular argument, as researchers choose what to measure based on what can be measured instead of asking what is the impact of the intervention on functioning. An example given was the possible impact of tube feeding not only regarding the child's growth parameters but also on parent well-being, mobility and participation.

Brainstorming ideas for implementation of the ICF in Research:

- Using existing clinics:
 - At McMaster and SickKids some clinics are organized around activities (e.g., feeding clinic, sleep clinic). The ICF could be a good fit to be used in those clinics and the usage of this could be evaluated when introducing a new format of recording the health information relevant to these issues.
- Involving Students:
 - Survey of students at the beginning of their programme and at the end, whether they understand the concept of the ICF and whether they apply it and what is the influence on families (see what effect it has on clinical behaviour)
 - short-term outcome: whether they understand it
 - middle-term outcome: whether they apply it
 - long-term outcome: does it make a difference for people?
 - Mapping exercises (questionnaires → ICF) to understand the dynamics within the ICF
 - Survey on Students with Disabilities in Higher Education based on the ICF (population based) → helps to understand which interventions may be better directed to individuals and which need to be linked to the environment
 - Implementation of ICF into curriculum training of early educators
- Environment as a correlate or determinant of functioning
 - Nature of mobility activities and the environment – how are they interdependent?
 - Need to coordinate services across policy domains – the ICF could function as a common language between agencies that provide different services (Health, Education, Social Welfare)
- Transition to school study (CIHR grant proposal by Magdalena Janus, McMaster University)
 - Pilot study on mapping the difficulties and problems of children onto the ICF (understand functioning and disability in a pre-selected group considered to need extra resources in education systems)

- Children in preschool receive interventions in a one-to-one format vs. different format in school (indirect support through the teacher, group setting), although the goals might be the same. Parents frequently don't realize that different settings can pursue the same goals. The ICF could serve as a common way to describe needs of children in different settings
- Use of the ICF as a tool for analyzing clinical problems
 - During the history taking process and assessment of patients the ICF could be a support in covering all the components of health of a patient and thus show that we don't always have to intervene in the traditional way as physicians.
 - It could also serve as a tool to generate hypotheses about the interrelations of the different health components and the problems occurring in order to develop appropriate intervention plans that are based on a bio-psycho-social model.
 - Following this approach, the ICF could also assist in identifying patient-important outcomes (patient identified goals) and help to plan how to assess these outcomes.
 - Many times, there is no particular best way of doing things in clinical practice, so environmental and personal factors do impact (generally by looking at people's own habits of thinking and acting).
 - There are families that want us to focus on problems (they don't want to hear about environmental issues) → we can change this attitude only if we change the relationship with the parents and accept to be on equal terms with them (but parents are also 'trained' by using the the health system to act this way). The ICF could help to find a common basis of mutual understanding of what are the issues and what can be done about them.
- "Wish-list" for clinical research – possible research questions:
 - Does ICF-based thinking (analysing, planning interventions, communicating with families) improve outcomes?
 - Does ICF-based thinking improve team collaboration (processes of care)?
 - Does education make a difference, and if so, to whom? (different understanding, satisfaction, outcomes, the way teams function) → series of connects that in the end should lead to the improvement of care of children, but it is a complicated pathway to change.
 - Does explicit ICF thinking improve parents' thinking about the situation of their child – i.e., put things in perspective (understanding the broader way of thinking: do such parents feel better understood and better taken care of – even if we cannot address the biological problem right now.)

Implementation Projects Discussion

For the different topics that were discussed over the two days, the following ideas were collected as possible ways of implementation of the ICF.

Professional Education

- Interprofessional teaching: by introducing the ICF to students or professionals from different areas during interdisciplinary teaching events (at University Level or as Continuous Professional Education), this could help to show the use of the ICF as a common language and help to establish interdisciplinary understanding and pattern of relationships during the professionalizing process.
- Knowledge transfer should also be directed towards professionals outside the direct context of patient care to make them more aware of the ICF and its potential and possible applications for their goals and interests (e.g., policy makers, consumers, funders)

Communication

- When communicating with colleagues and other professionals that are not familiar with the ICF it would be preferred to focus on the concepts rather than details. The ICF can be overwhelming when looked at it in classification detail, but the concepts are compelling and provide entry points for a change in attitudes on a professional and patient level.
- Interprofessional reports could be sent to the family in a ICF format focussing on the different components of health instead of describing the patient from the point of view of different professionals and in different professional jargons. The documentation of visits and case discussions could also be done in that format. Especially families with children with complicated lives rely on reports and need them to reflect their issues and problems as well as suggestions for intervention.

Health Services

- In order to make use of existing instruments (measures, questionnaires) within the framework of the ICF, these have to be linked to the different ICF-Items.
- The ICF can be used to identify needs of patients in a broader sense, especially of patients with chronic conditions, and help to manage waiting lists in a different way, allowing a more customized response to patient needs.

- Overall, this approach will also identify the need for new measures by revealing which components of health are not yet well described by standardized instruments or measurements.

Research

To decide upon which topics to pursue in implementing and researching the ICF we tried to focus on two aspects: What is most relevant? What is easily deliverable?

General approach:

- We should try to evaluate any new research project that we are thinking of regarding the implementation and benefits of the ICF in describing the problem and the results.
- In research projects that are already underway, we should try to add the activities/participation dimension to describe what impact any intervention has and make activities evidence-based.

In discussing how to implement and research the ICF we agreed on the following ideas:

- Start in areas where the ICF is already established (e.g., Developmental Paediatrics, Children's Treatment Centres)
- In these settings, patients and families are being cared for by a team, so the quality of the team determines any intervention that has been decided upon. When introducing the ICF into standard care, two research questions would be:
 - **Does ICF-based thinking improve collaboration of the team?**
 - **Does ICF-based thinking improve the outcomes of patients and families – and if so, which ones?**

Potential research approaches:

- Translate reports into ICF language and concepts:
 - Without having to change anything in the actual way care is being delivered a first approach could be to use the form of documentation that is produced on a regular basis and modify this information in such a way that it is structured according to the components of health described by the ICF. To assess the impact of this modification, parents and professionals could be asked to analyze the different report formats and evaluate how much and which information they can get out as well which form of report they feel is more informative and helpful.
 - Use raw data, make it into a traditional report and make it into an ICF-based report and see what makes more sense to parents.
 - Identify different purposes for which reports are written and see if they fulfil these purposes.
- Measure team coherence:
 - There exist instruments to measure team coherence and those could be applied before and after introducing ICF-based thinking and

changing the way the team assesses patient needs and develops plans for care.

- Measure outcomes:
 - This approach would be the most complex, as first of all adequate outcome measures have to be identified that would make it possible to reflect the different components of health and therefore need to be broader than focussing on body functions or satisfaction.
 - Monitor processes in different settings and define some quality indicators (e.g., coherence of goals with assessments, etc.)

Potential Deliverables/Results:

- With these approaches we would expect to obtain a better understanding of families concerning the functioning of the children with disabilities and how recommendations and interventions can improve functioning.
- Investing time early in the rehabilitative process in assessing functioning and environmental factors might have an impact on how interventions are planned in the sense that these would have rather to focus on the idea of having a “different” child instead of a “broken” child that needs to be fixed.
- Colleagues from Germany proposed that as there already exist several children’s treatment centres that have introduced the ICF it might be possible to compare the family-centredness in these centres with that in comparable centres that did not yet introduce the ICF.

Final round of discussions

In the final round with all members the above research questions to be addressed in the future were reworded as follows and some conceptual as well as critical remarks regarding the feasibility of answering those questions were made:

- **Q. 1: What concept of health (as structured in reports) do parents, clinicians and teachers want, need, prefer, understand and value?**
 - The reports would need to be written based on the same instructions and indications of purpose. In addition to the report one would need to interview the person producing the report on the underlying concepts and talk to the recipients to understand their reaction. This probably would require a mixed methods study.
 - As an idea for a pilot study one could start with a survey among potential recipients of reports and ask “What kind of information would you want to be included in a report to you?” (i.e., parents, teachers, health professionals)
 - In the same line, another survey could address what parents expect from assessments, treatments and outcomes and how they reflect their concept of health.

- Additional information could be gathered among the professionals regarding their training, their professional identities as well as subjective theories regarding concepts of health and attitudes towards chronic health conditions and disabilities.
- Another study could consist in analyzing a series of reports and try to map them onto the ICF and count frequencies and level of details. This would be a starting point, indicating which components of health are represented in these reports and which are not.

➤ **Q. 2: Does an approach to assessment that is informed by concepts of the ICF influence people's experiences of the processes of care?**

- This question seems much more complex to be answered, as satisfaction is generally high in any case, so no significant differences might be identified, if we try to measure the "experience".
- It might be necessary to assess and study first what defines an experience of patients and families that are receiving care within the health system. Therefore this question might only be able to be approached after having obtained more information with the study ideas outlined above.
- Maybe we need to reframe this question again.

➤ **Additional Ideas:**

- Review of measures that are in use in developmental paediatrics and map them onto the ICF – this could be linked to previous work at McMaster with a compilation of measurement instruments that have been critically appraised and summarized in a database called "All About Outcomes" (<http://www.canchild.ca/en/ourresearch/allaboutoutcomes.asp>)
- Analyze the database of clinical trials in children with chronic paediatric conditions to see which components of health are being addressed with the outcome measures applied in each trial (study under way: PI Eyal Cohen & Amy Houtrouw, Sickkids, Toronto)

References and Links

Hollenweger, J., & Lienhard, P. (2008). Entwicklung eines standardisierten Abklaerungsverfahrens. *Schweizerische Zeitschrift Fuer Heilpaedagogik*, 14, 11-12.

Kraus de Camargo, O. (2007). Die ICF-CY als Checkliste und Dokumentationsraster in der Praxis der Frühförderung. *Frühförderung Interdisziplinär*, 26, 158-166.

Leonardi, M. (2006). The definition of disability: what is in a name? *Lancet*, 368, 1219.

