| THE C | RGAN | THE PERSON | | | |
|--------------------------------------|--------------------------------------|---|----------------------------------|--|--|
| Structural change at the organ level | Functional change at the Organ level | Skills, Abilities (ADL) of the individual | Social, Economic Consequences | | |
| Eye Health | Visual Functions | Functional Vision | Quality of Life | | |
| | | | | | |

ion (Near-)Normal Vision

Range of Normal Vision

Mild Vision

Moderate Vision Loss

Severe

Profound Vision

(Near-) Blindness Near-Blindness

Blindness

VISUAL STANDARDS

ASSESSMENT and REHABILITATION of VISION-RELATED FUNCTIONING

DRAFT of a Report prepared for presentation at the World Ophthalmology Congress – Hong Kong, 2008 of the International Council of Ophthalmology and the Vision-2008 conference – Montreal, 2008 of the International Society for Low Vision Research and Rehabilitation

BACKGROUND

This report on the Assessment and Rehabilitation of Vision-related Functioning is being prepared in cooperation between the International Council of Ophthalmology (ICO) [1] and the International Society for Low Vision Research and Rehabilitation (ISLRR) [2] for presentation at the

World Ophthalmology Congress [³], June 28 – July 2, 2008 in Hong Kong and at the **Vision-2008** conference [⁴] on Vision Rehabilitation, July 7 – 9, 2008 in Montreal.

Input was obtained from many sources, including the ICF Research Branch, of the Institute for Health and Rehabilitation Sciences, a WHO Collaborating Center for the Family of International Classifications, in Munich, Germany [5]

The report builds on prior ICO and ISLRR reports and WHO documents, notably the

1999 ISLRR report – Guide to the Evaluation of Visual Impairment [6]

2002 ICO report – Aspects and Ranges of Vision Loss [⁷]

2006 ICO report – Vision Requirements for Driving Safety [8]

2003 WHO Consultation on the Characterization of Vision Loss [⁹], requesting more emphasis on the functional aspects of vision loss.

2005 World Health Assembly Resolution WHA58.23 [¹⁰], requesting world-wide emphasis on the prevention, management and rehabilitation of disability in general, and on the **2006 World Health Assembly Resolution** WHA59.25 [¹¹], requesting more emphasis on the prevention, treatment and rehabilitation of vision loss in particular.

The 1999 report of the ISLRR and the 2002 report of the ICO established the importance of differentiating between various *aspects of vision loss*, notably the aspect of **Visual Functions**, which describes how the <u>eye</u> functions and the aspect of **Functional Vision**, which describes how the <u>person</u> functions in vision-related activities. In these reports emphasis was placed on population surveys, where statistical averaging hides individual differences.

The 2206 ICO report extended the considerations to driver's license requirements, where individual characteristics are sometimes more important than statistical averages.

As societal attention is extended (as evidenced in the WHA resolutions) from the prevention and treatment of disease to its functional consequences and their rehabilitation, it is imperative that we more clearly define those consequences and provide means to measure their remediation.

<u>The report aims at</u> (a) expanding the awareness of all those involved with eye care to the functional consequences of vision loss, and (b) pointing to ways in which the effectiveness of vision rehabilitation can be measured.

The first aim is consistent with the WHO's definition of Health as a condition of optimal physical, mental and social well being and with the International Classification of Functioning, Disability and Health (ICF) [12]. The second aim is mandatory as society increasingly demands the practice of evidence-based medicine. The report will hopefully contribute to a better understanding by patients, practitioners and governments of the relationships between eye health and Quality of Life, to more effective communication between the various stake holders, and to a better assessment of the cost effectiveness of rehabilitative interventions.

Subsequent reports may be needed to provide more details about actual methods of assessment and about comparisons of outcomes in a variety of settings.

Correspondence:

Please send comments and contributions to standards@icoph.org.

ASPECTS of Health and Functioning

The seemingly simple term "health" describes a rather complex interaction of many conditions. It can be approached from different points of view. Four main aspects are often recognized [¹³]. Of these, two refer to the organ level; two refer to the person as a whole.

- > The first aspect is that of the anatomical and structural integrity of the organ.
- > The next aspect describes how the *organ* functions.
- Organ function alone, however, cannot adequately describe how the *person* functions. The next aspect, therefore, describes the vision-related skills and abilities of the person that are available for the performance of Activities of Daily Living (ADLs).
- > The last aspect places the person in a societal context and describes the societal and economic consequences of any functional deficits.

This is summarized in Table 1. As we proceed from left to right across the table, the context in which we view each aspect widens, from the tissue, to the organ, to the person, and finally to the society in which that person functions.

These aspects can be used to describe any health condition. In the field of vision we will use the term **Visual Functions** to describe how the *eye* and the visual system function; we will use the term **Functional Vision** to describe how the *person* functions in vision-related Activities of Daily Living (ADLs) [¹⁴]. The more general term **Vision-related Functioning** can be used to include both aspects.

The four aspects are linked, but the links are not fixed, since various health care interventions can modify the links. If the links were fixed no health care interventions would be possible.

