REPORT BY THE ADVISORY BOARD TO REVIEW THE

DEFINITION OF THE NEED FOR LONG-TERM CARE

26 January 2009
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2. *Das neue Begutachtungsassessment zur Feststellung von Pflegebedürftigkeit, Abschlussbericht Hauptphase 1* (The New Assessment Procedure for Determining the Need for Long-term Care, Final Report on the First Main Phase), Institute for Nursing Sciences at the University of Bielefeld, Medical Advisory Service of the Health Insurance Funds of Westphalia-Lippe (*Medizinischer Dienst der Krankenversicherung Westfalen-Lippe*), Authors: Dr. Klaus Wingenfeld, Dr. Andreas Büscher, Dr. Barbara Gansweid, Bielefeld/Münster, 25 March 2008


*) Available only in German on:

www.bmg.bund.de/cln_179/nn_1376632/SharedDocs/Standardartikel/DE/AZ/P/Glossarbe

griff-Pflegebed_C3_BCrftigkeitsbegriff.html
5. **Möglichkeiten der Berücksichtigung von RAI 2.0 und/oder RAI HC bei der Erarbeitung eines zukünftigen Begutachtungsinstruments** (Options for Considering RAI 2.0 and/or RAI HC in Developing an Assessment Instrument for the Future), expert opinion prepared within the context of the pilot project conducted by the Central Association of the Health Insurance Funds: **Maßnahmen zur Schaffung eines neuen reliablen Begutachtungsinstruments zur Feststellung der Pflegebedürftigkeit nach dem SGB XI** (Measures to Create a New Reliable Assessment Instrument to Determine the Need for Long-term Care according to Book Eleven of the Social Code), Alice Salomon Hochschule Berlin, Authors: Prof. Dr. Vjenka Garms-Homolová in cooperation with Diplom-Psychologin Katrin Theiss, November 2007.
Preliminary Remarks by the Chairman of the Advisory Board

The Advisory Board to Review the Definition of the Need for Long-term Care submits its final report with a proposal for a new definition of the need for long-term care and corresponding assessment procedure for determining the need for long-term care. The final report was unanimously approved at a meeting of the Advisory Board on 26 January 2009. Its most important goal is improving and changing the situations of people requiring long-term care whose independence is impaired.

The results illustrate options that policymakers can make use of in taking action to further develop long-term care. At the same time, they also provide a basis for well-informed social discourse on a topic of central importance for the future: quality-assured, dignified, long-term care and support for people who require assistance, which corresponds with their personal needs. The result of the Advisory Board’s work, the new definition of the need for long-term care, reflects a paradigm shift.

With the study on the implementation that has been requested by the Federal Ministry of Health, the Advisory Board will provide additional instruments and procedures for the implementation of the proposals subsequent to the report. The results thus far confirm the expectation that a new way of seeing people in need of long-term care and better long-term care can become reality.

The Advisory Board was able to work in a constructive climate of good faith and mutual respect, which benefitted its work greatly. I would like to thank all of the members of the Advisory Board for their goal-oriented cooperation in open, courteous discussions in which recognisable efforts were made to shape proposal with positive prospects for future success that could be supported by all. An important contribution was made in this context by the study completed by the Institute for Nursing Science of the University of Bielefeld (Dr. Wingenfeld and Dr. Büscher) and the Institute for Public Health and Nursing Research at the University of Bremen (Prof. Görres), along with the work done by the Medical Advisory Service of the Central Federal Association of Health Insurance Funds (Prof. Windeler) and the Medical Advisory Service of the Health Insurance Funds of Westphalia-Lippe (Dr. Gansweid and Dr.
Heine), as well as the Center for Social Policy of the University of Bremen (Prof. Rothgang). The working group under the direction of Prof. Udsching, which presented a proposal for a revision of the legal provisions of Section 14 and 15 of the SGB XI, should also be mentioned. Without this work, the development and testing of a new assessment instrument would not have been possible.

Special thanks go to the members of the editorial group (chaired by Dr. h.c. Jürgen Gohde) Klaus Dumeier, Prof. Gabriele Kuhn-Zuber, Gert Nachtigal, Prof. Peter Udsching and Dr. Irene Vorholz.

Thanks are also due to the members and the chairman of the pilot project’s Steering Committee, Paul Jürgen Schiffer and Klaus Dumeier, the members of the Presidium Sabine Jansen, Prof. Peter Udsching and K.-Dieter Voß.

Christine Wilcken took great care in editing the final report and oversaw its publication. I would like to thank her sincerely for the support she provided for the Advisory Board’s work.

Dr. h.c. Jürgen Gohde
Introduction: Task and Objective

In this report, the Advisory Board to Review the Definition of the Need for Long-term Care presents the results of its deliberations on the establishment of a new definition of the need for long-term care and of a new, reliable, and nationally uniform assessment instrument for determining the need for long-term care according to the Social Code Book XI (Sozialgesetzbuch XI; Ger. abbr. = SGB XI).

Point of Departure

The definition of the need for long-term care according to the SGB XI and the procedure for assessing the need for long-term care based on this definition have been subject to critical discussion since long-term care insurance was first introduced. One of the main criticisms is related to the fact that the definition of the need for long-term care in the SGB XI is too narrow, focuses too much on performed activities of daily living, and has a somatic bias. Consequently, essential aspects, such as communication and social participation, are overlooked, and the need for general care, supervision, and guidance by persons with limited competence in everyday activities is not given sufficient consideration. One result of this tendency to overlook other problems and needs is the growing number of persons suffering from limited competence in everyday activities due to dementia or some other cause not receiving adequate support through the benefits of the long-term care insurance. On the contrary, the definition of the need for long-term care according to the SGB XI (Section 14, SGB XI), as it now stands, is responsible for considerable deficits in the care of this group of persons.

People suffering from dementia who require long-term care in the sense of the SGB XI, and who have been classified in one of the levels of care between levels I and III, receive the same benefits from long-term care insurance as other insured persons do. However, not everyone suffering from dementia is in need of care in the sense of the law governing long-term care insurance on grounds of this condition alone.

In determining the need for long-term care, the assistance required by people suffering from dementia is now taken into consideration mainly by referring to help in the form of “guid-
ance”, “supervision” and “support” (cf. Section 14 paragraph 3 SGB XI). Additional, more
general needs for supervision and care (where there is a tendency to wander off, endanger
one’s self or others, fear, delusions, aggression) are not covered. This is generally considered
unjust, since the need for general supervision and care regularly puts a great burden on family
members, and those affected are often unable to comprehend why these special needs have,
up until now, only been given isolated consideration in long-term care insurance law in com-
parison to basic care and housekeeping.

Other aspects of the present procedure to determine the need for long-term care have also
been subject to criticism, for example the rules to determine the need for long-term care of
children, which are still not considered satisfactory, despite isolated attempts at optimisation
within the context of the last revision of the assessment regulations.

Against this background, it was determined in the coalition agreement dated 11 November
2005 that preparations should be made, mid-term, to revise the definition of the need for long-
term care.¹ The first concrete steps towards such a revision were taken when the Federal Min-
istry of Health resolved to create a new definition of the need for long-term care along with a
new, reliable, and nationally uniform assessment instrument for determining the need for
long-term care according to the SGB XI, and, consequently, to establish an Advisory Board to
review the definition of the need for long-term care.

In the view of the Federal Ministry of Health, the complexity of the task made it impossible to
establish a new definition of the need for long-term care and a corresponding assessment pro-
cEDURE within the context of the Long-term Care Further Development Act of July 2008.² It
would only be possible to consider decisions concerning the introduction of a new definition
of the need for long-term care on the basis of sound findings in the field of nursing science. In
addition, the effects of the most recent reform in long-term care insurance were also to be
taken into consideration.

¹ Coalition Agreement of 11 November 2005, Chapt. 9.2., line 4519 (p. 92).
² Letter from State Secretary Dr. Schröder, Federal Ministry of Health, dated 5 October 2006.
**Task and Objective**

The Federal Ministry of Health commissioned the Advisory Board to draft concrete and scientifically sound proposals and options for action as a basis for future decisions concerning changes in the current definition of the need for long-term care and the corresponding assessment procedure. In this context their financial effects on long-term care insurance and/or other areas of social benefits were to be subject to specific clarification.

The importance and practical application of the definition of the need for long-term care is closely related to the assessment procedure used to determine the need for long-term care and provides the basic framework for it. Hence, the development of a new definition of the need for long-term care and a corresponding New Assessment Procedure had to be closely coordinated. Correspondingly, its ability to be implemented in conjunction with a nationally uniform assessment instrument had to be examined and tested beforehand, taking alternative definitions of the need for long-term care into consideration, while at the same time revising the new assessment instrument. Before legislators can make a decision concerning a change in the valid definition of the need for long-term care and the corresponding evaluation procedure, options for taking action must be identified and tested.

The point of departure for developing a new definition of the need for long-term care should be a broader concept of long-term care than is currently found in the SGB XI. The recommendation to create a broader definition of long-term care for all social funding agencies, in order to take the requirements for help and support in various areas of social benefits into account comprehensively, which was made by a working group of the Federal Committee on Long-term Care in 2002, was also included in the discussion. The need for activation, supervision, and care related to areas of life beyond performed activities of daily living, in the sense of Section 14 SGB XI, as well as the need for medical nursing care, the ability to communicate, and the need for social support should be encompassed by the definition of the need long-term care. Starting from this point, only the needs for assistance that can be realistically

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3  *Recherche und Analyse von Pflegebedürftigkeitsbegriffen und Einschätzungsinstrumentarien*, Institute for Nursing Science at the University of Universität Bielefeld (Wingenfeld, Büscher, Schaeffer), 23 March 2007, p. 32.
addressed in laws related to benefits and services should be included in the development of a new definition of the need for long-term care.⁴

Within the framework of the assessment procedure that was to be developed parallel to the expanded definition of the need for long-term care, it was a question of developing and testing a new model for an assessment instrument that was not yet prescribed by the legislative, while at the same time taking an alternative definition of the need for long-term care into consideration, which is still under development and has not yet been adopted by legislators.

Revising the current definition of the need for long-term care must – in the view of the Federal Ministry of Health – preclude “problems of acceptance” among the insured persons as well as “financial risks” for the long-term care insurance system. Under the premise that long-term care insurance should also remain a “core system for providing security” in the future, it neither can nor should cover the costs for all of the assistance required by people in need of long-term care and the elderly.⁵ Therefore, one of the important aspects of the task was to answer the question as to the financial effects that the change would have on long-term care insurance and/or other areas of social benefits.

The main task with which the Advisory Board was charged was the formulation of a new definition of the need for long-term care and the development of an assessment procedure within the scope of the SGB XI, thus there was a strong focus on the further development of long-term care insurance. It was, nevertheless, still important within the framework of the review of the definition of the need for long-term care, to appropriately clarify whether and how long-term care insurance should be positioned within a comprehensive concept of determining what is required by people in need of long-term care. This question, with its far-reaching ramifications, is also connected, on the level of planning individual assistance, to the target, cited in the coalition agreement, of an overall concept that places assistance to the elderly, the disabled and people in need of long-term care in relation to each other.

⁴ Paper by the Federal Ministry of Health “Maßnahmen zur Schaffung eines neuen Pflegebedürftigkeitsbegriffs und eines neuen bundesweit einheitlichen und reliablen Begutachtungs-Instruments zur Feststellung der Pflegebedürftigkeit nach dem SGB XI”.
⁵ Paper by the Federal Ministry of Health “Maßnahmen zur Schaffung eines neuen Pflegebedürftigkeitsbegriffs und eines neuen bundesweit einheitlichen und reliablen Begutachtungs-Instruments zur Feststellung der Pflegebedürftigkeit nach dem SGB XI”.
The Advisory Board has fulfilled this task and objective by drafting a recommendation for the revision of the definition of the need for long-term care. With this report, it submits a realistic and implementable proposal for a new formulation of the definition of the need for long-term care and for the design and introduction of a nationally uniform assessment instrument, as well as providing answers to the question of financing.
Chapter 1: Working Method / Steps of Deliberation

On 10 October 2006, the Federal Ministry of Health established the Advisory Board to Review the Definition of the Need for Long-term Care. The Advisory Board was composed of representatives sent by various organisations and institutions as well as scientific experts from the field. The organisations, institutions and the individual experts were selected so that all interests, competencies, and areas of activity related to “long-term care” were taken into consideration. The first meeting of the Advisory Board was convened on 13 November 2006.

On 29 April 2008, one of the members of the Advisory Board, Dr. h. c. Jürgen Gohde (chairman of the Kuratorium Deutsche Altershilfe [German Foundation for the Care of Older People]), was named as chairman. He took over the chair from Wilhelm Schmidt, the president of the Deutscher Verein für öffentliche und private Fürsorge (German Association for Public and Private Welfare), who had resigned as the chairman of the Advisory Board. The vice-chairman of the Advisory Board is Prof. Dr. Peter Udsching, Chief Judge of the Federal Social Court in Kassel.

1.1 Pilot Project and Request for Proposals

Parallel to this, the Federal Ministry of Health asked the Central Associations of Long-term Care Insurance Funds to execute a pilot project to the further development of long-term care insurance within the framework of Section 8 paragraph 3 SGB XI. The development and introduction of a nationally uniform assessment instrument on the basis of the SGB XI are tasks for with the Central Associations of the Health Insurance Funds are responsible in collaboration with the Joint Medical Advisory Services of the Health Insurance Funds (Ger. abbr. = MDS/MDK-Gemeinschaft). On the basis of a definition of the need for long-term care, which was to be formulated, a completely new assessment instrument, not yet prescribed by legislators, was to be developed and tested in a pilot project in order to further the pioneering steps in the development of long-term care insurance. Options for action were to be illuminated, showing whether and how the criticism that has been lodged against the current definition of

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6 Members of the Advisory Board listed in Appendix 1.
7 Section 53a No. 2 SGB XI.
the need for long-term care and its effects can be remedied in an appropriate manner. A Steering Committee, composed of representatives of the Federal Ministry of Health, the Central Associations of the Long-term Care Insurance Funds, the Medical Advisory Service of the Central Association of the Federation of Health Insurance Funds, the chairman of the Advisory Board and scientific experts assumed direct responsibility for overseeing the project.⁸

The Advisory Board accompanied the process of developing and testing a new assessment instrument to determine the need for long-term care. Its task was to recommend a formulation of a new definition of the need for long-term care. The results of the pilot project were to provide the Advisory Board with the necessary basis for deliberation and decision making.

Request for Proposals

The pilot project “Measures to Establish a New Definition of the Need for Long-term Care and a New, Nationally Uniform and Reliable Assessment Instrument to Determine the Need for Long-term Care according to the SGB XI” was to include one preliminary and two main phases.

The task and objective of the preliminary phase entailed the analysis and evaluation of the definition of the need for long-term care and the assessment or evaluation instruments based on comprehensive national and international research. The intention is to make a fundamental body of knowledge available on which further steps towards adopting a new definition of the need for long-term care and the adaptation of the assessment procedure can be based.

This preliminary phase of the pilot project is to be followed by two subsequent phases. The plan was to develop a new, practical assessment procedure on the basis of the results of this preliminary phase during the subsequent First Main Phase and to subject it to practical testing during the Second Main Phase.

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⁸ Members of the Steering Committee were Prof. Dr. Martin Moers (University of Applied Sciences Osnabrück), Klaus Dumeier (Chairman of the Steering Committee), Paul Jürgen Schiffer (VdAK/AEV), Hanka Bendig (GKV-SV), Harald Kesselheim (AOK-BV), Prof. Axel Mühlbacher (University of Applied Sciences Neubrandenburg), Wilhelm Schmidt/Dr. h.c. Jürgen Gohde (Chairman of the Advisory Board), Dr. Matthias von Schwanenflügel/Dr. Christian Berringer/Dr. Eckard Grambow (Federal Ministry of Health), Gerd Kukla (IKK-BV – participation until 31 May 2008 ), Meinolf Moldenhauer (BKK BV participation until 30 April 2008 ), Dr. Pick (MDS - participation until 27 March 2007).
Initially, the Central Associations of the Long-term Care Insurance Funds published a national request for proposals for the completion of the preliminary study.\(^9\) In early November 2006 the Institute for Nursing Sciences at the University of Bielefeld (Ger. abbr. = IPW) was chosen from among a number of applicants and commissioned to conduct the preliminary phase.

