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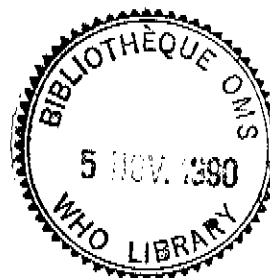
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ЕВРОПЕЙСКОЕ РЕГИОНАЛЬНОЕ БЮРО

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CONSULTATION ON STUDY ON DISABILITY CONTROL
AT PRIMARY AND SECONDARY LEVEL

Report on a WHO meeting

Prague, Czechoslovakia
13-15 January 1987



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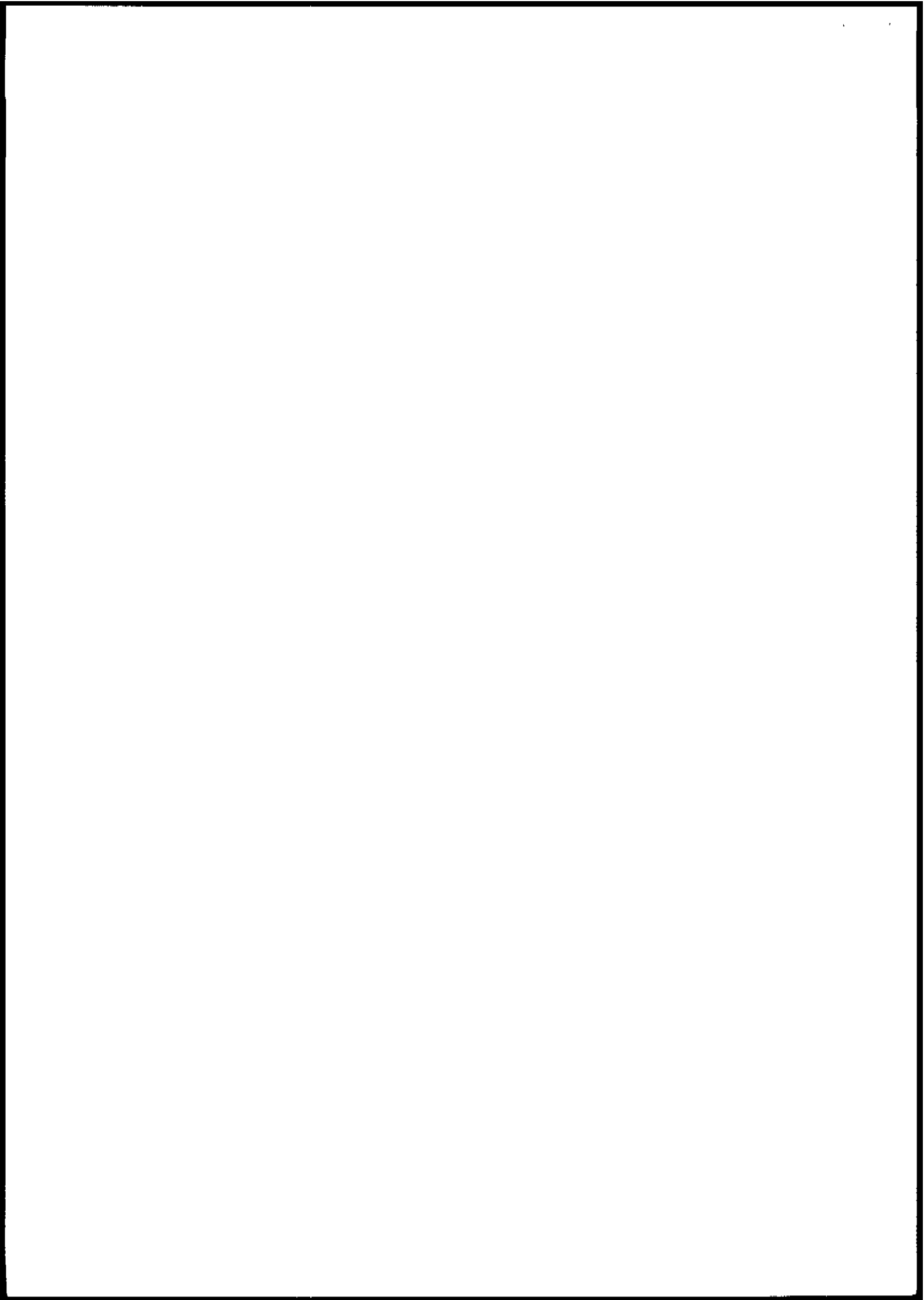
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1. Purpose of the consultation

The purpose of the consultation was to review a research project concerned with disability control at primary and secondary level in children from birth to five years, started in October 1986 by a project team led by Dr Dunovsky, Head of the Department of Paediatrics, Institute for Postgraduate Education of Physicians and Pharmacists (ILF) in Prague. The consultation specifically set out to:

- review the general research strategy
- review study protocols particularly those prepared for the three and five year examinations and for the proposed retrospective study
- review results of a pilot study (data collected on 143 children in five districts)
- consider international collaboration in the study and its implications for child care and disability control in Europe.