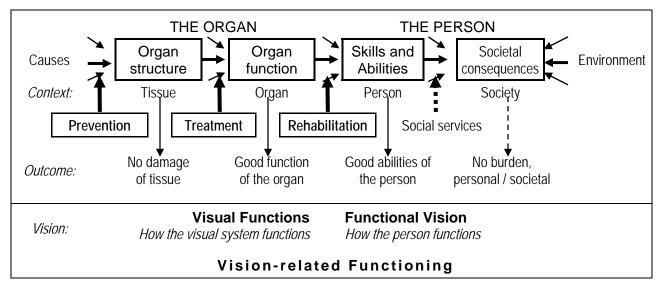


Table 1 – INTERVENTIONS and desired OUTCOMES

Table 1a shows one possible application of these aspects, in this case to driving ability [*8].

Table 1a – VARIOUS ASPECTS of Driving Ability

Acuity test

Driving ability

Driving in

VISUAL FUNCTIONS vs. FUNCTIONAL VISION

An important distinction is that between Visual Functions and Functional Vision. These seemingly similar terms describe very different aspects of vision-related functioning. This section will list a number of differences, which will be summarized in Table 2.

Visual Functions describe how the eyes and the basic visual system function. With few exceptions, they can be measured for each eye separately. One can have an impairment (e.g. due to a cataract or a retinal scar) in one eye, but normal function in the other eye.

Functional Vision, on the other hand, describes how the person functions. The concept cannot be applied to one eye. A person cannot be disabled in one eye and not in the other eye.

Tests of Visual Functions determine <u>threshold performance</u> in a controlled environment, where only a single parameter is varied in any one test.

For instance: visibility of a target can be affected by varying the parameters of <u>symbol</u> size (or distance), <u>contrast</u> and <u>illumination</u>. When we vary the symbol size while keeping contrast and illumination constant, we perform a visual acuity test. When we vary contrast, while keeping size and illumination constant, we perform a contrast sensitivity test (as on the Pelli-Robson chart). When varying only the illumination of large, high contrast targets, we perform a dark adaptation test.

Tests of Functional Vision, on the other hand, must determine <u>sustainable performance</u> in a real-life environment, where multiple uncontrolled parameters may vary simultaneously and in unpredictable combinations. The <u>safety margin</u> between threshold and sustainable performance has been characterized as a performance reserve [¹⁵]; often the difference is a factor 2x or 3x. The 2006 report on driver's license requirements pointed out that these vision requirements indeed define a safety margin, not a scientifically determined threshold.

Visual Function tests can be strictly limited to visual parameters. In **tests of Functional Vision**, non-visual factors may influence the outcome and the broader term vision-related functioning may be more appropriate. E.g.: reading print is primarily a visual task, but it also requires literacy and understanding of the topic and the language, which are non-visual skills.

The measurement of Visual Functions can thus only provide an *estimate* of Functional Vision.

Scoring and **scaling** also are different. For visual functions, applying Weber-Fechner's law and taking the logarithm of the measured value often is a valid approach (as in logMAR) [¹⁶]. For questionnaire data about functional vision, Rasch analysis [¹⁷] often is needed.

Table 2 - VISUAL FUNCTIONS vs. FUNCTIONAL VISION

| | Visual Functions (How the visual system functions) | Functional Vision (How the person functions) | | | |
|----------|---|---|--|--|--|
| Examples | Visual acuity, field, contrast, dark adaptation, color vision, etc. | Orientation and Mobility, Daily Living Skills, Communication, Sustained near activities | | | |
| Measured | For each eye separately | For the person as a whole | | | |
| Tests | Single variable, under controlled conditions | Multiple variables, under complex, real-life conditions | | | |
| Criteria | Threshold performance | Sustainable, supra-threshold performance | | | |
| Involves | Visual parameters only | May also reflect non-visual factors | | | |
| Scoring | Logarithmic scale | Rasch analysis | | | |

FUNCTIONAL VISION and QUALITY OF LIFE (QoL)

Since the introduction of the NEI-VFQ [¹⁸], interest in the last column of Table 1 has increased significantly. This is often described as "Quality of Life"; although a clear definition of the concept has often been lacking [¹⁹].

Assessment of Quality of Life essentially remains a subjective assessment. "Satisfaction" may be the best term to describe the balance between self-defined expectations and self-assessed performance. A farmer may feel lost in a big city; a city dweller may feel equally lost in a rural community. Both will say that their Quality of Life has decreased.

Table 3 lists items that can be assessed under each of the three aspects. It is clear that the three lists are very different and require very different methods of assessment. Yet, many questionnaires combine questions from all three columns under the single heading of Quality of Life. When processing such questionnaires or surveys, a better separation should be made between the different categories.

THE PERSON THE ORGAN Skills and Societal Organ Organ Etiology **Environment Abilities** structure function consequences Visual Functions **Functional Vision Quality of Life** Self care Self confidence Items Acuity Searching, fixation Household management Making, keeping friendships Contrast Communication Fear of falls Glare face recognition Coping skills Visual Fields Reading Organizing life, assistance Kinetic, static Mobility Fulfilling roles Color vision Meal preparation, eating family, work Dark adaptation community Shopping, Hobbies Ftc. Depression Vocational skills Dimension Visual function tests Activities of Daily Living Participation in Society Assessment One parameter at a time Multiple, interacting parameters Psycho-social well being Criterion Sustainable performance **Individual Satisfaction** Threshold performance Accuracy Precise, objective Objective, subjective elements Highly subjective Outcome measure for Outcome measure for Ultimate goal for all USE: Medical and surgical care interventions **Rehabilitative** interventions Comment Visual acuity is widely used, Rehabilitation plans must also Vision loss can be a major but other parameters (field, reflect needs and priorities. factor, but Quality of Life must contrast sensitivity) should be Outcomes must be measured consider many non-visual

Table 3 – INVENTORIES for different aspects

against pre-set goals

factors as well.

considered also

Comparing the three functional aspects, we note that most visual functions can be measured fairly accurately, since threshold performance can be objectively defined. The assessment of functional vision contains more "soft" elements; *sustainable performance* can be subject to various interpretations, even when tasks and protocols are standardized. Quality of Life assessment, finally, is the most subjective; yet, if the Quality of Life is not improved, the ultimate goal of either medical or rehabilitative interventions is not achieved.