*Research Report*

The report compiled by the IPW in fulfilling this task, *Recherche und Analyse von Pflegebedürftigkeitsbegriffen und Einschätzungsinstrumentarien* (Research an Analysis of Definitions of the Need for Long-term Care and Assessment Instruments) dated 28 February 2007 (referred to as the Research Report), was presented to the Advisory Board during a meeting on 20 March 2007. On the recommendation of the Advisory Board, the authors augmented the report submitted on 28 February 2007 in order to provide a more precise description of the assessment system in Japan and the alternative assessment system proposed by the Joint Medical Advisory Services of the Health Insurance Funds. The revised report was submitted to the Steering Committee on 23 March 2007.\(^{10}\)

In keeping with the request for proposals, the report focuses on how a scientifically grounded understanding of the need for long-term care can be formulated and also presents a comprehensive description, analysis, and comparison of numerous assessment instruments. In this context the options and limits of the adaptation and/or combination of assessment instruments are extensively demonstrated. Special attention is devoted to the “alternative assessment procedures” developed by the Joint Medical Advisory Services of the Health Insurance Funds.

The research on definitions of the need for long-term care took various sources into consideration, including models of nursing theory, systems to ensure nursing care in other countries, and the work of international organisations. In this context the authors of the report identified the aspects of functional dependency and personal assistance as the two central concepts used to characterise the need for long-term care. From the perspective of works on nursing theory, a common understanding of the need for long-term care also includes the dependency on per-

\(^{9}\) Limited request for proposals according to Section 3 No. 1 paragraph 2 in combination with Section 3 No. 3 VOL/A.

\(^{10}\) Published under: [http://www.gkv.info/site/fileadmin/user_upload/PDF/Pflegeversicherung/ipw_bericht_20070323.pdf](http://www.gkv.info/site/fileadmin/user_upload/PDF/Pflegeversicherung/ipw_bericht_20070323.pdf).
sonal assistance, which results from the imbalance between impairments, burdens, and demands, on the one hand, and individual resources for coming to terms with them, on the other.

Based on these considerations, the authors of the reports derived various elements of a definition of the need for long-term care. Accordingly, a person is designated as in need of long-term care when, due to a lack of personal resources through which it would be possible to compensate for or overcome physical or psychological injuries, the impairment of physical or cognitive/psychological functions, health related problems or requirements, he/she is not able to engage independently over longer or shorter periods of time in activities of daily living, independently manage health issues, other areas of life, or social participation, and is therefore dependent on personal assistance. The authors of the study recommended taking this type of basic understanding into consideration during the impending deliberations of a new definition of the need for long-term care.

Within the context of the analysis of the assessment instruments, the authors of the study initially surveyed the experience and decision-making processes in other countries. Altogether, 38 different assessment instruments were taken into consideration. In this context it could be determined that the procedures preferred all over the world – analogous to the previously mentioned elements of the definition of the need for long-term care – begin by describing the dependence on personal assistance, along with characteristics such as the loss of functions, psychological problems and behavioural disorders, and then determine the extent of the need for long-term care on this basis.

Within the context of the comparison of different assessment instruments, the instruments EASY care, FACE, RAI 2.0 and RAI HC were recognized as being basically suited for use in determining the need for long-term care. It was, however, not possible to recommend any of these instruments without reservations when certain details and methodological aspects were taken into consideration. In the authors’ assessment, each of these instruments requires context-specific adjustments. This conclusion is also related to the fact that any decision on a

11 These instruments could be divided into three groups: instruments for determining a comprehensive need for long-term care, instruments for more intensive determination of the need for long-term care in more specific areas, and instruments to assess need in relation to children.
12 A conditional recommendation was given for the instruments CANE, RCN Assessment and RUM.
13 In addition, the instruments cited demonstrated weaknesses, especially due to lacking or limited results with regard to the methodological quality and the complexity of their application.
new definition of the need for long-term care will have subsequent effects on the assessment procedure, which could not yet be anticipated.

The “Alternative Assessment Procedure” (Alternatives Begutachtungsverfahren; Ger. abbr. = ABV), which is currently under development, could also not be recommended. The ABV displayed shortcomings with regard to its range in terms of content, the systematic organisation of content, the way it addressed the need for prevention/rehabilitation, and the way it reflected psychological problems. In as much as the approach adopted towards the development of an evaluation system can already be recognized, it seems to be in need of optimisation, as is also the case with the other instruments.

In view of the assessment of children, it was concluded that none of the analysed instruments provided a convincing approach. A new, convincing approach to the assessment of children up to the age of 14 could not be established with the instruments currently available.

In summarising the findings, it was recommended, with regard to a New Assessment Procedure, that one of the established instruments (FACE, EASY Care or RAI) or the alternative assessment procedure developed by the MDK-Gemeinschaft be taken into consideration as a possible basis for developing an assessment instrument, or that an instrument not based on one of the available procedures be developed and coordinated with the process of reviewing and developing a definition of the need for long-term care from the outset.

The authors of the report saw the second option as the more promising approach towards developing a viable instrument within the set timeframe. The possibility of adapting an established instrument and/or combining other instruments would lead to extensive questions with regard to content, methods, practical application, and in some cases also licensing; it would also involve excessive effort and therefore be expected to take too much time. Much the same is true of the possibility of attempting to further develop the Alternative Assessment Procedure. In addition, references were also made to the question of assessing children, which, in all probability, cannot be solved through the first option. Conversely, the alternative of developing a new assessment instrument would offer more leeway for harmonising the development of the instrument with the process of reviewing and revising the definition of the need for long-term care. Changes in the structure of an existing instrument, which may be necessi-
tated by a lack of agreement with the definition of being in need of long-term care in terms of content, would lead to considerable complications. In view of these facts, the authors of the report recommended initiating the development of a new assessment instrument that includes approaches found in the existing instruments while strictly adhering to the principle of a modular structure.

In light of the opinion that none of the assessment procedures studied could be introduced without modifications, the Advisory Board discussed the alternatives presented by the authors of the report and unanimously recommended the development of a new assessment over the option of using an established assessment. At the same time, the Advisory Board decided to begin the process of drafting a new definition with the elements of a definition of the need for long-term care that were cited in the Research Report. This decision was made in the wake of a recommendation by the working group within the Advisory Board charged with the “formulation of a definition of the need for long-term care”.

The Advisory Board therefore decided, during its second meeting on 20 March 2007, to jointly develop a new assessment instrument and a new definition of the need for long-term care based on a broad definition of the need for long-term care and to adjust the one to fit with the other modularly in an integrated process.

Central Questions of the Request for Proposals – First and Second Main Phases

On the basis of these decisions, the Advisory Board formulated central questions for the request for proposals for the development and testing of a new, modular assessment instrument. A first draft of the central questions, which were to be taken into special consideration within the context of the request for proposals, emerged from the Advisory Board meeting of 20 March 2007. These were revised and more precisely defined within the context of a subsequent consultation process.¹⁴

¹⁴ The central questions were circulated among the members of the Advisory Board jointly revised. The various opinions were taken into consideration in the final formulation of the central questions.
It was to be ensured that the following central questions were answered in developing a concept for the assessment instrument:

1. In which way and to what extent will gaps in the care and supervision of people in need of long-term care be closed through the new assessment instrument and the new definition of the need for long-term care? Which types of need for assistance that have not been recognised under the current definition and the current assessment procedure will be taken into consideration by the new definition and new procedure? Which types of need for assistance will not be taken into consideration?

2. How will the assessment of children in need of long-term care be regulated within the context of the new assessment instrument? How will the need for additional assistance as a result of illness or disability be determined in relation to that of a healthy child of the same age?

3. Which possibilities and limits result from the modular design of the assessment instrument?

4. How and within which framework are the undetermined definitions of “areas of everyday life” and “social participation” integrated into the modularly designed assessment instrument?

5. How does the assessment instrument take the structures and demands of different social security agencies responsible for the funding of services into consideration? Does the assessment instrument provide or support the determination of need across a number of benefit areas, for example as a basis for a personal budget?

6. In which form should or are the areas of illness, disability and the need for long-term care differentiated in actual assessment practice? Does the modular structure of the assessment instrument make it possible to clearly assign the responsibility for benefits to various agencies responsible for organising the provision of benefits?
7. Which additional connections, developments and consequences result from an extended definition of the need for long-term care for the SGB V, IX, XI and XII in terms of social law and fiscal policy?

8. Which possibilities and limits result, with regard to the determination of the extent of the need for assistance, when time is not measured as a factor?

9. Which options and limitation exist with regard to this instrument for individual care planning?

10. What will the New Assessment Procedure entail (duration of the assessment, training)? To which profession should the assessors belong and which competencies should they have?

11. How does the new assessment instrument take the subjects’ right to self-determination into account? How are their individual wants and needs taken into consideration, and how is transparency ensured for those affected in every stage of the procedure?

On the basis of these central questions a request for proposals for the first and second main phases of the pilot project was published by the Central Associations of the Long-term Care Insurance Funds within the context of the pilot programme in keeping with Section 8 paragraph 3 SGB XI for applicants throughout Europe.\[15\]

In addition to answering the central questions, the request for proposals required that the following central tasks be taken into consideration in devising a new assessment instrument:

- The New Assessment Procedure should make it possible to objectively, comprehensibly and repeatably describe the individual long-term care situation, i.e take the applicant’s disabilities, resources and the need for assistance into consideration.

• The results of the assessment must be transparent and comprehensible for the insured person.
• The basis of the assessment must enable the long-term care facility to draft a long-term care plan for the person in need of long-term care.
• In order to avoid the need for long-term care, to compensate for a disability, and to maintain independence, it should be ensured that in every assessment – even when there is no assignment of a long-term care level – the applicant’s preventive and rehabilitation needs, as well as necessary measures to provide technical aids and appliances, can be determined and documented.
• It must be possible to compile an assessment report in an economically acceptable period of time. The timeframe for a first and subsequent assessment reports should, as a rule, require no longer than 45-60 minutes for the entire length of the home visit.
• In devising a New Assessment Procedure it should be ensured that the procedure for determining the need for assistance by children in need of long-term care is designed in a manner suited to the situation.
• Adverse circumstances and – to the extent legally necessary – preconditions for the recognition of hardship cases are to be reviewed in the assessment instrument.
• The assessment procedure must be able to identify disabilities and resources, to weight them, and enable benefits to be clearly assigned. The system of evaluation used in the assessment instrument and the weight assigned to individual modules of the procedure are to be designed in a manner that circumvents the uncontrolled expansion of the number of persons entitled to benefits under long-term care insurance.
• The modular character of the assessment instrument must enable the direct assignment of the need for assistance to individual agencies responsible for organising benefits.
• Participation in life in society, in the sense of being able to lead life in a manner that is as independent and self-determined as possible, is to be taken into consideration in an independent module of the assessment instrument.
• A plausibility test of information regarding services provided must be ensured.
• Formal quality control of the content of the assessment procedure must be ensured.

• Information that is relevant to caregivers’ retirement benefits must be collected.

Within the context of test phase, the assessment procedure should be reviewed by an independent institution with regard to its validity\textsuperscript{16}, reliability\textsuperscript{17}, sensitivity\textsuperscript{18}, specificity\textsuperscript{19}, and sensitivity to change\textsuperscript{20}. In addition, a clear estimation of the financial effects of the New Assessment Procedure on long-term care insurance should be possible at the conclusion of the test phase. Most importantly, a comparison should be made between these results and the current basis for assessment.

The Institute for Nursing Sciences at the University of Bielefeld (Ger. abbr. = IPW), the Medical Advisory Service of the Health Insurance Funds of Westphalia-Lippe (Ger. abbr. = MDK Westfalen-Lippe), the Medical Advisory Service of the Central Association of the Federation of Health Insurance Funds (Ger. abbr. MDS) and the Institute for Public Health and Nursing Research (Ger. abbr. = IPP) at the University of Bremen submitted a joint proposal as a working group in response to the request. In July 2007 this proposal was accepted by the Central Association of the Long-term Care Insurance Funds. In order to complete the task, the working group agreed to the following division of the tasks: the responsibility for devising a new assessment instrument (First Main Phase) was to be assumed jointly by the IPW, under the direction of Prof. Dr. Schaeffer, Dr. Wingenfeld and Dr. Büscher, and the MDK Westfalen-Lippe, under the direction of Dr. Gansweid and Dr. Heine, the practical testing (Second Main Phase) was to be undertaken by the IPP, under the direction of Prof. Dr. Görres, and the MDS, under the direction of Prof. Dr. Windeler.

Prof. Dr. Garms-Homolová was commissioned to complete an accompanying study on the “Möglichkeiten der Berücksichtigung von RAI 2.0 und/oder RAI HC bei der Erarbeitung eines zukünftigen Begutachtungsinstruments” (Possibilities for Considering RAI 2.0 and/or RAI HC in Drafting an Impending Assessment Instrument) in July 2007. The task included the scientific evaluation of the interRAI assessment system (RAI 2.0 and RAI HC) and find-

\textsuperscript{16} Targetting of the actual measurement of the need for long-term care – validity.

\textsuperscript{17} Ability of the tests to be reproduced with the same result – reliability.

\textsuperscript{18} Compilation of those affected.

\textsuperscript{19} Exclusion of those not affected.

\textsuperscript{20} Proof of important changes.
ing answers to the questions that arose from the IPW’s research report of 23 March 2007. In the opinion of the Steering Committee, however, this study did not produce any new aspects warranting consideration with regard to the possibility and limits of adapting or modifying the interRAI assessment system in developing a new assessment system.

1.2 Working Procedure

1.2.1 Timetable

In light of the Long-term Care Reform’s coming into force on 1 July 2008 and the legislative period’s ending in autumn of 2009, the Federal Ministry of Health determined a timeframe for the work on the pilot project that was to start by 1 November 2006 and be concluded by 30 November 2008. As a result of the decision to expand the database, which was adopted by the Steering Committee and the Advisory Board in June 2008, the presentation of the Final Report to the Federal Ministry of Health by the Advisory Board was postponed until 31 December 2008.

From the very beginning, those responsible for conducting the project saw the timetable as extremely ambitious. The development of a scientifically grounded and practical assessment procedure, along with its subsequent testing in practice, represented a very ambitious and complex task. The time plan required the work to be organised on a tight schedule. The work was always completed within the set timeframe.

1.2.2 Working Phases

In keeping with the division into three working phases, the available results were always evaluated at the end of each phase, in order to determine whether and with which questions the project should be continued, before entering into the next phase. The work was completed according to the following chronology:

In the preliminary phase, which began in early November 2006, a comprehensive analysis and evaluation of national and international definitions of the need for long-term care and instruments of assessment and evaluation were undertaken. This research provided a basis of knowledge upon which further steps towards the formulation of a new definition of the need for
long-term care and the adaptation of the assessment procedure could be based. In this con-
junction, the suitability of existing assessment instruments was specifically examined. The
preliminary phase was completed with the presentation of the research report on 28 February
2007.21

In the directly ensuing First Main Phase, the project group, the Institute for Public Health and
Nursing Research of the University of Bielefeld and the MDS Westphalia-Lippe developed a
new, practical, standardised, and generally recognised assessment procedure to survey indi-
vidual needs for assistance on the basis of disabilities and impairments with the option of as-
signing the subject to a Level of Care. The First Main Phase also encompassed a pre-test in
order to provide important information with regard to the development of an assessment sys-
tem, the practicability of the new assessment instrument, and the time required during this
early phase. The project group submitted an interim report on 31 December 2007. The First
Main Phase ended with the presentation of the final report on 29 February 2008.

In the Second Main Phase, which began on 1 March 2008, the Institute of Public Health and
Nursing Research of the University of Bremen and the Medical Advisory Service of the Cen-
tral Association of the Federation of Health Insurance Funds evaluated the suitability and pos-
sible consequences of the assessment instrument developed during the First Main Phase by
using scientific methods to analyse empirical data. The main objectives of the Second Main
Phase were the scientific evaluation of the quality of the newly developed assessment instru-
ment and the estimation of possible content-related and financial consequences of a revised
definition of the need for long-term care and new concept for the assessment instrument. The
first results were presented on 31 July 2008 in an interim report, which was presented to the
Advisory Board on 27 August 2008. The final report on the Second Main Phase was submit-
ted by the project group on schedule on 31 October 2008 and presented within the context of
the meeting of the Advisory Board on 6/7 November 2008.

1.3 Organisation of the Project

The Advisory Board monitored the progress and execution of the pilot project. It operated
independently of the Steering Committee, the project group and the Federal Ministry of

21 The revised version of the report was presented on 23 March 2007.
Health. During the course of its fifteen meetings, the Advisory Board was provided with information on the progress of the project and actively engaged in a lively discussion of the questions that were to be addressed.\textsuperscript{22} The focus of the discussions was always on reaching both results and a consensus.

