

		THE ORGAN		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
<b>(Near-)Normal Vision</b>	Range of Normal Vision	<b>VISUAL STANDARDS</b>  <b>ASSESSMENT</b> <b>and</b> <b>REHABILITATION</b> <b>of</b> <b>FUNCTIONAL VISION</b>  <b>SUMMARY</b>			
	Mild Vision Loss				
<b>Low Vision</b>	Moderate Vision Loss				
	Severe Vision Loss				
	Profound Vision Loss				
<b>(Near-)Blindness</b>	Near-Blindness				
	Blindness				

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 builds on prior ICO and ISLRR reports and WHO documents, notably the **1999 ISLRR report** – Guide to the Evaluation of Visual Impairment [<sup>1</sup>] and the **2002 ICO report** – Aspects and Ranges of Vision Loss [<sup>2</sup>].

*This report emphasized population studies, where averages hide individual differences.*

**2006 ICO report** – Vision Requirements for Driving Safety [<sup>3</sup>].

*This report emphasized individual abilities, which may be better or worse than the average.*

**2003 WHO Consultation on the Characterization of Vision Loss** [<sup>4</sup>].

*This consultation requested more emphasis on the functional aspects of vision loss.*

**2005 World Health Assembly Resolution WHA58.23** [<sup>5</sup>], *requesting world-wide emphasis on the prevention, management and rehabilitation of disability in general, and on the*

**2006 World Health Assembly Resolution WHA59.25** [<sup>6</sup>], *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 eye functions and the aspect of **Functional Vision**, which describes how the person functions in vision-related activities.

The **current report** emphasizes the **Assessment and Rehabilitation of Functional Vision**. It points to ways in which the functional aspects of vision loss can best be assessed and in which the effectiveness of vision rehabilitation can be measured. This assessment is mandatory 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, and as society increasingly demands the practice of evidence-based medicine. To do this, we need to more clearly define those consequences and provide means to measure their remediation.

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.

## ASPECTS of Health and Functioning

The seemingly simple term “health” describes a rather complex interaction of many factors. Four main aspects are often recognized [<sup>7</sup>]. 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.

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.

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. Table 1a shows one possible application of these aspects, in this case to driving ability [3].

Table 1 – INTERVENTIONS and desired OUTCOMES

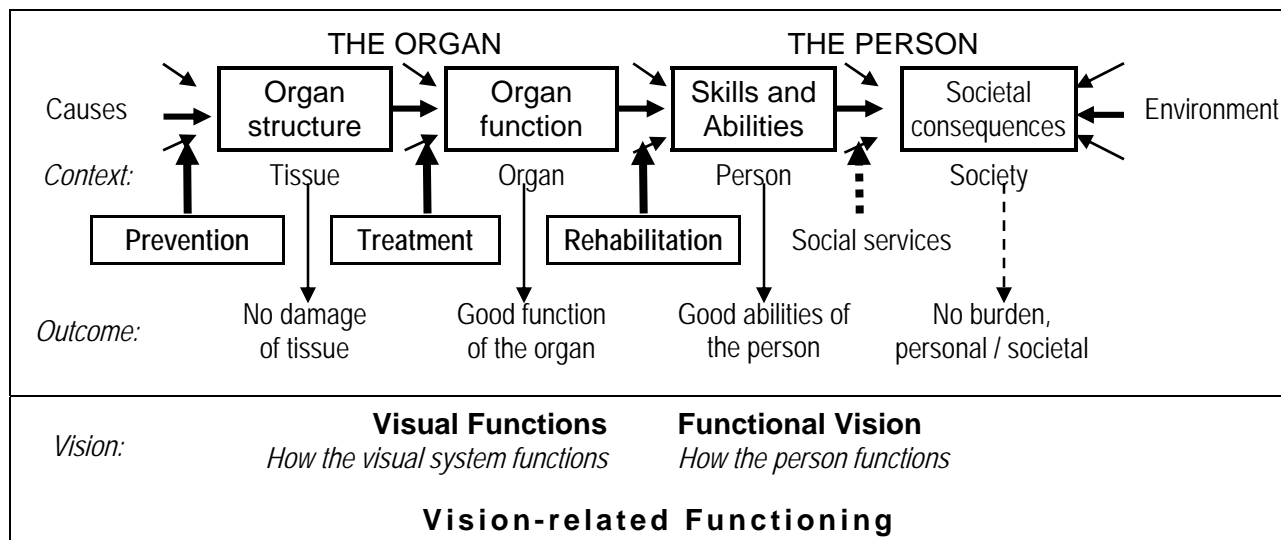
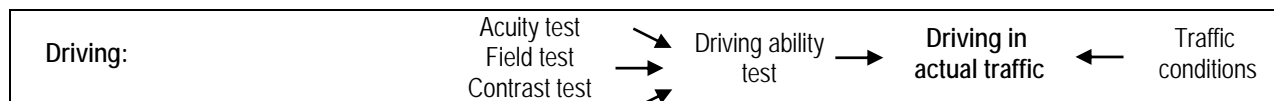