For rehabilitation the column of visual skills is most important. Since these are in the center column, individual rehabilitation plans must consider their relation to the left-hand as well as to the right-hand column. Rehabilitation plans must be based not only on the presence of deficits (left), but also consider the individual importance and relevance of those deficits on the right [²⁰]. Based on these factors, individual goals must be set; so that the rehabilitative outcomes can be measured against these specific, rather than against some general set of questions that may include abilities that were not part of the rehabilitation plan.

APPLICATIONS of Functional Vision assessment

Assessment of Functional Vision can be used for different purposes.

Prediction of performance problems is needed to determine the eligibility for disability benefits. It is also needed for licensing requirements, such as for a driver's or a pilot's license.

Often these tests consider only visual functions, because the measurement of visual functions is easier than the assessment of functional vision. Figure 1a illustrated that the predictive value of letter chart acuity and similar measures is limited because they are not in the same column as the performance that is to be predicted. Tests that assess a variety of factors at once and thus find deficits that result from a combination of factors and might be missed by testing each factor separately may be more predictive. E.g. a test in a driving simulator reveals more components of driving ability than does a letter chart test. The appendix of the 2006 ICO report on driving [8] contains examples of tests that measure more than letter chart acuity, but are simpler to administer than an actual driving test.

In **Medical and Surgical Outcome studies**, measures of visual functions, such as visual acuity, usually provide the <u>primary outcome measure</u>. They may be augmented with <u>secondary outcome measures</u> of vision-related skills and of Quality of Life. Many questionnaires exist that focus on the results of cataract surgery. As cataract and refractive surgery expand to multi-focal and accommodating lenses, the scope of these questionnaires needs to be expanded.

The NEI-VFQ was developed to be less disease-specific, so that it can be used for a wider variety of conditions and interventions. This may be an advantage when used as a secondary outcome measure. For measuring specific outcomes, as specified in a rehabilitation plan, its global nature is a disadvantage. An important question concerns the relative validity and usefulness of general questionnaires (such as the NEI-VFQ) vs. disease specific questionnaires (cataract, AMD, diabetic retinopathy) in a variety of settings.

Vision Rehabilitation Outcome studies is the area where better assessment of Functional Vision is the most urgent, since for vision rehabilitation assessment of vision-related skills and abilities is the *primary outcome measure*, not a secondary one as it usually is for medical and surgical interventions. At a time that evidence-based outcome research is demanded in all areas of medicine, the proper and consistent documentation of results in vision rehabilitation is still unsatisfactory.

COMPREHENSIVE VISION REHABILITATION

Considering the three aspects discussed so far is essential for effective vision rehabilitation. However, they are not the only factors important for comprehensive rehabilitation. While many Low Vision clinics initially concentrate on "Low Vision Aids" (LVAs), to enhance the use of residual vision, comprehensive rehabilitation requires additional attention to non-visual factors and skills and to the environment. This is summarized in Table 4.

Low Vision *skills* and *devices* are important for vision enhancement. Sometimes, however, *"vision substitution"* skills need to be considered as well. Vision substitution refers to the use of non-visual functions, such as touch and hearing. A patient, who prefers a magnifier to read letters and bills, may prefer talking books for recreational reading.

Hand in hand with the provision of aids needs to be attention to the patient's attitude and motivation. Vision loss in the elderly is a frequent cause of depression. If this is not recognized, visual aids alone may not be effective; without visual aids that reduce the effects of the vision loss, the treatment of depression alone may not be effective either.

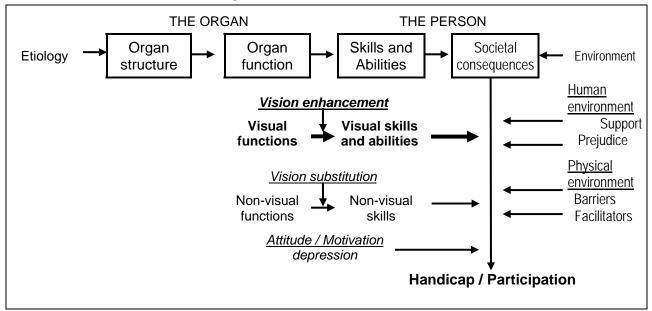


Table 4 – Comprehensive VISION REHABILITATION

Beyond the patient, we need to pay attention to the patient's environment. This includes the human environment of family members and friends, as well as the work or school environment.

Adequate support can significantly alleviate the burden of vision loss; prejudice, on the other hand, can significantly aggravate the impact. Therefore, education and information of the patient's home, work or school environment must be considered in any rehabilitation plan.

The physical environment can likewise provide barriers as well as facilitators. The ICF provides a special category for these factors. Home, school and workplace adaptations must be considered in any rehabilitation plan. These may vary from low-tech such as better lighting and better contrast, to high-tech such as a computer with voice output.