The Advisory Board’s task consisted of evaluating the results presented by the project group and making recommendations to legislators on how to proceed. This specifically included a recommendation for the formulation of a definition of the need for long-term care. Preliminary work to this end was done by a working group of the Advisory Board, which consisted of members of the Board or its representatives.\textsuperscript{23} The working group was led by Prof. Dr. Udssching.

1.4 The Conferences and Workshop

The scientific discussion within the Advisory Board was accompanied and continued within the context of two conferences and a workshop staged by the German Association for Public and Private Welfare. In response to a suggestion made by the Advisory Board, Wilhelm Schmidt, the chairman of the Advisory Board at that time, offered to have the conferences staged under the auspices of the German Association for Public and Private Welfare. In addition to including experts in the field in the process of developing a new definition of the need for long-term care and the New Assessment Procedure, they also served to promote a constructive discourse among experts as well as the examination of the process from different perspectives.

\textit{Conference on 14 December 2006}

One of the first conferences took place immediately after the Advisory Board was constituted on 14 December 2006, to launch the pilot project to develop a new definition of the need for


long-term care.\textsuperscript{24} It offered an initial overview of work on the model project and provided a good opportunity for the exchange of opinions concerning the needs and conceptional options for a new definition of the need for long-term care from the view of the protagonists involved. The results of the conference were addressed in the discussion process within the Advisory Board.

Conference on 8 November 2007

The discussion among experts that accompanied the work of the Advisory Board was continued in another conference staged by the German Association for Public and Private Welfare on 8 November 2007.\textsuperscript{25} In this context - in addition to the presentation of the study by Prof. Dr. Garms-Homolovà on two instruments of the interRAI assessment system (p. 20) – a debate took place focussing especially on the memorandum signed by Prof. Klie et al. “Die Quadratur des Kreises in der Begutachtung der Pflegebedürftigkeit” (Squaring the Circle in the Assessment of the Need for Long-term Care).\textsuperscript{26} The signers of the memorandum emphasised that they were in favour of the objective of developing a new definition of the need for long-term care and the corresponding assessment procedure without reservations. The memorandum was neither expected nor intended to cause division within the scientific community. The purpose of the memorandum was to point out fundamental methodological problems in view of the politically determined timeframe. The development of a procedure had taken far longer than three years in most other countries. In this respect the planning at that time failed to address criteria such as the sustainability in the development of a robust assessment procedure. In addition, concerns with regard to the participation of representatives of special interest groups were expressed. The signatories to the memorandum therefore spoke in favour of repeating the process of requesting proposals as soon as possible and including certain qualifications.

\begin{thebibliography}{9}

\bibitem{24} The papers presented at the conference were published in the \textit{Archiv für Wissenschaft und Praxis der sozialen Arbeit} 2/2007. The schedule and a list of discussion participants can be accessed under: \url{www.deutscher-verein.de}.

\bibitem{25} The papers presented at the conference can be accessed under: \url{www.deutscher-verein.de/03-events/2007/gruppe4/f-473-07-fachkonferenz-pflegebeduerftigkeitsbegriff}.


\end{thebibliography}
Workshop on 2 June 2008

In order to prepare for the Advisory Board’s more extensive consideration of the effects of a new definition of the need for long-term care on the benefits system and laws regulating it, the Advisory Board asked the German Association for Public and Private Welfare to conduct a workshop in which experts participated in order to discuss the results with the Advisory Board. The workshop entitled “Pflegebedürftigkeit im Kontext von SGB XI, SGB IX und SGB XII” (The Need for Long-term Care within the Context of SGB XI, SGB IX and SGB XII) was staged by the German Association for Public and Private Welfare on 2 June 2008. Three working groups were established within the context of this workshop (Working Group 1: Definitions of the need for long-term care and disability – describing the living situations of people who are disabled and in need of long-term care; Working Group 2: Benefits for those in need of long-term care and measures to aid in the integration of disabled persons / Working Group 3: Determination of the need for long-term care, participation, and rehabilitation). Their findings were discussed during a final plenary discussion.

1.5 Communication

Within the framework of its work, the Advisory Board always maintained and promoted the principles of transparency and participation. This was ensured, on the one hand, through the previously cited conferences and workshops staged by the German Association for Public and Private Welfare. On the other, the reports compiled during the pilot project – the Research Report as well as the Final Reports of the First and Second Main Phases – were published via the Internet. In addition, there was always “internal” communication through the organisations that were members of the Advisory Board and each of their representatives.

In response to a query by the FDP faction, State Secretary Marion Caspers-Merk reported to the Committee on Health of the German Bundestag on the current stand of the Advisory Board.

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Board’s work on 7 May 2008. The Committee was provided with extensive information concerning the pilot project and the results that had been presented thus far.

In view of the establishment of a Federal-Laender Working Group, a compulsory dialogue was initiated between the Federal Ministry of Health and the Laender. Within the Advisory Board the establishment of a Federal-Laender Working Group had been encouraged.

1.6 Expansion of the Database

During the course of further deliberations and discussions within the Advisory Board, the need for additional clarification of the structural and financial consequences that a new definition of the need for long-term care and the assessment procedure would have on the social welfare system became evident. The point of departure for the discussion was that the testing of a New Assessment Procedure had, up until that point, only been undertaken among the SGB XI applicants. This was practical to the extent that a large proportion of the future benefit recipients would thereby be included and there seemed to be no other way of presenting an assessment of such a large number of them within the prescribed time period. However, this approach resulted in the exclusion of those who had hitherto not applied for long-term care benefits according to the SGB XI, but who may indeed be entitled to benefits under a new definition of the need for long-term care and the corresponding assessment procedure, for example disabled persons in integration assistance facilities, people suffering from dementia, and others in need of assistance. Furthermore, at this time the fiscal effects on the agencies responsible for funding the provision of social assistance had not yet been considered as a topic.

Subsequently, the Advisory Board came to an agreement to take these questions into account by expanding the pilot project that was already underway. The Advisory Board was aware of the resulting postponement of the date on which its report would be submitted to the Federal

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28 Committee on Health of the German Bundestag - Ausschusdrucksache 16(14)0383.
29 Directly after the Advisory Board was constituted. Information of the Bundestag through answers from the Federal Government to a query by the FDP faction on the composition and the work undertaken by the Advisory Board, BT-Drs. 16/3389 and BT-Drs. 16/3399.
30 Letter from State Secretary Dr. Körner, Ministry for Social Affairs, Health Family, Youth and Senior Citizens of the Land of Schleswig-Holstein as well as a similar letter from Friedrich Seitz, Head of the Office of the Bavarian State Ministry for Labour and Social Affairs, Family and Women, both on 22 August 2008 to State Secretary Dr. Schröder, Federal Ministry of Health, as well as a corresponding reply 6 October 2008.
Ministry of Health. With the execution of an expanded study the Advisory Council wanted to make use of an opportunity to submit representative data on the recipients of integration assistance, people suffering from dementia, and others in need of assistance.

The Medical Advisory Service of the Central Federal Association of Health Insurance Funds was commissioned by the Central Federal Association of Health Insurance Funds, under Section 8 paragraph 3 SGB XI, to complete a study on the effects of a new definition of the need for long-term care on social assistance agencies. The application for expansion was intended to assess the extent to which additional benefit recipients, who had hitherto not submitted an application under SGB XI, were to be expected and now included. Furthermore, the fiscal effects for long-term care insurance and social assistance agencies were also to be studied; also in view of the people included in the main project currently underway. The project group presented the corresponding study on 8 January 2009.

1.7 Supplementary Report by the Advisory Board

After an interim report submitted to the Minister by the Chairman in preparation of the final report by the Advisory Board, the Minister requested, during a meeting on 15 October 2008, that the Advisory Board submit a supplemental report by Easter of 2009. The Advisory Board was asked to review possible strategies and concrete implementation steps and to introduce a new definition of the need for long-term care on the basis of the findings and recommendations of the final report and a New Assessment Procedure in the SGB XI, as well as to assess possible alternatives and recommendations.

In this conjunction the focus is on the following questions:

1. Which preparatory and accompanying measures are necessary in the Advisory Board’s view in order to introduce a new definition of the need for long-term care and a New Assessment Procedure? Must additional administrative prerequisites be established, and if so, which?

2. Is a gradual introduction of the New Assessment Procedure possible and how could this be done? Is it possible for the “new” and the “old” assessment pro-
cendures to coexist – and if so should applicants have an option to choose – and which consequences would that have?

3. What options exist, within the framework of an implementation concept, for differentiating with regard to when the New Assessment Procedure is introduced according to certain criteria (i.e. regionally differences in the introduction and/or testing phases; differentiation according to certain groups of applicants or persons entitled to benefits, e.g. gradual introduction beginning with all applicants over 90 years of age or under 65 years of age)?

4. In which form and for which period of time should and can the preserved rights of those who have hitherto received benefits from social and private long-term care insurance be recognised? What effects can a new assessment have in this context?

5. How can the benefits of the long-term care insurance be adapted to the new differentiation in the degrees of need? Should the claim to benefits be differentiated uniformly according to the new degrees of need, or does it make more sense to differentiate according to the area in which the impairment is focused?

6. Which other possibilities exist to limit the risk of unwanted costs in its wake, particularly social and private long-term care insurance?

7. What costs will result from measures and scenarios developed on the basis of questions 1 to 6 for social and private long-term care insurance (benefit expenditures, administrative expenditures incurred by the long-term care insurance funds and by the medical advisory services of the health insurance funds?

During the meeting on 9 December 2008 State Secretary Dr. Schröder again explained the intention and implementation of the Federal-Laender Working Group to Address the Interface Problems of Long-term Care Insurance, Integration Assistance and Long-term Care Assistance. A working proposal was submitted to the Advisory Board via the Presidium on 8 January 2009.
Chapter 2: Determining the Findings / Results of the Study

2.1 Introduction

On the basis of the preliminary study completed by the Institute for Nursing Sciences at the University of Bielefeld, the Advisory Board decided to develop and test a new assessment instrument. The analysis and the comparison of existing assessment procedures have shown that no procedure in its current version is suited to accommodate a broad definition of the need for long-term care.

In answering the central questions formulated by the Advisory Board for the development and testing of a new assessment instrument, the following results can be presented:

2.2 The New Assessment Procedure

The new assessment instrument that was developed during the course of this process (the New Assessment Procedure – Ger. abbr. = NBA) was drafted jointly by the Institute for Nursing Sciences at the University of Bielefeld and the Medical Advisory Service of the Health Insurance Funds in Westphalia-Lippe and presented to the Advisory Board to Review the Definition of the Need for Long-term Care at the beginning of March 2008.

It included a number of important changes in relation to the currently employed assessment procedure. The instrument is aimed especially at the comprehensive consideration of the need for long-term care, thus it avoids a narrow focus on the need for assistance in conjunction with performed activities of daily living, which is characteristic of the current assessment procedure and the currently provisions of the SGB XI. The instrument considers both physical impairments and cognitive/psychological deficits and disorders, which entail a specific need for support. In contrast to the current assessment procedure, the gauge used to estimate the need for long-term care is not the time needed to provide the long-term care, but the degree of independence in performing activities of daily living or managing areas of everyday life. The new instrument thereby emulates widely recognised international models. It is based on an internationally accepted understanding of the need for long-term care.
In order to underline the fundamental changes in particular, the Advisory Board decided during the course of deliberations to substitute the term “Degree of Need” for the term “Level of Care” currently used to designate degree of the need for long-term care. The new designation marks a new departure in how the need for long-term care is assessed for long-term care insurance and is suited to help avoid problems with regard to the acceptance and communication of the new assessment instrument and a new definition of the need for long-term care.

2.2.1 Structure of the New Procedure

The new assessment instrument is divided into four segments:

2.2.1.1 Collecting Information

There is a close link between the type of information and the current assessment procedure. It encompasses general information on the applicant and the assessment situation, information on the care available and the person or persons providing long-term care, information on illnesses, functional impairments, and the history of health problems to date. At the same time, the persons being assessed are able to describe their situations in their own words and depict the problems that are most pressing and the measures that need to be taken from their own perspective.

2.2.1.2 Survey of the Findings

In addition to reviewing previous findings and other information, the assessor is expected to form an independent opinion regarding the injuries and impairments of the person in need of long-term care.

2.2.1.3 Assessment of the Need for Long-term Care

The third part of the new instrument encompasses eight areas or “modules” with which the impairment of the subject’s ability to independently perform activities of daily living and managing areas of everyday life is determined. The results of this assessment are the basis for determining the degree of need for long-term care (Degree of Need). The modules therefore
represent the core of the New Assessment Procedure and encompass all of the characteristics that contribute to determining the degree of need for long-term care or are used to describe other limitations in independence (need of assistance). This part also encompasses questions regarding particular constellations of need with regard to long-term care, to assess the need for rehabilitation measures and prevention-relevant risks.

2.2.1.4 Presentation of the Findings and Recommendations

In addition to determining the degree to which independence has been lost in relation to individual activities and managing areas of everyday life and the degree of need for long-term care (Degree of Need), this part of the of the assessment instrument offers leeway for recommending concrete measures, for example on how to stabilize the domestic care situation or improve the supply of aids and appliances.

In addition to the instrument itself (assessment form), an assessment manual with information on its application was developed along with a key to using the findings of the assessment in individual planning of assistance and care.

2.2.2 Judging the Need for Long-term Care

2.2.2.1 Aspects of Long-term Care and the Need for Assistance Taken into Consideration

The eight modules with which the degree of individual impairment is determined each encompassing a group of similar activities, abilities or areas of everyday life:

1. *Mobility*: mobility over short distances and the ability to transfer the position of the body.
2. *Cognitive and communication abilities*: memory, perception, thought, judgement, communication (intellectual and verbal “activities”).
3. *Behaviour and psychological problems*: behaviour that may be self-endangering or endanger others or involve other problems, including psychological problems such as anxiety, panic attacks or delusions (ability to deal with inner-impulses to act and emotions independently).
4. *Self-care*: personal hygiene, ability to get dressed, eat and drink along with functions related to bladder and bowel movements.
5. *Ability to deal with illness-/therapy-related demands and stress*: activities aimed at coming to terms with the demands and stress resulting from an illness or therapy measures, such as taking medications, dressing wounds, handling physical aids and appliances, engaging in extended therapies within and beyond the domestic setting.

6. *Managing Everyday Life and Social Contacts*: budgeting time, adherence to a rhythm of being awake and sleeping, spending available time sensibly (corresponding to needs) and maintaining social relationships.

7. *Activities Outside of the House*: participation in social and, in a very broad sense, cultural activities (including mobility outside of the domestic setting).

8. *Household Maintenance*: household activities and regulation of necessary business dealings for everyday life (use of services, interaction with public authorities, financial affairs).

### 2.2.2.2 Determining the Degree of Need for Long-term Care

Using the new procedure initially provides partial findings for each module, which are to a certain extent indicative (e.g. Module 1: indication of the degree of independence in activities related to mobility or transferring the position of the body). In a second step, the partial findings are combined in the form of an overall finding according to certain predetermined calculation rules (assessment methodology). In this conjunction, a differentiation is made between the need for long-term care and the need for assistance:

- In order to determine the degree of need for long-term care (Degree of Need), the results of the module 1 to 6 are combined and represented as a value on a scale of 0 and 100 points. This scale is divided into a number of ranges, each of which corresponds with a certain Degree of Need. More detailed information can be found in the report submitted by the developers of the instrument. The new system that classifies degrees of need, including the point ranges, was defined on the basis of considerations of objective content and methods. There may be alternatives to the classification levels recommended by the project group, however any changes will require a review by experts.

- The modules 7 and 8 (activities outside of the domestic setting and household maintenance) will be examined on their own and serve, in a similar manner, to aid in determining the degree of need for assistance. In order to determine the Degree of Need, i.e. to determine the degree of need for long-term care, it is not necessary to include the results of the as-
essment of these modules in the calculations. It does make sense, in the interest of a comprehensive assessment of the situation of individual need, to maintain these modules as a component of the instrument. They are of particular value for comprehensive counselling, recommendations for the optimisation of the domestic care situation, as well as in planning individual care and assistance.