Siebes, R. C., Ketelaar, M., Gorter, J. W., Wijnroks, L., De Blécourt, A. C. E., Reinders-Messelink, H. A., Van Schie, P. E. M., & Vermeer, A. (2007). Transparency and tuning of rehabilitation care for children with cerebral palsy: a multiple case study in five children with complex needs. *Developmental Neurorehabilitation*, 10, 193.

World Health Organization (2001). *International Classification of Functioning, Disability and Health (ICF)*. Geneva: World Health Organization.

World-Health-Organization (2007). *International Classification of funtioning, disability and health: children & youth version: ICF-CY*. Geneva: WHO press.

- Email List about ICF: <http://mailman.mcmaster.ca/mailman/listinfo/icf-l>
- Parametrix Software: <http://www.parametrix.ch/ws/de/phoenix/>
- UDS – WeeFIM: <http://www.weefim.org/>
- Swiss site for ICF-based assessment: www.sav-pes.ch (recently not accessible)
- Research site Munich: www.forschung-patientenorientierung.de
- KIGGS-report: http://www.kiggs.de/experten/erste_ergebnisse/English_Articles/index.4ml
- CanMEDS physician competency framework: <http://rcpsc.medical.org/canmeds/>
- PARADISE research project site: <http://paradiseproject.eu/partners/lmu/>
- CanChild – All about Outcomes: <http://www.canchild.ca/en/ourresearch/allaboutoutcomes.asp>

Appendix

List of participants
Copies of presentations

Attendants ICF-Meeting

Name	email	Professional background	Institution
Teresa Carter	CarterT@mcmaster.ca	Developmental Paediatrics	McMaster
Marilyn Wright	WRIGHTM@HHSC.CA	Physiotherapy	McMaster
Nora Fayed	fayedn@univmail.cis.mcmaster.ca	Occupational Therapy	McMaster
Peter Rosenbaum	rosenbau@mcmaster.ca	Developmental Paediatrics	McMaster
Moyez Ladhani	ladhanim@mcmaster.ca	General Paediatrics	McMaster
Jan Willem Gorter	gorter@mcmaster.ca	Physiatry	McMaster
Janette McDougall	janette.mcdougall@tvcc.on.ca	Social Work	Thames Valley
Heather Marrin	hmarrin@erinoakkids.ca	Occupational Therapy	Erinoak Kids
Anne Klassen	aklass@mcmaster.ca	Epidemiology & Statistics	McMaster
Olaf Kraus de Camargo	krausdc@mcmaster.ca	Developmental Paediatrics	McMaster
Liane Simon	liane.simon@saxofanselm.de	Early Intervention	Hamburg University
Armin Sohns	sohns@fh-nordhausen.de	Early Intervention	Nordhausen Univ. Applied Sciences
Judith Hollenweger	judith.hollenweger@phzh.ch	Special Education	Zurique School of Education
Nicole Habenicht	nicole.habenicht@kispi.uzh.ch	Nursing	Zurique University
Magdalena Janus	janusm@mcmaster.ca	Psychology	McMaster
Debra Hughes	dhughes@mcmaster.ca	Research assistant	McMaster
Adrienne Harvey	harvey.adrienne@gmail.com	Physiotherapy	McMaster
Amy Houtrouw	HoutrowA@peds.ucsf.edu	Physiatry	UCSF
Carla Sabariego	carla.sabariego@med.uni-muenchen.de	Psychology	Munich University - WHO Collaborating Centre
Shawna Wade	swade@hollandbloorview.ca	Occupational Therapy	Holland-Bloorview
Mike Livingston	mike.livingston@gmail.com	Student	
Gabriel Ronen	roneng@mcmaster.ca	Child Neurology	McMaster
Eyal Cohen	eyal.cohen@sickkids.ca	Paediatrics	SickKids
Dianne Parr	dianne.parr@hwdsb.on.ca	Parent	Family Advisory Board MacKids






International Meeting to Facilitate the Use of the ICF

Hamilton, ON, Canada
 August 12th & 13th 2010





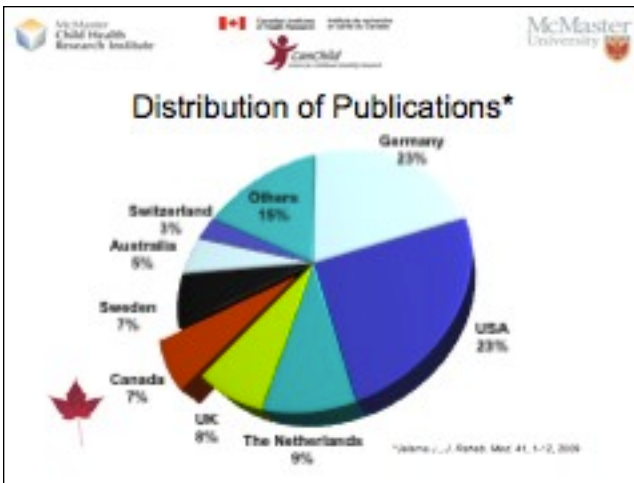
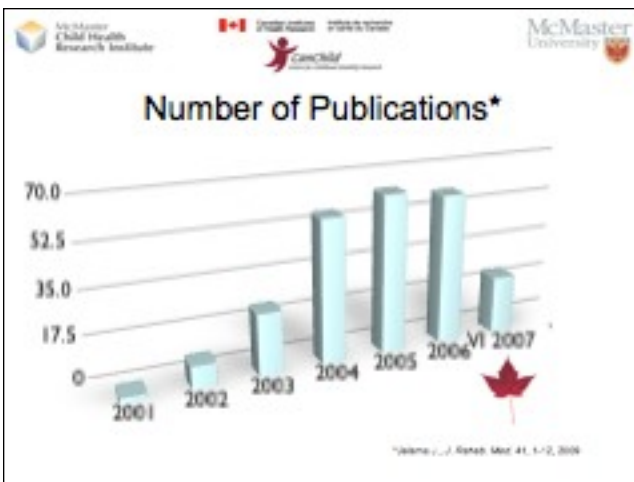



Welcome!



- Housekeeping
- Introduction and Objectives







McMaster Child Health Research Institute

CanChild

McMaster University

Canada - Germany

- 2933 inhabitants per OT in Canada
- 410 inhabitants per OT in Germany
- 500 inhabitants per physician in Canada
- 300 inhabitants per physician in Germany
- Human Development Index (long & healthy life, knowledge and standard of living): <http://globalis.gvu.unu.edu/>
 - Canada 3rd place
 - Germany 14th place

McMaster Child Health Research Institute



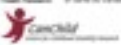

CanChild

McMaster University

How the ICF can be useful*

- Clinical decision making: *We must have a way to study our interventions in order to treat the right conditions at the right time and in the right manner.* (Judy Hawley, P.T.)
- Professional collaboration: *We waste a lot of time and an enormous amount of effort in the transition between services [for children] because we don't have a common language.* (Rune Simeonsson, M.D.)
- Outcomes: *Functional status is among the most predictive elements in terms of utilization as well as outcomes.* (Robert Kane, M.D.)


*Report of Committee on Vital and Health Statistics (Simeonsson, R., et al., 1998)

Objectives

1. Develop ideas on how to implement the ICF
2. Collaborate across Canada

➡ When the meeting is over, how can we tell that it was really good?








- When we leave on Friday night we will:
 - have made new friends
 - have discussed about our experiences with the ICF
 - have a better idea of gives & gets
 - have at least 2 deliverable project ideas to facilitate the use of the ICF in Canada (possibly in collaboration with other countries)
 - want to meet again
 - ...








Day 1

9:00 Welcome & Introduction, Olaf Kraus de Camargo

9:30 Implementation Example – Early Intervention, Liane Simon
10:00 Implementation Example – Neuro-Rehab, Nicole Habernicht

10:30 Coffee Break

11:30 Implementation Example – Special Education, Judith Hollenweger
11:30 Implementation Example – Patient Education, Carla Salasiego
12:00 Implementation Example – Student Education, Amin Sofha


12:30 Lunch

13:30 Workshop A: The ICF and Professional Education, Room 204
(Facilitators: Nora Fayad & Olaf Kraus de Camargo)
Workshop B: The ICF and Health Services, Room 244 (Facilitators: Marilyn Wright & Jan Willem Gorter)

15:00 Coffee Break

15:30 Workshop A: The ICF and Professional Education, Room 244
Workshop B: The ICF and Health Services, Room 204
17:00 End of Sessions

18:00 Dinner at the University Club





Day 2

9:00 Summary of Day 1

9:15 Workshop C: The ICF and Communication with Professionals and Parents (Facilitators: Marilyn Wright & Jan Willem Gorter)
Workshop D: The ICF in Clinical Research (Facilitators: Nora Fayed & Peter Rosenbaum)

10:45 Coffee Break

11:15 Workshop C: The ICF and Communication with Professionals and Parents
Workshop D: The ICF in Clinical Research

13:00 Lunch

14:00 Research Projects Discussion
16:30 End of Meeting

17:30 After-Meeting BBQ (Brazilian Churrasco) at Olaf's place (100 Chedoke Ave.)