In summary, the Assessment and Rehabilitation of Vision-related Functioning must consider a broad range of functions. The next section will discuss some of the classifications and lists that are available to assist in this task.

TERMINOLOGY related to ASPECTS OF FUNCTIONAL LOSS

Since different publications describe functional losses with different terminology, it is important to discuss the similarities and differences between these terminologies, before discussing any of the available tools in more detail. Table 5 summarizes and compares various terminologies. Some of the terms used are discussed in the notes below.

- (1) Aspects. The term "dimensions" has also been used. This term has mathematical and physical connotations. Dimensions are usually orthogonal; one dimension can be changed without affecting other dimensions. To describe human functioning, the term "aspects" is recommended, since it implies the importance of the observer's point of view.
- **(2) Organ.** This term is used in the sense of "organ system". In ICF [12], the terms "body" and "body system" are used. ICF includes the brain and the mind under the descriptor "body". Accordingly, it treats higher, cognitive visual functions as part of "vision" and the "visual system". Today, many congenital vision problems are recognized as being wholly or partly cognitive in nature (Cerebral Visual Impairment, CVI) [²¹]. (The term cortical visual impairment is also used, but is often too restrictive, since many lesions are sub-cortical.)
- (3) **Disorder.** This term is used to include all deviations from the natural order, including diseases, injuries, scars, anomalies, deformities, loss, etc.
- **(4) Disorder, Impairment, Disability, Handicap.** These terms, used in ICIDH [²²], have a negative connotation. If a scale is attached, a zero value will indicate normal function
- (5) Body Structure, Body function, Activities, Participation. The main terms used in ICF are more neutral terms. If a functional scale is attached, a zero value will indicate no functioning at all. Normal functioning will often be given a value of "100". Notice, however, that the modifiers suggested in ICF are based on difficulty, and thus still represent a negative scale.
- **(6) Body Structure.** This aspect is similar to the disorder aspect. Note that ICF includes the brain and mind under this heading. ICD-10 and ICD-9 [²³] or ICD-9-CM [²⁴] are the primary classifications for this aspect; ICF contains only broad categories in its s-codes.
- (7) Activities. ICF chose "activity" as the label for the aspect that ICIDH labeled as "dis-ability" (= ability loss). Note that the activity and ability concepts are inseparable. Listing an activity without specifying the level of ability at which it can be performed is as meaningless, as is listing an ability level without specifying the activity to which it refers. Therefore, no ICF code is complete without a *modifier* to indicate the level of ability (positive scale) or of difficulty (negative scale).
- **(8) Participation.** This aspect places the individual in a social setting ("life situation"). ICIDH listed the "handicap" that prevented full participation. In ICF the term "handicap" was dropped because of its negative connotations. ICIDH described the handicap aspect mainly as a "loss of independence". Note that the ICF choice also recognizes that "participation" (interdependence) is a higher ideal than complete independence.
- **(9) Health condition.** This term is often defined as describing health deficits, such as disease, disorder, injury. Curiously, this definition would imply that good health is not a health condition.
- **(10) Functioning, Disability, Health.** "Functioning" is the main title of ICF. Note that it commands a positive scale (0 = no function, 100 = normal function). For some purposes a negative scale (0 = no loss, 100 = total loss) can be preferable. For this purpose the term "disability" is included as a subtitle. The term "health" is a general term to which no scale is attached; it broadly denotes the general purpose of the World **Health** Organization.

Table 5 – TERMINOLOGY related to ASPECTS OF FUNCTIONAL LOSS

| | THE (| ORGAN ² | THE PERSON | | | | |
|--|---|---|---|---|--|--|--|
| ASPECTS: | Structural change, at the Organ level | Functional change at the Organ level | | | | | |
| , | | | | | | | |
| ICIDH (1980) (Negative terms ⁴) | Disorder ³ | Impairment | Dis-ability | Handicap | | | |
| 1 | | | | | | | |
| ICF (2001) (Neutral terms ⁵) | Body Structure 6 | Body Function 6 | Activities ⁷ | Participation 8 | | | |
| | Health Condition ⁹ (ICD-9, ICD-10) | | | | | | |
| Loss | (Impairment) | Impairment 11 | npairment ¹¹ Limitation ¹² (Capacity) | | | | |
| Use of the term Disability ¹³ | | Disability = impairment as in "Americans with Disabilities Act" (ADA) | Dis-ability = ability loss as in "Disabled Veterans" | Disability = economic as in "Being on disability" | | | |
| Coding 14 | ICF-s codes | ICF-b codes | ICF-d codes (or a and p codes) | | | | |
| • | | | Contextual Factors – e codes External / personal barriers / facilitators | | | | |
| 1 | | | _ | _ | | | |
| Application to | Eye - | Vision-related Functi | ioning / Vision Loss 15 | Vision-related | | | |
| VISION | Health | Visual Functions ¹⁶ measured quantitatively | Functional Vision ¹⁷ described qualitatively | Quality of Life ¹⁸ | | | |
| Performance Tests | | Performance on eye tests <i>E.g.: Visual Acuity</i> | Performance on ADL skills <i>E.g.: Reading ability</i> | Performance on job-related and social tasks | | | |