Table 1a – VARIOUS ASPECTS of Driving Ability



## VISUAL FUNCTIONS vs. FUNCTIONAL VISION

**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** are a mainstay of ophthalmology. They are performed by varying the stimulus, one variable (such as size, illumination, contrast) at a time, in a controlled environment, until the subject reaches a fixed threshold performance.

**Tests of Functional Vision**, on the other hand, are performed by presenting a standardized task and assessing the variable performance of the subject. The task must simulate a real-life environment, where multiple parameters may vary simultaneously and in unpredictable combinations. Furthermore, we are interested in sustainable performance, rather than in threshold performance. There is a substantial safety margin or comfort margin between threshold and sustainable performance [8]; often the difference is a factor 2x or 3x. The 2006 report on driver's license requirements pointed out that vision requirements for driving indeed define a safety margin, not a scientifically determined threshold.

Although the measurement of Visual Functions can provide a statistical *estimate* of Functional Vision, it can never replace the direct, individual assessment of Functional Vision.

**Visual Function tests** can be strictly limited to visual parameters. In **tests of Functional Vision**, non-visual factors may influence the outcome. 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.

Table 2 – **VISUAL FUNCTIONS vs. FUNCTIONAL VISION**

	<b>Visual Functions</b> <i>(How the visual system functions)</i>	<b>Functional Vision</b> <i>(How the person functions)</i>
<i>Examples</i>	Visual acuity, field, contrast, dark adaptation, color vision, etc.	Orientation and Mobility, Daily Living Skills, Communication, Sustained near activities
<i>Measured</i>	For each eye separately	For the person as a whole
<i>Method</i>	Variable stimulus; fixed, threshold performance	Standardized task; variable performance or difficulty
<i>Tests</i>	Single variable, under controlled conditions	Multiple variables, under complex, real-life conditions
<i>Criteria</i>	Threshold performance	Sustainable, supra-threshold performance
<i>Involves</i>	Visual parameters only	May also reflect non-visual factors

## **FUNCTIONAL VISION and QUALITY OF LIFE (QoL)**

Since the introduction of the NEI-VFQ [9], 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 [10].