2. Details of the consultation

The consultation was hosted by the Institute for Postgraduate Education of Physicians and Pharmacists (ILF) in conjunction with the World Health Organization under a Technical Service Agreement and in accordance with proposals of Professor B. Zachau-Christiansen following his preliminary visit.

The meeting was sited at the ILF buildings in Prague, and included a field visit to the town of Benesov and to a small health centre at Bystrice. Here, discussion took place with paediatricians involved in the project. The consultation programme and list of participants is shown in annexes 1 and 2, respectively.

3. Opening remarks

- 3.1 The consultation was opened by Dr Hana Hermanova, WHO Regional Officer for Elderly, Disability prevention and Rehabilitation, who welcomed the participants on behalf of Dr J.E. Asvall, WHO Regional Director for Europe and Dr P.O. Petersson, Acting Director, Programme Management.

Dr Hermanova drew the participants' attention to Targets 3 and 4 of the WHO European strategy for achieving 'Health for All by the Year 2000' (HFA 2000). These targets aimed at a reduction in morbidity and disability of 10% by the year 2000 and a healthier and economically more satisfactory life for disabled persons. Close links between the WHO programme of disability prevention and rehabilitation with the United Nations Decade of Disabled Persons (UNDDP) 1983-1992 was emphasized. The Czechoslovakian authorities were thanked for their efforts in supporting the developments of the study and for the organization of this WHO consultation.

- 3.2 Dr Dunovsky welcomed participants in the consultation to the Institute for Postgraduate Education of Physicians and Pharmacists (ILF). He stressed that the major aim of the project was to identify and/or develop relevant means and measures to prevent the occurrence of impairment and disability in childhood, or if disability occurs, to reach the optimal social integration of disabled children into family and society. He pointed out the increasing importance of problems of disabled children in the world as a whole and related this to the emphasis in WHO's Targets for HFA 2000, on the prevention of disabling conditions and the care of children with these problems.

The project under discussion arose from already well-advanced plans for the establishment of a fully comprehensive programme throughout Czechoslovakia of prevention and early detection of childhood disabilities. The opportunity to discuss the further progress of the project in detail, and to contribute to the quality of life for disabled children everywhere in the world was appreciated.

- 3.3 Formal greetings to the consultation participants were also extended by Professor Macuch, Head of the Institute for Postgraduate Education of Physicians and Pharmacists (ILF). He outlined the function of the Institute in the Health Care Programme in Czechoslovakia.
- 3.4 Dr P.O. Petersson, WHO Regional Office for Europe Acting Director, Programme Management was unable to attend the consultation but sent a message of welcome and support, which was presented to the meeting.

4. Background to the study and background material

Czechoslovakia has a comprehensive system of preventive and curative child health care, practised by paediatricians at primary and secondary care level. From January 1987, a revised system of child health examinations is being introduced in experimental districts by the Health Ministries in the Czech and Slovak Socialist Republics.

The project under discussion takes place within this national context. Internationally the project has relevance to Targets 3 and 4 of the WHO European strategy of HFA 2000, as already mentioned.

A number of working papers and background documents were made available by the research team, and a list of all working documents can be found in annex 3.

5. Project outline

5.1 Aims of the project

a) Determination and validation of measures and procedures for the prevention, reduction and early detection of sensory and locomotor impairments in children aged 0-5 years and the systematic introduction of these procedures into a comprehensive national programme of prevention of child diseases.

- b) Description of the methods and techniques used for counselling treatment, medical and social rehabilitation and resocialization offered to children with sensory and locomotor impairments.
- c) Practical application of WHO concepts outlined in 'Targets for Health for All by the Year 2000' of prevention, early detection and improved care of children with sensory and locomotor impairments.
- d) Development of conditions for a further detailed elaboration of the system of uniform preventive medical examinations in childhood.