- (11) Impairment. ICF allows use of the term "impairment" for disorders. We prefer to use the term "impairment" only for the aspect of functional loss. E.g. we prefer to call a cataract a "disorder", which causes an "impairment" (vision loss), rather than: a cataract is a structural impairment, which causes a functional impairment.
- **(12) Limitation, Restriction.** ICF uses the term "limitation" in the context of activities and the term "restriction" in the context of participation. The term "capacity" is used to indicate how the person *could* function; the term "performance" is used to indicate how the person *does* function.
- (13) Disability. The term "disability" deserves special discussion, since it is widely used, but its meaning varies among users. The term can be used for several different aspects. E.g.: in the "Americans with Disabilities Act" it is practically synonymous with "Americans with Impairments". In "Disabled Veterans" it denotes a loss of the ability. This is the meaning that was used in

ICIDH. In "being on disability" the term denotes a social and economic consequence. In the AMA Guides [25] the term is used to refer to the interaction between individual skills and societal demands: a person can be disabled for one job, but not for another one. Some may say that well adapted totally blind persons are *visually disabled*, because they lack visual skills. Others may say that they are not disabled in a more general sense, since they can manage in all life situations; they just use a different set of abilities. In ICF, any of these uses is permitted, but the ICF guidelines warn against using terms that may stigmatize or label people.

Confusion may thus result if the term disability is used without making it clear which aspect is meant. A recent report of the U.S. National Research Council [²⁶] explores in great detail to what extent *visual disability-as-impairment* can predict *economic disability* as determined by the Social Security Administration. One of its conclusions is that this question involves policy decisions and cannot be answered on the basis of scientific research alone.

To enhance clarity, this report will avoid the use of the term disability. Where needed, the term "ability loss" will be used since it is more specifically linked to the ability aspect.

(14) Coding. The ICF contains different coding sections for the different aspects; it uses the same set of domain descriptors for the "Activities" and for the "Participation" aspects. Under "activities" these descriptors refer to the execution of a task; under "participation" they refer to involvement in a life situation. The amount of overlap may vary. ICF contains another important section for "Contextual Factors" that define the context in which the activity takes place. Contextual factors can be external or personal; they can act as barriers or as facilitators.

Note that ICF terms cannot be used alone. They always need a modifier or several modifiers to indicate the level of difficulty or ability.

- (15) Vision Loss. The term "Vision-related Functioning" is a general term, which can be applied to the aspect of organ function ("how the eye functions") as well as to the activity and participation aspects ("how the person functions"). The term "Vision Loss" can indicate any loss of vision-related functioning. It is preferable over the term "Blindness", since vision loss can be used with modifiers such as mild, moderate, severe, profound and total loss, whereas blindness is a dichotomous, black-and-white term that does not allow any modifiers. Widespread use of the terms "legal blindness" (USA) and "blindness" (WHO) for people with residual vision should be abandoned, because they cause needless confusion. The terms "severe vision loss" (= legal blindness, USA) and profound vision loss (= blindness, WHO) as used in ICD-9-CM [25] are more descriptive.
- E.g.: Macular Degeneration is a leading cause of "vision loss"; it is not a leading cause of "blindness", since it never affects peripheral vision, unless combined with other disorders.
- (16) Visual Functions. This term refers to organ function. Note that the noun is "Functions" (plural); "Visual" is an explanatory adjective. The parameters of organ function, such as visual acuity, visual field, contrast, color, dark adaptation etc., can generally be measured psychophysically with fair accuracy and for each eye separately.
- (17) Functional Vision. This term refers to how the individual functions in Activities of Daily Living (ADL). Note that the noun is "Vision" with "Functional" as an explanatory adjective. Functional Vision includes activities such as reading, writing, face recognition, mobility etc. These activities can only be assessed for the individual, not for each eye separately.
- (18) Vision-related Quality of Life. To improve the Vision-related Quality of Life is the ultimate goal of all vision rehabilitation programs. This is the most subjective aspect. Its assessment should involve not only visual factors but also personal factors, such as coping skills and depression; it may also be influenced by societal attitudes and social policy.

AVAILABLE TOOLS

Since many tools already exist to assess Visual Functions, as discussed in the 1999 ISLRR and the 2002 ICO report, this report will concentrate on tools to measure **Functional Vision** and **Vision Rehabilitation outcomes**.

Functional vision can be considered from two points of view. When seen in the context of the ultimate *result*: improved quality of life, not only the *ability* to perform a specific task must be considered, but also the *need* for that task. When seen in the context of the *underlying organ deficits*, we must consider the *resources* needed to perform the task. As discussed earlier, those resources not only include vision enhancement aids, but also vision substitution skills, and consideration of personal attitudes and motivation (Table 4).

There is a need, therefore, for a **two-dimensional matrix** of ADLs, with one dimension representing the **tasks** and **goals** to be achieved, and the other dimension representing the availability of various **resources**, including non-visual resources. This may require a sub-set of the Activities and Participation domain in ICF. ICF encourages the development of such special adaptations (ICF annex 8).

Tools for Functional Vision assessment may be separated into two broad categories:

- > Tools that measure or observe actual performance
- Questionnaires that ask individuals to rate their own performance.

The **observation** group is rather limited. Generally, the assessment of functional vision is more qualitative than that of visual functions.

Reading performance is an obvious target. Measurement of reading acuity and plotting of para-foveal scotomata belongs in the visual function column. Measurement of reading speed and reading endurance belong in the functional vision column. Reading enjoyment fits in the Quality of Life column. The MN-read test [²⁷] plots reading speed against print size for short paragraphs to obtain an estimate of how far above the print size threshold an individual needs to be to perform most effectively. A project in the EU [²⁸] developed longer reading segments of standardized length in various languages. It thus provides a better measure of *sustainable* reading performance.