„Daniel“, Jörg Daniel Matthes (1998)






The Team

Nancy Murphy
June Lim
Jan Willem Gorter
Marilyn Wright
Nora Fayed
Peter Rosenbaum



Summary of Day 1

- ICF in Health Services:
 - Outcome measures:
 - linking existing measurements to the ICF
 - identify the need of measures
 - identify needs, resource allocation
 - Spreading ICF between different professions, professional societies, parents, patients
 - making the use feasible and relevant

Summary of Day 1

- ICF in Education:
 - Opportunities for Education
 - staff education
 - interprofessional teaching
 - Knowledge Translation (KT)
 - board members, sponsors
 - parent organizations, parents
 - patients



Canadian Institutes
of Health Research

Instituts de recherche
en santé du Canada



McMaster
Child Health
Research Institute



Inspiring Innovation and Discovery



International Research Meeting for the Implementation of the ICF

Date:

12th & 13th of August 2010

Location:

McMaster University, Institute of Applied Health Sciences, Room 201



Mohawk/McMaster Institute for Applied Health Sciences (IAHS)

1400 Main Street West Rm. 201

Hamilton, Ontario, Canada L8S 1C7

phone: (905) 525-9140

Directions From points north and east (i.e. Hwys 401/407/QEW - Toronto/Oakville/Burlington): - take Hwy #403 West to Hamilton

- take the **Main Street West exit** and immediately **turn left (west)** at the lights
- Proceed thru 4 lights and pass McMaster Health Sciences Centre.
- Stay in the right lane and take the right filter lane to Cootes Drive towards Dundas; take the first off ramp to the right into the University
- Turn right and continue past the parking kiosk, towards Main St. to parking lot 'I' (see campus map). Enter the lot and retain the parking ticket.

Program

August 12th

8:00 Registration & Breakfast

9:00 Welcome & Introduction, Olaf Kraus de Camargo

9:30 Implementation Example – Early Intervention, Liane Simon

10:00 Implementation Example – Neuro-Rehab, Nicole Habenicht

10:30 Coffee Break

11:00 Implementation Example – Special Education, Judith Hollenweger

11:30 Implementation Example – Patient Education, Carla Sabariego

12:00 Implementation Example – Student Education, Armin Sohns

12:30 Lunch

13:30 Workshop A: The ICF and Professional Education, Room 201

(Facilitators: Nora Fayed & Olaf Kraus de Camargo)

Workshop B: The ICF and Health Services, Room 244 (Facilitators: Marilyn Wright & Jan Willem Gorter)

15:00 Coffee Break

15:30 Workshop A: The ICF and Professional Education, Room 244

Workshop B: The ICF and Health Services, Room 201

17:00 End of Sessions

18:00 Dinner at the University Club

August 13th

9:00 Summary of Day 1

9:15 Workshop C: The ICF and Communication with Professionals and Parents (Facilitators: Marilyn Wright & Jan Willem Gorter)

Workshop D: The ICF in Clinical Research (Facilitators: Nora Fayed & Peter Rosenbaum)

10:45 Coffee Break

11:15 Workshop C: The ICF and Communication with Professionals and Parents

Workshop D: The ICF in Clinical Research


13:00 Lunch

14:00 Research Projects Discussion


16:30 End of Meeting

17:30 After-Meeting BBQ (Brazilian Churrasco) at Olaf's place (Chedoke Ave. 103)

ICF-CY and Early Intervention Experiences



Liane Simon

Diakonie  Diakonisches Werk
Hamburg-West/Südholstein


Early Intervention Center Norderstedt



Diakonie  Diakonisches Werk
Hamburg-West/Südholstein

History

- 2004 development of a checklist to establish the ICF-status of children (0-6 years)
 - Marijke Kafka-Backmann
 - Olaf Kraus de Camargo
 - Jürgen Kühl
 - Liane Simon
- 2005 implementation of the checklist at two early intervention centers in northern Germany
- 2006 interviewed 80 early intervention professionals to establish the pros and cons of the checklist
- 2007 publication of the ICF-Checklist

Diakonie  Diakonisches Werk
Hamburg-West/Südholstein

ICF Checklist from 2004-2010



The checklist is now part of our everyday routine

Who are we?



Team of 25 people

- Special education teachers
- Psychologists
- Occupational therapists
- Physiotherapists
- Speech therapists
- Pediatricians

Diakonie  Diakonisches Werk
Hamburg-West/Südholstein

Early Intervention Program in Germany



Nationwide program to support proper development of all children starting at early childhood:

- Inquiry, consultation, therapy and education
- available to families with children between 0 - 6 years
- free for the families, paid by public funds
- More than 2000 centers supporting more than 80.000 children


Diakonie  Diakonisches Werk
Hamburg-West/Südholstein

How do we work ?


- easy to contact
- frequently at the child's home
- focusing on the resources available within the family
- interdisciplinary approach
- context related



Whom do we work with?



- Children with mental or physical disabilities
- Babies and premature babies with developmental risks
- Children with gaps in or a delayed development
- Children with behavioral disorder, learning difficulties or difficulties in acquiring skills
- **And their family**



ICF-CY – Why?

Pro and Contra of Working with the ICF Checklist

Pro	Contra
Common language	Frequently regarded as not detailed enough
The judgments of all disciplines are valued equally	Dispute about competences
Requires teamwork	Cannot be used by one discipline alone
First classification that reaches beyond the bio-medical view. It encompasses the environmental factors, activities and participation of the child	Nobody knows it, wants it or pays for it
Parents feel taken serious and appreciated	Many parents expect an ICD diagnosis
Furtheres the education of professionals in their own discipline	
Promotes interdisciplinarity	
Supports the establishment of common goals and common acting of the team around the child	

How do we use the ICF Checklist?

- Is applied to every child we see
- Is conducted every 6-12 month
- Interdisciplinary inquiry at the first visit(s)
- Video-consultation in teams
 - The person, who works with the child and it's family presents the facts to the team
 - Question round
 - Video demonstration of the child
 - Hypothesis and exchange of thoughts and impressions
 - Finally the team agrees on the maximally 6 main points of the ICF-Checklist that are followed up during the next 6 month

Diakonie  **Diakonisches Werk**
Hamburg-West/Südholstein

ICF- Checkliste für Kinder

Welche Informationen wurden verwendet?

Aufzeichnungen

Direkte Beobachtungen

Informationen vom Patient/Eltern

Sonstige: _____

Profession:

Arzt/Ärztin

Psychologe/Psychologin

Pädagoge/Pädagogin

Therapeut/-in

Sonstige: _____

Zielbereiche der Förderung:
(Bitte anschließend nach ICF-CY Kriterien auflisten)

- | | |
|---------|---------|
| • _____ | • _____ |
| • _____ | • _____ |
| • _____ | • _____ |

Name des Kindes: _____ Alter: _____

Gesundheitsdaten

Schwangerschaft normal Risiko-Schwangerschaft

Geburt spontan sectio vaginale Operation

Geburtskomplikationen Ja Nein

Geburtsgewicht Geburtsgröße Geburtskopfumfang

Apgar

Körperlänge Längenperzentile

Körpergewicht Gewichtsperzentile

Kopfumfang Kopfumfangperzentile

Händigkeit: rechts links beide unklar

Akute Erkrankungen in den letzten 6 Monaten? Ja Nein
Wenn ja, welche? _____

Psychische Belastungen in den letzten 6 Monaten? Ja Nein
Wenn ja, welche? _____

Medikamentöse Dauerbehandlung? Ja Nein
Wenn ja, welche? _____

Hilfsmittel? Ja Nein

Wenn ja, welche?

Brille/Sehhilfe	Autositz
Hörgerät/CI	Sitzschale
Orthesen	Lagerungskeil
Einlagen	Badehilfe
Gehilfe/Stützen	Pflegebett
Walker	Lifter
Rollstuhl mechanisch	Talker
E-Roll	PC
Therapiestuhl	Sonstiges _____

Ordnen Sie bitte die ätiologischen Diagnosen zu:

Prä- und Perinatale Schädigung

Angeborene Fehlbildungen

Schädel-Hirn-Trauma

Zerebrale Hypoxie

Neurometabolische Erkrankungen

Neuromuskuläre Erkrankungen

Hirntumoren

Entzündliche Erkrankungen des Nervensystems

Epilepsie

Sonstiges _____

unbekannt

Erklärung:

Die Fehler 1-5 haben folgende Bedeutung in Bezug auf das Alter des Kindes:

1 = ungeschädigt, nicht verzögert oder ausreichende Unterstützung

2 = geschädigt, verzögert oder keine ausreichende Unterstützung

3 = weitere Förderung oder Diagnostik erforderlich

4 = Zeitbereich der Förderung

5 = nicht anwendbar

Die Ziffer 4 sollte erst nach der interdisziplinären Fallbesprechung gewählt werden.

Die Überschriften können optional verwendet werden, um einen raschen Überblick zu erhalten oder für eine zusammenfassende Bewertung.

Körperfunktionen

B1 Mentale Funktionen	1 2 3 4 5
B110 Bewusstsein	1 2 3 4 5
B114 Orientierungsfunktionen	1 2 3 4 5
B117 Intelligenz	1 2 3 4 5
B120 Basale kognitive Grundfunktionen	1 2 3 4 5
B122 Globale psychosoziale Funktionen	1 2 3 4 5
B126 Funktionen von Temperament/Persönlichkeit	1 2 3 4 5
B130 Psychische Energie Antrieb	1 2 3 4 5
B134 Schlaffunktionen Einschlafen Durchschlafen	1 2 3 4 5
B140 Aufmerksamkeitsfunktionen	1 2 3 4 5
B144 Gedächtnisfunktionen	1 2 3 4 5
B147 Psychomotorische Funktionen	1 2 3 4 5
B152 Emotionale Funktionen	1 2 3 4 5
B156 Wahrnehmungsfunktionen	1 2 3 4 5
B160 Denkfunktionen	1 2 3 4 5

B164 Höhere Kognitive Leistungen Exekutivfunktionen	1 2 3 4 5
B167 Kognitiv sprachliche Funktionen	1 2 3 4 5
B172 Rechnen betreffende Funktionen	1 2 3 4 5
B176 Ment. Funktionen kompl. Bewegungshandlungen	1 2 3 4 5
B180 Selbstwahrnehmung Zeitwahrnehmung B2 Sensorische Funktionen	1 2 3 4 5
B210 Sehvermögen	1 2 3 4 5
B215 Funktionen von Strukturen des Auges	1 2 3 4 5
B230 Hörvermögen	1 2 3 4 5
B235 Vestibuläre Funktionen	1 2 3 4 5
B240 Tinnitus Fallneigung Schwindel	1 2 3 4 5
B250 Funktionen des Schmeckens	1 2 3 4 5
B255 Funktionen des Riechens	1 2 3 4 5
B260 Propriozeptive Funktionen	1 2 3 4 5
B265 Tastsinn	1 2 3 4 5
B270 Temperatur Druck Vibrationsempfinden	1 2 3 4 5
B280 Schmerz	1 2 3 4 5
B3 Stimm- und Sprechfunktionen	1 2 3 4 5
B310 Stimmfunktionen	1 2 3 4 5
B320 Artikulationsfunktionen	1 2 3 4 5
B330 Redefluss Sprechrhythmus	1 2 3 4 5
B340 Alternative stimmliche Äußerungen	1 2 3 4 5