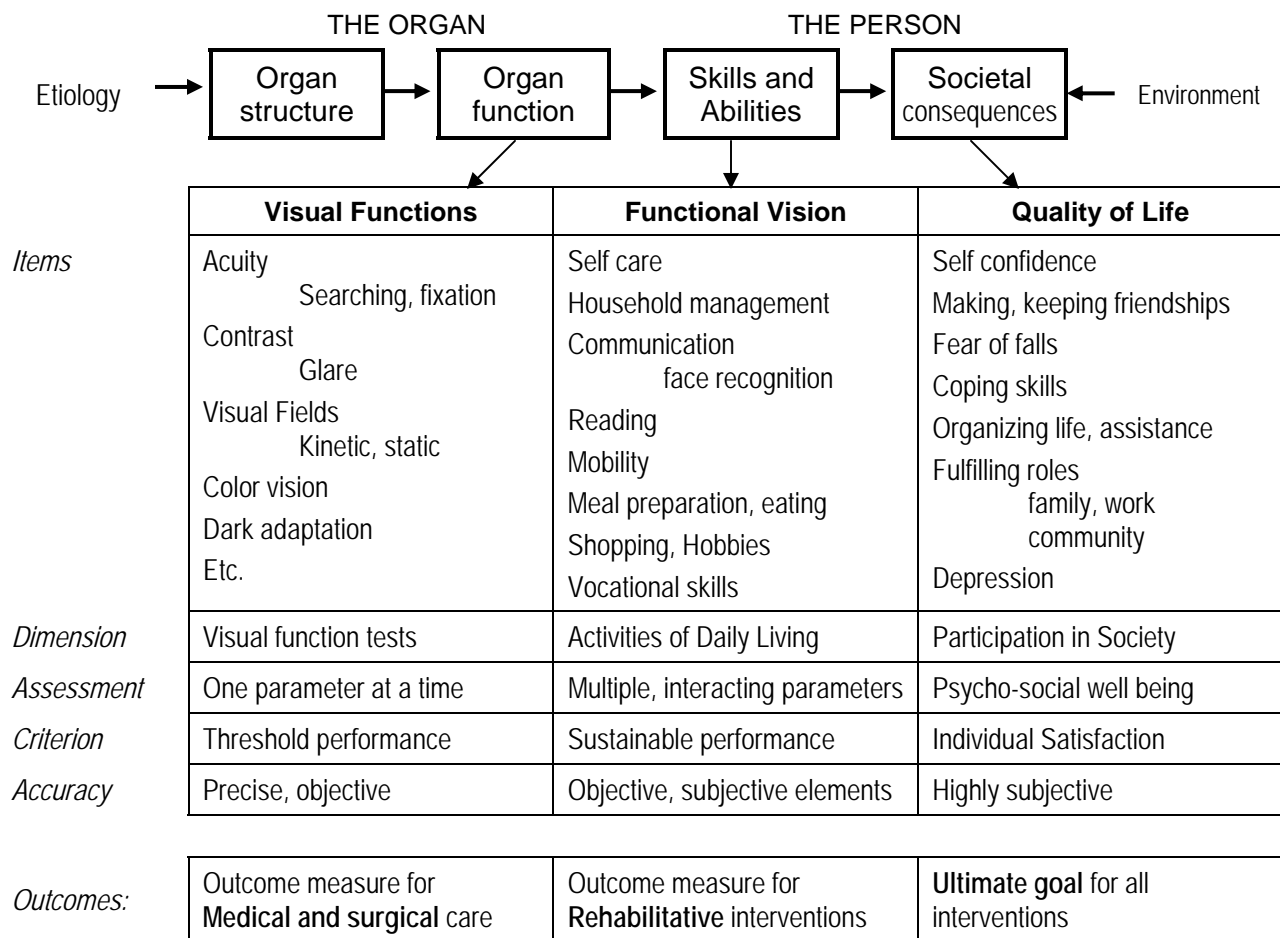
Assessment of Quality of Life essentially remains a subjective assessment. “Satisfaction” may be the best term to describe the balance between self-defined expectations and self-assessed performance. A farmer may feel lost in a big city; a city dweller may feel equally lost in a rural community. Both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

Table 3 lists items that can be assessed under each of the three aspects. The three lists are very different and require very different methods of assessment. 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. 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.

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.

For rehabilitation the column of visual skills in Table 1 is most important. The rehabilitation plan for any individual must consider factors to the left as well as to the right. They must be based not only on the mere presence of organ deficits on the left, but also consider the individual needs and the relevance of tasks and objectives on the right [11]. Based on these factors, individual goals must be set, against which the rehabilitative outcomes can be measured. As indicated in Table 1 and at the bottom of Table 3, rehabilitative outcomes require criteria that are different from those for medical or surgical outcomes.