Observation of **ADL performance** on the job or in a home environment requires a counselor-teacher or other observer. This has the advantage of adaptability to a wide variety of circumstances, but the disadvantage of lack of standardization. Timed performance can often be used to get an objective measurement result [²⁹]. Different individuals may react differently, however, to the trade-off between fast performance and a low error rate.

Driving performance can be observed in a driving simulator or on the road. Simulator tests are expensive; on-the-road observation introduces the evaluator as a subjective element. It has been shown that even if evaluators have check lists, their reference criteria may change over time [³⁰]. The distribution over different columns in Table 1a explains why visual acuity alone is not a strong predictor of actual, on-the-road driving performance. This is one area where the consideration of need is important, since the need to drive varies widely in different environments.

Questionnaires are widely used to avoid the difficulties of actual observation. They may be completed by the subject or administered by a technician, on the phone or in person. Either way, they reflect the patient's self-assessment, rather than assessment by a third party. A wide variety of questionnaires exists. A study by de Boer [31] revealed that many lack proper psychometric validation. Statistical methods, such as Rasch analysis, based on item response

theory, are emerging to transform questionnaire responses and similar items to an interval scale.

Massof's Activities Inventory [^{32,33}] provides a hierarchical system, in which *tasks* are grouped under *goals*, which are grouped under *objectives*. He points out that even if the *task* of reading the newspaper is impossible, the *goal* of keeping up with the news may be satisfied through alternative resources, such as radio or TV. Thus, one may have an ability loss for a certain task, but not for the broader goal to which that task usually applies.

Different types and levels of questionnaires are needed.

- (1) A **short list** of a few **broad questions** is needed, to identify a <u>need for rehabilitation</u>. The questions should be short and simple enough to be routinely asked of all patients with some degree of vision loss. The questions should not be restricted to obvious visual deficits, but should include broader issues that are often overlooked, such as frustration and depression.
- Once the need for some form of rehabilitative interventions has been established, the patient should be scheduled for a rehabilitation interview. Here **longer list** of more **detailed questions** are needed to develop an *ability profile* and to <u>prioritize the rehabilitative needs</u>. These questions should address not only the *visual ability* to perform various tasks, but also the *individual need* to perform them and whether these needs can be or have been met by other means. For instance: a person living in a care home will have very limited needs for cooking and meal preparation; a person who can hardly walk because of severe arthritis has limited need for extensive Orientation and Mobility training. For use in this context, lists should be comprehensive, so that no areas are overlooked, but also flexible to adjust to individual needs. Long lists, such as the Activity Inventory, mentioned above, require branching that can be much facilitated by computer presentation.
- (3) Based on the profile of individual abilities and needs, an **individual rehabilitation plan** needs to be established with **criteria for its achievement**. Tools are then needed to <u>assess specific rehabilitative outcomes</u> (or the lack thereof) through validated tests or questionnaires that can be administered both <u>before</u> and <u>after</u> the intervention. That assessment should be based only on questions or tests that relate to the specific rehabilitative goals that were set and not be diluted with items that were not addressed in the rehabilitation plan.

ASSESSMENT RESULTS

For rehabilitation purposes it is most useful to assess various abilities and to construct an *ability profile* to highlight the areas most in need of help.

For some administrative applications, however, it may be desirable to combine various ability measures into a single ability estimate. This *single number approach* necessarily looses much detailed information and, therefore is not applicable to rehabilitation plans. The single number approach requires that the various scales be comparable. An example of such an approach across specialties can be found in the AMA *Guides* [25].

The ICF introduction states that no "activities and participation" code is meaningful unless followed by a modifier to indicate the ability (or difficulty) to perform that activity. Unfortunately, these modifiers are only based on non-standardized, subjective descriptors, such as mild, moderate and severe difficulty. More objective ratings are desirable.

For visual functions, such as visual acuity, it is well recognized that expressions such as "lines lost" or "lines gained" are not meaningful unless the lines are equally spaced with regard to their difficulty. On most traditional Snellen charts, this is not the case. A logarithmic progression of letter sizes, based on Weber-Fechner's law, solves this problem. Such a logarithmic progression was first proposed by Green in 1868 [34], but only gained widespread acceptance a century later, when the NEI incorporated it in the ETDRS protocol.

Once the geometric progression of letter sizes is converted to a linear score, such as the logMAR score or the VAS score [6,7], the latter scores can be used to calculate differences or averages or for graphical presentation.

Scoring of **questionnaire responses** presents a similar problem. Simply counting the number of answers does not provide a reliable scale. A questionnaire that contains several questions of equal difficulty can be compared to a letter chart with several lines of the same size. A list with only easy items can differentiate between patients with severe or profound losses, but not between normals and those with minimal losses. The opposite is true for lists with only difficult items. Mathematical ways to extract actual interval scales for task difficulty and individual ability through Rasch analysis and other means have been explored by Massof [17] and others.