In order to determine the Degree of Need, the results of the modules 1 to 6 are combined and represented as a value between 0 and 100 points. This scale is divided into a number of segments, each of which corresponds with a certain degree of need for long-term care:
0 to 9 points: no need for long-term care
10 to 29 points: Degree of Need B1
30 to 49 points: Degree of Need B2
50 to 69 points: Degree of Need B3
70 and more points: Degree of Need B4.
Degree of Need B4 + special constellation of need: Degree of Need B5.

The division into five degrees of need (B1 to B5) is designed so that people in need of long-term care who have a relatively low level of impairment and receive no benefits according to the current regulation of long-term care insurance can be assigned to a Degree of Need. This should ensure that people who are dependent upon nursing care are not categorized as “not requiring long-term care”.

The new system of degrees of need and the point ranges were defined on the basis of objective scientific considerations of methods and content.

2.2.3 Assessment of Children

The assessment of the need for long-term care by children makes use of the same assessment form. The result of the assessment does not, in this case, describe the degree of independence, but rather the degree to which it varies from the level of independence expected of children whose level of development corresponds with their ages. The age limits used in this conjunction are determined by drawing on broadly based research and the assessment of studies on child development as well as the differentiation of age-typical development levels which can be found in other assessment instruments.
2.2.4 Usefulness of Instruments for the Assessment of Additional Aspects of Need

2.2.4.1 Surveying the Need for Prevention and Rehabilitation

The new procedure surveys risks on which a specific need for prevention is based. These include health-related risks, environmental factors, and behaviour-related risks. In addition, the instrument foresees a review of the need for rehabilitation measures and other preconditions to clarify the need for medical rehabilitation. This clarification is far more systematic than within the framework of the current assessment procedure. In modules 1 “Mobility”, 2 “Cognitive and communication abilities”, 4. “Self-care” and 5. “Managing demands related to illness and/or therapy” the assessor is expected to assess the developmental tendencies with regard to independence and abilities. The assessor is expected to indicate whether, and if so how, a higher degree of self-sufficiency can be regained (or whether there are possibilities of keeping the situation from becoming worse). On this basis, and taking the individual capacity for rehabilitation into consideration, an explicit recommendation should be made concerning the initiation of rehabilitation measures. In the case of a negative decision, the assessor is required to provide an explanation of the grounds for it.

2.2.4.2 Provision of Therapeutic Aids and Appliances

The instrument, like the current assessment procedure, surveys the status of the provision of therapeutic aids and appliances and requires the assessor to provide an explicit estimation of the extent to which the need for therapeutic aids and appliances is covered. It also documents whether the existing therapeutic aids and appliances are actually used and whether there is a need for instruction in the use of the therapeutic aids and appliances.

2.2.4.3 Drafting an Individual Assistance or Care Plan

The results of the assessment can be used in drawing up an individual assistance or care plan. In some areas the instrument collects much more information than is the case with the nursing care assessments currently used in long-term care facilities. It also provides a basis for individually planning assistance in other areas. In terms of formulating recommendations on individual nursing care, as is now done in current assessment procedures, the new proce-
dure offers a sufficient (and more comprehensive) basis than the current assessment instrument.

2.2.5 Conclusion

The new assessment instrument is aimed at bringing the assessment into line with the demands of nursing science. Through a broader understanding of the need for long-term care, and the orientation away from the use of the time needed to provide the care as a standard of measurement, the instrument also addresses central points that have always given rise to controversial discussions in past years. The characteristic needs of persons suffering from dementia, in particular, are taken into sufficient consideration. At the same time, the procedure is designed so that those that suffer solely from physical impairments are not at a disadvantage.

Furthermore, the instrument is also designed in a manner that is easy to use. Through brief and straightforward wording, as well as uniform scales, the instrument is easily comprehended by the assessor and easy to deal with in practice.

2.3 Discussion of the Necessity of Changing the Definition of the Need for Long-term Care

2.3.1 Working Procedure of the Working Group on the Definition of the Need for Long-term Care (Directed by Prof. Dr. Peter Udsching)

2.3.1.1 Point of Departure for the Discussions in the Working Group

The point of departure for the discussions on the necessity of changing the currently binding definition of the need for long-term care in the SGB XI was the recognition of the fact that the definition applied to those who were in need of assistance in an unequal manner. It is biased, above all, towards the needs of people who have become frail due to old age. The catalogue of performed activities that alone determines the need for long-term care in Section 14 paragraph 4 SGB XI excludes, above all, people with cognitive and psychological impairments. There are, however, also other areas in which the need for assistance is not
properly taken into account. Thus, judicial findings have, for example, clearly shown that the provision of care for children in need of long-term care, even beyond those with mental disabilities (e.g. Morbus Down), is not adequately addressed by a definition of the need for long-term care that focuses on performed activities of daily living. To the extent that care is provided by the parents, benefits for home care from the statutory health insurance system according to Section 37 paragraph 3 SGB V do not come into question. At the same time, the children’s limitations in dealing with illness or disabilities, which determine their need for assistance from their parents, are not taken into account under the current definition of the need for long-term care, which focuses on performed activities of daily living.

A change in the definition of the need for long-term care in SGB XI is however also necessary from the standpoint of nursing sciences. Experts on nursing science have admonished, with good reason, that the definition of the need for long-term care focused on performed activities of daily living, which only serves to delineate the group of persons entitled to benefits in SGB XI, unjustifiably creates the impression of an extensive obligation to provide care for people with limited autonomy. From the perspective of nursing sciences, there is no justification for reducing the definition of the need for long-term care to somatic deficits that have an effect on the performance of activities of daily living.

The unequal treatment of people in need of assistance due to a loss of physical functions, on the one hand, and those with cognitive impairments, on the other, is also seen as extremely problematic by the courts. A chamber decision by the Federal Constitutional Court, in which this unequal treatment was judged to be an “admissible risk selection” in a “partial coverage system”, has been subject to criticism in the literature. The Federal Social Court only refrained from passing the verdict that it was unconstitutional on grounds that in a completely new system of social insurance, like long-term care insurance, a certain grace period was to be granted in order to gain more experience (thus the wording in: BSG SozR 3-3300 Section 14 No. 8, p. 55).

31 Cf. BVerfG, decision from 22 May 2003, 1 BvR 452/99, FamRZ 2003, 1084 as well as SozR 4-3300 Section 14 No. 1; NZS 2003, 535.

32 Cf. especially Baumeister, NZS 2004, 191.
2.3.1.2 First Interim Step: Evaluation of Existing Alternatives for Determining the Need for Long-term Care

In a meeting on 9 March 2007 the working group (under the direction of Prof. Dr. Peter Udsching) turned its attention to the findings of the research report by the Institute for Nursing Sciences (Institut für Pflegewissenschaft Ger. abbr. = IPW) at the University of Bielefeld on definitions of the need for long-term care and assessment instruments used internationally (called the Research Report). The working group’s recommendation to the Advisory Board was for the development of a new assessment instrument, because the existing instruments that were studied could not be used for the purpose of long-term care insurance without adaptation.

Fundamentally, the members of the working group saw three possible solutions for the intended reform of the definition of the need for long-term care:

- Expansion of the current definition beyond the somatic focus on performed activities of daily living (the “narrow” solution);
- Development of a comprehensive, new definition of the need for long-term care that ensures that those who have not been taken into account up until now (e.g. people suffering from dementia and disabled persons) will be included (“mid-range” solution);
- Definition of the need for long-term care on the basis of a concept of “long-term care oriented on participation in social activities” (“broad definition”).

The working group recommended that a new definition of the need for long-term care be as broad as possible for the work in the Advisory Board and to structure it modularly in order to open up alternative decisions for a subsequent legislative process.

2.3.1.3 The New Assessment Procedure – A Suitable Basis for a New, Comprehensive Definition of the Need for Long-term Care

The new definition of the need for long-term care, as a precondition for benefits from long-term care insurance, should insure that illness- or disability-related needs for assistance beyond medical intervention, which health insurance is required to cover, are comprehensively
taken into consideration. In the opinion of nursing care experts this requires a paradigm shift in assessing the need for support on the basis of the comprehensive assessment of all physical and cognitive (or psychological) deficits. The extent of the need for assistance, which is determined under the current system (Section 15 SGB XI) by the time required to provide the care and the frequency or the rhythm of the assistance (e.g. several times a day/24 hours a day), shall no longer be indicative. The emphasis will instead be shifted solely to the degree of independence or the loss of independence in performing activities of daily living and/or in the managing areas of everyday life. The need for long-term care is represented as an impairment of independence; the degree of dependence on personal assistance is determined by the extent of the impairment. In this context the time the caregiver needs to provide assistance no longer plays a role.

The working group sees in the new (assessment instrument) a suitable basis for realising the targeted goal of comprehensively integrating all disabilities and functional deficits into the definition of the need for long-term care and, consequently, ensuring equality in the participation of everyone in need of long-term care in the benefits of long-term care insurance. The working group therefore proposed a new legal definition of the need for long-term care on the basis of a new assessment instrument as a precondition for benefits from the long-term care insurance (Section 14 SGB XI – new version) and formulated the preconditions for graduated levels of long-term care insurance benefits (Section 15 SGB XI – new version) (Appendix 2). Based on the definitions in Section 14 SGB XI determined by principles of nursing science, the recommendations formulated in Section 15 on the preconditions and graduated levels of benefits are only to be seen as possible examples of implementation.34

2.3.2 Structural Principles of a New Definition of the Need for Long-term Care from a Legal Perspective

The paradigm shift away from the extent to which care is required and towards determining the degree to which independence is impaired, forces us to abandon traditional patterns of thought. This begins with the abandonment of the currently decisive focus on performed ac-

33 *Das neue Begutachtungsassessment zur Feststellung von Pflegebedürftigkeit*, compiled by the Institute for Nursing Sciences at the University of Bielefeld (Schaeffler, Wingenfeld, Büscher) and the Medical Advisory Service of the Health Insurance Funds of Westphalia-Lippe (Heine, Gansweid), Bielefeld/Münster, 25 March 2008.

34 On the difficulties involved in transforming the New Assessment Procedure into legal regulation see 2.3.2.2.2. below.
tivities of daily living as a means of evaluating the need for long-term care. Once the current system of viewing the extent and the frequency of assistance no longer plays a role as a factor for evaluating the need for care, the focus on performed activities of daily living will become superfluous. The need for assistance in relation to individual measures, which were previously added up in order to determine the Level of Care, shall no longer be the determining factors.

Thus, the question as to “what effect not taking household maintenance into consideration may have on the recognition of a Level of Care” is based on a misunderstanding, particularly when it is pointed out that 45 minutes have always been taken into consideration for such needs. The New Assessment Procedure (NBA) is not intended to leave this need for assistance in maintaining a household out of consideration. It is merely recommended that whether someone is incapable or capable of maintaining a household is not determined separately. The “time factor”, which was predominant up until now, will also now be left out of consideration (Section 15 paragraph 3 SGB XI).

2.3.2.1 Abandoning the Factor of “Time”

The question as to whether it would be possible to abandon the factor of time as a criterion in the newly determined preconditions for graduated levels of long-term care insurance benefits (Section 15 SGB XI – new version) was the subject of a number of controversial discussions within the working group. The factor of time already plays an ambivalent role in determining the need for long-term care under the current system: on the one hand it cannot be denied that care is a service that is remunerated according to the time it takes to provide it. Correspondingly, the additional financial expense that must be met by a person in need of long-term care is essentially determined by the amount of time required for the required assistance. The risk covered by the long-term care insurance is therefore inseparably linked to the factor of time. On the other hand, the factor of time is not suited for the implementation of one of the most essential objectives of the reform, i.e. the inclusion of psychological and/or cognitive impairments in the definition of the need for long-term care. Because the need for twenty-four-hour general supervision, e.g. in order to avoid self-injury or endangering others, is already found, as a rule, in connection with less severe forms of this type of impairment (such as dementia). According to the system applied up until now, persons affected in this manner always had to be assigned to Level of Care III, even though the mere fact that a caregiver is
occupied for a certain period of time at a certain place does not justify such a classification. Furthermore, the factor of time and the term “care by the minute” (Minutenpflege), which has come to be associated with it, is now used to disparage long-term care insurance on the whole. In addition, time is only an easily quantifiable and verifiable criterion at first glance. In fact, it only appears to be a rational criterion, as has been recognised in recent judicial findings.\(^{35}\) Another aspect of the use of the factor of time as a basis for evaluation, which has always been problematic, is the question of whether and to what extent the concrete care situation should also play a role in evaluating the need for long-term care (for example, the living environment as well as the constitution and working methods of actual caregivers).\(^ {36}\) The Federal Social Court was never required to take a clear standpoint on this question.

2.3.2.2 The Criteria for the New Assessment System

The criterion of time should be replaced by a detailed analysis of human capabilities and behaviours, in which the impairments that are found can be evaluated in terms of their severity on the basis of a point system. A weighted point total will provide an indication of the degree to which a person is dependent on personal assistance and, thus, also the level of their claim to long-term care insurance benefits.

2.3.2.2.1 Evaluation System and Weighting

The degree to which independence is impaired is initially surveyed according to a four-stage scale for individual activities:

- independent - 0 points, mainly independent – 1 point,
- mainly dependent – 2 points, dependent – 3 points

In a subsequent step, the individual results of a module are added up and classified on a scale of one to five. The scale of one to five is intended to ensure strong differentiation on this level. Coincidently, the previous system also operated with a division into five levels of care:

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\(^{35}\) Cf. BSG SozR 4-1300 Section 48 No 6. The assessor is allowed “to apply more generous standards in borderline cases”.

\(^{36}\) In the case of stationary care, the assessment of need was made more objective by the stipulation in the assessment guidelines that a standardised flat was to be used as a basis for all assumptions.
Level of Care 0, levels of care I to III, and hardship cases. In the overall evaluation within a module, the following differentiation is used:

- independent
- slight impairment
- considerable impairment
- severe impairment
- complete/extensive loss of independence

The degree of need for long-term care (Degree of Need) should not be derived from the combined assessment of all of the modules without filtering. Based on empirical findings, experts recommend a system of weighting aimed particularly at taking the time needed to care for and supervise people with physical and intellectual deficits into consideration in a fitting and appropriate manner. In this way, the fact is taken into account that the modules “self-care” and “mobility” roughly cover what are now the activities that are valid for assessing benefit claims under the SGB XI. In the opinion of the experts, they still play a central role for the characterisation of the need for long-term care and should be accorded a weight of 50% (self-care 40% and mobility 10%). The areas of “cognition and behaviour” and “managing everyday life and social contacts” are together accorded a weight of 30%. It is proposed that independence in meeting illness- and therapy-related demands should be weighted at 20%.

2.3.2.2 Problems of Implementation

This admittedly brief description of the assessment steps illustrates the fact that the New Assessment Procedure will be arguably more difficult than the previous system for non-experts to understand. To this extent, it confirms the premise that “just“ solutions, as a rule, involve a high degree of differentiation and therefore seem inherently complicated. The working group recognises the difficulties that are likely to result from this, not only in terms of communicating the New Assessment Procedure to the media, but also with regard to how they affect decisions by the administration and legal protection. It will only be possible to properly verify the assessments in legal proceedings by bringing in an expert witness familiar with the MDK instrument (and the assessment regulations). Without support from expert witnesses, on the other hand, social court judges will not be able to adequately monitor the decisions. With regard to the system currently in place, however, it must again be pointed out that the possi-
bility of reviewing the time values determined by the assessor only appears to be a rational option.

The lack of transparency that results from the differentiation in the assessment system will be compensated, according to arguments presented by the experts, by the stringent execution of assessments by the assessors inherent in the system, since the assessors have no leeway in making decisions. The comparatively comprehensive survey, in comparison to the system currently in place, of all impairments and functional disorders that play a decisive role for the need for assistance may also lead to a higher level of acceptance on the part of those affected, because they perceive that their need for assistance is taken into account more comprehensively than in the current system. This may contribute to those affected more readily accepting a result found on this basis (assignment to a Degree of Need).

During the process of transforming the New Assessment Procedure into legal regulations, it will be necessary to determine a conclusive catalogue of the activities and abilities that, if subject to a limitation or impairment, will play a decisive role in determining the need for long-term care in Section 14 (paragraph 2) SGB XI. This seems to be necessary because the assignment to different benefit groups (degrees of need) is to be derived from an overall survey of all of the areas that are to be taken into consideration. In addition essential areas of life must be weighted in order to properly assess the extent of care and supervision needed by persons with physical deficits, on the one hand, and with intellectual/psychological impairments, on the other. This weighting must also be regulated by law. In addition, the decisive point values for determining the degrees of need must also be determined in law.