B4 Innere Systeme	1 2 3 4 5
B455 kardiorespiratorische Belastbarkeit	1 2 3 4 5
B5 Funktionen des Verdauungstrakt	1 2 3 4 5
B510 Nahrungsaufnahme	1 2 3 4 5
B515 Verdauung	1 2 3 4 5
B525 Defäkation Kontinenz	1 2 3 4 5
B540 Ernährungszustand	1 2 3 4 5
B550 Wärmeregulation	1 2 3 4 5
B6 Urogenitale Funktionen	1 2 3 4 5
B620 Miktionsfunktion Kontinenz	1 2 3 4 5
B7 Neuromuskuläre und bewegungsbezogene Funktionen	1 2 3 4 5
B710 Gelenkbeweglichkeit	1 2 3 4 5
B715 Gelenkstabilität (Hüftluxation)	1 2 3 4 5
B730 Muskelkraft	1 2 3 4 5
B735 Muskeltonus	1 2 3 4 5
B750 Motorische Reflexe	1 2 3 4 5
B760 Willkürbewegungen (Auge-Hand-Koordination)	1 2 3 4 5
B765 Unwillkürliche Bewegungen (Tremor, Dyskinesie, Tics)	1 2 3 4 5

Körperstrukturen	
S1 Struktur des Nervensystems	1 2 3 4 5
S110 Gehirnstruktur inklusive Hirnnerven	1 2 3 4 5
S120 Rückenmark	1 2 3 4 5
S2 Augen und Ohren	1 2 3 4 5
S270 Auge	1 2 3 4 5
S280 Ohr	1 2 3 4 5
S3 Stimme Sprache	1 2 3 4 5
S4 Innere Systeme	1 2 3 4 5
S410 Struktur des kardiovaskulären Systems	1 2 3 4 5
S420 Struktur des Immunsystems	1 2 3 4 5
S430 Struktur des Atmungssystems	1 2 3 4 5
S5 Verdauungs- Stoffwechsel und Hormonsystem	1 2 3 4 5
S6 Urogenitalsystem reproduktives System	1 2 3 4 5
S610 Harnwege Nieren	1 2 3 4 5
S630 Geschlechtsorgane	1 2 3 4 5
S7 Bewegungsstrukturen	1 2 3 4 5
S710 Kopf Nackenregion	1 2 3 4 5
S730 Obere Extremität	1 2 3 4 5
S750 Untere Extremität Hüfte	1 2 3 4 5
S760 Rumpf	1 2 3 4 5
S8 Haut und Hautanhangsgebilde	1 2 3 4 5

Aktivität und Partizipation	
D1 Lernen	1 2 3 4 5
D110 Beobachten	1 2 3 4 5
D115 Zuhören	1 2 3 4 5
D120 Basale sinnliche Wahrnehmung	1 2 3 4 5
D121 Zielgerichtete sensorische Exploration	1 2 3 4 5
D130 Nachmachen Nachahmen	1 2 3 4 5
D131 Spiele Spielen lernen	1 2 3 4 5
D133 Sprechen lernen	1 2 3 4 5
D135 Üben	1 2 3 4 5
D140 Lesen lernen	1 2 3 4 5
D1403 Kindliche Konzeptbildung	1 2 3 4 5
D155 Sich Fertigkeiten aneignen	1 2 3 4 5
D160 Aufmerksamkeit fokussieren	1 2 3 4 5
D175 Probleme lösen	1 2 3 4 5
D177 Entscheidungen treffen	1 2 3 4 5
D2 Allgemeine Aufgaben und Leistungsanforderungen	1 2 3 4 5
D210 Durchführen einer Aufgabe	1 2 3 4 5
D220 Durchführen mehrerer Aufgaben	1 2 3 4 5
D230 tägliche Routine durchführen	1 2 3 4 5
D235 Kontinuität im Verhalten	1 2 3 4 5

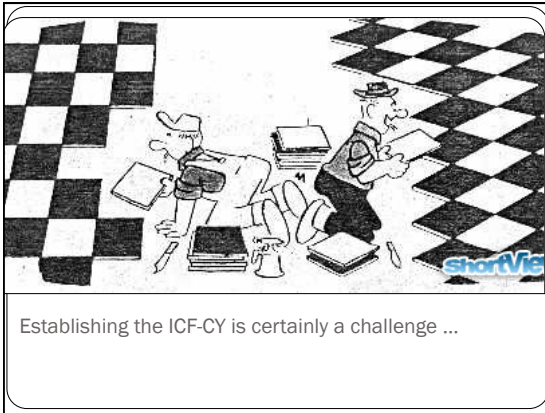
D3 Kommunikation	1 2 3 4 5
D310 Gesprochene Mitteilungen verstehen	1 2 3 4 5
D315 Nonverbale Mitteilungen verstehen	1 2 3 4 5
D330 Sprechen	1 2 3 4 5
D331 Vorsprachliche Äußerungen	1 2 3 4 5
D335 Nonverbale Mitteilungen produzieren	1 2 3 4 5
D350 Konversation	1 2 3 4 5
D355 Diskussion	1 2 3 4 5
D360 Kommunikationsgeräte nutzen	1 2 3 4 5
D4 Mobilität	1 2 3 4 5
D410 Körperposition wechseln	1 2 3 4 5
D412 Spontanbewegungen	1 2 3 4 5
D415 In einer Körperstellung verbleiben, wenn die Situation es erfordert	1 2 3 4 5
D420 Sich verlagern	1 2 3 4 5
D430 Gegenstände anheben/tragen	1 2 3 4 5
D440 Feinmotorik der Hand	1 2 3 4 5
D445 Hand und Armgebrauch	1 2 3 4 5
D450 Gehen bzw. altersentsprechende Fortbewegung	1 2 3 4 5
D460 Sich in verschiedenen Umgebungen fortbewegen	1 2 3 4 5
D465 Selbstständiges Fortbewegen mit Gerät	1 2 3 4 5

D5 Selbstversorgung	1 2 3 4 5
D510 Sich selbst waschen	1 2 3 4 5
D520 Seine Körperteile pflegen	1 2 3 4 5
D530 Zur Toilette gehen	1 2 3 4 5
D540 Ankleiden Auskleiden	1 2 3 4 5
D550 Essen	1 2 3 4 5
D560 Trinken	1 2 3 4 5
D565 Gefahren erkennen und vermeiden	1 2 3 4 5
D570 Auf seine Gesundheit achten	1 2 3 4 5
D6 Haushalt	1 2 3 4 5
D640 Im Haushalt helfen	1 2 3 4 5
D660 Anderen helfen	1 2 3 4 5
D7 Interpersonale Interaktionen	1 2 3 4 5
D710 einfache interpersonale Interaktionen	1 2 3 4 5
D720 komplexe interpersonale Interaktionen	1 2 3 4 5
D730 Beziehungen zu Fremden	1 2 3 4 5
D740 Beziehungen zu Betreuern	1 2 3 4 5
D750 Beziehung zu Gleichaltrigen	1 2 3 4 5
D760 Familienbeziehungen	1 2 3 4 5

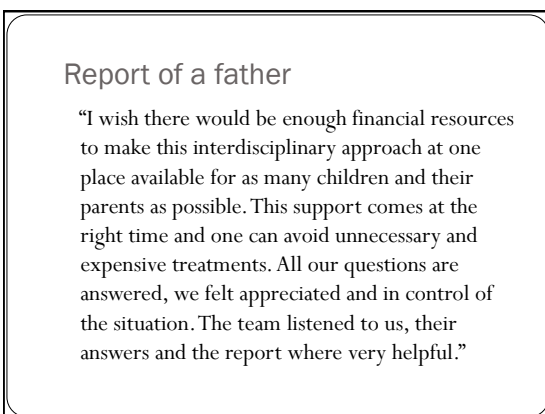
D8 Hauptlebensbereiche	1 2 3 4 5
D810 Informelle Ausbildung	1 2 3 4 5
D811 Spielen	1 2 3 4 5
D815 Vorschulerziehung	1 2 3 4 5
D817 öffentliche Erziehung	1 2 3 4 5
D9 Gemeinschaft Soziales Staat	1 2 3 4 5
D910 Leben in der Gemeinschaft	1 2 3 4 5
D920 Erholung Freizeit	1 2 3 4 5
D92000 Spiel mit Kindern	1 2 3 4 5
D940 Menschenrechte, Selbstbestimmung, Autonomie	1 2 3 4 5
Kontext und Umweltfaktoren	
E1 Produkte und Technologien	1 2 3 4 5
E1100 Verfügbarkeit notwendiger Lebensmittel	1 2 3 4 5
E1101 Verfügbarkeit notwendiger Medikamente	1 2 3 4 5
E115 Hilfsmittel für den persönlichen Gebrauch im täglichen Leben	1 2 3 4 5