Table 3 – **INVENTORIES** for different aspects



## APPLICATIONS of Functional Vision assessment

Assessment of Functional Vision can be used for different purposes.

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

Often these tests consider only visual functions, because the measurement of visual functions is easier, faster and often more objective than the assessment of functional vision. It should be realized, however, that while there may be a statistical correlation between visual functions and functional vision, individual performance may be better or worse than the statistical average. This is illustrated in Table 1a, taken from the 2006 ICO report on driving. This report recommended that driving license requirements should recognize a gray zone for borderline cases, where a test of on-the-road test performance should provide the ultimate basis for denying or awarding a, possibly restricted, driver’s license.

When determining disability benefits, visual function measurements (most often visual acuity) are often preferred, because they are more objective and more likely to show the same result from different examiners.

In **Medical and Surgical Outcome studies**, measures of visual functions, such as visual acuity, usually provide the *primary outcome measure*. They may be augmented with *secondary outcome measures* of vision-related skills and *tertiary outcome measures* of Quality of Life. Many questionnaires exist that focus on the results of cataract and refractive surgery. As the options in this field have increased, surgeons are increasingly realizing that patient satisfaction depends on more than letter chart acuity. Patient and procedure selection based on the patient's goals, objectives and personality is increasingly recommended.

The NEI-VFQ and similar questionnaires were developed to be less disease-specific, so that they can be used for a wider variety of conditions and interventions. Their broader scope may be an advantage when used as a tertiary outcome measure. For measuring specific outcomes, as prescribed in a rehabilitation plan, their global nature is a disadvantage.

**Vision Rehabilitation** is the area where better assessment of Functional Vision is the most urgent, since for vision rehabilitation outcomes the 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.

In this context three levels of questions can be distinguished.

One or two **very simple questions** are needed as part of each general eye exam to determine whether further exploration of rehabilitation issues is warranted.

If the initial answer is yes, then a **broader** list of **more detailed questions** is needed, to explore the patient's goals, problems and priorities. Based on these questions, an individual **rehabilitation plan** needs to be defined, with specific goals. Practical experience unfortunately shows that even in specialized rehabilitation services intake interview are often conducted 'by the seats of the pants', rather than in a structured way.

At the conclusion of the rehabilitation plan, the results need to be assessed with a list of **focused questions**, relating to the specified goals.

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 often still unsatisfactory. Yet the recent publication of what probably is the first randomized controlled study of the effectiveness of a specific vision rehabilitation protocol [<sup>12</sup>] gives hope for the future. This study showed dramatic effect size differences between the treated individuals and those on a waiting list; more details are discussed later.

## COMPREHENSIVE VISION REHABILITATION

The three aspects discussed so far are not the only factors important for comprehensive vision rehabilitation. While most 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 skills and to the environment. This is summarized in Table 4.

