



## Background

Persons with a visual impairment experience more difficulty performing activities of daily living without help,<sup>1-4</sup> experience more restrictions in participation in society,<sup>5-7</sup> and have a higher prevalence of loneliness,<sup>8;9</sup> depression<sup>10-13</sup> and emotional distress.<sup>14</sup> In line with this, many studies showed that visually impaired people have a lower quality of life.<sup>3;15-17</sup> In order to improve their quality of life, Multidisciplinary Rehabilitation Centers (MRC) in the Netherlands try to help visually impaired persons overcome their visual disability. However, due to an increasing number of patients with visual impairment and rising medical costs, the need for more efficient, transparent and evidence-based care is also rising. An important reason to conduct the study described in this thesis was that the MRCs realized that the rehabilitation needs of their patients were not being investigated in a structured way. Consequently, it was not clear to them whether rehabilitation services provided the most appropriate care to serve the individual needs of each patient. Moreover, as there was no systematic assessment of needs directly after enrolment, a systematic evaluation of these needs was problematic. This implied that little was known about the effects of rehabilitation, which is in line with international studies on this topic.<sup>18</sup> Available studies in the Netherlands measured rehabilitation outcome using different vision-related quality of life scales.<sup>19-21</sup> However, these instruments focus on specific topics and are probably not applicable to every individual.

Therefore, the aim of the work presented in this thesis was to develop a valid, reliable and feasible tool to investigate and evaluate rehabilitation needs of visually impaired persons. This tool is a Dutch version of Massof's Activity Inventory (AI) nested in the International Classification of Functioning, Disability and Health (ICF): called the 'D-AI'. In addition, the content of rehabilitation and the longitudinal outcomes in a Dutch MRC were observed from enrolment up to 4 and 12 months later.

This chapter summarizes the developmental process of the D-AI; an overview of the content of the D-AI is presented in Table 1.

Table 1. Overview of the developmental phases of the Dutch ICF Activity Inventory.

|   | Objectives/<br>Domains | Goals<br>(+sub-<br>goals) | Task<br>(+sub-<br>task) | Response<br>options                          | Routing<br>structure  | Remarks  |
|---|------------------------|---------------------------|-------------------------|--|---|--|
| <b>Massof's<br/>Activity<br/>Inventory*</b> | 3                      | 50                        | 464                     | GI: 0-3<br>GD: 0-4/n.a.<br>TD: 0-4/n.a.      | GI: all<br>GD: if GI $\geq$ 1<br>TD: if GD $\geq$ 1                     | Used as input for<br>development of the D-AI   |
| <b>Research<br/>draft 1<br/>D-AI</b>        | 10                     | 68<br>(+47)               | 813<br>(+97)            | GI: 0-3<br>GD: 0-4/n.a.<br>TD: 0-4/n.a.      | GI: all<br>GD: if GI $\geq$ 1<br>TD: if GD $\geq$ 1                     | Based on input from focus<br>groups, literature study,<br>patient files and additional<br>feedback   |
| <b>Research<br/>draft 2<br/>D-AI</b>        | 10                     | 65<br>(+26)               | 842<br>(+112)           | GI: 0-3/n.a.<br>GD: 0-4/n.a.<br>TD: 0-4/n.a. | GI: all<br>GD: if GI $\geq$ 1<br>TD: if in TPL-15                       | Based on pilot study<br>(evaluation of feasibility,<br>and comparing results to<br>usual intake in patient<br>files)   |
| <b>Current<br/>D-AI</b>                     | 10                     | 48<br>(+7)                | 467<br>(+51)            | GI: 0-3/n.a.<br>GD: 0-4/n.a.<br>TD: 0-4/n.a. | GI: all<br>GD: if GI $\geq$ 1<br>TD: after 'shared-<br>decision making' | Based on baseline<br>analyses (descriptive<br>statistics, test-retest<br>reliability, factor analyses,<br>internal consistency, and<br>consensus-based<br>discussions) |

\*Personal correspondence (Massof, 2006); ICF: International Classification of Functioning, Disability and Health; GI: Goal Importance scores; GD: Goal Difficulty scores; TD: Task Difficulty scores; n.a.: 'not applicable'; TPL-15: Top-15 Priority List (containing all goals with a top-15 priority score).

