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National Institute
for Public Health and
the Environment

WHO Family of International Classifications (FIC)

NEWSLETTER

Volume 5, Number 1, 2007

Revision of the International Classification of Diseases

WHO announced in April 2007 a major online project to revise ICD-10, since 1990 the global standard to report and categorize diseases, health-related conditions and external causes of disease and injury, for the compilation of useful health information related to deaths, illness and injury (mortality and morbidity).

For the first time, WHO is inviting stakeholders to participate in the ICD revision through an Internet platform. This update is vital in order to keep up with recent progress in medicine and the use of information technology in the field of health, and to improve the basis for international comparisons. The first meeting of a steering group to oversee the revision took place in Japan from 16 to 18 April 2007. Any user can enter suggestions to improve the ICD via a new web application called "ICD-10 Plus" <http://extranet.who.int/icdrevision>. Any user who registers can contribute to the revision and back his or her proposal with evidence. Users can also see what others have proposed and discuss these topics through a blog. These suggestions will be reviewed by expert groups and formulated as an ICD-11 draft, which is the second step in the revision process. The draft will be formulated using a "wiki", similar to the widely known Internet encyclopedia "Wikipedia" but with stricter editorial rules, to jointly author the next version of this international public good.

Emerging diseases and scientific developments, combined with advances in service delivery and health information systems, require a revision of this global classification. One major need is to improve the relevance of the ICD in primary care settings (clinics, doctors' offices and frontline health services), as that is where most people are treated. Another key driver is the development of computerized health information systems that require classifying electronic patient records according to the ICD.

It is expected that this Internet-based revision process provides a wide scientific input, a good transparency and an exchange with a wide range of users, making the final ICD-11 more useful. The Internet platform will also allow testing of the new classification before WHO Member States accept it as a global standard.

WHO has established various Topic Advisory Groups to serve as the planning and coordinating advisory body for specific issues in the update and revision process. These Groups are composed of renowned international health leaders and chaired by:

- Mental Health: S. Hyman (USA)
- External Causes: J. Harrison (Australia)
- Rare Diseases: S. Ayme (France)
- Internal Medicine: K. Sugano (Japan)

More groups are under construction. The Revision Steering Group will oversee the coordination and the overarching tasks and will be chaired by Professor Christopher G. Chute of the Mayo Clinic College of Medicine in the USA.

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Published by

WHO-FIC Collaborating Centre in the Netherlands.

Responsibility for the information given remains with the persons indicated.

Material from the Newsletter may be reproduced provided due acknowledgement is given.

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ISSN: 1388-5138

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WHO will run this platform in English. A Global Network of WHO Collaborating Centres will be able to run this Internet application in Arabic, Chinese, French, Russian and Spanish (UN Official Languages), while other languages may be supported by partners (such as in Japanese) to enable participation of all interested parties. These centres will also channel their national or regional proposals to the system.

WHO collaborates through this platform with all interested parties, including governments and non-governmental agencies, academia, industry and public to make the new classification system best fit their needs.

It is envisaged that there will be three distinct versions of the new ICD: a succinct version for use in primary care, a detailed version for use in specialty settings and an advanced version for use in research.

For more information and access to the platform click the link below

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Comments on the intended revision, leading to ICD-11

Finally, there is the announcement of a next ICD for a since 1990 profoundly changed health care system by unexpected new diseases and medical and information technology.

Not written down but quite obvious for users is the multifunctionality of ICD-10. The same term, for example dementia (F00-F03), can be used for different purposes to class a reason for encounter, a reason for a preventive measure, an episode of care, a diagnosis, an admission to or discharge from hospital, a cause of death. All these applications of the same term refer to their usefulness as a piece of a specific kind of information. The same term might also be used as a characteristic of another piece of a more specific kind of information included in the intensional definition of

that piece, for example dementia in Parkinson's disease, or as a classification rule, for example dementia in HIV disease (F02.4) or cause of death (B22.0).

Terminological systems are more aware than classifications of the multifunctionality of terms and have developed categorial structures to cope with the different functions of a term. A good example in the classification of surgical procedures is a blood vessel that can be coded as the place of an operation (= a piece of information), as the way along which one can reach another place (= a characteristic) and as transplantation material for the same patient of another one (for which a rule is needed for distinction).