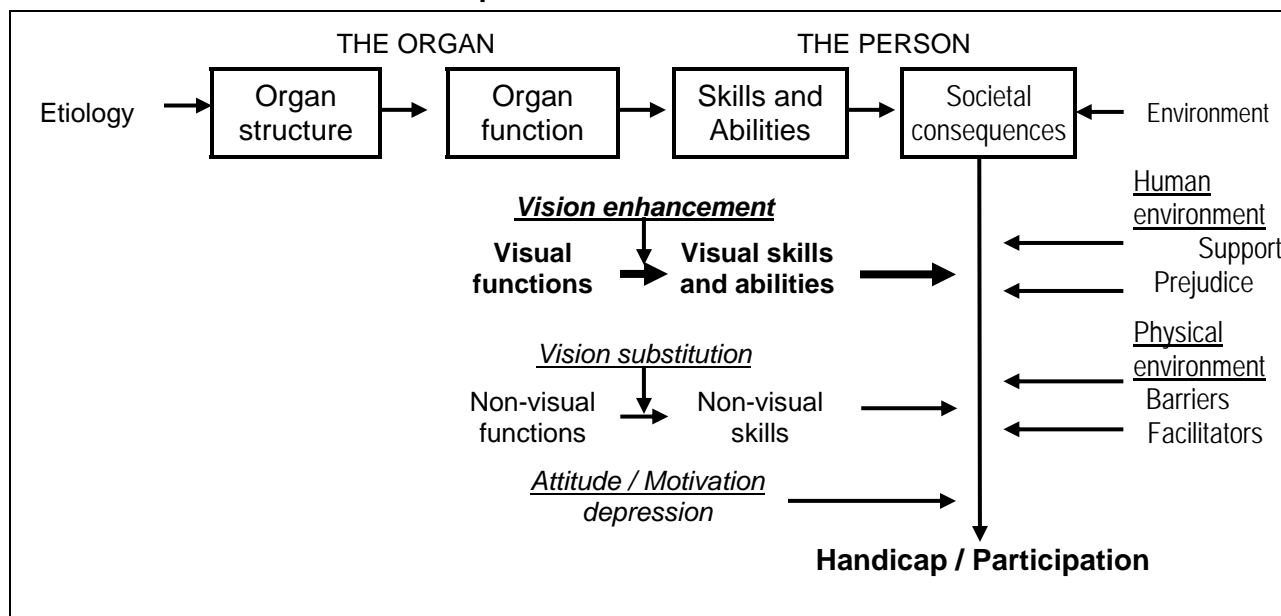
Low Vision *skills and devices* are important for vision enhancement. Sometimes, however, "*vision substitution*" skills need to be considered as well. Vision substitution refers to the use of non-visual functions, such as touch and hearing. A patient, who prefers a magnifier to read letters and bills, 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, whereas without visual aids that reduce the effects of the vision loss, the treatment of depression alone may not be effective either.

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.

Table 4 – **Comprehensive VISION REHABILITATION**



The physical environment can likewise provide barriers as well as facilitators. 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 computers 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.

## AVAILABLE TOOLS

Many tools exist to assess Visual Functions; they were 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 describes the **ability** to perform specific **activities**. These two aspects are inseparable. Mentioning ability without specifying the activity to which it refers is as meaningless as mentioning an activity without specifying whether or not a person has the ability to perform it.

The *International Classification of Impairments, Disabilities and Handicaps* [13] (ICIDH, WHO, 1980) focused on factors that cause the loss of abilities (dis-ability). This has been called the Medical Model of Disability. Its successor, the *International Classification of Functioning, Disability and Health* [14] (ICF, WHO, 2001) shifted the attention to the societal consequences of

functional losses. This is known as the Social Model of Disability. The two models are not contradictory, but rather complementary.

The **medical model** is important for individual health care; it views disability as a challenge for individual rehabilitation. Rehabilitation of hearing loss is different from rehabilitation of vision loss, although both may lead to social isolation; rehabilitation of peripheral vision loss is different from rehabilitation of central vision loss.

The **social model** is important for public health and health care policy, which are important domains for the WHO. It views disability as a social challenge. Where ICIDH mentioned handicap vs. independence, ICF mentions participation and interdependence. ICF added important categories for environmental factors. As a result, however, ICF is more focused on disability as a permanent condition, possibly as an entitlement, than on rehabilitation.

Vision rehabilitation clearly needs both points of view. ICF mentions reading, together with thinking and problem solving, as a subcategory of Applying Knowledge, which, of course, is the ultimate goal of most reading; in that context reading print and reading Braille are combined. ICF offers no differentiation for various resource modes, such as reading print, reading Braille or using talking books.

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

- **Observation** of actual performance.
- **Questionnaires** that ask individuals to rate their own performance.