The working group conducted intensive discussions as to whether the constitutional principle of fundamentality required that the additional regulation of details be included in the law, according to which the procedure to determine the extent of the impairment of independence or disabilities would be determined; systematically it would have had to have been introduced as paragraph 3 in Section 15. After a discussion of this question within the Advisory Board, it was resolved to recommend that reference be made to the assessment guidelines in this conjunction.
2.3.3 Effects of the New Definition of the Need for Long-term Care on Laws Related to Long-term Care Insurance Benefits and Services

The working group assumed that the Advisory Board would be responsible for evaluating the effects of a new definition of the need for long-term care on the basis of the current benefit system. There is no other way of delineating the consequences that result merely from the expansion of the definition or the preconditions for benefits. There is no question regarding whether legislators will be able to make extensive changes in the current benefit system in the wake of a comprehensive reform.

The New Assessment Procedure leads, like the current assessment system to the determination of a status with regard to the need for long-term care, classified according to five graduated degrees of need. The assignment to a Degree of Need determines the amount of benefit to which the insured person is entitled – as in the existing system. The type of benefit is completely independent of this. The variously expressed concern that the consideration given to impairments in a certain area of life (e.g. managing illness- and therapy-related demands) could lead to a reduction in benefits in other areas (such as for domestic nursing care according to Section 37 paragraph 2 SGB V) is not shared.

It will be necessary to make changes in the laws relating to benefits and services as they stand under the current system, in cases where services are oriented on the performance of activities of daily living, as is the case in Section 36 paragraph 2 SGB XI. Accordingly, “basic nursing care and household maintenance / housekeeping encompass benefits and services related to the activities of daily living cited in Section 14 paragraph 4 SGB XI”. If legislators intend to continue differentiating with regard to benefits for domestic nursing care between the low benefit levels for voluntary nursing care (long-term care allowance according to Section 37 SGB XI) and the higher benefit amounts for professional nursing care (long-term care benefits in kind according to Section 36 SGB XI), legal regulations (Section 36 paragraph 2 SGB XI) must be adopted determining for which benefits the so-called in-kind benefits can be substituted. This will also be necessary in order to establish the necessary distinction between domestic nursing care as a benefit provided by the mandatory health insurance system (now already found in Section 36 paragraph 2, 2nd subsection SGB XI) as well as in order to create a reliable basis for supplemental care assistance provided under social assistance law.
It will also be necessary for legislators to decide on how to deal with the improved benefits for persons with limited competence in everyday life, according to Section 45b SGB XI and Section 87b SGB XI, which were introduced in the new Long-term Care Further Development Act. It is sometimes claimed that it is impossible to explain to the population at large that the reform of the definition of the need for long-term care will actually lead in certain cases to fewer benefits for persons with limited abilities to function in everyday life, i.e. the group for which the reform was specifically intended. The working group cautions that maintaining these special benefits after introducing a new comprehensive definition of the need for long-term care must be evaluated against the standard of Art. 3 paragraph 1 of the Basic Law. It must also be verified whether the intended, comprehensive definition of the need for long-term care in keeping with the principle of equality fundamentally allows for different legal regulations for benefits for persons with cognitive disorders. Particularly the introduction of the regulations in Sections 45a and 45b SGB XI of the Long-term Care Further Development Act was justified primarily by the fact that the need for assistance by those affected was not, or not sufficiently, addressed by the existing system. Giving equal consideration to all somatic and intellectual/physical impairments was specifically intended to lead to people with limited competence in everyday life being able to participate equally in the system of benefits.

In the event that the experts’ recommendation that the existence or lack of abilities essential for maintaining a household are not separately surveyed is followed, the effects on subsidiary benefit systems must be considered. It should, however, be noted that this does not entail a decision with regard to the use of benefits from long-term care insurance for maintaining a household. It is merely a consequence of the new orientation of the evaluation procedure: since the time required to provide the needed assistance is no longer apparent as an evaluation factor, the time required to maintain the household is also no longer taken into account.

2.3.4 Positioning a Comprehensive Definition of the Need for Long-term Care in the SGB I

Legislators will need to decide whether to adopt a comprehensive definition of the need for long-term care in the SGB I in order to determine an orientation framework for the other areas of social benefits in which the need for long-term care plays a role as a criterion in determining the eligibility for other benefits. This objective seems to make sense, but was subject to
controversial discussions within the working group. Numerous objections were also raised at the workshop staged by the German Association for Public and Private Welfare. Foremost among the critical remarks was the expression of concern that a general regulation, which would include a definition of the need for long-term care roughly parallel to Section 10 SGB I and define a general claim to assistance,\(^\text{37}\) would raise expectations that could not be fulfilled by the existing system of social security and especially not by long-term care insurance, which is only intended to provide partial coverage. In addition, there is the objection that a general directive on the need for long-term care and the general regulation of the right to participation by disabled persons in Section 10 SGB I would inevitably overlap. The German Association for Public and Private Welfare pointed out that the working group aptly argued in its position paper that there would still be a need for regulation of the special preconditions for benefits in the case of the need for long-term care in every branch of social benefits law after the adoption of a general norm in the SGB I. A norm in the SGB I would only be of declaratorial importance and therefore have more of a symbolic than a normative character.

\(^{2.3.5}\text{The Effects of the New Definition of the Need for Long-term Care on the Relationship between Long-term Care Insurance and Social Assistance (Integration Assistance and Care Assistance)}\)

The newly conceived definition of the need for long-term care and the New Assessment Procedure encompasses the impairments and functional disorders of disabled persons, including the extent to which they are related to aspects of participation, more comprehensively than the current system, which focuses on performed activities of daily living. A specific consequence of this will be that a larger number of people with mental disabilities will fulfil the preconditions for long-term care insurance benefits than was previously the case and will also often be assigned to higher degrees of need than has been the case up until now.

However, the working group does not see itself in a position to judge whether, and to what extent, the New Assessment Procedure is also suitable for determining the need for integra-

\(^{37}\text{Subsequent to the recommendation in the IPW Research Study on the New Assessment Procedure Section 10a SGB I could be reworded as follows: “A person is need of long-term care when that person is permanently or temporarily completely or partially unable, due to physical or psychological injuries or the impairment of physical, cognitive or psychological functions, to compensate for or come to terms with health-related burdens or demands and is therefore dependent upon assistance from others. People who are in need of long-term care have a right to support and assistance in independently performing activities of daily living, in independently coming to terms with illness, and in independently managing areas of life and activities outside of the home.”}
tion assistance, thus making it possible to develop a uniform assessment procedure for both benefit areas. In the view of the working group, its task also did not include submitting proposals to legislators on how to regulate the relationship between long-term care according to the SGB XI and benefits for integration assistance according to Section 53 and following of the SGB XII.

This is also fundamentally true of the relationship between the provisions of the SGB XII regarding care assistance (Sections 61 to 66 SGB XII). To this extent, an extensive need for adaptation can be recognised with regard to the proposed definition of the need for long-term care, because Sections 61 and following of the SGB XII, pertaining to the group of persons entitled to benefits, refer to the definitions in Section 14 paragraph 1 and 4 SGB XI and are, therefore, related to the concept determined there, which defines the need for assistance on the basis of performed activities of daily living; this is to be completely abandoned in the wake of a new definition of the need for long-term care.

2.4 Final Report Second Main Phase

Within the framework of the project entitled “Measures to Establish a New Definition of the Need for Long-term Care and a New, Nationally Uniform and Reliable Assessment Instrument to Determine the Need for Long-term Care according to the SGB XI”, a new instrument for assessing the need for long-term care was jointly developed by the Institute for Nursing Sciences of the University of Bielefeld, and the Medical Advisory Service of the Health Insurance Funds of Westphalia-Lippe within the First Main Phase. In this conjunction, findings and experience from the research were absorbed and implemented in a practically deployable assessment instrument. During practical testing of this instrument by the Medical Advisory Service of the Central Association of the Federation of Health Insurance Funds in Essen and the Institute for Public Health and Nursing Research at the University of Bremen within the context of the Second Main Phase, the instrument was examined with regard to its suitability, goal orientation, and practical applicability.
2.4.1 Statistical Survey of Applicants According to their Degree of Independence

The New Assessment Procedure (NBA) is based on five degrees of need, which, unlike the current assessment procedure, do not reflect the time required to provide the assistance, but rather the degree of independence and the resulting need for personal assistance.

Among the adult applicants, the New Assessment Procedure led to 1.74 % being categorised as independent/not requiring long-term care, 22.62 % as slightly impaired, in their independence, 30.27 % as considerable impaired, 26.11 % as severely impaired and 16.38 % as extremely impaired; in the case of 2.98 % of the applicants a special constellation of need was determined.

2.4.2 The Quality of the Findings

The findings of the Second Main Phase are representative. Random samples of individual parts of the study can, by and large, be viewed as well balanced. There are no statistically significant differences between the applicants who participated in the study and those who did not. Gender aspects were taken into consideration in the study. There were no relevant gender differences in the random samples, so that the random samples also correctly reflect the applications currently being submitted to the MDK.

With regard to the quality criteria, the reliability (degree of reliability of a measurement) can be characterised as “good” and the validity ("Is what is supposed to be measured, being measured?") as “very good”. The New Assessment Procedure also makes it possible to reliably measure relevant changes among the insured persons (e.g. deterioration of their condition). These are excellent results for a newly developed instrument, which is, however, still open for further development based on experience with its everyday use (a learning procedure).

Additional possibilities for an optimisation will therefore be used: Compliance between the assessors could be increased by training them more intensively and thus improving the reliability of the procedure. Later adjustments within individual modules as a result of additional experience with the instrument may also prove to be helpful.
The weighting of the modules in relation to each other and the construction of the overall instrument will not be affected by this; it has proved to be useful.

2.4.3 Surveying Cognitive Impairments

With regard to the surveying cognitive impairments, the New Assessment Procedure completely fulfils the expectations related to it. This group of persons, which was previously difficult to assess, was addressed successfully by the New Assessment Procedure. Hence, one of the most important goals of the new assessment instrument has been realised. Yet at the same time, physically impaired persons are not at a disadvantage as a result of the assessment. In comparison with the Test for the Early Recognition of Dementia with Differentiation from Depression (TFDD), as a recognized reference procedure for surveying cognitive disorders, the New Assessment Procedure provides very good results (validity) in the area of Modules 2 (Cognitive Disorders) and 3 (Behavioural Disorders). The agreement between the two procedures was 89%.

2.4.4 Recommendations for Rehabilitation Measures

The frequency of recommendations for rehabilitation measures according to the New Assessment Procedure is higher, at 4.09%, than in the present study according to the current procedure at 1.41%. The possibility of recommending additional clarification of the need for rehabilitation in the New Assessment Procedure, for example by initiating an assessment by a medical specialist, was seldom used, totalling 0.74%. The result, as to how the rehabilitation potential will be estimated for a high percentage of the people assessed, should be the subject of an additional study.

2.4.5 Practical Application

The time required for an assessment according to the New Assessment Procedure was roughly 60 minutes and thus within the timeframe of the current assessment. For children, the time required was somewhat higher, at 70 minutes. In the practical application of the New Assessment Procedure the information on the medical history, case history as regards care, situation with regard to care and supervision, and the findings surveyed must, above all, be formulated.
This can be partially standardised, in free text with individual information, but should at any rate not be neglected. Here again the experience with the New Assessment Procedure is likely to lead to more improvements in terms of the time and effort involved in its performance.

2.4.6 Assessing Children

With regard to the assessment of children, the results were positive on the whole, although they were not as clearly indicative as the results for adults. Since the database for children’s assessments is still small, more experience must be gained. In addition, it is expected that the results can be improved in practice when the assessors are more familiar with the new instrument and have been thoroughly trained. As cautioned by the authors of the report on the First Main Phase, it should also be considered whether the assessment for children in its present form should continue to be used for children up to the age of 18 months.

2.4.7 Distribution of the Degrees of Need

The levels of care from the current process must be judged differently in terms of content than the degrees of need according to the New Assessment Procedure (NBA).

Currently, people in need of long-term care are distributed into one of three care levels according to Sections 14, 15 SGB XI based on the frequency of assistance within the context of basic care (personal hygiene, nutrition, mobility) and the time that is required to provide it.38 People in need of care in Level of Care I (considerable need for long-term care) require care at least once a day, those in Level of Care II (severe need for long-term care) require basic care at least three times a day at different times as well as assistance a number of times a week in caring for their households. People in need of long-term care in the Level of Care III (in extreme need of long-term care) require assistance for basic care 24 hours a day, 7 days a week, as well as household help a number of times per week. Section 15 paragraph 3 SGB XI determines the required minimum time for care in this conjunction. Consequently, the time required for the necessary benefits of basic care and help in maintaining the household for people in need of long-term care in the Level of Care I should entail 90 minutes on a weekly average, whereby more than 45 minutes must be devoted to

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38 The need for assistance only in maintaining a household does not – as can be seen in Section 15 paragraph 1 SGB XI – result in the recognition of a considerable need for long-term care.
For people in need of long-term care in the Level of Care II, the time required should be three hours with at least two hours for basic care. For those in need of long-term care in the Level of Care III, at least five hours are required with four hours devoted to basic care.

In light of the classification in degrees of need in the new assessment instrument, it is not possible to equate the system with the levels of care according to the current assessment procedure (levels of care I to III) with regard to what each level entails; a direct comparison of the two instruments is therefore impossible. The New Assessment Procedure introduces a new classification of need for long-term care. It is oriented on the degree of independence and is thereby also able to evaluate it in a more differentiated manner in order to depict the result in degrees of need.

2.4.8 Fiscal Effects on Long-term Care Insurance

In the final report on the Second Main Phase model calculations of the effects of the introduction of the New Assessment Procedure on the expenditures for benefits in long-term care insurance have been carried out. They are intended to provide an impression of the possible expenditure effects under defined conditions (see below). The results presented are based on status quo framework conditions. This means:

- The distribution of outpatient/inpatient benefits corresponds with the current distribution among those now need of long-term care.
- The distribution of types of benefits corresponds with the current distribution.
- The amounts of benefits on which it is based correspond with the amounts that are currently determined by law.

Changes in these framework conditions, which are important for benefit expenditures, are conceivable – through legislative decisions or, for example, through changes in the behaviour of the applicants.

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39 What is meant here is the time required daily on average throughout the week – cf. BSG, decision dated 17 June 1999 – Az: B 3 P 10/98 R.
In addition, the expenditures depend upon,

- Which scores a person in need of long-term care attains in the New Assessment Procedure and
- Which threshold values are determined for the definition of the degrees of need

The scores in turn depend upon the internal characteristics of the instrument, especially on the design of the items and modules, as well as their weighting. The characteristics of the instruments have, however, been determined by considerations based on sound nursing science. Statistical calculations for the sake of orientation have shown that only very drastic shifts, for example in the weight of the modules, actually lead to changes that are relevant in terms of expenditures. These shifts can, however, no longer be justified by nursing science. For this reasons no modifications of the instrument itself were undertaken for the evaluation. Changes are, on the other hand, possible for the point values that divide the individual degrees of need for long-term care from one another (threshold values). If the threshold values are shifted to higher point values, then fewer people in need of long-term care are categorised as having higher degrees of need or any Degree of Need for which benefits are provided. If the thresholds are shifted down, then more people in need of care become entitled to benefits. In the final report on the First Main Phase, a recommendation was made for such threshold values.41 However, this recommendation is not based on the findings of nursing science in the same manner as, for example, the modular weighting is, and it is supported, at best, by very preliminary data (pre-test). Relatively slight shifts in the threshold values also lead to marked effects on the benefit expenditures. For these reasons, the threshold values between the degrees of need were modified.

2.4.8.1 Scenarios for Determining Threshold Values

Every assessment made with the New Assessment Procedure produces a result with a total score of between 0 and 100 points that depicts the Degree of Need for long-term care. This score is divided into degrees of need on the basis of threshold values. The definition of the values has a decisive influence on the classification of those entitled to benefits according to degrees of need. It is theoretically possible that the threshold values could be determined arbitrarily, thus a wide variety of possible combinations is conceivable. The point of departure for

the model calculations was a combination of threshold values undertaken in the First Main Phase, which in turn resulted in a certain classification. A claim to benefits (Degree of Need 2) begins at a threshold value of 30 points.

In addition to this fundamental or basic model, two types of scenarios were taken into consideration:

**Model 1:** The threshold value that defines the entry into the benefit system is kept constant at a value of 30 points. The threshold values that mark the entrance into the degrees of need 3 and 4 are varied systematically. In this context the intervals between the threshold values remain constant.