## Developing a first draft

### Basis of the new questionnaire

Several steps were taken to develop an assessment tool that investigates and evaluates rehabilitation needs for visually impaired persons from the patient's perspective. The basic concept for this new assessment tool was the 'Activity Inventory' (AI). The AI has a hierarchical structure in which 'tasks' (specific cognitive and motor activities) that serve a common purpose are nested under umbrella 'goals'. The self-reported importance of goals and (for goals of at least some importance) self-reported difficulty of goals is rated. Next, the self-reported difficulty of tasks underlying relevant goals is rated. The AI was initially developed in the USA. Therefore, as described in **Chapter 2**, the first step in the developmental process of the D-AI was to translate the original AI into Dutch. As expected<sup>22</sup> substantial cross-cultural differences became apparent, as several items in the original AI were not applicable to the Dutch situation and some relevant items were missing. Thus, to develop a Dutch version of the AI, the content of the AI needed a thorough review.

### **Identifying the content of the items**

The next step in the developmental process of the D-AI was to collect a useful set of items emerging from focus group discussions with visually impaired persons and with rehabilitation experts.

**Chapter 2** describes how the content of (a first draft of) the D-AI was created. For this purpose, focus group discussions were organized. Six focus groups were formed with a total of 41 visually impaired people and seven focus groups with a total of 50 rehabilitation professionals (experts), to further explore the field of patients' visual rehabilitation from different stakeholders' perspectives. The input contributed to the first draft of the D-AI. Additional data were collected by means of screening patient files, attending home visits, visiting the information department and studying literature, to reveal (further) undetected rehabilitation needs. Subsequently, a first draft of the D-AI was created. Activities that served a common purpose were pooled together and nested under the goal that they served.

### **Structuring the content of the D-AI**

The use and value of the ICF in rehabilitation medicine has been extensively discussed in literature.<sup>23;24</sup> Moreover, MRCs in the Netherlands expressed their interest in using the ICF to better understand and communicate about the needs of their patients, starting with an assessment during the intake phase. Therefore, all goals were organized into the "Activities and Participation" domains of the ICF. Generally speaking this did not result in any difficulties. However, categorization of the goals 'Feeling fit', 'Handle feelings' and 'Acceptance' led to some discussion. It was decided that these goals were not categorized by the domain 'General tasks and demands', which includes the topic 'Handling stress and other psychological demands (other specified/unspecified)' (d2408/d2409). This ICF item focused primarily on stress, which did not properly reflect the items of the D-AI. Moreover, it was preferred to mention the goals 'Feeling fit', 'Handle feelings' and 'Acceptance' in the last part of the questionnaire because of the emotional impact these questions may have on the patient. Therefore, a 10<sup>th</sup> domain (which is not covered by the "Activities and Participation" domains of the ICF) "Coping with mental (emotional) health aspects" was added to the D-AI.

Compared to the original AI, considerable modifications were made. The content of the D-AI was extended, resulting in a much more detailed assessment tool, covering a broad range of possible rehabilitation needs. A result of this expansion, and the fact that activities pooled together were nested under the goal that they served, was that the exact categorization of tasks underneath goals was not necessarily the same as in the original AI. For example, in the

original AI, the mobility item “arrange (and use) transportation to...” was only present as a task underneath several goals. In the D-AI, mobility issues are brought together under several goals such as “riding a bike” or “using public transportation” and nested under the “Mobility” domain (d4). These goals are now built-up by specifying very detailed tasks, e.g., “buying a ticket at the ticket machine” and “recognizing the right stop.” However, the item “getting at the site” is still present as an activity of various goals. Other examples of new goals (including more detailed underlying tasks) in the D-AI are ‘Watching TV’, ‘Reading’, ‘Writing’, and goals related to education or vocation, and to the ICF domain “Interpersonal interactions and relationships” (e.g., goal “Interaction with strangers”). In addition, some hobby-related goals such as “hunt and shoot” and “leatherwork” from the original AI were left out of the D-AI because the patient files and focus groups revealed that these hobbies were uncommon in the Netherlands.

### **Using feedback for further improvements**

For each item a question was formulated and, subsequently, the new D-AI was sent to experts working at MRCs who were asked to review (a specific part of) the D-AI with regard to the content, the classification and the formulation. Each domain was reviewed by at least three experts. In addition, a professional in the ICF specifically evaluated the classification of the ICF domains. A final revision resulted in a ‘research draft’ of the D-AI which consisted of 68 goals and 813 tasks (available from the authors). In addition, as described in **Chapter 2**, five goals were built up by sub-goals (n=47), including sub-tasks (n=97). These sub-goals are specific and personal hobbies such as “going to the cinema”.