The **observation** group is limited. Generally, the assessment of functional vision is less precise than that of visual functions.

Observation of **reading performance** is an obvious target. The MN-read test [<sup>15</sup>] and other tests with standardized sentences can be used to plot reading speed against print size. In addition to the print size threshold, one can thus determine how far above the size threshold an individual needs to be to read short paragraphs most effectively. The resulting critical print size is not always as sharply defined as the threshold. A European project [<sup>16</sup>] developed longer reading segments of standardized length in various languages. It thus provides a better measure of *sustainable* reading performance.

Returning to the aspects discussed earlier, we notice that there are different aspects to reading. Measurement of reading acuity and plotting of 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.

Observation of **simple, standardized tasks** in the office, not only provides a means for timing the performance, it can also give useful insight in the person's motivation and approach to problem solving.

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. As with reading speed, timed performance can often be used to get an objective measurement result [<sup>17</sup>]. Different individuals may react differently, however, to the trade-off between fast performance and a low error rate.

Self-report **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 [18] revealed that many lack proper psychometric validation. Rasch analysis, a statistical process based on item response theory, is slowly gaining broader acceptance to transform questionnaires and similar item lists to an interval scale, better suited to statistical analysis.

### Relevance of questions

The construction of the NEI-VFQ (the Visual Function Questionnaire of the National Eye Institute) [19] stimulated the development of many other instruments and legitimized their use. Since the NEI-VFQ was developed for use in the US, adaptations were made for use in other cultures [4]. In some cultures caring for an elderly parent may be considered an honor; in others it may be considered a burden. In some countries riding a bike is a recreational activity; in others it is a basic means of transportation.

A study by Stelmack et al [11] found that many items of the NEI-VFQ cannot be changed by rehabilitation. If such items are included when evaluating the result of an intervention, they will dilute the results and make it appear that the intervention was less effective.

Equally important is to ask not only about the ability to perform a task, but to also assess the need to perform that task. For a person living alone, cooking may be important; when the same person moves to a retirement home with prepared meals, cooking becomes far less important.

One problem is to find a compromise between questionnaires that are all-inclusive but too long and others that are short but do not cover all bases.

Massof et al developed an **Activity Inventory** [20,21 22] that lists 459 task in a tree structure under 50 goals and 3 objectives. The patient is first asked whether a certain group of activities presents problems and is important. If it presents no problems or is deemed unimportant, that entire branch is skipped. This allows asking each patient a limited number of individualized questions, without sacrificing comprehensive coverage. For instance, 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.

### Graded difficulty

When a school test, designed for third graders is presented to first graders, most will fail, because the items are too hard. For fifth graders, the same test will appear too easy. Therefore, different tests are needed for students of different ability levels. The same holds true when testing subjects with different levels of visual ability.

It is obvious that reading small print is harder than reading large print, but it is not obvious how to measure the difference on a consistent scale. This is where Rasch analysis can provide a solution.

**Rasch analysis** assumes that the subjective difficulty of an item reflects the difference between the objective difficulty of the item and the abilities of the individual. A specialized statistical analysis of many subjects answering many questions can then provide difficulty scores for each item correlated with ability scores for each individual.

It is desirable that the difficulty of the items be spread evenly. Several items of similar difficulty will overemphasize that difficulty level, but will not contribute to differentiation between subjects with better or worse ability.

As with the example of school grades, the difficulty of the items needs to match the abilities of the subjects. Subjects who have macular degeneration will generally have lesser abilities than those who have undergone modern cataract surgery. So, the many questionnaires designed for cataract patients may not be optimal for AMD patients.