Table 6 compares the difficulty ranges listed in ICF to the impairment ranges used in ICD-9-CM and in the previous ICO and ISLRR reports. The latter ranges can also be used for senses and abilities other than vision. They recognize that normal performance of Activities of Daily Living is supra-threshold performance that leaves a reserve for exceptional demands. When used with an *ability score*, it leaves room for exceptional performance, such as by an Olympic athlete or a speed reader. The six ranges can also be collapsed to two or to three broader ranges. Use of only two ranges is not recommended, since it promotes dichotomous, black-and-white thinking. Three ranges are advocated by Hyvärinen [35] for assessment of children, and are used as normal / low vision / blindness in WHO statistics.

When an ability scale is used [6,7,8,14,16], the value "100" is a reference standard, not an absolute limit. This is analogous to the fact that the visual acuity scale extends beyond 20/20 (1.0). 20/20 (1.0) is only a reference standard, since most normal adults have better than 20/20 (1.0) acuity.

The ICF modifiers represent a *difficulty scale*. They, therefore, cannot deal with exceptional performance (a negative value for normal performance is counter-intuitive). They recognize five ranges by combining the ranges of severe and profound deficit. The basis for the percentage scores attached to the ICF ratings is not explained. It is only suggested that these should be calibrated separately for each application domain.

Table 6 – GENERAL SCALES of FUNCTIONING, applied to VISION

| Impairment | | | formance Functional | | ICF Difficulty | | Statistical use [*] | | | |
|-------------------|--|---------------------------|--------------------------|---------------------------|-----------------------|--|---------------------|---------------------------------|---------------------|---------------|
| Ranges | | | 6 ranges | Ability Score | | ranges | | Difficulty | Importance | |
| | Exceptional performance | | | | 120 | | | | | |
| Normal | Normal or near- normal | Normal or main near- Sigh | Uses mainly | Reserve for extra demands | Reference Standard | 100 | No difficulty | 0 % - 4 % | Not difficult | Not important |
| Mild deficit | | | Sighted techniques | Can perform, lost reserve | Good | 80 | Mild difficulty | 5 % – 24 % | Slight, moderate | |
| Moderate deficit | functioning | Uses mainly | Needs help occasionally | Fair | 60 | Moderate difficulty 25 % – 49 % Severe difficulty 50 % – 95 % | difficulty | Slightly, moderate, | | |
| Severe deficit | Visual functioning restricted or impossible | Low Vision techniques | Needs help frequently | Poor | 40 | | | Very, extremely difficult | very important | |
| Profound deficit | | restricted or Uses | Marginal functioning | Marginal | 20 | | | | | |
| Total deficit | | Blind techniques | Can't function visually. | Can't | 0 | Complete difficulty | 95 % – 100 % | Impossible | Extremely important | |

Massof's studies [33] have found that even five ranges may not be handled consistently across respondents. When respondents were given five response options, he found that the best statistical consistency was obtained by collapsing the responses to only four categories when rating the difficulty of a task (not difficult / slightly, moderately difficult / very, extremely difficult / impossible), and to only three categories when rating the importance of a task (unimportant / slightly, moderately, very important / extremely important).

In this regard it should be remembered that there is a difference between the statistical difficulty ratings of tasks across a population and the difficulty of various tasks for any one individual. An individual with exceptional ability may rate as easy a task that most people find difficult; an individual with poor ability may find a task difficult that most people rate as easy. Also, while the difference between slightly, moderately and very important may not be reliable statistically, it may still be useful in prioritizing rehabilitation objectives at the individual level.

This manuscript contains the **PART 1** of the final report. Comments on this part are welcome at <u>standards@icoph.org</u>.

PART 2 will contain an overview of available instruments. Contributions for PART 2 are welcome at standards@icoph.org.

NOTES and REFERENCES

The International Council of Ophthalmology (ICO) traces its history to the first international meeting of ophthalmologists, held in Belgium in 1857. The ICO is the executive body of the International Federation of Ophthalmological Societies (IFOS), which serves as a coordinating body for all national and regional ophthalmological societies and, since 2005, also for subspecialty societies. The Council is supported by an Advisory Committee whose members are chosen to represent all geographical areas and all subspecialty areas. The ICO sponsors the biannual World Congress of Ophthalmology [*4], formerly known as the 4-annual International Congress of Ophthalmology. Its web site is: www.icoph.org.