### **Pilot and feasibility study**

**Chapter 3** describes how the content of the newly developed D-AI was evaluated in a limited pilot study. To further improve the face and content validity of the D-AI it was evaluated whether the most relevant topics were included, and whether all questions and response options were clear and satisfactory. For this purpose, 20 patients and 3 assessors (professionals usually involved in the intake process at the MRC) were asked about their perceptions of and experiences with the D-AI using a computer-assisted telephone interview. In **Chapter 4**, the patient files of the same participants were studied in more detail to examine to what extent the rehabilitation needs identified by the usual intake without the D-AI in the MRCs in the Netherlands (derived from the patient files) differed from the needs identified by the structured intake using the D-AI. This information was used to further revise the D-AI and to provide better insight into the use of the D-AI.

A feasibility study (**Chapter 3**) revealed that no topics had been overlooked. Patients and assessors found no need to include any additional items. However, they felt that some questions needed rephrasing to improve their clarity. In addition, some minor adaptations were made to the content of the D-AI. Based on the findings in **Chapter 3**, it was also concluded that the D-AI had some important positive qualities, e.g., the assessors indicated that they found the D-AI to be a practical instrument, a more objective way to assess rehabilitation needs, and that it makes the intake less dependent on the individual qualities of the intaker. In addition, most patients were positive about the interview and its assessment by telephone.

Some recommendations were made based on the evaluations. The pilot study revealed that the response option for the importance question did not always represent how the patient felt about a topic. For example, the goal 'household tasks' was often described as 'not applicable' because the participant had a housekeeper'. Therefore, patients reported that 'not important' did not in fact reflect their feelings/response. Based on these results, the answer category 'not applicable' was added for answer options for the question on goal importance. Another important result was that patients and assessors indicated that the D-AI interview was too long. Therefore, it was decided to apply a new routing structure for the start of a larger validation study; only a selection of goals with relatively high priority scores would be fully assessed at the task level. This was expected to further increase feasibility and decrease the administration time.

In **Chapter 4**, patient files of participants in the feasibility study were studied more thoroughly. This allowed to investigate to what extent the rehabilitation needs identified by the usual intake without the D-AI in the MRCs in the Netherlands (derived from the patient files) differed from the needs identified by the structured intake using the D-AI. Overall observed agreement between both intake methods was 73.0% (range for separate goals: [0 – 100%]) and the overall analyses revealed only a fair Cohen's kappa of 0.27 (range for separate goals [-0.09 – 1.00]). Furthermore, patient files revealed that no rehabilitation needs were missing as responses in the D-AI. The mean number of rehabilitation needs (goals) identified in the patient files was 6.9 (standard deviation (SD)=5.1) versus 24.0 (SD=11.2) after assessing the D-AI. If (hypothetically) the D-AI was considered to be the gold standard, only 22.6% (SD=14.3) of the rehabilitation needs could be identified in the patient files. In contrast, if the content of the patient files was (hypothetically) considered to be the gold standard, 79.3% (SD=28.2) of the rehabilitation needs was identified by the D-AI. All goals that were (at least once) missed by the D-AI were further analyzed to uncover the reason why they were missed and to improve the D-AI if necessary (e.g.,

adaptations in formulation). It is also noteworthy that only 43.4% of the rehabilitation needs that emerged during the entire rehabilitation trajectory was recognized in the first phase of the usual intake (telephone interview and visual functioning examination). This indicates that many rehabilitation needs were identified during the course of rehabilitation, which raises the question whether all rehabilitation needs were in fact identified by the end of the rehabilitation program. This supports the opinion of the MRCs that a systematic approach (such as provided by the D-AI) is needed. Moreover, looking at the patient files, the first item to be reported as a problem was often “reading”. However, the individual priority lists showed that other goals may be equally and/or more important and difficult. When investigating rehabilitation needs, it seems that patients and/or rehabilitation professionals (e.g., intakers) may tend to focus on some specific topics. As rehabilitation aims to improve quality of life of the patient, it is important to have an unbiased overview of the needs of the patient from his/her own perspective. Therefore, it was concluded that the more structured and standardized assessment from the patient’s perspective is expected to provide more valid information.

## **Larger validation study**

As the content of the D-AI had substantially increased the assessment time, the number of items in the D-AI had to be reduced by selecting the most relevant and discriminating items so that MRC would be able to use the D-AI in clinical practice. Moreover, for a better interpretation of the scores, it was necessary to establish the underlying dimensions of the new D-AI. In addition, MRCs wanted to have a better insight into the rehabilitation needs of patients right after enrolment and during the course of rehabilitation. Therefore, a larger validation study was started by assessing the D-AI before the start of rehabilitation, as well as at 4 and 12 months later.