**Verbal descriptors**

A further consideration is that not all subjects will use the same verbal descriptors. The ICF states that “activities and participation” codes are only meaningful if followed by a modifier to indicate the difficulty of performing that activity. Unfortunately, the ICF modifiers are only based on subjective descriptors, such as mild, moderate and severe difficulty. Although these descriptors are followed by percentage ratings, there is no indication of how such percentages should be calculated. More objective ratings would be desirable. Optimists may underestimate the difficulty they experience, pessimists may overemphasize it. It has been found, for instance, that the difference between mild and moderate difficulty is not statistically reliable and should not be included in the statistical analysis. This does not mean, however, that such a difference could not be used to prioritize goals among the answers of a single individual.

**Table 5 – GENERAL SCALES of FUNCTIONING, applied to VISION**

Impairment Ranges	Descriptors of Visual Performance			Functional Vision Score		ICF Difficulty ranges		Statistical use	
	2 ranges	3 ranges	6 ranges					Difficulty	Importance
	<i>Exceptional performance</i>				120	--		--	
Normal	Normal or near-normal visual functioning	Uses mainly Sighted techniques	Reserve for extra demands	Reference Standard	100	No difficulty	0 % – 4 %	Not difficult	Not important
Mild deficit			Can perform, lost reserve	Good	80	Mild difficulty	5 % – 24 %	Slight / moderate difficulty	Slightly / moderately / very important
Moderate deficit	Visual functioning restricted or impossible	Uses mainly Low Vision techniques	Needs help occasionally	Fair	60	Moderate difficulty	25 % – 49 %		
Severe deficit			Needs help frequently	Poor	40	Severe difficulty	50 % – 95 %		
Profound deficit		Uses mainly Blind techniques	Marginal functioning	Marginal	20	Complete difficulty	95 % – 100 %	Impossible	
Total deficit			Can't function visually.	Can't	0				

Note the difference between an ability score (0 = no ability) and a difficulty / disability score (0 = no loss). The ability score can be extended beyond 100 for exceptional performance.

The Functional Vision Score in Table 5 was used in the 1999 ISLRR and the 2002 ICO report, and can be adapted for any function. It is used for the percentage calculations in the vision chapter of the 5<sup>th</sup> and 6<sup>th</sup> revision of the *AMA Guides to the Evaluation of Permanent Impairment* [23], where it replaced an earlier scale based on employability estimates in 1925. It has been found to correlate well with other functional vision measures [24]. Many scales, including the ICF scale and the AMA scales for functions other than vision, do not differentiate between

severe and profound deficits. For disability benefits and similar applications, this distinction may not be very important. For rehabilitation it is important, since it represents the range where rehabilitation gradually shifts from enhancement of residual vision to reliance on vision substitution.

**One example – The LOVIT study**

The recently reported Low Vision Intervention Trial (LOVIT) [12], provides the first example of a study that rigorously adhered to the principles outlined above.

- It was a multi center study of a well defined rehabilitation protocol, conducted by the Department of Veterans Affairs.
- It compared treatment to randomized controls that were placed on a 4 month waiting list (the usual VA waiting time).
- Evaluation used Rasch validated questionnaires.
- Evaluation was done by telephone interviewers, who were masked as to whether they were interviewing a treated or an untreated subject.
- The interviews were done after 4 months, well after the end of the approximately 5 week rehabilitation period. This approach emphasizes longer term effects.
- The results showed impressive treatment effects, as show in Table 6.

**Table 6 – Effect sizes in the LOVIT study**

Outcome	controls	treated	Effect size
<b>Visual reading</b>	-0.37		+2.40
Vision overall	-0.20		+1.67
Visual motor skills	-0.04		+1.71
Information processing	-0.20		+1.38
Mobility	-0.27		+0.66

Stelmack et al – Arch. Ophth., May 2008

The effect size was greatest for visual reading, which was the objective of the protocol. There was a spillover effect on vision overall, visual motor skills and visual information processing. There even was a small effect for mobility, which was not a rehabilitation objective. This demonstrates that effects that are not directly related to the rehabilitation objective should not be used to judge the effectiveness of the intervention.

That there was a small but demonstrable deterioration among the waitlisted controls is an argument to start vision rehabilitation early, as soon as the need has been established.

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