- The International Society for Low Vision Research and Rehabilitation (ISLRR) was established in 1993 to provide a focal point for all workers and researchers in the field of vision rehabilitation. It sponsors a 3-annual international congress [*5]. Its journal is Visual Impairment Research. Its web site is: www.ISLRR.org.
- The 2008 World Ophthalmology Congress will be held June 28 to July 2, 2008 in Hong Kong, China. It will also be the 31th International Congress of Ophthalmology, the 20th Hong Kong Ophthalmological Symposium and the 12th Chinese Ophthalmological Symposium. Its web site is: www.WOC2008HongKong.org.
- The Vision-2008 congress of the ISLRR [*2] will be held July 7 to 9, 2009 in Montreal, Canada. Prior congresses were held in Melbourne (1990), Groningen, Netherlands (1993), Madrid (1996), New York (1999), Göteborg, Sweden (2002) and London (2005).
- The ICF Research Branch was established in 2001. It concentrates on the development of "Core Sets" to extend ICF to various disease conditions. Thus far, Core Sets have been developed for chronic musculosceletal disorders, chronic widespread pain, breast cancer, depressive disorders, stroke, low back pain, osteoarthritis, osteoporosis, rheumatoid arthritis, chronic ischaemic heart disease, diabetes mellitus, obesity, and obstructive pulmonary disease.
- International Society for Low Vision Research and Rehabilitation (ISLRR). *Guide for the Evaluation of Visual Impairment.* (1999). Available at www.ski.org/Colenbrander.
- 7 International Council of Ophthalmology (ICO). *Visual Standards, Aspects and Ranges of Vision Loss, with emphasis on Population Surveys*, (Apr. 2002). Available at: www.icoph.org/standards.
- International Council of Ophthalmology (ICO). Visual Standards, Vision Requirements for Driving Safety, with emphasis on Individual Assessment, (Febr. 2006). Available at: www.icoph.org/standards.
- 9 See http://whqlibdoc.who.int/hq/2003/WHO_PBL_03.91.pdf
- 10 See www.who.int/gb/ebwha/pdf files/WHA58/WHA58 23-en.pdf
- 11 See www.who.int/gb/ebwha/pdf_files/WHA59/A59_R25-en.pdf
- World Health Organization. *International Classification of Functioning, Disability and Health* (ICF), World Health Organization, Geneva, (2001). Successor to ICIDH [*23].
- Colenbrander A. *Dimensions of Visual Performance*, Low Vision Symposium, American Academy of Ophthalmology, <u>Transactions AAOO</u>, 83:332-337, 1977.
- 14 Colenbrander A. Aspects of Vision Loss Visual Functions and Functional Vision. Visual Impairment Research, 5(3): 115-136 (Dec., 2003). Available at: www.ski.org/Colenbrander.
- Whittaker SG, Lovie-Kitchin J. *Visual requirements for reading,* Optometry and Vision Science 70: 54-65 (1993).
- 16 Colenbrander A. *Measuring Vision and Vision Loss.* Vol. 5, Ch. 51 in Duane's Clinical Ophthalmology, Tasman, Jaeger eds., Lippincot Williams and Wilkins, 2002 edition.
- 17 Massof RW. The Measurement of Vision Disability. Optom Vis Sci 79:516-552 (2002).

- Psychometric Properties of the National Eye Institute Visual Function Questionnaire (NEI-VFQ), Mangione CM et al. Arch. Ophthalmol. 116:1496-1504 (1998).
- 19 Mitchell J, Bradley C. *Quality of life in age-related macular degeneration: A review of the literature.* Report to AMD Alliance International (2006). Published at www.amdalliance.org
- 20 Stelmack JA. Stelmack TR. Massof RW. *Measuring low-vision rehabilitation outcomes with the NEI VFQ-25.* Investigative Ophthalmology & Visual Science. 43(9):2859-68, (2002)
- Visual Impairment in Children Due to Damage to the Brain. (Bax M., Dutton G. Ed.) MacKeith Press, London (in preparation)
- World Health Organization. *International Classification of Impairments, Disabilities and Handicaps* (ICIDH-80), World Health Organization, Geneva, (1980).
- World Health Organization. *International Classification of Diseases, 9th Revision (ICD-9)* (1977), and *10th Revision (ICD-10)* (1992), World Health Organization, Geneva, used for international statistical reporting.
- 24 U.S. Public Health Service. *International Classification of Diseases, 9th Revision Clinical Modification* (ICD-9-CM). First edition: Commission on Professional and Hospital Activities, Ann Arbor, (1978). Later editions by others. Used in the USA for clinical reporting.
- American Medical Association, *Guides to the Evaluation of Permanent Impairment* American Medical Association, Chicago,. 5th Ed. 2001, (6th Ed. in preparation).
- National Research Council. *Visual Impairments. Determining Eligibility for Social Security Benefits.* Lennie P, Van Hemel SB eds. National Academy Press, Washington, DC, (2002).
- 27 Legge GE et al. MNREAD Acuity Charts, manual. Lighthouse Low Vision Products. (1994).
- 28 Hahn GA,. Penka D, Gehrlich C, et al. *New standardised texts for assessing reading performance in four European languages*. British Journal of Ophthalmology. 90(4):480-4 (2006)
- Owsley C, McGwin G Jr., Sloane ME, et al. *Timed instrumental activities of daily living tasks:* relationship to visual function in older adults. Optometry & Vision Science. 78(5):350-9 (2001)
- Tant MLM. Visual performance in homonymous hemianopia: assessment, training and driving. PhD Thesis, Groningen, 2002. Available at: http://irs.ub.rug.nl/ppn/235146404.
- de Boer MR, Moll AC, de Vet HC, Terwee CB, Volker-Dieben HJ, van Rens GH. *Psychometric properties of vision-related quality of life questionnaires: a systematic review.* [Review, 79 refs] Ophthalmic & Physiological Optics. 24(4):257-73, 2004 Jul.
- Massof RW., Hsu CT, Baker FH. et al. *Visual Disability Variables. I: The Importance and Difficulty of Activity Goals for a Sample of Low-Vision Patients*. Arch Phys Med Rehabil 86:946-953 (2005)
- 33 Massof RW, Hsu CT, Baker FH. et al. Visual Disability Variables. II: The Difficulty of Tasks for a Sample of Low-Vision Patients. Arch Phys Med Rehabil 86:954-967 (2005)
- Green J. On a new series of test-letters for determining the acuteness of vision, Transact. Amer. Opth. Soc. 4th meeting (1868), p 68-71.
- Hyvärinen, L., Classification of Visual Impairment and Disability. Bull. Soc. Belge Ophtal., 215, 1-16, 1985.