E120 Hilfsmittel zur persönlichen Mobilität und zum Transport	1 2 3 4 5
E127 Spielsachen und kindergerechte Produkte	1 2 3 4 5
E130 Produkte und Technologien für Bildung und Ausbildung	1 2 3 4 5
E150 Barrierefreiheit im öffentlichen Bereich	1 2 3 4 5
E155 Barrierefreies familien und kindgerechtes Wohnen	1 2 3 4 5
E165 finanzielle Situation	1 2 3 4 5
E2 Natürliche und vom Menschen veränderte Umwelt	1 2 3 4 5
E215 Bevölkerungsstruktur, Minderheit	1 2 3 4 5
E250 Laute und Geräusche	1 2 3 4 5
E260 Luftqualität	1 2 3 4 5
E3 Unterstützung und Beziehungen	1 2 3 4 5
E310 Unterstützung durch Familie und Angehörige	1 2 3 4 5
E325 Unterstützung durch Gleichaltrige Freunde Nachbarn	1 2 3 4 5
E330 Fachleute der pädagogischen Berufe	1 2 3 4 5
E340 Zusätzliche Hilfs- und Pflegepersonen	1 2 3 4 5
E350 Haustiere	1 2 3 4 5
E355 Fachleute der Gesundheitsberufe	1 2 3 4 5
E365 Andere Fachleute	1 2 3 4 5

E4 Einstellung	1 2 3 4 5
E410 Einstellungen der Eltern	1 2 3 4 5
E411 Einstellungen der Geschwister	1 2 3 4 5
E415 Einstellungen der Freunde und Bekannte	1 2 3 4 5
E425 Einstellungen von Gleichaltrigen und Nachbarn	1 2 3 4 5
E430 Einstellungen von Fachleuten pädagogischer Berufe	1 2 3 4 5
E450 Einstellungen von Fachleuten der Gesundheitsberufe	1 2 3 4 5
E455 Einstellungen anderer Fachleute	1 2 3 4 5
E5 Dienste, Systeme und Handlungsansätze	1 2 3 4 5
E570 Versicherung (GKV, MDK, Sozialhilfeträger etc.)	1 2 3 4 5
E575 Andere soziale Unterstützung	1 2 3 4 5
E580 Gesundheitswesen, Pflegeeinrichtungen, Heime	1 2 3 4 5









The ICF-Checklist helps us supporting families

Diakonie  Diakonisches Werk
Hamburg-West/Südholstein

KINDERSPITAL ZÜRICH

ICF in Neuro Rehabilitation


Implementation Example

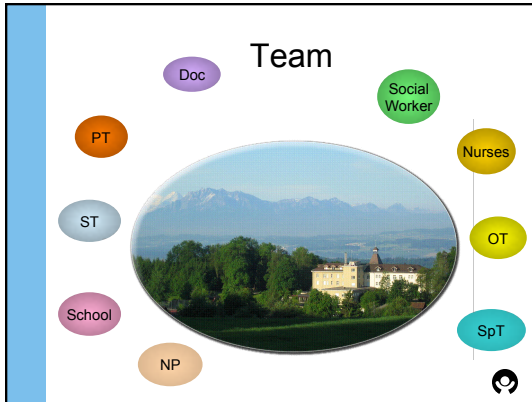
University Children's Hospital Zurich
Rehabilitation Center



Diversity

- 48 children and adolescents
- 3 units (early rehab, kids, teenager)
- neuro-rehabilitation and orthopedics





ICF means:

Admission
beginning of
discharge planning

ICF means:

We all focus on the child's
individual needs!

This is where all our work
comes together!



1

Day 1

- Multidisciplinary meeting with parents (+ child)

Goal setting

- Where will the child live after rehab?
- How can we make this possible?

Electronic file:

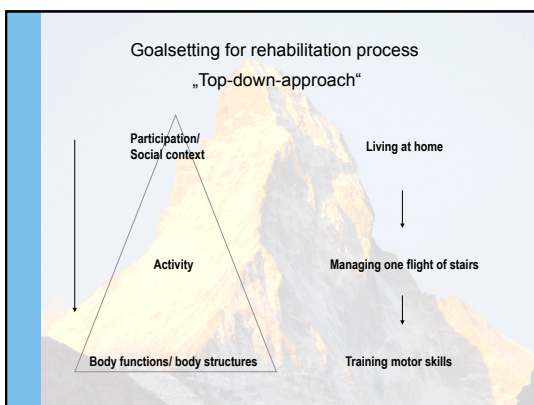
Activity and Participation						
Mobility	+	Self-care	+	Interpersonal Interaction	+	Additional
	Y N		Y N		Y N	

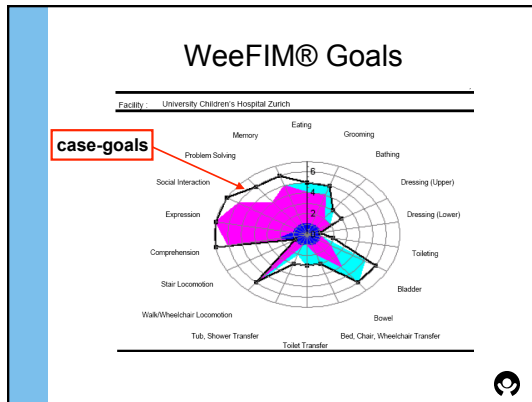
DIAGNOSES	WestPM		GES	AREAS OF LIFE before Admission
	Self-care			
	Motor			1 HABITATION •
	Cognition			2 SCHOOL EDUCATION •
	TOTAL			3 FREETIME •

GOALS at Admission	
GOALS/EXPECTATIONS	
Patient	
Parents	
Referring Physician	

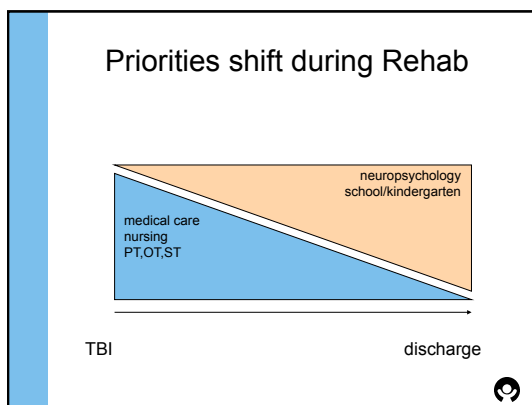
Rehab-Team	GOALS Area of life at Discharge	ACTIVITY and PARTICIPATION	FUNCTIONS	CONTEXT
	1 HABITATION •			
	2 SCHOOL EDUCATION •			
	3 FREETIME •			

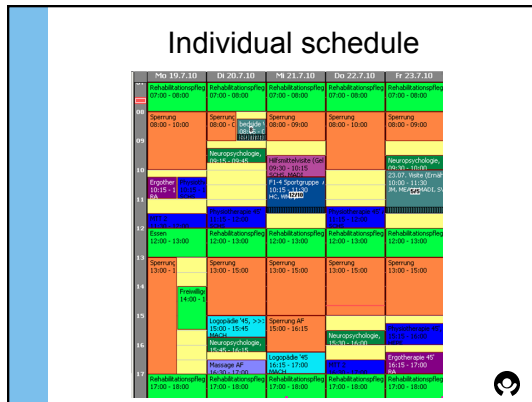
RESOURCES	
Patient	Family/Social network











1 8 15 ...

Weekly Meetings

- Electronic file → ICF
- Short multidisciplinary meeting
- New focus, new developments?
- New goals?

1 49 105


Interim Meetings

- Electronic file → ICF
- Multidisciplinary meeting
 - New goals?
- Meeting with parents
 - New goals?

1 49 105 **Discharge**

Discharge

- Rehab goals are reached
- Maximum level of participation/independence
- Child and family are comfortable with going home




ICF – what changed?

- Focus on participation, areas of life
- Multidisciplinary goal setting
- More „democracy“



Thank you for your attention!




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Children's University Hospital Zurich
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Mail to: Nicole.Habenicht@kispi.uzh.ch

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Applying the ICF-CY in Education: The new national eligibility procedure in Switzerland


Prof. Dr. Judith Hollenweger
Zurich University of Teacher Education
International Research Meeting for the Implementation of the ICF
Hamilton, 12 August 2010

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A New Eligibility Procedure for Education: Overview

- Conceptual considerations
- Philosophy and components
- Implementation


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Conceptual considerations

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Research

Special properties of education

Policy domain

- Right to education
- Compulsory attendance for all children
- Aims and means of education are subject to debate

Major life area

- Major impact on development and learning
- School engagement – experience of autonomy, belonging and competence
- Participation in education is an important contributor to adult health

Intervention setting


- Services for children with disabilities are provided by the education system
- Identification, assessment, planning and service provision are embedded in the process of education

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Research

Target groups in health and education

Health Contexts

„From Cell to Society“

Public Health

Disease Groups

Patient

Organ – Systems

Molecules - Genes

Education Contexts

„From Society to ???“

Society

Sub-groups of Society

Individual

Organ – Systems


Molecules - Genes

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Research

Which information is „fit-for-purpose“ in education?

“Deficit orientation”

Understand problems

differential diagnostic criteria to establish a syndrome (e.g. learning disabilities)

functional properties linked to disease

Functioning in ICF used for mapping

components of abilities as criteria to establish competencies (e.g. ability to learn)

functional properties linked to participation

“Competency orientation”


Plan for intervention


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2

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Aggregation and transformation processes in education						
		Chronological Perspective				
		Situation/ Input	Assessment/ Analysing	Assignment/ Planning	Intervention/ Acting	Evaluation/ Outcome
Systems Perspective	Policy Perspective					
	Organisational Perspective					
	Interactional Perspective					
	Individual Perspective					
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7						



What does „Eligibility“ represent?

Relation between present situation and a vision (capability, empowerment, competence, satisfaction, productivity, ...)

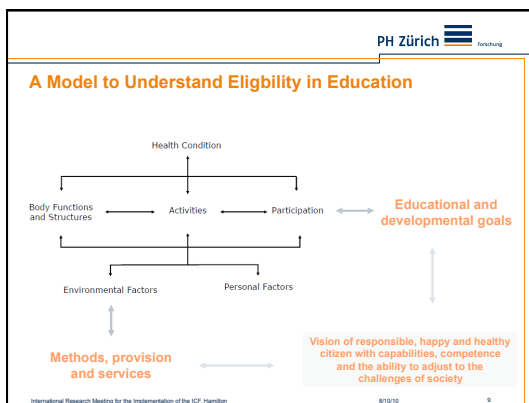
Assumptions about important components or milestones → Which goals are instrumental for that vision?