**Model 2:** All of the threshold values are gradually increased in the same manner.

Table 1 contains the model calculation used in the threshold values for the total of five scenarios:

- Variation 1A or 2A according to the recommendation made in the First Main Phase,
- Variation 1B or 2B, which is intended to ensure cost-neutrality in outpatient care,
- Variation 1C or 2C, which is intended to ensure cost-neutrality in both outpatient and inpatient care.42

### Table 1: Threshold Values of the Variations Examined

<table>
<thead>
<tr>
<th></th>
<th>Variation 1A</th>
<th>Model 1 Variation 1B</th>
<th>Variation 1C</th>
<th>Variation 2A</th>
<th>Model 2 Variation 2B</th>
<th>Variation 2C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Degree of Need 1</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>11.25</td>
<td>12.5</td>
</tr>
<tr>
<td>Degree of Need 2</td>
<td>30</td>
<td>30</td>
<td>30</td>
<td>30</td>
<td>33.75</td>
<td>35</td>
</tr>
<tr>
<td>Degree of Need 3</td>
<td>50</td>
<td>56.25</td>
<td>58.75</td>
<td>50</td>
<td>55</td>
<td>57.5</td>
</tr>
<tr>
<td>Degree of Need 4</td>
<td>70</td>
<td>81.25</td>
<td>87.5</td>
<td>70</td>
<td>76.25</td>
<td>80</td>
</tr>
<tr>
<td>Degree of Need 5</td>
<td></td>
<td>Degree of Need 4 with a special constellation of need</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In the case of Variation 1A and 2A, the threshold value combination is the same as the one recommended in the First Main Phase.

42 Cost neutrality is hereby assumed to be correspondence with the estimated costs when the current assessment procedure is applied vs. the New Assessment Procedure, within a tolerance of approx. +/- 2 %. Fundamentally, however, one must assume a residual uncertainty for both the subsequent and previous cost estimates.
2.4.8.2 Results

Table 2 contains the results of the model calculation for the five scenarios. As the table shows, the basic variation results in increased expenditures of 3.4 billion euros for the social long-term care insurance. By varying the threshold values, these additional expenditures can, however, be reduced and near cost-neutrality can be ensured in the Variations 1C and 2C.

Table 2: Comparison of the Absolute Frequency in Status Quo and in Various Scenarios

<table>
<thead>
<tr>
<th>Variation</th>
<th>Benefit Recipients in each Degree of Need / Level of Care (I-III)</th>
<th>Benefit Expenditures in billion euros</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>B 2 / I</td>
</tr>
<tr>
<td>Current Definition of Need for Long-term Care</td>
<td>1,964,288</td>
<td>1,044,008</td>
</tr>
<tr>
<td>1A/2A</td>
<td>2,023,242</td>
<td>772,461</td>
</tr>
<tr>
<td>1B</td>
<td>2,023,242</td>
<td>1,024,071</td>
</tr>
<tr>
<td>1C</td>
<td>2,023,242</td>
<td>1,127,897</td>
</tr>
<tr>
<td>2B</td>
<td>1,875,670</td>
<td>811,207</td>
</tr>
<tr>
<td>2C</td>
<td>1,843,019</td>
<td>919,319</td>
</tr>
</tbody>
</table>

2.4.9 Conclusion

The instrument that was developed represents a very good basis for translating the determined degree of dependency on long-term care into long-term care insurance benefits. In order for it to be employed in practice, a reliable connection must be established between the boundaries of the degrees of need (and with them the threshold values of the scores) and the related claims to benefits. In this conjunction, it should be ensured that the classification takes the degree of dependency into consideration in an appropriate manner, while at the same time the financial consequences for the social security system remain calculable. The project group responsible for the Second Main Phase calculated the economic effects of the introduction of various increments and submitted the results to the Advisory Board for consideration. An al-
teration of the assignment of degrees of need and levels of benefits can also be considered either as an alternative or as an additional measure.

In conclusion, the project group recommended the instrument that was developed as productive, suitable and practical for the assessment of people who may be in need for long-term care in the sense of an expanded definition of the need for long-term care that corresponds with the findings of modern nursing sciences.

2.5 Reciprocal Structural Effects on other Areas of Social Benefits, Particularly on Social Assistance (Care Assistance, Integration Assistance)

2.5.1 Description of the Problem

The implementation of a new and comprehensive definition of the need for long-term care in laws related to benefits and services has direct and reciprocal effects on other areas of social benefits and, in this context, especially on integration assistance for disabled persons and on care assistance according to the SGB XII. A particular problem in this context is the lack of an overall concept of supervision and care of people who are in need of long-term care, disabled, and elderly. However, particularly as a result of the close interconnections and through the many points of contact between benefits according to the SGB IX, XI and the SGB XII, such an overall concept seems essential.

2.5.2 Systematic Organisation of Social Insurance Law / Relationship of the SGB XI to the SGB XII

The different legal character of benefits according to the Social Code Books XI and XII – social insurance law in the SGB XI, on the one hand, and public welfare law in the SGB XII, on the other – reflects a clear priority system. When the preconditions are fulfilled, citizens initially have a claim to benefits that they have gained by paying contributions, in this case benefits from long-term care insurance.

While there was virtually no connection between the benefits from integration assistance and other social benefits before the introduction of long-term care insurance, the introduction of
long-term care insurance as of 1995 brought system-imminent changes with it. Along the fact that the costs were carried by different agencies made a determination of the boundaries necessary. This was initially undertaken in orientation on the location where the benefit was provided, since no long-term care insurance benefits are provided (Sections 43 paragraph 1, 71 paragraph 4 SGB XI) in facilities for the disabled. In order to mitigate the problem of long-term care-type benefits being provided in facilities for the disabled, Section 43a SGB XI was introduced, according to which a lump sum payment for nursing care expenditures at a rate of max. 256 euros per month was provided by the long-term care insurance fund.

There is now, for the most part, very little difficulty in determining the boundaries between care assistance benefits according to the SGB XII and long-term care insurance benefits according to the SGB XI, since the limited-extent, lump sum, long-term care insurance benefits are provided for a clearly defined share of the care required by people in need of long-term care. The additional need for long-term care not covered by the long-term care insurance (supplemental benefits and expanded definition of the need for long-term care) is the personal responsibility of the person in need of long-term care, in cases where there is a need for long-term care according to the stipulations of the SGB XII, social welfare benefits can be claimed.

2.5.3 Consequences of the New Definition of the Need for Long-term Care

With the introduction of an expanded definition of the need for long-term care oriented on participation, the following effects present themselves:

- When the SGB IX came into force in 2001, a paradigm shift was effected, which also had decisive influence on the interests of people in need of long-term care. People with disabilities have also been fundamentally seen as people in need of long-term care, at the latest, since the new definition of the concept of disability in § 2 SGB IX. However, not every person with a disability is also in need of long-term care according to current law. Accordingly, the need for long-term care is a subset of disability according to the understanding of social law. There are also a number of situations in life in which a disability without the characteristic of the need for long-term care exists. However, the more comprehensive the definition of the need for long-term care is, the larger the group of disabled persons will be who are also considered to be in
need of long-term care. It should also be added that long-term care oriented on participation overlaps with integration assistance to a greater degree.

- An overall concept is also necessary because the benefits of integration assistance and participation benefits according to the SGB IX, which are anchored in the social welfare law, are always subsidiary in rank to insurance benefits. In the actual providing of services, the assistance to facilitate participation is, on the other hand, more comprehensive. The objective and goals of participation (Section 10 SGB I and § 4 SGB IX) overlap with the objective of long-term care circumscribed in Section 2 paragraph 1 SGB XI – also from the perspective of a new, more extensive definition of the need for long-term care.

- In the wake of the formulation of long-term care insurance law as a provision of partial coverage against the risk of the need for long-term care, long-term care insurance will continue to provide only lump-sum benefits of limited volume. Therefore, the population must be informed of the fact that in order to cover the need that has now become obvious through the more comprehensive assessment, it will be necessary in certain cases to draw on personal means or other types of social benefits.

- It is also necessary that the relationship and thus the interface between integration assistance and care assistance be described in light of a more extensive definition of the need for long-term care based on the principle of participation, so that the law can also be applied as clearly and free of dispute in the future. A new definition of the need for long-term care will not make integration assistance superfluous. The approach of integration assistance, to enable a disabled person to participate in society, differs from that of long-term care. The New Assessment Procedure is also not intended to completely depict the individual needs for assistance by disabled people in need of long-term care who apply for integration assistance, because its primary objective is to classify those assessed in terms of degrees of need. The necessary breadth for planning individual assistance will not be achieved through the New Assessment Procedure. However, the New Assessment Procedure still seems to be fundamentally suited to provide important and useful information for the determination of the need for integration assistance and care assistance.
2.6 Financial Effects of the Implementation of the New Definition of the Need for Long-term Care and the Corresponding Assessment on Social Assistance Agencies and the Long-term Care Insurance Funds (Supplemental Project – Dec. 2008 Rothgang et al.)

2.6.1 Introduction

The most important goal of the Second Main Phase was to review the reliability and practical suitability of the New Assessment Procedure for the evaluation of the need for long-term care. The population studied was, however, limited to applicants according to SGB XI benefits. Therefore, it was not possible to determine how the new assessment instrument and a new definition of the need for long-term care affected persons who had never submitted an application for benefits according to the SGB XI because they saw no prospect of success under the old process. A second group of potential SGB XI benefit recipients systematically under-represented due to the design of the Second Main Phase were disabled people in facilities for the disabled. In addition, the question as to the fiscal effects for the social assistance agencies was not the subject of the Second Main Phase. In order to pursue these questions, a supplemental project was developed and agreed to in the summer of 2008.

2.6.2 Research Brief

The expansion proposal is aimed at answering three questions, which will be studied in three working blocks:

1. How many disabled people currently receiving benefits through integration assistance, would receive SGB XI benefits in future as a result of the implementation of a new definition of the need for long-term care and the corresponding assessment procedure, and which financial consequences would this have on long-term care insurance and the social assistance agencies?

2. How large is the proportion of “others in need of long-term care” who have not submitted applications to date but who would receive SGB XI benefits in the wake of an implementation of a new definition of the need for long-term care and the corresponding assessment
in future, and which financial consequences on long-term care insurance and for social assistance agencies are related to this?

3. Which additional expenditures may arise for social assistance agencies in the area of care assistance in facilities as a result of the increased number of cases and the increase in the degrees of need on the part of people in need of long-term care on an inpatient basis?

### 2.6.3. Implementation

Different methods are used in answering these questions, thus the results exhibit varying degrees of reliability:

- **Working Block 1**: In order to determine the effects of the new definition of the need for long-term care and the corresponding New Assessment Procedure on disabled persons in facilities for the disabled, a total of 242 assessments in facilities for the disabled were undertaken by the MDK Westfalen-Lippe in the district of Westphalia-Lippe, in which the degrees of need of disabled persons in the sample were classified according to the New Assessment Procedure. Since all of the recipients of integration assistance in inpatient facilities in NRW regularly submit applications for SGB XI benefits and the result of the assessment process according to the currently valid process is thereby available, it is possible for the sample to determine which shifts result from the change to the New Assessment Procedure. The results will then be extrapolated to the national level.

- **Working Block 2**: In order to assess how many “people in need of assistance” who have never previously submitted an application for SGB XI benefits will now be able to claim long-term care insurance benefits and which expenditures will result from these claims for the agencies that administer long-term care insurance, Ulrich Schneekloth, project director in charge at TNS Infratest, conducted a re-analysis of the data from the interview for the “Möglichkeiten und Grenzen selbständiger Lebensführung im Alter“ (Possibilities and Limits of Living Independently in Old Age, Ger. abbr. = MuG) studies.43

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43 For the study on the possibilities and limits of living independently in old age, TNS Infratest was commissioned by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth to conduct representative interviews in 2004 and 2007 (Schneekloth/Wahl 2005 and 2007). The survey data were used for a reanalysis, which was specifically undertaken for this study.
- **Working Block 3**: Unlike the Working Blocks 1 and 2, the Working Block 3 is related to a group of persons already studied in the Second Main Phase. By using mathematical models it was possible to estimate to which extent additional expenditures are incurred by the social assistance agencies when the residents of homes are classified according to the New Assessment Procedure. In order to calculate the fiscal effect, the determination of both the thresholds (including the variations) and the benefit sums from the report on the Second Main Phase were adopted. Thus, these calculations are derived from mathematical models that operate on assumptions that are varied depending on the scenario, and not on implementation recommendations. The results of these model calculations can also be drawn upon to make adjustments in benefit law.

### 2.6.4 Financial Effects on Social Assistance Agencies and the Long-term Care Insurance Funds in Overview

The application of the New Assessment Procedure leads, on the one hand, to a change in the number of persons classified as “in need of long-term care” (*volume effect*). According to the results of the Second Main Phase, there is a slight reduction in the number entitled to benefits in outpatient care, while there is a (somewhat higher) increase in the number of people entitled to benefits in inpatient care. In addition, there is a *structural effect*, which consists of the fact that in both outpatient and inpatient care the new degrees of need are, on average, higher than the levels of care to which they are equated under benefit law. This effect is of greater fiscal relevance than the volume effect. Drawing on the assumptions that were introduced in the Second Main Phase concerning the threshold values for the individual degrees of need and the claims to benefits related to them, qualitative prognoses concerning the type and direction of the fiscal effects on the long-term care insurance system and social assistance agencies, as well as the effects on those in need of long-term care and service providers, can be derived. In this conjunction, a differentiation should be made between the way the three groups of people because they were defined differently in the three working blocks. Table 3 summarises the effects of the long-term care insurance and the social assistance agencies.

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44 Variation 1A is used here as a basic model (terminology of the Report on the Second Main Phase), the threshold values of which correspond with the proposal from the First Main Phase.

45 The currently valid levels for the claims to benefits according to the SGB XI are used, whereby the new degree of need 2 is equated with the old level of care I, the new degree of need 3 with the old level of care II and the new degree of need 4 with the old level of care III.
Table 3: Type and Direction of the Financial Effects on Long-term Care Insurance and Social Assistance Agencies

<table>
<thead>
<tr>
<th></th>
<th>Long-term Care Insurance</th>
<th>Social Assistance Agencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Applicants for inpatient care up until now</td>
<td>Increased expenditures because of volume and structure effects (see Second Main Phase)</td>
<td>Increased expenditures for care assistance due to the effects in terms of structure and volume (Estimation in Report)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Applicants for outpatient care up until now</td>
<td>Increased expenditures because the structural effect plays a greater role than the volume effect (see Second Main Phase)</td>
<td>Increased or decreased expenditures depending on the manner in which supplemental care assistance is provided</td>
</tr>
<tr>
<td>“Those Otherwise in Need of Help”</td>
<td>Increased expenditures because of a growing number of people in need of long-term care (Estimation in Report)</td>
<td>Increased expenditures because of a growing number of people in need of long-term care</td>
</tr>
<tr>
<td>Disabled people in facilities for the disabled</td>
<td>Increased expenditures because of a growing number of people in need of long-term care (Estimation in Report)</td>
<td>Roughly the same decrease in the expenditures by the social assistance agencies (Estimation in Report)</td>
</tr>
</tbody>
</table>

2.6.5 Social Policy Conclusions of the Study

In addition to the fiscal effects already cited in the final report on the Second Main Phase, additional fiscal effects are also to be expected in the wake of the implementation of the New Assessment Procedure, such as:

- Increased expenditures by the social assistance agencies resulting from the growing number of people in need of long-term care among those otherwise in need of assistance,

- Increased expenditures by the social long-term care insurance for “those otherwise in need of assistance” who have not yet received applications for long-term care insurance benefit, but who will be partially entitled to benefits when the New Assessment Procedure is implemented,
• Additional expenditures by the statutory long-term care insurance system for disabled persons in facilities for the disabled and the corresponding reduction in expenditures by the social assistance agencies and

• Increased expenditures by the social assistance agencies for care assistance in facilities.

The weight of the corresponding fiscal effects will especially depend upon the definition of the threshold for the degrees of need.