By defining categories and distinctive attributes to objects (pieces of information), a terminological system can be used to present different views of these objects. E.g. it could present all procedures on blood vessels, or all operations using blood vessels as a route, or all operations on transplants. For surgical procedures defining the categories and attributes that define the object look pretty straight forward. For diseases defining the categorial structure is not that straight forward. One reason why it is not that easy is because a disease is not a clear and concrete (or real) object like a surgical procedure. Diseases come in many forms, as natural kind terms like Down's syndrome (which has no intensional definition) or as synthetic kind terms like HIV. Defining the different meanings of diagnostic terms, first requires the understanding of the complexity of the subject field. Different meanings require different categorial structures. Development of these structures requires terminological knowledge.

One might hope that the development of ICD-11 might be driven by categorial structures that brings it not only in line with more current medical knowledge but also with terminological knowledge.

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Editorial

Work related to classifications seems to be tiresome for those who are not involved. We know better! The content of this newsletter shows the contrary. A lot of activities took place, several activities and new developments are planned.

In order to give a short impression to our readers we list some of them:

- *the ICD-11 organization has been set up,*
- *a new version of ISO 9999 is available,*
- *the ICF-CY will be presented in its final version this autumn in Venice (and translations are already on its way),*
- *the NACC organized its 13th annual ICF conference,*
- *a conference of the Washington Group on disability statistics and Eurostat is planned for September 2007 in Dublin (ICF based survey and census sets of questions),*
- *the Asia Pacific Network of the WHO-FIC planned a meeting in Kyoto, Japan, September 10-11, 2007,*
- *the annual WHO-FIC meeting will be held in Trieste, Italy, Oct. 28 – Nov. 3, 2007.*

See for more details the contributions in this newsletter.

This newsletter is being provided only once a year, but a lot of relevant classification related information is available on a continuous base (through websites of) WHO-FIC Collaborating Centres, such as:

- *WHO information on the WHO-FIC in the 6 working languages of WHO, <http://www.who.int/classifications/en/>*
- *Dutch WHO-FIC Collaborating Centre, website in English and Dutch on all members of the WHO-FIC www.rivm.nl/who-fic*
- *French newsletter Flash Informations Handicap, for information flashinfo@ctnerhi.com.fr*
- *North American WHO-FIC Collaborating Centre, ICF newsletters, ICF clearing house (list), NACC conferences on ICF, ICD <http://www.cdc.gov/nchs/about/otheract/icd9/nacc.htm>*

- For addresses and websites of other WHO-FIC Collaborating Centres (Australia, China, France, Italy, Nordic countries, Portugal, Russia, Spain, Japan, Mexico, Nigeria, South Africa) see WHO website <http://www.who.int/classifications/network/collaborating/en/index.html>

Do you have more information which is of interest for our readers? Please let us know. Share your knowledge!

International Organizations

WHOFIC Network Meeting

28 October - 3 November 2007



Information Power: Owning and Sharing

The 2007 Annual meeting of the WHO Network of Collaborating Centres for the Family of International Classifications (WHOFIC2007) will be held in Trieste, Italy.

The meeting is co-organized by the WHO Collaborating Centre for the Family of International Classifications in Italy and the Measurements and Health Information Systems (MHI) Department of the World Health Organization.

Attendance of the meeting is on invitation only.

International Organization for Standardization

Assistive products for persons with disability - Classification and terminology, ISO 9999, fourth edition, 2007

In this classification (ISO 9999) assistive products (including software) are classified according to their function. The classification consists of three hierarchical levels and each of the codes consist of three pairs of digits. Like in other classifications: codes, titles, explanatory notes, inclusions, exclusions and cross-references are given for each level of the classification. Besides the explanatory text and the classification itself, a table of conversion between the previous (2002) edition and this edition of the International Standard and an alphabetical index are provided in order to facilitate the use of and to improve the accessibility of the classification. In this fourth edition of ISO 9999, the title has been changed from "Technical aids for persons with disabilities - Classification and terminology" to "Assistive products for persons with disability - Classification and terminology". Hence "Technical aids" are referred to as "Assistive products". The former class 21 "Aids for communication, information and signalling" has been revised and replaced by a new class 22 "Assistive products for communication and information".