Assumptions about methods, provision and services → Which means are instrumental for that vision?



The diagram illustrates the concept of 'Eligibility' through a central vision: 'Vision of responsible, happy and healthy citizen with capabilities, competences and the ability to adjust to the challenges of society'. This vision is supported by two main components: 'Educational and developmental goals' (top) and 'Methods, provision and services' (bottom). A child's image is positioned to the left of the vision, indicating the target population. Arrows show the flow from the vision to the goals and methods, and from the goals and methods back to the vision.

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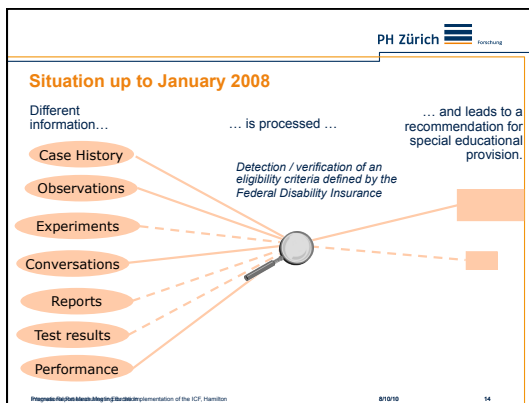


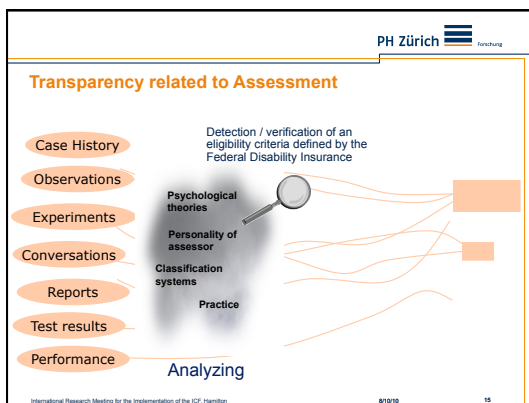
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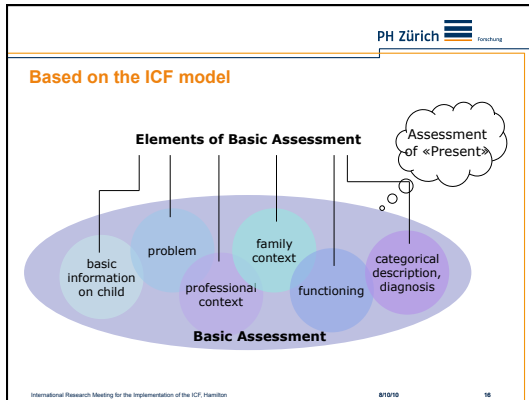
Organisation of Information

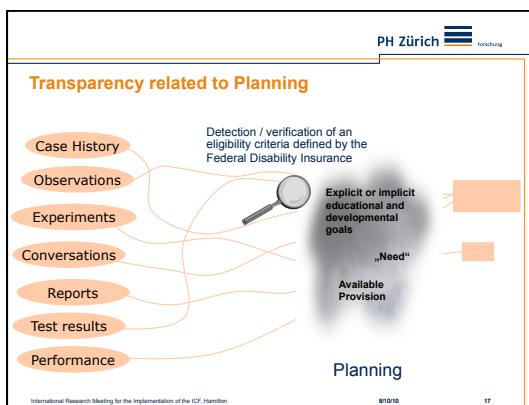
		Chronological Perspective				
		Situation/ Input	Assessment/ Analysing	Assignment/ Planning	Intervention/ Acting	Evaluation/ Outcome
Systems Perspective	Policy Perspective					
	Organisational Perspective					
	Interactional Perspective					
	Individual Perspective					

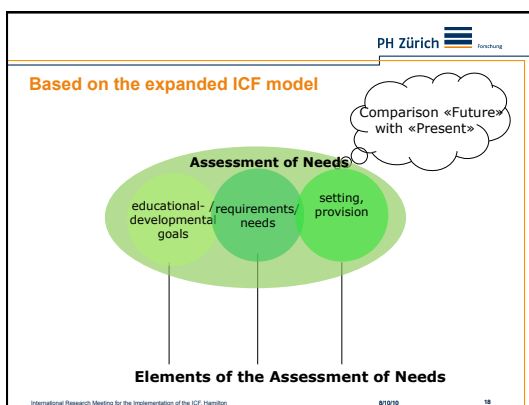
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Valid, reliable and comparable documentation

Valid:
use of information is „fit-for-purpose“
→ Development of ICF item list specifically for eligibility purposes

Reliable:
consistent assessment procedures / measurements and information generation
→ Development of standards and guidelines to cross-walk assessment tools and ICF items (content and extent)


Comparable:
same information available for all children
→ Development of an Electronic Tool

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Information fit-for-purpose: ICF list of items

Data collection exercise undertaken to understand practice to establish eligibility: identify determinants of "need" and "requirements".

Rationale for selection of ICF items: explanatory power to differentiate "levels of need" or "requirement for adaptations".

Methodology applied to develop the list: Explorative Regression Analysis (identify items with high explanatory value), Factor Analysis (represent items with highest loadings from relevant components), Cluster Analysis (represent important constellations), Frequencies (selection of most commonly used items), Correlations between ICF items and "needs and requirements" added to item selection process.


Item list bridges clinical practice (description of functioning & disability) with educational practice (planning interventions to reach goals in participation).

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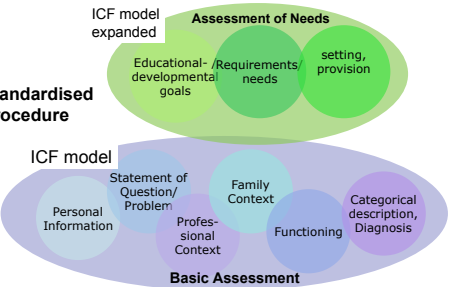
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Standardised Procedure



ICF model expanded

Assessment of Needs

Educational-developmental goals, Requirements/needs, setting, provision

ICF model


Personal Information, Statement of Question/Problem, Family Context, Professional Context, Functioning, Categorical description, Diagnosis

Basic Assessment

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Implementation

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Implementation and Adaptation


Nation-wide activities

- Standardisation process across cantons (terminology, quality standards for institutions, common procedures) provides useful implementation context
- Professional Associations to be involved in standardisation of assessment
- Regional Seminars for the persons responsible for the implementation at Cantonal levels
- Initiative to install common monitoring processes

Cantonal and local level activities

- Integration of procedure into cantonal concepts related to Special Needs Education (linking "high incidence" to "low incidence" and "regular")
- Clarification of roles and procedures in local context
- Training of case-managers and other persons involved
- Adaptation of electronic tool and data management to suit data protection regulation

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Embedding the procedure in the larger context

Clarification of relationships to other applications of ICF-CY in education

- description of functioning and disability in children
- procedures and tools related to individual educational planning

Integration of selected information into national education statistics

- Small set of items to describe functioning and disability (to be defined)
- Variable describing level of educational goals pursued for the child/youth (general vs. individualised curriculum or educational programme)
- Variable for additional resources received (e.g. hours of speech therapy per year)

Development of a monitoring mechanism

- Distribution of resources compared to functioning, family background and educational goals (e.g. at re-evaluation after two years)
- Understanding regional differences
- Adjustment of content to practice (e.g. using consensus conferences)

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Forschung

Thank you for your attention!

www.sav-pes.ch

Information on project, data collection tool and elements of procedure
German, French and partially in Italian

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ICF-based patient education program for stroke-patients

Carla Sabariego, MPH
Institute for Health and Rehabilitation Sciences
Research Unit for Biopsychosocial Health
Ludwig-Maximilians-University

Carla Sabariego

August 2010

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Background

This patient education program was developed in the **Ludwig-Maximilians-University**, Munich, Germany in the scope of a priority projects program (<http://www.forschung-patientenorientierung.de>)

The development of the patient education was supported by the **German Federal Ministry of Education and Research (BMBF)**

The **feasibility** and **acceptability** of the patient education were evaluated in a pilot study

The **effectiveness** of the patient education is being evaluated in a **RCT**

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Rehabilitation is the health strategy that enables people with health conditions experiencing or likely to experience disability to **achieve and maintain optimal functioning in interaction with the environment**

In order to achieve this goal the **active involvement of patients in managing their own health care and rehabilitation process**, in partnership with health professionals, is essential!

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Rehabilitation hopes to ...

enhance **self-management skills** in order to empower people to handle their disease on their own

empower patients in improving their skills in fulfilling everyday life tasks

To achieve this, patients need to be **aware** of their own **level of functioning** and **self-efficacy**

Suitable tool: Patient Education!

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How does the ICF come in here?