Additional expenditures of 0.58 billion euros for care assistance in facilities would result for the social assistance agencies from the Basic Variation 46. At the same time, the social assistance agencies’ costs for disabled persons in facilities for the disabled will be reduced by about 0.20 billion euros, which must be provided as additional benefits according to Section 43a SGB XI by the long-term care insurance system. By determining other threshold values, these fiscal effects are shifted between social assistance agencies to the point of being cost-neutral and beyond, in the case of the long-term care insurance at least to the point of a clear reduction of the expenditure increase. In total, increased expenditures of at least 0.24 billion euros (in Scenario 1C) remain for the social insurance agencies and social long-term care insurance.47 Which of the variations is preferred is ultimately a political question. Table 4 presents an overview of all of the fiscal effects as a function of the threshold value scenarios. However, the group of the “those otherwise in need of assistance” should be taken into consideration, i.e. people who have a need for long-term care under the threshold for claiming benefits in effect up until now, and have never applied for long-term care insurance benefits for this reason, but who may be prompted – by the introduction of the New Assessment Procedure – to submit an application with a prospect of success. The resulting costs for the long-term care insurance system can only be roughly estimated. This – uncertain – estimation results in additional expenditures of another 400 million euros, which are not included in the table. If the Degree of Need 1 also entailed a claim to benefits, considerable additional benefits could be expected here.

46 Cf. footnote 41.
47 Regarding the scenarios, cf. 2.4.8.
Table 4: Fiscal Effects of New Assessment Procedure Using Different Scenarios to Determine the Threshold Values

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Additional Expenditures Depending on the Threshold Value (in billions € per annum)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1A</td>
</tr>
<tr>
<td>Social assistance agencies</td>
<td></td>
</tr>
<tr>
<td>Care assistance in facilities</td>
<td>0.58</td>
</tr>
<tr>
<td>Integration assistance</td>
<td>-0.20</td>
</tr>
<tr>
<td>Total</td>
<td>0.38</td>
</tr>
<tr>
<td>Long-term care insurance</td>
<td></td>
</tr>
<tr>
<td>Benefits according to Section 43a</td>
<td>0.20</td>
</tr>
<tr>
<td>SGB XI</td>
<td>3.40</td>
</tr>
<tr>
<td>other benefits¹</td>
<td>3.60</td>
</tr>
<tr>
<td>Total²</td>
<td></td>
</tr>
<tr>
<td>Long-term care insurance and social assistance</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>3.98</td>
</tr>
</tbody>
</table>

1) The estimates are adopted from the final report of the Second Main Phase (Windeler et al. 2008: 104).
2) 1.07 billion euros represent a contribution level of 0.1 percentage points to social long-term care insurance – Stand 2009.

Up until this point, only one of the parameters that can serve as a possible “adjustment screws” in controlling expenditures, namely the definition of the threshold values for the degrees of need, has been addressed for the expenditures. The fiscal effects can also be influenced by adjusting the laws related to benefits and services and the benefits provided under these laws.

If the new degrees of need according to the New Assessment Procedure are equated with the old levels in terms of benefits law, the result is an “upgrading” of those in need of long-term care today as well as an expansion of their claim to benefits. Yet it is still a case of the same people with the same abilities and the same deficits. It can, on the one hand, be argued that the New Assessment Procedure recognises their needs more precisely, and that the expansion of benefits is therefore correct. On the other hand, it can be argued that in the wake of the New Assessment Procedure it is not the level of benefits (in a partial coverage system) that should
be changed, but rather the structure of the system giving cognitive impairments more consideration and somatic impairments less. If the latter argument is accepted, then an adjustment of the benefits law downwards would be the logical consequence. In the inpatient sector, the distribution of the long-term care insurance benefits could be adjusted to correspond to the remuneration for care in homes.

There are also possibilities of making adjustments through the legal framework related to the *provision of care*, particularly with regard to the remuneration provided for homes. In the case of a given home population, the new assessment will result in more income for the homes if the connection between remuneration classification in homes and the Level of Care/Degree of Need is maintained and levels of care rates remain unchanged. To the extent that staffing levels differentiated according to degrees of need are used, this will also result in changes in staffing and quite likely also to changes in the benefits and services offered. Since increasing the budgets of homes is not the objective of the revised definition of the need for long-term care, adjustments could be undertaken here. Thus, a budget-neutral transition could be agreed to, or the introduction of a different system of remuneration, derived from the degrees of need, could be considered, or the care rates could be reduced. The latter could either be undertaken in agreements on the levels of compensation or introduced by legislators in connection with the formulas used for their calculation.

Whether the increased expenditures by the funding agencies responsible for providing financing, which were calculated under the status quo conditions, must be accepted, or whether one (or a number) of the described methods for reducing the increased costs is applied, is a political question that must be decided by the responsible political bodies in a democratic process. The present report merely pursues the objective of illustrating the fiscal consequences of certain decisions and providing decision makers with the information needed to make a rational decision.
Chapter 3: The Advisory Board’s Recommendations

3.1. Preamble

Our society must measure itself on how it treats people, how it encounters people with a need for long-term care and/or disabilities and, especially, on how it enables them to participate in the life of society.

The proposal for a new definition of the need for long-term care addresses this task in order to improve the situation of the person affected and to initiate an ethically relevant shift in perspective: the orientation away from an image of people in need of long-term care that focuses on their deficits and lacking abilities, towards one that allows us to recognise the extent of their independence.

Focussing on the extent of their independence enables a holistic and context-related perception of the living situations of the people in need of long-term care and thus more fairness in taking people’s impairments into consideration; in addition it also helps to avoid unequal treatment of people with different disabilities or entire groups of people.

Taking consideration of people’s desire to remain independent is an expression of esteem, it demonstrates respect for their living situations, recognises their dignity, and promotes their sense of responsibility in the same way that it promotes reliable solidarity on behalf of people in risk situations that overtax their strength and their options for dealing with them.

The limited resources available for the implementation make highly transparent, person-oriented assistance a necessity; the determination of financial priorities must take the framework conditions of a society in which people live longer and the resulting increase in the number of persons in need of long-term care into account.

People in need of care have a right to quality assured, dignified care, support, and consideration in keeping with their personal needs, and aimed at promoting their abilities until the end of their lives.
3.2 The Need for a Change in the Definition of the Need for Long-term Care

The current definition of the need for long-term care in the SGB XI does not correspond with the current state of knowledge in nursing sciences. This is true, for one, of the limited basis for making assessments, which is related solely to the need of assistance help in performing activities of every day living. On the other hand, the use of the factor of time as a unit of measurement for the extent of the assistance required in individual cases is not appropriate according to the findings of nursing sciences.

The currently valid definition of the need for long-term care also unevenly represents people’s requirements for assistance. The catalogue of activities that is the only indication used to determine the need for long-term care according to Section 14 paragraph 4 SGB XI exhibits considerable shortcomings in the consideration it gives to people with cognitive and psychological impairments. The unequal treatment of those in need of assistance as a result of the loss of physical functions is also a reason why change is needed.

Furthermore, the current definition of the need for long-term care and the assessment instruments that accompany it have proved to be insufficient in assessing children.

The Advisory Board therefore recommends a definition of the need for long-term care that addresses these aspects and does them justice.

3.3 A Differentiated Definition of the Need for Long-term Care Oriented on People’s Living Situations and their Degree of Independence

The Advisory Board believes that what is needed is a definition of the need for long-term care that encompasses all physical and intellectual or psychological impairments and disorders along with an assessment system that flexibly takes the circumstances and needs of people in need of long-term care and assistance into account and ensures a high degree of differentiation and transparency as well as acceptance for those affected.

Surveying the need for support on the basis of an extensive assessment of physiological, cognitive, and psychological limitations requires a paradigm shift in the assessment of the need
for support. Instead of the time required to provide care, and the frequency and rhythm of the assistance provided, the focus is only on the degree of independence or the loss of independence in performing activities. The same is true of managing areas of everyday life.

3.4 The New Assessment Instrument

During the examination of the existing assessment instruments in both the preliminary study by the Institute for Nursing Sciences at the University of Bielefeld and in discussions within the Advisory Board, it became evident that none of them is able to simultaneously do justice to a comprehensive understanding of the need for long-term care and the demands of long-term care insurance. An adaptation of these instruments and/or their combination is also problematic due to extensive questions regarding the content, methods, practical considerations and, in certain cases, licensing rights.

Therefore, the Advisory Board decided in favour of a new assessment instrument that corresponds with international standards. It was developed by the Institute for Nursing Science at the University of Bielefeld (Ger. abbr. = IPW) and the Medical Advisory Service of the Health Insurance Funds of Westphalia-Lippe and tested by the Institute fur Public Health and Nursing Research at the University of Bremen (Ger. abbr. = IPP) and the Medical Advisory Service of the Health Insurance Funds in Essen. The “New Assessment Procedure” (Neue Begutachtungsassessment or NBA) fulfils the criteria with regard to reliability, validity, sensitivity, specificity and sensitivity to change. The results of the study are representative.

Experience in the testing phase shows that the assessors must be thoroughly trained in how to deal with the New Assessment Procedure. The assessors should already have had some form of qualified training and sufficient professional experience.

3.5 The New Assessment Procedure as an Instrument to Assess the Need for Long-term Care

The Advisory Board recommends the New Assessment Procedure as an instrument to assess the need for long-term care in the sense of an expanded, all-encompassing definition of the need for long-term care.
The New Assessment Procedure offers a good foundation for the appropriate implementation of the proposed all-encompassing definition of the need for long-term care. It contributes to the realisation of the envisioned objective, namely making the benefits of the long-term care insurance system available to all people in need of long-term care in recognition of the principle of equality.

The New Assessment Procedure encompasses both the possibility of describing the need for long-term care in terms of nursing science as well as its implementation in social law. It is also an example of a learning system, which is able to improve its characteristics in relation to its purpose by means of evaluation and to integrate new findings of nursing sciences.

The procedure is fundamentally suited and can be practically implemented for assessing people in need of long-term care in the sense of an expanded and comprehensive definition of the need for long-term care.

There is still a need for optimisation, however, especially with regard to the module “self care” (Module 4), the module “activities outside of the home” (Module 7) as well as in the assessment of special constellations of need. The need of optimisation exists just as much with regard to the assessment of the need for long-term care as in conjunction with the assessment of the need for long-term care for children. Because of what is currently still a relatively small database for children, information on additional experience must be collected.48

The Advisory Board recommends pursuing the improvement options that became evident during the Second Main Phase of testing and adjusting the New Assessment Procedure correspondingly and further developing it. The Advisory Board estimates that the problems can be solved in the near future.

3.6 Describing Situations of Need through the Modules

The modular structure of the New Assessment Procedure represents activities and areas of life that are relevant in determining the need for long-term care and which make it possible to survey partial areas of the need for long-term care that can be clearly differentiated in terms of content.

Cognitive limitations and especially modes of behaviour are reliably surveyed. Physical limitations are comprehensively surveyed to the same extent.

The New Assessment Procedure is suited for taking gender aspects into consideration.

The Advisory Board considers the modular assessment procedure for an essential improvement over the current evaluation system. It finds that the living situations of people with intellectual disabilities, dementia and geronto-psychiatric disorders, in particular, are more satisfactorily surveyed.

3.7 Classification in Degrees of Need

The Advisory Board recommends that the term “Level of Care” be replaced by the term “Degree of Need” in order to more clearly express the new, comprehensive understanding of the need for long-term care.

In determining the assignment to a Degree of Need, the degree of dependency on personal assistance must be appropriately taken into consideration. A larger number of degrees of need contributes to greater equality in taking need into consideration in this context. The Advisory Board accepts the proposal for the determination of five degrees of need in the New Assessment Procedure under the provision that these are tied to benefits. In this conjunction, the increments “slight impairment of independence”, “considerable impairment of independence”, “severe impairment of independence” and “extreme impairment of independence resulting in special requirements for long-term care” (Degree of Need 4 with a special need constellation)” are adopted in keeping with the New Assessment Procedure.

For the assessment of the degree of need for long-term care and/or the determination of the Degree of Need, the module “activities outside of the home” (Module 7) and the module “maintaining a household” (Module 8) are not necessary in terms of methodical considerations, since the contents relative to nursing care are already addressed in other modules. They are, however, needed for comprehensive counselling and for individual planning of care and assistance, hence they will also be taken into consideration in the assessment in the future.
The combined assessments of all modules should not flow into the determination of a Degree of Need unfiltered. What is recommended is a system of weighting with the objective of taking the time required for the care and supervision of people with physical and cognitive as well as psychological deficits into consideration in an objective and appropriate manner.

3.8 Determining the Need for Rehabilitation

The New Assessment Procedure determines the need for rehabilitation in the sense of temporary medical rehabilitation according to Section 26 SGB IX. Nevertheless, there are still considerable questions with regard to the clarification of the need for rehabilitation.

Because of the increased importance and greater recognition of the need for rehabilitation before, after, and during long-term care, as well as the legal obligation for its provision, the Advisory Board recommends that special attention be devoted to the fields of prevention and rehabilitation in implementing the New Assessment Procedure and that further studies are conducted in order to determine whether the number of recommendations corresponds with the actual need for rehabilitation benefits.

The training of assessors to determine the need for rehabilitation on the part of people in need of long-term care must be improved.

3.9 Suitability for Drafting Individual Care, Assistance and Service Plans

The New Assessment Procedure takes risks and situations of need into consideration in order to derive findings that can be used for planning care, assistance and services; it is also suited for determining the need for care according to the given degree of independence. It can therefore serve as a basis for planning care and services within the context of the SGB XI. The New Assessment Procedure is not a substitute for a comprehensive care, assistance and services plans. This remains the task of the social security agencies and the service providers.

In cases where benefits from a number of social security systems come into question for a person, the modular structure of the New Assessment Procedure allows its findings to be used as a source of orientation in determining central areas of need.
3.10 Proposal for New Legal Regulations in Sections 14 and 15 SGB XI

Within the framework of the implementation in social law, a final catalogue of the activities and abilities that are to be taken into consideration is required. In addition, a weighting of the areas of everyday life that have a determining effect must be undertaken in order to appropriately assess how much care and supervision is required by persons with physical deficits, on the one hand, and cognitive and psychological impairments, on the other. It will also be necessary to determine the point values for classification in the various degrees of need and to establish binding assessment guidelines in law.

The Advisory Board confirms that the working group responsible for formulating a definition of the need for long-term care has succeeded in presenting a proposal for a definition of the need for long-term care that is suited for a new regulation of the definition of the need for long-term care in Sections 14 and 15 SGB XI implementing the new assessment instrument. (Appendix 2)

After discussing the matter, the Advisory Board does not consider the adoption of a new definition of the need for long-term care in the SGB I to be practical, especially because it contradicts the systematic organisation of the SGB I, which describes types of assistance and not living situations.

3.11 The Effects of a New Definition of the Need for Long-term Care on the Laws Regulating Long-term Care Insurance Benefits and Services

The Advisory Board confirms that the legal adaptation of the regulations in the laws related to benefits and services is necessary.

The New Assessment Procedure leads to the determination of a status of the need for long-term care graduated into as many as five degrees of need depending on the degree to which independence is impaired.

The assignment to a Degree of Need determines, as in the existing system, the volume of benefits, but not their type nor what they entail. Because of the departure in the new definition of the need for long-term care from the performed activities of daily living, changes in benefits
law in the SGB XI are necessary to the extent that it focuses on performed activities of daily living. In this conjunction, Section 36 paragraph 2 SGB XI, in particular, must be examined.

The Advisory Board agrees unanimously that the recognition of preserved rights is indicated in order to ensure the preservation of the legal standing of insured persons who have heretofore received benefits on the basis of the current regulations.

Furthermore, there is a need to clarify how assistance for people with functional impairments due to dementia, with intellectual disabilities, and/or psychological conditions in nursing homes within the framework of Section 87b SGB XI and from benefits according to Sections 45a and 45b SGB XI as well as structural measures (low-threshold programmes) according to Section 45c and 45d SGB XI can be maintained. There is also a need for clarification with regard to Section 43a SGB XI. Details of the law related to benefits and services must be regulated within the framework of the implementation process.

3.12 Effects of the New Definition of the Need for Long-term Care on other Social Benefits Systems

The Advisory Board determines the necessity of examining the effects of a more extensive definition of the need for long-term care on other social benefits systems in terms of benefits law (for ex. care assistance) and on integration assistance according to SGB XII. It is, especially necessary to establish the relationship between the need for long-term care and disability in terms of laws related to benefits and services.

3.13 Financial Effects

The Advisory Board takes note of the model calculations submitted within the context of the final report on the Second Main Phase and sees the data as a useful basis for making necessary political decisions.