### **Baseline measurements**

For the large validation study, an updated version of the D-AI was created based on the results of the pilot study (**Chapter 3** and **Chapter 4**). This updated version (available from the authors) of the D-AI consisted of 65 umbrella goals (plus 26 sub-goals) and 842 tasks (plus 112 tasks underlying sub-goals, plus 5 open-ended questions). The D-AI was assessed in two parts (**Chapter 5**). In the first part of the D-AI (D-AI-1), the goal importance (rated on a scale from “not important” (0) to “very important” (3), or “not applicable” (missing)) and (if goal importance >0) the goal difficulty (rated on a scale from “not difficult” (0) to “impossible” (4), or “not applicable” (missing)) of all goals was assessed. The

priority score was calculated automatically by the computer program by multiplying the importance and difficulty scores so that all goals could be ranked from the highest to the lowest priority to create an individual top-priority list. For feasibility reasons, in the second part of the D-AI (D-AI-2), only tasks nested under goals that had the same as or a higher priority score than the fifteenth goal of the priority list were assessed. Patients were recruited directly after enrolment at the MRC; of these, 241 patients completed the baseline measurement.

#### *Investigating rehabilitation needs*

**Chapter 8** provides insight into which goals had the highest scores on importance, difficulty and priority for the total study population and for several subgroups. It appeared that immediately after enrolment, 'Reading', 'Writing', 'Acceptance', 'Watching TV', 'Feeling fit', 'Personal correspondence', 'Handle feelings', 'Regulatory and information', 'Mobility outdoors' and 'Mobility indoors' had the (top 10) highest priority scores. Moreover, the results revealed that different subgroups had different priorities. This information may be useful for, e.g., policymakers and researchers.

#### *Examination of item characteristics/descriptive statistics*

**Chapter 5** presents some descriptive statistics. Frequencies of the missing data for all items were calculated. Moreover, other descriptive statistics (e.g., floor and ceiling effects) were analyzed and considered for item reduction. Results of these analyses were used as input for consensus-based discussions to further improve the questionnaire. Removal of items was considered if there was a relatively high number of missing values (i.e., >50%) or floor and ceiling effects (i.e., >15% of the respondents achieved the highest or lowest possible score); however, usually there was a combination of reasons behind the consensus-based decision to remove items from the D-AI.

#### *Factor structure of goals*

**Chapter 5** also aimed to elucidate the underlying factor structure of the goals in the D-AI and to produce a shorter version of the D-AI. For goals that were fully assessed at the task level by at least 80 participants (i.e., for 14 goals), Exploratory Factor Analyses (EFAs) were performed at the task level for that specific goal. In this developmental phase of the D-AI, it was expected that EFAs in this relatively small study population would provide enough information to make a first shift to reduce the number of items and to identify the global factor structure of the tasks underlying each goal. Once a factor structure was hypothesized, additionally, confirmatory factor analyses (CFA) were performed

for the same samples to remove redundant items. Once the descriptive measures of model fit were optimized by deleting items, another EFA was performed for the scale's final form. Using CFAs it was possible to detect item pairs which measured a similar concept in order to select the best item.

Except for one goal, factor analysis model parameters were at least reasonable (**Chapter 5**). The underlying factor structure (based on shared traits/visual functions) provides more detailed information on the kind of rehabilitation needed. For example, the goal "Daily shopping" revealed three different factors: "find your way", "find the right product", and "reading involved with shopping". It is possible that a participant indicates that tasks within the factor "find your way" are easier than tasks underlying the factor "reading involved with shopping". In this case, prescribing optical aids would probably be more appropriate than mobility training to be able to achieve the umbrella goal of "Daily shopping".

#### *Internal consistency of tasks underlying goals*

As a measure of internal consistency, in **Chapter 5** Cronbach's alpha's were calculated. Many participants responded with the response category "not applicable", so missing data were imputed for participants if at least 50% of the items in the (sub-)scale was available. Only for goals that were fully assessed at the task level by at least 80 participants was the unidimensionality determined beforehand, thereby providing an interpretable meaning. For task scales with  $n \geq 80$ , Cronbach's alpha ranged from 0.74 to 0.93, suggesting a sufficient to high internal consistency (**Chapter 5**).