5.2 Methods of the project

The project is a field study with prospective and retrospective elements. In the prospective study, six districts of Czechoslovakia have been chosen with different demographic characteristics from rural agricultural communities to urban industrial communities. Data will be collected by community paediatricians at 10 days of age, 4 months, 8 months, 1 year, 3 years and 5 years of age on all children born between 1 November 1986 and 31 October 1987 in the six districts (between 9-10 000 children in total). Family, social, medical and anthropometric data will be collected at the same time.

All data will be entered onto a medical record book which is precoded for subsequent computerization. Instruction manual and videos have been developed with the help of specialist consultants in neurology, orthopaedics, ophthalmology and of otorhinolaryngology to ensure uniformity of examinations. The susceptibility of the proposed examinations and the data collection techniques has been tested in a small pilot study, the results of which are outlined in section 5.3 of this report.

The retrospective element of the study involved the use of the health records of children born in the same six districts as for the prospective study between 1 January 1981 and 31 December 1982. Data from the health records will be evaluated by the project team assisted by specially designated paediatricians and the local community paediatricians in an attempt to ascertain when motor and sensory impairments were diagnosed and the nature and effectiveness of treatment and management offered to the children. It is proposed that the retrospective study be carried out in 1989.

5.3 Pilot study results

The pilot study, completed in late 1986, had the following objectives:

- to assess the comprehensiveness of the instruction for medical examinations and recording of the data,
- to ensure that the proposed system can be implemented within the daily practice of the community paediatricians and to estimate the time needed for the medical examinations,
- to collect and analyse preliminary empirical results.

Pilot study data were collected by 10 paediatricians from five selected districts in the Czech Socialist Republic. Each paediatrician was asked to examine 16 children, four at 10 days, four at 4 months, four at 8 months and four at 12 months. Two of each group of four would be healthy and the other two with impairments and/or disabilities. Data was in fact collected on 143 children, 17 being lost to the pilot study.

The pilot study demonstrated that the contents of the examinations were suitable for the community paediatricians. They were essentially comprehensible, though some changes were proposed and accepted. Particularly in the formulation of obstetric and neonatal histories it was found that close cooperation with obstetric departments was indispensable. Modification of the family medical history taken during the study was also proposed and accepted. Initially the examinations were found to take between 40 and 60 minutes, this was reduced to between 25 and 30 minutes after practice. In the healthy children examinations took 15 minutes. The examination at 12 months took closer to 50 minutes, mainly because of the need to summarize the medical history for the first year of life.

The project team acknowledged that the number involved in the pilot study was so small that significant conclusions could probably not be drawn from analysis of the pilot study data. However, the data do highlight some possible relationship, which can be explored in the main study data. Example of this is the possible relationship between the functioning ability of the family and sensory and motor disorders. The pilot results suggest that the lower the functioning ability of the family, the higher the incidence of sensory and motor disorders. In addition to highlighting possible valuable hypotheses for future research, the pilot has also demonstrated ways in which results of the main study data may be processed. It is suggested that data processing will take place on two levels; cross-sectional, with the object of determining the relations between different symptoms and functional systems at particular stages of the investigation, and longitudinal to study the dynamics of relationships and developmental trend in different symptoms or diagnostic groups over time.

6. Main discussion points during the consultation

6.1 Definition of the precise aims of the project

The investigators prepared detailed background documentation, which is not part of this report, but can be obtained upon request to the World Health Organization Regional Office for Europe, Office for Elderly, Disability and Rehabilitation, 8 Scherfigsvej, Copenhagen 2100, Denmark. The titles of the main documents are listed in annex 2. One of the hypotheses suggests that the project will be able to determine suitable measures and procedures for the prevention and reduction of sensory and motor handicaps of children aged 0-5 years.

It was pointed out in the discussion that the nature of the project does not allow for the determination of measures and procedures for primary prevention, although secondary and tertiary prevention are within the scope of the project. This limitation in the capacity of the project was accepted by the project team, though it was felt by the participants in the consultation that the project as a whole may throw useful light on the etiology of certain disabilities thus assisting the development of primary preventive programmes.

6.2 Problems of terminology

The consultation considered a number of terminological problems related to ambiguous or unclear terms used in the instruction manual issued to doctors carrying out the examinations (see annex 2, documents 2a, 5a and 5b). Participants accepted the proposal that a glossary of health care terminology, published by WHO and edited by James Hogarth¹ should be used as general reference and basis for terminology used in the project. An exhaustive list of the terms discussed during the consultation will not be given in the report, but two examples serve to illustrate the terminological problem raised by consultation participants.