The Advisory Board finds that political bodies have considerable leeway in determining the number of degrees of need for which benefits are foreseen, as well as the given benefits in the individual degrees of need, the definition of the threshold value for the individual degrees of need, and the weighting of the modules, the handling of which will ultimately determine the
consequences for the provision of long-term care and the financial situation in the areas of the social benefits affected. Care must be taken that there is no discrimination against those who were entitled to benefits previously. Problems that may emerge should be resolved through the regulation of preserved rights and targeted descriptions of benefits within the context of implementation.

The Advisory Board finds that it is possible, under certain conditions, to develop a proposal for a solution, which is roughly comparable to the current volume of benefits on the basis of existing laws. To this extent, the Advisory Board views its brief as fulfilled, without having the intention of making a preliminary selection in this context.

In order to clarify the type and manner of the financial effects of the New Assessment Procedure on long-term care insurance and social assistance, the Center for Social Policy Research (Ger. abbr. = ZeS) at the University of Bremen considered various scenarios and submitted model calculations. These also take consideration of people who were hitherto not, or only partially, covered by the benefits provided through long-term care insurance (people with disabilities in institutions, people requiring special help, and people who have been assigned to what is called the Level of Care 0 up until now). In the final result, these scenarios showed structurally induced increases in costs, particularly the agencies financing the provision of services and for those who paid for services themselves.

The Advisory Board sees an important starting point for the implementation of the New Assessment Procedure and its application in the ideas generated by this study.

At first sight, depending upon the scenario, recognisable additional expenditures by the long-term care insurance system and higher or lower expenditures for the social assistance system and those paying for themselves can be seen. It does not seem possible to allow the New Assessment Procedure with the threshold values of the original variation 1A and the old benefits law to exist alongside of each other unchanged, if one is unwilling to accept additional expenditures and/or benefit reductions.

The Advisory Board therefore sees a need to formulate political goals and to determine calculations that make the implementation viable. According to the study, they could be achieved

49 The Original Variation 1A is the threshold value combination proposed in the First Main Phase, cf. Abschlussbericht Hauptphase 1 (Final Report on the First Main Phase), 2008, p. 85.
through adjustments in the threshold values, laws related to benefits and services, including contract law, as well as the agreements on remuneration. Adjustments of the threshold values will most likely be suited as a means of adjusting the rise in the expenditures to the present level of benefits. Other scenarios can also be imagined and are plausible, for which changes in the laws related to benefits and services as well as the form of benefits are a prerequisite. Primarily, social-context concepts for people with a need for long-term care and/or a disability, or forms of benefits especially in outpatient care, as well as increased efforts in the fields of prevention and rehabilitation are conceivable.

At any rate, increases in the number of cases will need to be considered as a result of demographic development.

The Advisory Board will therefore calculate various concrete scenarios within the context of the implementation plan.

In defining threshold values, it is imperative that the demographic challenge is kept in mind. Determining the threshold values as an instrument for curtailing benefits would ultimately only lead to a postponement of the problems in relation to the provision of care for people who are old, in need of care, and/or disabled. It must be ensured that neither people who are in need of long-term care or who are disabled or both, nor the social security agencies responsible in cases of need, are unilaterally burdened by the changes.

In light of the demographic challenge, ensuring that contributions to the cost of long-term care continue to be made in a spirit of solidarity has become the responsibility of society on the whole; within the framework of which it is to be expected – considering the increase in the number of people in need of long-term care, simultaneous changes in family structures, decreasing human resources, and the desire to remain in a domestic environment – that the relationship between and the appraisal of outpatient and inpatient benefits may also be affected.

The New Assessment Procedure and the new definition of the need for long-term care on which it is based will not only lead to a change in the way people in need of long-term care are viewed, as also to better care.
Index of Abbreviations

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<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>ABV</td>
<td>Alternatives Begutachtungsverfahren (Alternative Assessment Procedure)</td>
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<tr>
<td>CANE</td>
<td>Camberwell Assessment of Need for the Elderly</td>
</tr>
<tr>
<td>EASY care</td>
<td>originally an instrument to initially assess the physical, mental and social health of elderly persons living in a domestic environment, now a comprehensive assessment</td>
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<tr>
<td>IPW</td>
<td>Institut für Pflegewissenschaft (Institute for Nursing Sciences) at the University of Bielefeld</td>
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<tr>
<td>IPP</td>
<td>Institut für Public Health und Pflegeforschung (Institute for Public Health and Nursing Research) at the University of Bremen</td>
</tr>
<tr>
<td>interRAI</td>
<td>various instruments used within the international RAICOoperation</td>
</tr>
<tr>
<td>FACE</td>
<td>Functional Assessment of the Care Environment for Older People</td>
</tr>
<tr>
<td>MDK Westfalen-Lippe</td>
<td>Medizinischer Dienst der Krankenversicherung Westfalen-Lippe (Medical Advisory Service of the Health Insurance Funds of Westphalia-Lippe)</td>
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<tr>
<td>MDS</td>
<td>Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen (Medical Advisory Service of the Central Associations of the Federation of Health Insurance Funds)</td>
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<tr>
<td>NBA</td>
<td>Neues Begutachtungsassessment (New Assessment Procedure)</td>
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<tr>
<td>RAI 2.0</td>
<td>Resident Assessment Instrument for people in homes</td>
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<tr>
<td>RAI HC</td>
<td>Resident Assessment Instrument Home Care</td>
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<tr>
<td>RCN Assessment</td>
<td>Royal College of Nursing’s Older People Assessment Tool</td>
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<td>RUM</td>
<td>Resource Use Measure</td>
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<td>SGB I-XII</td>
<td>Social Code Books I-XII</td>
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<td>TFDD</td>
<td>Test for the Early Recognition of Dementia with Differentiation from Depression</td>
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Appendices

Appendix 1

a) Members of the Advisory Board to Review the Definition of the Need for Long-term Care at the Federal Ministry of Health

Dr. h.c. Jürgen Gohde, Kuratorium Deutsche Altershilfe (German Foundation for the Care of Older People)
*Chairman of the Advisory Board as of 29 April 2008*

Wilhelm Schmidt, Deutscher Verein für öffentliche und private Fürsorge e.V., (German Association for Public and Private Welfare)
*Chairman of the Advisory Board until 28 April 2008*

Prof. Dr. Peter Udsching, Chief Judge of the Federal Social Court (Bundessozialgericht),
*Vice-Chairman of the Advisory Board*

Prof. Dr. Sabine Bartholomeyczik, Chair for Epidemiology – Nursing Sciences, University Witten / Herdecke

Dr. Fritz Baur, Bundesarbeitsgemeinschaft der überörtlichen Träger der Sozialhilfe (Federal Working Group of Regional Social Assistance Agencies)

Andreas Besche, Verband der privaten Krankenversicherung e.V. (German Association of Private Health Insurance Funds)

Klaus Dumeier, Director of the Steering Committee

Stephan Dzulko, Verband Deutscher Alten- und Behindertenhilfe e.V. (German Association for the Assistance of the Elderly and Disabled)

Dr. Franz Fink, Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege (Federal Association of Non-statutory Welfare Organisations)

Karin Evers-Meyer, Member of the Deutscher Bundestag (MP), Federal Commissioner for the Interests of People with Disabilities
Bärbel Habermann, Deutscher Verein für öffentliche und private Fürsorge e.V. (German Association for Public and Private Welfare)

Dieter Hackler, Federal Ministry for Family Affairs, Senior Citizens, Women and Youth

Erika Huxhold, Federal Ministry of Labour and Social Affairs

Sabine Jansen, Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz (German Alzheimer Association – Dementia Self-help)
Member of the Presidium of the Advisory Board

Jens Kaffenberger, Sozialverband VdK Deutschland (Social Organisation VdK Deutschland)

Harald Kesselheim, AOK-Bundesverband (Federal Association of Local Health Insurance Funds)

Sigrid König, Bavarian State Ministry for Labour, Social Order, Family Affairs and Women

Dr. Hellmut Körner, Secretary of State, Ministry for Social Affairs, Health, Family, Youth and Senior Citizens of the Land of Schleswig-Holstein

Dr. Monika Kücking, GKV-Spitzenverband (National Association of Statutory Health Insurance Funds)

Helga Kühn-Mengel, Member of the Deutscher Bundestag (MP), Federal Commissioner for the Interests of Patients

Prof. Dr. Gabriele Kuhn-Zuber, Deutscher Behindertenrat (German Disability Council)

Prof. Dr. Heinrich Kunze, Aktion Psychisch Kranke e.V. (Action for People with Psychological Impairments)

Dieter Lang, Verbraucherzentrale Bundesverband e.V (Federation of German Consumer Organisations)

Herbert Mauel, Bundesverband privater Anbieter sozialer Dienste e.V. (Federal Association of Private Social Service Organisations)

Gert Nachtigal, Bundesvereinigung der Deutschen Arbeitgeberverbände (Confederation of German Employers’ Associations)

Dr. Peter Pick, Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen (Medical Advisory Service of the Central Federal Association of Health Insurance Funds)
Membership was in abeyance during the project phase
b) Members of the Working Group on the “Formulation of a Definition” within the Advisory Council to Review the Definition of the Need for Long-term Care

**Prof. Dr. Peter Udsching**, Chief Justice of the Federal Social Court, *Chairman of the Working Group*

**Dr. Franz Fink**, Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege (Federal Association of Non-statutory Welfare Organisations)

**Sigrid König**, Bavarian State Ministry for Labour, Social Order, Family and Women

**Werner Korte**, Bundesarbeitsgemeinschaft der überörtlichen Träger der Sozialhilfe (Federal Working Group of Regional Social Assistance Agencies)
Klaus Lachwitz, Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e.V. (Federal Association Life Help for People with Intellectual Disabilities)

Herbert Mauel, Bundesverband privater Anbieter sozialer Dienste e.V. (Federal Association of Private Social Service Organisations)

Dr. Peter Pick, Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen (Medical Advisory Service of the Central Federal Association of Health Insurance Funds)  
*(Membership was in abeyance during the project phase)*

Jutta Prem, Federal Ministry of Labour and Social Affairs

Prof. Dr. Doris Schiemann, Department of Economics and Social Sciences – Nursing Science, University of Applied Sciences Osnabrück

Paul Jürgen Schiffer, Verband der Ersatzkassen e.V. – vdek (Federation of Substitution Insurance Funds)

Franz Wagner, Deutscher Pflegerat e.V. (German Council of Nursing)

Ulrich Wendte, Ministry of Labour, Social Affairs, Health and Family Affairs, *Land* Brandenburg

Michael Willamowski, Bundesvereinigung der kommunalen Spitzenverbände (Federal Alliance of Central Associations of Local Authorities)
Appendix 2 Proposal for the Provision of Standards for a Definition of the Need for Long-term Care

Section 14 Definition of the Need for Long-term Care

(1) A person is deemed to be in need of long-term care, when said person is found, according to the specific stipulations of the following articles, to exhibit impairments to independence or disabilities and therefore be dependent upon assistance from others. This applies to persons with physical and psychological impairments, impairments related to physical, cognitive or psychological functions, and health-related burdens or requirements that cannot be independently compensated or overcome.

Of decisive importance are impairments to independence or disabilities in the areas of:

1. mobility,
2. cognitive abilities,
3. behaviour and psychological problems,
4. self-care,
5. management of demands resulting from illness and therapy,
6. management of everyday life and social contacts,
7. activities outside of the home,
8. maintaining a household.

The impairment of independence or disabilities, and the need for assistance from others, must be long-term, presumably for at least six months, and entail an extent equivalent to at least that determined in Section 15.

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50 Nos. 7 and 8 are not taken into consideration for the classification in Degrees of Need according to Section 15. They primarily serve the implementation of Section 7a paragraph 1 article 2 SGB XI.
In this context, the following activities and abilities are to be specifically considered:

1. In the field of mobility: changing positions in bed, assuming a stable sitting position, standing up from a seated position/changing seats, ambulation within the living area and climbing stairs.
2. In the field of cognitive and communicative abilities: recognising people from the immediate environment, sense of direction, sense of time, memory, performance of multi-step daily tasks, making decisions in everyday life, understanding facts and information, recognising risks and dangers, communicating essential needs, understanding requests, and participating in conversations.
3. In the field of behaviour and psychological problems: motorically manifested behaviour disorders, nocturnal agitation, self-destructive or autoaggressive behaviour, damage to objects, physically aggressive behaviour towards others, verbal aggression, other conspicuous vocal behaviours, resistance against nursing care and other support measures, delusions, hallucinations, anxiety, apathy, depressive moods, socially inadequate modes of behaviour, and otherwise inadequate actions.
4. In the field of self-care: personal hygiene (washing front upper body, shaving, combing hair, dental care, cleaning dentures, washing genital area, showering or bathing – including washing hair), dressing and undressing (dressing and undressing upper body, dressing and undressing lower body), nutrition (preparing food in mouth-sized portions/pouring drinks, eating, drinking), excretions (use of toilet/toilet chair, the consequences of urinary incontinence/dealing with a permanent catheter/urostomy, consequences of a bowel incontinence/coming to terms with/dealing with a stoma)
5. In the field of dealing with illness-/therapy-related demands and burdens: medication, injections, care of intravenous access devices, aspiration or administering oxygen, instillations, application of cold/hot compresses, monitoring and interpreting physical states, handling physical aids and appliances, changing bandages/care of wounds, caring for wounds related to a stoma, regular use of disposable catheters, use of bowel stimulants, therapy measures in a domestic environment, time and technology intensive measures in a domestic environment, doctor’s visits, visits to other medical/therapeutic facilities, extended visits to medical/therapeutic facilities and visits to facilities for the purpose of early intervention measures (only in the case of children)
6. In the field of managing areas of every day life and social contacts: structuring daily routines and adapting to changes, resting and sleeping, occupying oneself, making plans for the future, interaction with people in direct contact and maintaining contact to persons beyond the immediate environment.

7. [In the field of activities outside of the home: leaving the home and mobility outside of the home, use of local public transportation, riding in a car, participation in cultural, religious or sporting events, attending school, kindergarten, work, a workshop for the disabled, day care facilities and participation in additional activities with other people.

8. In the field of maintaining a household: shopping for daily needs, preparing simple meals, simple and complex clearing up and cleaning tasks, use of services, managing financial and administrative affairs.]^{51}

To the extent that reference is made to the activities and abilities after No. 5, benefits for home nursing care according to Section 37 paragraph 2 SGB V remain unaffected.

(3) Impairments of independence or disorders in relation to the activities and abilities cited in paragraph 2 are to be classified according to their degree of expression in the four categories independent, mainly independent, mainly dependent, and dependent. A partial result is to be determined on the basis of the activities and disorders surveyed for each area and depicted on a five-level scale. The combination of all results is to be expressed in a total point value, whereby the areas after paragraph 1 are to be weighted as follows:

1. Mobility: 10%
4. Self-care: 40%
5. Management of illness and therapy related demands: 20%
6. Management of everyday life and social contacts: 15%.

^{51} Nos. 7 and 8 are not taken into consideration for the classification in Degrees of Need according to Section 15. They primarily serve the implementation of Section 7a paragraph 1 article 2 SGB XI.
Section 15 Degree of Need of Long-term Care

(1) Long-term care insurance benefits are calculated according to the degree of the impairment of independence in the areas cited in Section 14 according to the following graduated scale on the basis of the total point value according to Section 14 paragraph 3:

- Degree of Need 1: little impairment of independence (10-29 points)
- Degree of Need 2: considerable impairment of independence (30-49 points)
- Degree of Need 3: severe impairment of independence (50-69 points)
- Degree of Need 4: extreme impairment of independence (more than 70 points)
- Degree of Need 5: extreme impairment of independence, combined with special requirements in terms of nursing care (Degree of Need 4 with a special constellation of need).

(2) Decisive for the classification of children in a Degree of Need is solely the degree of the impairment of independence or abilities that results from their illness or disability in relation to children who have developed in keeping with their age. For the classification in a Degree of Need, Section 15 paragraph 1 applies correspondingly.

Section 16 Authorisation of the Regulation

The Federal Ministry of Health is authorised, in agreement with the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, and the Federal Ministry of Labour and Social Affairs through a statutory ordinance to enact provisions, subject to the consent of the Bundesrat, for the assessment of the degree of impairment in the individual areas cited in Section 14 paragraph 2 within the context of assessments conducted according to Section 18.

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52 The total point value cited in paragraph 1 corresponds with the proposal for the original variation 1A from the First Main Phase, cf. Abschlussbericht Hauptphase 1 (Final Report on the First Main Phase), 2008, p. 85.