- ✓ The **ICF** is a useful tool to **comprehensively** express the experience of patients living with health conditions
- ✓ The **ICF** and its model have successfully been used in **rehabilitation practise** by health professionals
- ✓ **Practical tools** are **available** (e.g. ICF Core Sets)

The bio-psycho-social perspective of the **ICF** model and classifications can **structure** the process of enhancing the perceived self-efficacy of patients in managing their **functioning and disability**

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ICF based patient education

The patient education program consists of **five closed one-hour sessions over five days with four participants**


The program is structured into three modules:

Module 1	Module 2	Module 3
Identifying problems in functioning	Identifying problems in impaired areas, looking for solutions, providing information where to find solutions	Reflecting on the patient's level of functioning
One day	Three days	One day

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August 2010



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**However....
before we go to the modules,
I would like to show you
some steps of the development phase...**

Module 1 Identifying problems in functioning One day	Module 2 Identifying problems in impaired areas, looking for solutions, providing information where to find solutions Three days	Module 3 Reflecting on the patient's level of functioning One day
---	---	--

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ICF-based Patient Education - Development



Step 1: Definition of relevant specific areas of the life domain functioning

Step 2: Development of strategies to enhance perceived self-efficacy in the specific areas of the life domain functioning


Step 3: Development of material and instructions

Step 4: Pilot test

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 August 2010

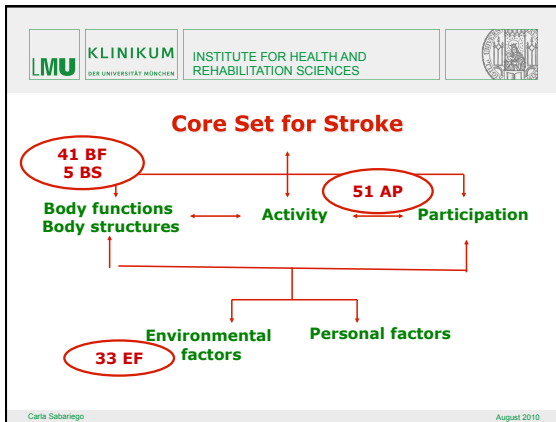
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Step 1: Definition of relevant specific areas of the life domain functioning

- ✓ **ICF Core Sets** represent an operationalisation of the experience of functioning and disability from a condition-specific perspective
- ✓ The **Comprehensive ICF Core Set for Stroke** was used to select the relevant specific areas of the life domain functioning which could become limited after a stroke event

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Step 2: Development of strategies to enhance perceived self-efficacy

ICF provides the **structure** and the **framework** of the patient education. However, the ICF does not provide a **methodology**!


- ✓ We choose the **social-cognitive learning theory** (Albert Bandura) to develop the methodology
- ✓ **Perceived self-efficacy**: people's beliefs about their capabilities to produce designated levels of performance in particular domains of functioning
- ✓ Ways of enhancing self-efficacy: **mastery** and **vicarious** experiences

Carla Sabariego
August 2019



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Step 3: Development of material and instructions

✓ Creation of a pool of cards containing relevant areas of the life domain functioning: Seventy seven out of the 130 ICF categories of the Comprehensive ICF Core Set for stroke were selected

ICF code	ICF -rephrase text
0000	General
0100	Activities of daily living
0200	Communication
0300	Learning
0400	Emotional and psychological functions
0500	Energy and vitality
0600	Interpersonal relationships
0700	Life domains
0800	Participation
0900	Personal identity
1000	Physical functions
1100	Psychological functions
1200	Social functions
1300	Spiritual, cultural, and religious functions
1400	Thinking
1500	Understanding
1600	Values and beliefs
1700	Willingness to engage in activities
1800	Work and productivity
1900	Work and productivity
2000	Work and productivity
2100	Work and productivity
2200	Work and productivity
2300	Work and productivity
2400	Work and productivity
2500	Work and productivity
2600	Work and productivity
2700	Work and productivity
2800	Work and productivity
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3000	Work and productivity
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7600	Work and productivity
7700	Work and productivity
7800	Work and productivity
7900	Work and productivity
8000	Work and productivity
8100	Work and productivity
8200	Work and productivity
8300	Work and productivity
8400	Work and productivity
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9700	Work and productivity
9800	Work and productivity
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ICF code	ICF -rephrase text
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6400	Work and productivity
6500	Work and productivity</

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Step 3: Development of material and instructions

- ✓ ICF categories were **excluded** if they
 - ✓ (1) referred to exclusion criteria for participation in the training program, e.g. consciousness functions (b110) or orientation functions (b114)
 - ✓ (2) required specialist knowledge to judge whether one has limitations in them, i.e. motor reflex functions (b750) or structure of the brain (s110)
- ✓ Selected ICF categories were **renamed** and put into colloquial language and for each category **examples** illustrating potential problems were defined

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Step 3: Development of material and instructions

- ✓ Each category was printed on the front side, examples on the back side of a paper card, respectively

<div>b210, b215</div> <div>Sight Eyes</div>	<div>d 440</div> <div>grasping & using small objects</div>	<div>e 155</div> <div>my living quarters</div>
<div>Examples</div> <div>double vision blindness in one eye runny eyes limited eye movement</div>	<div>Examples</div> <div>removing coins from a table sewing, holding a nail reaching for a bottle</div>	<div>Examples</div> <div>entrance (steps) narrow spaces (doors) furniture (high bookcases)</div>

- ✓ An **instruction guide** consistent with the pool of cards was developed for the group leader

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Step 3: Development of material and instructions

- ✓ In order to enhance the process of achieving and maintaining an optimal level of functioning **concrete information** about disease specific services and health care resources are necessary

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Step 3: Development of material and instructions

- ✓ A **guide** containing such information was developed based on a **comprehensive internet search**
- ✓ Special attention was paid to the **clarity** and **simplicity** of the information provided (**brief description of each offer and the supplier below**)
- ✓ As many **health care facilities and resources** as possible were included
- ✓ Only **supra-regional addresses** are listed, which can serve as **initial contacts**

Stroke

Health Services & Facilities Guide

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Step 4: Pilot test

- ✓ One **reference group** to test out the patient education program for potential difficulties

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Step 4: Pilot test

- ✓ **Two heterogeneous groups** (chronic stroke patients and acute stroke patients) to test out feasibility and acceptability of the patient education

The **manual** of the patient education was developed after the pilot test!

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ICF based patient education

The patient education program consists of five closed one-hour sessions over five days with four participants

The program is structured into three modules:

Module 1 Identifying problems in functioning One day	Module 2 Identifying problems in impaired areas, looking for solutions, providing information where to find solutions Three days	Module 3 Reflecting on the patient's level of functioning One day
---	---	--

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ICF-based Patient Education

Module I

Identifying problems in functioning

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Module 1 (First day)

Step 1: warm up, short round of introductions

- ✓ Name
- ✓ Profession
- ✓ how long have you been in the clinic
- ✓ No questions about the stroke event

Step 2: Presentation of aims and content of the patient education

Why do we offer a patient education?

In the rehabilitation clinic therapists have the task of identifying your problems and deciding on adequate solutions

Why do we offer a patient education?

After discharge you may face unexpected problems due to the stroke and its consequences

Why do we offer a patient education?

That is why we want to support you in identifying your problems for yourself so that you can find adequate solutions once you are back home

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Module 1 (First day)

Step 3: Participants are supported in identifying their current level of functioning and the aspects of the environment that influence it

- ✓ Patients receive cards with body functions, activities and participation and environmental factors categories
- ✓ Patients are requested step by step to sort cards using a red box for the limited areas and a white or green one for areas that are not limited

- ✓ Cards with limited areas and cards with areas not limited are bound using a red and a green cover, respectively

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Module 1 (First day)

Step 3: Questions

Character and Temperament (b126)

Have you had any problems with your character or temperament as a result of your stroke? **Examples:** changes in character or temperament, withdrawal from friends and family, stubbornness, emotional instability

Housework (d640)

Do you have problems doing housework as a result of your stroke? **OR** Do you think you will have problems doing housework as a result of your stroke?
Examples: doing the wash, ironing, cleaning, carrying out the trash

Medicines (e110)

Do medicines you have to take as a result of your stroke present a problem for you?
Examples: side effects, intolerance

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Module 1 (First day)

Step 5: Frequencies of limited areas are calculated, filled in a table and later presented to participants in module 2

Step 6: Based on the frequencies and participant feedback up to six limited areas are selected for module 2. Only limited areas that are selected by at least 75% of the participants are included!

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Module II

Identifying problems in impaired areas, looking for solutions and seeking information

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Module 2 (second to fourth day)

Step 1: Presentation of aims and content of module 2

Step 2: Two categories that were most frequently identified as limited in module 1 are chosen and discussed in each day

✓ It is recommended that categories on body functions are discussed first as patients have gained experience within this component during inpatient rehabilitation

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Module 2 (second to fourth day)

Step 3: Each patient is encouraged to identify problems related to selected categories and reflect on potential solutions for these problems in a group process

Stroke Health Services & Facilities Guide

✓ If patients cannot determine what their problems might be after discharge, the leader should help them realize that there will be problems and preparing them to face them after discharge.

Step 4: Patients are supported in seeking information about relevant facilities or services using our "Guide on services and health care resources for persons after stroke"

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Module 2 (second to fourth day)

Step 3 & 4: Each patient is encouraged to identify problems related to selected categories and reflect on potential solutions for these problems in a group process

- Which problems do you have regarding this area?
- Which solutions do you see for the problems you talked about?
- What is being done for these problems in the rehabilitation program?
- Does someone else see another solutions?



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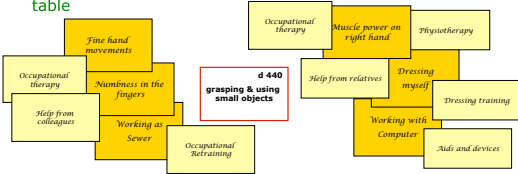
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Module 2 (second to fourth day)

Step 5: For each discussed category, identified problems and solutions are written on cards by the leader and put on the table



Step 6: At the end of each discussion, the leader summarizes verbally for each patient problems as well as related solutions

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ICF-based Patient Education

Module III

Reflecting the patient's own level of functioning

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Module 3 (fifth day)

✓ **Step 1:** Problems and solutions discussed in the previous days are summarized

Which areas we have talked about?

Areas regarding your body: Stability of arms or legs, muscle strength

Areas regarding your daily life: walking, driving a car, riding a bicycle

Areas regarding your environment: attitudes of friends

✓ All relevant issues discussed during the patient education are recapitulated

✓ relevant services identified in the "Guide on services and health care resources for persons after stroke" are stressed

Problems related to „driving a car“

Areas regarding your body: right hand and foot are paralyzed, reaction time

Areas regarding your daily life: shopping, general mobility is impaired, working (child work), getting into the car, gear changing, driving, using the pedals, braking, accelerating

Areas regarding your environment: spouse is working during the day, visits to friends, travel distance to work, danger of a car accident, insurance cover in case of a car accident

Personal factors: it is difficult to estimate the own problems, acceptance of problems, fear of road test

Potential solutions related to „driving a car“

Areas regarding your body:

Areas regarding your daily life: driving short distances, training arm and leg muscles, arranging daily routine with the family members, using public transportation

Areas regarding your environment: car adaptations, help from colleagues, neuropsychology (driving ability test), occupational rehabilitation

Personal factors: arrange more pauses, exercise patience

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ICF-based Patient Education

Summary

✓ **Structure is always the same**

✓ **Content meets the individual needs of group participants**

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ICF-based Patient Education

Effectiveness?