Example 1: the term 'spasm' is used on page 23 of the instruction manual for examinations for the first year of life (annex 2, working document 2a). It was felt that clearer definition of the meaning of the term was required and the project team were asked to clarify this in the manual.

Example 2: as part of the neonatal history recorded by doctors at the first examination (see annex 2, working document 2a), the doctors completing the details of the history are asked to record whether the child has had 'symptoms of hypoxia'. It was felt in the consultation that this heading was too vague and the project team was requested to give a clearer indication of the symptoms to which the heading referred.

The consultation sought to clarify with the project team some of the terms used as shown in the examples above, and changes should be made where appropriate.

6.3 Methodological problems

The consultation dealt with a number of methodological problems related to the project. The main methodological changes arising out of the consultation discussions are outlined in the recommendations. Some examples of the important methodological problems discussed during the consultation are outlined below:

The retrospective study and control districts

It was generally agreed in the consultation, that the influence of unknown and unquantifiable (within the context of the project) variables may be so great as to invalidate any comparison between children born in 1981 and those born in 1986. The project team were urged to reconsider the retrospective elements of the study and to attempt to identify suitable control districts. In these, the effectiveness of the project examinations in the early detection and effective management of sensory and motor impairments in children might be compared with the routine examinations carried out under the present system of health surveillance in Czechoslovakia.

¹ Glossary of Health Care Terminology, J. Hogarth, PHE Series No.4, Regional Office for Europe, Copenhagen, 1975.

The recognition of bias related to children eliminated from the study

The project team was urged to ensure that all available data on children eliminated from the study at any stage be retained and processed in order to recognize any bias arising from self-selection out of the study by a group with particular characteristics.

The introduction of a behavioural scale into the 3 and 5 year examinations

The project team was urged to introduce a behavioural scale perhaps in the form of a self-administered questionnaire despatched to parents along with the invitation to attend the examination. It was felt that the behavioural scale being used in the WHO European Longitudinal Study of Pregnancy and Childhood¹, could be adapted for use in this project.

Standardization of the environment during examinations

The project team were asked to ensure as far as possible that the environmental condition under which examinations took place were as standard as possible. It was felt by participants that the detailed neurological examination, particularly of babies, required a relatively standardized environment.

6.4 Discussion of the implications of disability control in the whole of Europe

The consultation spent considerable time considering the implications of this study for other European countries, having policies and programmes in preventive medicine in childhood. The main conclusions of the consultation are outlined in the recommendations.

7. Conclusions and recommendations

- 7.1 Having discussed the project in detail with the project team and seen the project in action in a small community health centre, the group strongly recommended that the research continue, with only minor changes.
- 7.2 Impressed by the cooperation among different experts at various levels and realizing the potential for the role of the general practitioner/family doctor within this cooperative system, the group recommended that the Czechoslovakian study provide a basis for a system of early detection of sensory and locomotor impairments which, with modifications, would be applicable to other countries in Europe.

¹ In collaboration with the WHO Regional Office for Europe under the supervision of Dr J. Golding, Wellcome Senior Lecturer, Dept. of Child Health, Royal Hospital for Sick Children, Bristol, United Kingdom.

It was further recommended in this context, that specific attention be paid to the adaptation of the project methods (including the instruction videos and manuals developed by the project team) for use by less sophisticated personnel and to meet the health needs of different countries with different health systems.

- 7.3 Information should be obtained from other Member states in Europe on similar studies of sensory and locomotor impairments. This information should then be disseminated, thus facilitating comparisons of methods and results. This will also assist in the implementation of recommendation 7.2.
- 7.4 The group recognized the necessity for close collaboration among WHO studies in Europe concerned with child health and disability prevention, and particularly recommended collaboration between the Czechoslovakian study and the Bristol/Moscow/Oslo project known as the WHO European Longitudinal Study of Pregnancy and Childhood.
- 7.5 There remains a paucity of information on the causation of sensory and locomotor impairments, and it is therefore recommended that action be taken to stimulate the coordination of basic research projects in this field, with the aim of developing scientifically-based primary preventive programmes.
- 7.6 The project team should work to clarify the potential confusion arising from terminological and methodological problems (more precise translation is required). Furthermore, national authorities should take note of the definitions developed by the project team, as background material for the committee preparing the tenth revision of the International Classification of Diseases.
- 7.7 The behavioural rating scale, developed in the Bristol project for the third and fifth year examinations, should be made available to the Prague investigators (after finalization and evaluation).
- 7.8 The project team should re-evaluate the retrospective study and, if possible, introduce a control group of children born in the same year as, and living in adjacent districts to, the study group children.
- 7.9 The project team should use existing data on those children failing for various defined reasons to complete the study. These data could then be compared with those on children who do complete the study in order to estimate the degree of bias.
- 7.10 The group should meet again, as a consultation, in about two years for the following purposes:
 - (a) to evaluate the initial results of the first year examinations;
 - (b) to discuss the final version of the instruction manual and questionnaire for the third and fifth year examinations; and
 - (c) to discuss and evaluate the definitive project for the retrospective study on the basis of the pilot study results.