ISO 9999 and ICF

In 2003, ISO 9999, which is a product of the International Organization for Standardization, was accepted as a related member of the World Health Organization Family of International Classifications (WHO-FIC). This International Standard ISO 9999 makes use of the terminology and definitions of the WHO International Classification of Functioning, Disability and Health (ICF, 2001). A separate document concerning the relationship between ISO 9999

subclasses or divisions and ICF classes has been distributed for comments. This document can be obtained on request from the WHO-FIC Collaborating Centre in The Netherlands, huib.ten.napel@rivm.nl. See for the report of preliminary results "The Netherlands, request for Comments (RFC) on ISO9999-ICF" in this newsletter. A Dutch classification derived from ISO 9999 (Cliq, Classification improves quality) has been developed by using the ICF in order to refine the ISO 9999 into a six level classification. The experience by doing this will be used in activities relating to next revisions of the ISO 9999 and improvement or updating of the ICF external factors (E chapter 1).

Addresses for proposals and copies

Proposals for changes or additions to the ISO 9999, both in respect of existing and proposed new classes/subclasses/divisions, which take into account the given rules for classification, may be submitted to a national member body of ISO with an accompanying explanation for the proposal. The new version of ISO 9999 is available in English, French and German and can be ordered from the national ISO member bodies. Other translations are expected to be available in due course such as a Dutch version (spring 2008) and a Japanese translation. For addresses of national member bodies of the International Organization for Standardization (ISO) see:

<http://www.iso.org/iso/en/prods-services/ISOstore/memberstores.html>

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FIC around the World

Nordic Countries

Health Classifications in the Nordic Countries

NOMESCO and the Nordic Centre for Classifications in Health Care have asked Björn Smedby and Gunnar Schiøler to write this book on the historic development of health classifications in a national and international perspective of 2006.

Björn Smedby wrote chapters on 'The history of the classification of diseases' and 'The growth of Nordic cooperation on classifications' and the DRG section in 'Developments of Common Nordic Classifications', written by Gunnar Schiøler, who was also responsible for 'ICF- international developments and Nordic cooperation'.

They describe the growth of a Family of 'multinational' classifications, departing from ICD and ICF of WHO. It is a history comparable with other countries: the translation and adoption of classifications gives often rise to additional initiatives, that influence the international family on their turn. The drive behind these initiatives came for more than 40 years from Nomesco, the Nordic Medico-Statistical Committee. This holds also for the development of a related activity on the Anatomical Therapeutic Chemicals Classification with Defined Daily Doses (ATC/DDD), a related classification not mentioned in this overview.

The historic perspective helps to understand why there are Nordic classifications of 'external causes of injuries', 'surgical procedures', and 'DRG's', and why there is not a common classification for primary care.

The epilogue is not positive whether SNOMED CT may form the basis for a global and generally accepted solution for electronic medical records and other types of professional

communication. More is expected from an integration of statistical classifications into one or more terminology databases (pp 97, 98).

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North America

NACC meeting June 2007: sharing knowledge through the ICF

The 13th annual NACC Conference on ICF has been held June 5-7 in Niagara Falls, New York, USA. The theme for the conference derives from the premise that the ICF can contribute to Knowledge Translation in many fields related to disability and rehabilitation. The sharing of knowledge took place in several areas by a lot of paper presentations and poster presentations. For an overview of the full program see the home page website mentioned below.

Interesting topics presented were e.g.: mapping to functional assessment instruments (Carl Granger, Bhavna Bharadwaj, Amitav Mishra) and an ICF mapping workshop (Nenad Kostanjsek, see also article "Identification of candidate categories of the ICF for a generic ICF core set based on regression modelling" <http://www.biomedcentral.com/content/pdf/1471-2288-6-36.pdf>). "The future of America report" was presented plenary and discussed at length in a breakout session (see below).