Cost-effectiveness?

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Evaluation of the program...

Study Design
 multicentre randomized controlled intervention study with two follow ups: at discharge and 6 months after discharge

Sample Size
 213 stroke survivors (103 CG; 110 IG)

Cooperation partners
 Seven neurological rehabilitation clinics in the region of Bavaria, Germany

Interventions
 "usual treatment" plus "ICF-based patient education"
 "usual treatment" plus "placebo-intervention" (controls)

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What about the control group?

"Attention Placebo"
 the control group receives an intervention to the same extent as the intervention group

Information about stroke, symptoms, risk factors and health promoting behaviour
 +
 One focus group

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Basis of the ICF based patient education


ICF & ICF Core Set for Stroke

Outcomes

- ✓ Self-efficacy (Liverpool Self-Efficacy Scale)
- ✓ Functioning (Stroke Impact Scale)
- ✓ Life satisfaction (WHOQoL)


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Data Analysis (Fall 2010)


- ✓ Our **longitudinal data** will be analysed using **multilevel modeling of individual change**
- ✓ A **qualitative analysis** of the follow up data will bring information about **health resource use** in the follow up
- ✓ The **cost-effectiveness** of the intervention will be addressed in a **cost-utility-analysis**

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Publications

In print:

Neubert S, Sabariego C, Stier-Jarmer M, Cieza A. Development of an ICF based patient education program. *In print Patient Education and Counseling*


In preparation:

Effectiveness of an ICF based patient education program: a randomized controlled trial in a stroke population

Cost-utility-analysis of an ICF based patient education program among stroke patients


The manual is available on request in English or German!

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Any questions?

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 **FACHHOCHSCHULE NORDHAUSEN**

**„International Research
Meeting for the Implementation
of the ICF“**

**/ Implementation Example –
Student Education**

Hamilton, 12th of August 2010


12th of August 2010 Prof. Dr. Armin Sohns

 **FACHHOCHSCHULE NORDHAUSEN**

The ICF is one answer to the need of a paradigm shift for
Health & Social Care professionals

1. Which is the importance of that shift of focus for health
and social care systems and for their documentations?
2. How can this be transformed to the education of the
professionals and their specific tasks?
3. How can it be translated to the practice and where can
this be supported by a specific research?

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 **FACHHOCHSCHULE NORDHAUSEN**

- Our societies are changing - and with it the requirements
of development for our children – and the coming adults.
- There is necessity for the Social Care and the Health
System, to analyse the current situation - among the
rising needs and delineate the functional requirements
on an environmental-oriented focus.

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Example for the need of a paradigm change:
Early Intervention

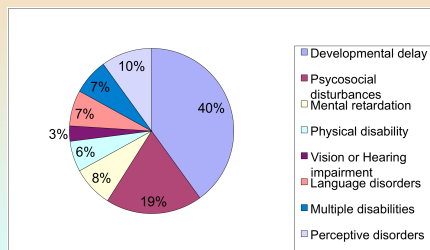
The increased risks for development are reflected in an increasing demand for Early Childhood Intervention

Traditionally the answer to this situation is to provide **therapy** for children depending on the analysis of the impairments or delays of „normal“ developments

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Diagnosis of children in Early Intervention Centers



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Kiggs 2006 / 2007

- Increase of multiaxial exacerbating factors (single parent, conflicts between parents, disaffection of the parents etc.). (Excessive demand on parenting)
- Particular risks within the infancy, especially regulatory disorders (e.g. excessive screaming; that has -in interdependency- an impact on the parent-child relationship).
- Particular dependency on parental didactics (intuitive communication), which is interfered with other factors like mental stress, depression or divided attention. (Mentally overloaded).
- Regulatory disorders correlate with limited competencies of parental relations and upbringing (absence of flexibility, distortion of sense and interpretation, aggressive or neglected behaviour, specific risk factor e.g. parents suffering from mental disorders)

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- 20% of the children (also the under 3 year old) show mental disorders,
- 5% of all children ADHD (Attention Deficit Hyperactivity Disorder) is diagnosed, other 5% show some symptoms in this regard
- barely 50% of our children present with at least one health impairment.
- there is an exceedingly high impact on economic, social and occupational living conditions

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Distortion of Sense

- Even though Kiggs has shown that only every 2nd child is healthy, 90% of the parents appraise their child as (very) healthy. A distortion of sense is reflected by the parents, which don't realize the risks and problems in the child development – a typical feature of the phenomenon of child neglect.

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- Comprehensive education studies and neurological research results emphasize the formative importance of the first years of age: „the race is halfway run when children begin school“.
- Fundamental neurological foundations are emerging or atrophying during infantile communication: “Use it or lose it“.

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Basis Needs

- In a classical pyramid of needs fundamental securities and skills are build on each other. To absorb knowledge and education, fundamental needs have to be satisfied first.

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- Encouragements like ‚reading a book‘ have greater effects on the intellectual development than therapeutic interventions that are detached from the life domains of the child and the family.
- Change from the focus “impairment” or “disability” to the aspect of “participation”

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Study in the County of North Friesland

41% (of all interviewed children) received Therapy (PT, OT, SPL) before entering school
25% of all children in kindergartens from 3 to 6 years receive a therapeutic intervention
10% of the children are supported by an Early Childhood Intervention Center

The need of Early Childhood Intervention is associated with the educational background of the mother

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Evaluations from the City of Neubrandenburg with children in special schools:

- 75% of the children had no aid through Institutions of Early Childhood Intervention, even though they received the diagnosis "special educational need".
- 25% of the children didn't receive any technical assignment and expertise

We have to assert, that the necessity is not captured sufficiently by the system of Early Childhood Intervention.

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- The question is, whether the system of help is actually aligned to those who need help at most.

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How effective are our Early-Aid-Systems?

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- Furthermore we have to ask, if the Social Support Systems have the possibility to act family-oriented.
- The system of ECI is inclined to show itself as an uncoordinated coexistence of support with vague professional requirements, high bureaucratic obstacles and few concepts considering the environment and parties involved

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ICF is strengthening the need of an environmental point of view for all involved professionals.
It aims to provide a common language
Some administrations did already introduce the ICF as mandatory in their statutes
This creates the need to operationalize the use of the ICF and to increase its professional acceptance

There is also the danger of cutbacks by the administrations by using the ICF to determine eligibility

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A good system must accessible!

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- Implementation of ICF-knowledge in the curriculum at the University of Applied Sciences

/ at Nordhausen (Social Work)
/ at Gera (Interdisciplinary Early Aid)

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New demands resulting of social transformations

- interdisciplinary
- a holistic approach
- social inclusion
- preventive approach

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The different tasks of Early Aid and the difficulties in realising them

<p>Early Identification</p> <p>•e.g. during regular development screening</p>	<p>diagnosis</p> <p>•interdisciplinary and individualized planning •International Classification of Disability, Function and Health (Kraus-de-Camargo 2007, Vööl 2007)</p>	<p>Intervention, education & advice, support</p> <p>•have to be flexible according to needs</p>
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- Interdisciplinary Team
 - Medicine, esp. Pediatrics
 - Therapists
(Physio – Occupational – Speech)
 - Psychologist
 - Social Worker
 - Pedagogues (also in Kindergartens)

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- Transdisciplinarity: the ability of one professional to apply elements of other disciplines into his own practice

Is this concept teachable during professional education?

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- The ICF as a Common Language for all Professions
- In clinics and health care centres
- Clinicians in the community
- Health and Social Care Administration
- Social Care Centres
- Kindergartens

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- Transdisciplinarity means

One person can do everything?

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Super-Professional !!

- Common way of thinking for all professionals
- ICF as the foundation of documentation for an interdisciplinary work
- All professionals should know about it and learn how to apply it
- 2 ways of teaching:

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- Single Modules for each profession – including the skills for an cooperation with other professions
- General modules for a all professions? (Specified for the experts)

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- Tasks for Research

There is a need for an **operationalisation** of the items on the basis of the ICF

- different checklists
- different core sets
- different instruments linked to the ICF items
- ...

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- ICF-Research Project Proposal in Germany

Items of the ICF-Checklists are - anonymized – collected in a database and will be evaluated systematically. A working group consisting of users (professionals from ECI Centres, SPC and I-Kindergartens) works together with the scientific members of project.

The collected data give us

- New informations about the possibility of sharing information between systems and the barriers that exist
- New answers about the needs of support looking from a participation point of view. What kind of support is offered? What is needed the most? What kind of needs determine what kind of help (home-based, centre-based etc.)? How does the cooperation work?
- It is the aim to improve the curricula for an education of professionals to apply the ICF.

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- Congress of Eurlly Aid (European Association of Early Intervention)

(<http://www.eurlyaid.net/>)

- For the 1st time in Germany (East)
- Main theme: ICF-CY

- Flyer

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The Vision

- Professionals must have an individual pedagogic perception, which focuses on particular interests and skills. This fact stands in opposition to the rigid German curriculum, which creates experts that provide a uniform aid
- If we designed a plan of special aid for each individual child in school, daycare or ambulant aid facilities, focusing on the strengths and motivation of each child, there shouldn't be the need for a (stigmatizing) label disabled-normal
- Some children need more specific aid and support in Early Childhood Intervention – in some cases this also applies to gifted children – and others need less individual aid. There is no need for administrative stereotypes anymore.
- There is more efficiency in coordinating the different professional approaches in one common concept. And there is hope that the cutbacks for each individual system can be avoided and a home-based supporting system can be strengthened

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