#### *Test-retest reliability*

**Chapter 5** also shows how test-retest reliability was investigated for the goals of the D-AI (version with 65 goals and 842 tasks) on a sub-sample of 25 patients who completed the D-AI-1 (at the goal level) a second time 2-4 weeks after the first assessment by the same interviewer. During this period, visual ability had to be (subjectively) unchanged. Due to the routing structure of the D-AI, goal difficulty questions were not always assessed at both test moments. Observed agreement (% , not corrected for chance) and Cohen's kappa values for goal importance questions were determined, and for goal difficulty questions, observed agreement and weighted Cohen's kappa values were calculated if test-retest data for at least 10 participants were available. Test-retest reliability was used to further improve the content and wordings of the D-AI if (weighted) kappa  $< 0.4$  and (simultaneously) the observed agreement  $< 75\%$ , or if the feedback of patients or assessors indicated to do so. As can be seen in **Chapter 5**, for most

goals the Cohen's (weighed) kappa for goal importance and difficulty was moderate to almost perfect. For the newly developed D-AI, the exact formulation of 23 (48%) goals (plus 4 sub-goals) was (slightly) rephrased.

#### *Consensus-based adaptations*

Based on the results of the above analyses and feedback from patients and assessors, consensus-based adaptations were made to the questionnaire. In general, several reasons contributed to a consensus-based decision to release items from the D-AI. The new, shorter D-AI which was produced retains the nine "Activity and Participation" domains of the ICF and one additional domain called "Coping with mental (emotional) health aspects", together with 48 goals, 7 sub-goals and 467 tasks with 51 sub-tasks. An overview of the goals in the new D-AI is shown in **Chapter 5** (the new Dutch formulations can be obtained from the authors). An English-language version was presented in Appendix 1 of **Chapter 5**, but this is not an official forward-backward translation).

#### **Longitudinal measurements**

Another important aim of the study was to evaluate the content of rehabilitation and the longitudinal outcomes in relation to rehabilitation programs followed in Dutch MRCs. With regard to the new questionnaire used in the observational study (i.e., the D-AI), attention was paid to the (longitudinal) interpretation of the D-AI. Therefore, in **Chapter 6** and **Chapter 7** rehabilitation needs were investigated immediately after enrolment (baseline, n=241) and again at 4 (n=219) and 12 (n=207) months later. These studies focused on the goals in the two domains with the highest priority scores: 'Learning and applying knowledge' (**Chapter 6**) and 'Coping with mental (emotional) health aspects' (**Chapter 7**). Linear mixed models were used to determine longitudinal rehabilitation outcomes for these goals and underlying tasks, corrected for possible confounders.

#### *Longitudinal measurements in two domains*

**Chapter 6** describes how rehabilitation needs for the goals and underlying task (sub)scales in the domain 'Learning and applying knowledge' of the D-AI (i.e., 'Reading', 'Writing', and 'Watching TV') changed over time. As some variables are known (or assumed) to influence visual functioning and/or longitudinal rehabilitation outcomes, these potential confounders were added to the linear models. Although the difficulty scores decreased over time, the differences were not significant at each measurement moment. Based on the interventions applied (e.g., prescribing optical aids) it seems reasonable to conclude that the decrease in perceived difficulty is the effect of rehabilitation. However, based on the current

study design, it is uncertain whether the rehabilitation did in fact cause the improvement.

**Chapter 7** describes the longitudinal outcomes of the goals 'Handle feelings', 'Acceptance', and 'Feeling fit' nested under the domain 'Coping with mental (emotional) health aspects'. After correcting for confounding variables, none of the underlying task difficulty scales changed over time. For goal difficulty scores, only 'Acceptance' was reported to be significantly less difficult at 4 and 12 months follow-up.

In contrast to difficulty scores of goals, importance scores of the goals in these domains did not change over time. It seems that opinions concerning what is of value for a particular patient remains relatively stable over time. This raises the question whether 'importance' is a useful evaluation variable, at least for the goals in domains 1 and 10 (**Chapter 6** and **Chapter 7**, respectively).

### **Implementing and using the D-AI**

Based on the results of the study, Royal Dutch Visio and Bartiméus decided to further implement the D-AI as part of their usual intake procedure (as described in **Chapter 8**). Both MRCs built an application (available via intranet) and started an implementation trajectory for the D-AI. Preliminary implementation results indicate that the concept of the D-AI is highly promising for investigating and evaluating a patient's rehabilitation needs in a clinical rehabilitation setting.

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