For information:
<http://cirrie.buffalo.edu/icf/conference/index.html>

Report "The Future of Disability in America" 2007

This report, prepared by the Committee on Disability in America and edited by Marilyn J. Field and Alan Jette, is released recently. The report is building upon two prior studies from the Institute of Medicine (Disability in America 1991 and Enabling America 1997). Topics included are e.g.: developments in

disability since the 1990s, disability monitoring, disability research, access to health care and support services, public and professional education. In the report the WHO International Classification of Functioning, Disability and Health (ICF) is used as the basic ingredient for terminology and concepts.

One of the recommendations listed in the report relates to the adoption and refinement of the ICF as the conceptual framework for disability monitoring and research. Others refer to the idea of using the ICF for setting priorities for research on environmental factors and to a recommended government-wide inventory of disability research activities using the ICF.

Regarding the ICF itself the report recommends:

- clarifying or otherwise resolving the lack of operational differentiation between the concepts of activity and participation
- explicitly incorporating quality of life in the framework of key concepts for understanding health and disability and conducting research
- developing classifications for personal factors affecting functioning and disability
- further developing the classification of environmental factors
- incorporating secondary health conditions as an ICF concept
- supplementing the ICF with a dynamic model of factors that influence the movement of individuals among states of functioning and disability.

The report is to be seen as a major step towards the use of the ICF for social policy, which is one of the WHO priority areas for the implementation of the ICF worldwide.

For information:
Field, M. J. and Jette, A., eds, The future of Disability in America, National Academies Press, 2007, ISBN 978-0-309-10472-2
For orders and free executive summary, see <http://www.nap.edu/catalog/11898.html>

The Netherlands

Request For Comments (RFC) on ISO9999-ICF

In the WHO-FIC Network meeting of October/November 2006 in Tunis, the Request for Comments (RFC) on the ISO9999-ICF crosswalk document has been announced, see also this Newsletter, Volume 4 Number 1, p 3. The ISO9999-ICF crosswalk document has been open for comment starting December 2006 and closing 1 May 2007. The online browsing facility has not been closed to enable some interested parties to view the document, which is not available in another form yet. Comments however, are no longer accepted.

The invitation to comment, with instruction on the procedure and further specified information has been sent to all members of the Implementation Committee and the Family Development Committee and members of the ISO workgroup.

In the Tunis meeting we referred to a personalized MS Word document for the RFC procedure. At the moment the RFC started, the web-based electronic RFC site had been completed. This meant that the ISO9999-ICF document could (and can) be browsed and comments could be submitted online. In the ISO-ICF file crosswalks to the ICF can be opened by clicking on the hyperlinks. We used this online document for the RFC instead of the MS Word document.

Results: Only a few (5) comments have been submitted via the webbrowser into the central database. Also a few reactions came via email. One reaction came from WHO-int EMRO with the suggestion to make Arabic a formal language of ISO as well.

Another email mentioned a fairly large, random scan throughout the iso-icf crosswalk document and had the impression that in general the code-to-code crosswalks seemed to be appropriate associations.

A number of emails from i.e. Australia and Portugal were concerned with the question where the ISO9999-ICF

document could be found on the internet. In most cases based on personal interest. Because of these personal questions we decided not to close down the ISO-ICF webbrowser.

The results of the collection will be reported and are to be discussed within our network and also communicated with ISO. Finally the network will have to make recommendations to the FDC concerning the value of the ISO9999-ICF crosswalk document e.g. in terms of consistency, validity and useability. This will be on the agenda of the WHO-Network meeting in Trieste in October this year.

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Early use of ICF-CY in: Team Collaboration in Dutch Paediatric Rehabilitation (the PROCP study)

The ProCP research project, which aimed to describe collaboration practices among the parents, rehabilitation and special-education professionals, engaged in the care for children with cerebral palsy in Dutch paediatric rehabilitation is one of the six interrelated studies of the PERRIN research programme (PEdiatric Rehabilitation Research in the Netherlands). PERRIN focuses on three major themes: (1) the course and determinants of activities and participation, (2) the development of instruments to measure the levels of functioning, and (3) the description of rehabilitation programmes. Taking the International Classification of Functioning, Disability and Health (ICF) as a conceptual framework, activities and participation are the central concepts in the PERRIN programme.