Annex 1

PROGRAMME

Monday, 12 January

Arrivals

Tuesday, 13 January

08.45 - 09.00	Registration
09.00 - 09.45	Introduction and definition of the content of the consultation (Dr Hermanova and Dr Dunovsky)
	Role of ILF in health services in Czechoslovakia (Prof. Macuch)
10.00 - 11.30	Briefing on the study (Dr Dunovsky)
	Discussion of the study
11.30 - 13.00	Detailed discussion on first four phases of the project (Dr Brichacek)
14.00 - 15.00	Results of pilot studies (Dr Brichacek)
15.30 - 16.30	Present state of research activities (Dr Struk)

Wednesday, 14 October

Departure 08.30	Field excursion to Benesov (EDP). Discussion with pediatricians involved in the project. Excursion to the computer centre.
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Thursday, 15 October

09.00 - 10.30	Proposals and discussion on examinations of children at 3 and 5 years of age - first draft (Dr Struk)
11.00 - 13.00	Retrospective study, proposals and discussions - first draft (Dr Kabele)
14.00 - 15.00	Research proposals for 1987 and onwards. General discussion.
15.00 - 16.00	Conclusions and recommendations. Closing session.

Annex 2

LIST OF PARTICIPANTS

Temporary Advisers

- Dr V. Brichacek, Dept. of Paediatricians, Institute for Postgraduate Education of Physicians and Pharmacists (ILF), Prague, Czechoslovakia
- Dr J. Dunovsky, Head, Dept. of Paediatricians, Institute for Postgraduate Education of Physicians and Pharmacists (ILF), Prague, Czechoslovakia
- Dr A. Emond, Department of Child Health, University of Bristol, Bristol, United Kingdom
- Dr R.K. Ignatyeva, Head of Unit, All-Union Semasko Institute for Research on Social Hygiene and Public Health, Ministry of Health of the USSR, Moscow, USSR
- Dr J. Pechstein, Kinderneurologisches Zentrum des Landes Rheinland Platz, Institut für Social Pädiatrie, Mainz, Federal Republic of Germany
- Dr Aldona Sito, National Research Institute of Mother and Child, Warsaw, Poland
- Dr N.J. Spencer, Consultant Paediatrician, Northern General Hospital, Sheffield, United Kingdom
- Dr Z. Stembera, Institute of Child and Mother Care, Prague, Czechoslovakia
- Dr B. Zachau-Christiansen, Children's Dept, Rigshospitalet, Copenhagen, Denmark

Observers

- Dr L. Giedre, Kaunas Medical Institute, Kaunas, USSR
- Professor K. Jährig, Universitäts-Kinderklinik, Greifswald, German Democratic Republic
- Research workers of the Research Laboratory of Social Pediatrics, Institute for Postgraduate Education, of Physicians and Pharmacists (ILF), Prague, Czechoslovakia.

World Health Organization - Regional Office for Europe

- Dr H. Hermanova
Regional Officer for Elderly, Disability and Rehabilitation
- Ms J. Brown
Secretary, Regional Office for Elderly, Disability and Rehabilitation

Annex 3

LIST OF WORKING PAPERS AND BACKGROUND DOCUMENTS

Working Papers

ICP/RHB 019/1	Provsional list of working papers and background documents
ICP/RHB 019/2	Scope and purpose
ICP/RHB 019/3	Provisional agenda
ICP/RHB 019/4	Provisional programme
ICP/RHB 019/5	Provisional list of participants

Background Material (to be prepared by project managers)

1. Final version of project.
2. Tools and methodology for evaluation of children during first year of life.
3. Trends in present European population developments (Wynnyczuk)
4. Pilot study for evaluation of children during first year of life (Brichacek)
5. Proposals for evaluation of children 3 and 5 years old
6. Proposals for retrospective study
7. System of uniform preventive paediatric care (Dunovsky)
8. Preventive services in Czechoslovakia (Dunovsky)
9. Health care system in Czechoslovakia (Dunovsky, Struk)