The ProCP study was started in 2002 and the difficulties professionals and parents encountered in the attainment of proposed “best practices” for team collaboration, such as an interdisciplinary team approach and the principles of family centred care (FCC) formed the basis of our

investigations. Although parents, team members and management are all committed to cooperation, coordination and integration of services, implementation of the prescribed approaches and collaboration in daily practice proved complex and is as yet not optimal. We clearly needed to enhance our insights into the characteristics and dynamics of today’s collaboration among parents, rehabilitation professionals and special education professionals if we were to improve current practices and ascertain the critical points (“bottlenecks”) that at present restrict them.

In two of the studies we conducted, the goal setting process played a central role. These studies concerned the analyses of the quality and content of the needs, principal problems and shared principal goals and the integration of needs and problems in the rehabilitation goals of 41 children with cerebral palsy. We analysed these items as formulated in the Children’s RAPs of these children (Rehabilitation Activities Profile for Children)¹. In the Netherlands the Children’s RAP is the benchmark for the formulation of interdisciplinary paediatric treatment plans. To determine the content of the treatment plans we extracted and organised the raw text data concerning the needs, problems and goals from the children’s RAPs, after which two raters independently linked the extracted content to the categories of *the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)*². Matches between needs, problems and goals, which were identified by ICF-CY-code comparisons, determined integration of needs and problems in the goals. The ICF-CY has been made available to us for this study by the WHO Workgroup before its definite publication in October this year in Trieste, Italy.

The ICF-CY proved very helpful in categorising the Children’s RAP items and yielded valuable information on the actual needs, key problems, and team goals for the young children

participating in our studies. Furthermore the ICF-CY code comparison made it possible to objectively evaluate whether children's needs and problems were integrated in the children's rehabilitation goals. The Cohen's Kappas for ICF-CY-encoding were, both on the category and the domain level of the ICF-CY, all in the range of "fair to good" (0.52-0.78). Consensus discussions mostly concerned the interpretation of the essence of the entries and the best matching ICF-CY category. Strict application of the linking rules^{3,4} and a sound knowledge of the conceptual and taxonomical principles of the ICF-CY as well as its components, domains and categories were indispensable. As the interpretation of the underlying categories depends upon the higher-level decisions, it was essential that encoding was performed in accordance with the ICF-CY hierarchy (from the component level, via the domain level down to the best fitting category). Although the ICF-CY proved very valuable in our study on goal setting in clinical practice, our evaluations also disclosed some demerits of the classification system. Despite the fact that the ICF-CY was specifically developed for children and youth we still encountered some encoding difficulties, for example we were unsure how to assign the goal "balance control". The best matching code seemed to be b235 (sensory function and pain; vestibular functions) but for children with CP the vestibular function is not necessarily the cause of the balance problems. Furthermore, an important restriction in our study on integration of needs and problems executed by ICF-CY code comparison method is that the links between preconditions, which are often at the body-function level, and actual activities are not always visible. Even though some needs or problems and goals do not match by ICF code, they may in fact be related. Take, for example, the need termed as "voluntary control over hands" that is encoded as b7 (body functions domain) and the goal

increase coordination and voluntary control of hand-arm use" that is encoded as d4 (activities-and-participation domain). While the need was translated into a goal defined as a trainable aspect at the activities-and-participation level, in our analysis it was denoted as a non-match.

Despite our minor matching problems we found the ICF-CY useful in categorizing needs, problems and treatment goals of children with cerebral palsy. It enabled us to successfully and objectively describe and evaluate the content and quality of services.

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2. World Health Organization. International Classification of Functioning, Disability, and Health – version for children & youth: ICF-CY. *WHO Workgroup for development of version of ICF for Children & Youth*. 2007. Geneva, Switzerland.
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4. World Health Organization. International Classification of Functioning, Disability, and Health (ICF). 2001. Geneva, Switzerland.

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Dutch WHO-FIC

Reprint of the Dutch ICF

In the Netherlands there is an increase of interest in the ICF. The ICF is being recommended in National legislation for what is called "Indicatiestelling", meaning; finding evidence or indications for persons which require some kind of support at home, enabling participation. This legislation is delegating a former national responsibility to the municipal level. To avoid inequality and unfairness in the assignment of support or means, the ICF is recommended as the language to enable evaluation and comparing of individual cases within and between municipalities.

As a result of this the Dutch ICF ran out of stock and needed a reprint. The reprinted and corrected version of ICF will be available by mid-summer. We also decided to develop a PDA version of the ICF. The PDA version contains the full text edition of ICF, including the Introduction and Annexes. Both editions are or will be available at: <http://home.bsl.nl>

Translation of ICF-CY into Dutch

As announced in our previous newsletter (Volume 4, Number 2, 2006) the newest member of the WHO FIC has been released and will be officially launched in October this year in Trieste, Italy. The Dutch centre is preparing the publication of the ICF-CY in the Dutch language. It is expected to be published before the end of this year.

Update of ICD-10 in Dutch

The online version of the Dutch ICD-10 has been updated with all updates for 2006. Textual corrections are also inserted completely, see <http://class.who-fic.nl>

The updates for 2007 are under preparation and will be available on the Dutch Centres online browser by fall this year.

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ICF References

The following bibliographic items are added to the Centre's database of ICF/ICIDH references¹:

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Reliability and sensitivity to change of measurement instruments used in a traumatic brain injury population
Clin Rehabil 20(2006)8, pp 686-700

2380 Battaglia M, Russo E, Bolla A, Chiusso A

International Classification of Functioning, Disability and Health in a cohort of children with cognitive, motor, and complex disabilities.
Developmental Medicine & Child Neurology 46(2), pp 98-106

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Rapportage ouderen 2006
Sociaal Cultureel Planbureau, 2006, 281 p

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Development of ICF Core Sets for patients with chronic conditions
J Rehab Med 36(0), pp 9-11

2368 Cook CE, Richardson JK, Pietrobon R

Validation of the NHANES ADL scale in a sample of patients with report of cervical pain: Factor analysis, item response theory analysis, and line item validity
Disability and Rehabilitation 28(2006)15, pp 929-935

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Prediction of long-term occupational performance outcomes for adults after moderate to severe traumatic brain injury
Disability and Rehabilitation 28(2006)9, pp 547-559

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Determinanten van dagelijkse activiteiten en sociale participatie van jongeren met cerebrale parese
Revalidata 28(2006)131, pp 6-27

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Identification of the most common patient problems in patients with chronic conditions using the ICF checklist
J Rehab Med 36(0), pp 22-29

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Distinguishing theories of dysfunction, treatment and care. Reflections on "Describing rehabilitation interventions"
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Evaluation of the Swedish version of the Modified Elderly Mobility Scale (Swe M-EMS) in patients with acute stroke
Clin Rehabil 20(2006)7, pp 584-597

2376 Lue Yi-Jing, Su Chwen-Yng, Yang Rei-Cheng

Development and validation of a muscular dystrophy-specific functional rating scale
Clin Rehabil 20(2006)9, pp 804-817

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Participation of disabled children: how should it be characterised and measured?
Disability and Rehabilitation 28(18), pp 1157-1164

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What are the boundaries of health and functioning - and who should say what they are
Disability and Rehabilitation 28(23), pp 1473-1474

2391 Murchland S, Wake-Dyster W

Resource allocation for community-based therapy
Disability and Rehabilitation 28(22), pp 1425-1432

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A multi-dimensional approach to the transition of children with developmental disabilities into young adulthood: The acquisition of adult social roles
Disability and Rehabilitation 28(2006)15, pp 915-928

2397 Nieuwenhuijsen ER

On health, ability and activity: Comments on some basic notions in the ICF commentary
Disability and Rehabilitation 28(23), pp 1477-1479

¹ The database is available at <http://www.rivm.nl/who-fic/icf.htm>, a page in Dutch: click on "download documentation ICF/ICIDH", a winzip file

- 2393 Nordenfelt L**
On health, ability and activity: Comments on some basic notions in the ICF
Disability and Rehabilitation 28(23), pp 1461-1465
- 2400 Nordenfelt L**
Reply to the Comments
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Disability and Rehabilitation 28(2006)9, pp 561-570
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Health and Quality of Life Outcomes 2005, 3(1):46
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