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of Handicap in Children

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STUDY ON EARLY DETECTION OF HANDICAP¹

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Introduction

The material living conditions in most of the European Region have improved in the last decade and this has been followed by a reduction in many serious diseases which previously affected the child population (chronic infectious diseases, nutritional diseases). Presumably the acute infectious diseases have also decreased in number, and in any case they are less serious because of better nutritional status and better hygiene.

In many countries attention has been drawn to two quite different disease categories: congenital anomalies and psychosocially caused disturbances in normal development. Attention has been drawn to these diseases partly because it has been possible for the resources in the health services to be directed towards this sector and partly to increased technological, psychological and sociomedical knowledge. Probably the increased attention also reflects the rise in the occurrence of the diseases. It seems that psychosocial disturbances in normal development are a growing problem in the industrialized societies. Working conditions cause more psychological strain. In some countries, the family structure is beginning to disintegrate, and the economic crisis in the Western economy has begun to influence the psychological and social wellbeing of families. However, the fact that there are few objective criteria for measurement and recording of such disabilities is a major difficulty. There are wide disparities between different countries in the apparent incidence of these disabilities, but also within the same country where different findings are obtained. Nevertheless the proportion of psychosocial problems in the preschool age is commonly estimated to be about 10%.

The same difficulties exist, but to a lesser extent, in respect of other types of handicap. In a WHO paper on birth defect surveillance², several epidemiological studies are reported as showing that 4 - 7% of live-born babies have one or more defects of varying degrees of severity which can be detected at birth or during infancy. Population studies have shown that 0.5% of all newborns have a chromosomal defect and another 0.5% have a metabolic disease of genetic origin. It is well known that a number of congenital anomalies are caused by environmental agents including chemicals, drugs and radiation. Most of the congenital anomalies are probably of multifactorial origin. In this respect the increasing use of chemicals and drugs and the increasing pollution of nature pose a growing threat to mankind. The best known case of environmental influence on congenital malformation is the thalidomide catastrophe.

Early detection of handicap is becoming more important since there are now new possibilities to treat the handicapped or prevent secondary handicaps. It is well known that some handicaps

¹ This working paper is intended for discussions only and should therefore not be used or quoted for other purposes. References to countries mentioned have not been cleared by the Governments.

² World Health Organization. Birth defect surveillance. Geneva (document A31/26)

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can be cured (e.g. hip dislocation) and others can be successfully treated by dietary or medicinal means (phenylketonuria, congenital hypothyroidism). Some of the handicaps are complicated (e.g. cerebral palsy) but the results show that increased knowledge and cooperation between specialists, social scientists and institutions for the care of handicapped persons give patients more chance of leading a bearable life than previously. In all these cases, early detection of handicap is important. If case-finding is delayed, successful treatment will be less likely or even totally impossible (e.g. in phenylketonuria, congenital hypothyroidism).

In recent years a new branch of medical science, teratology has contributed to the early detection of handicap. Technical development has made it possible to diagnose many of the inherited metabolic diseases where the primary biochemical defect is known. Unfortunately, most of those diseases can only be treated symptomatically and with limited success. But since it has been possible to remove amniotic fluid and cultivate the amnion fluid cells, the knowledge of chromosome and biochemical defects has been used in prenatal diagnoses and genetic counselling.

It has become more and more obvious that registration of handicaps is of great importance. Registers can be used for surveillance and epidemiological research. Steps have been taken to build up international registers, e.g. of congenital malformations. At the same time it seems that there is not the same readiness to take the political consequences in all respects of proved causalities, e.g. in traffic accidents.

The WHO Regional Office has previously been concerned with early detection and treatment of handicapping defects in young children; and in 1967 a working group was held on this topic¹. In April 1978 birth defect surveillance was discussed at the thirty-first World Health Assembly. The present study follows that of 1967.

Scope and purpose of the visit

As background for this study, data on present and planned activities in the countries visited were collected from literature and interviews. The aim is to describe and evaluate the organization behind early detection of handicapped children and the methods used, and also to study the system of referrals for further examinations and/or treatment. The development and use of registers are studied. It is not the intention to study either primary prevention or treatment of handicaps. Only children of preschool age are considered. The term handicap is defined broadly to include physical as well as mental and functional disabilities of a certain magnitude (not arbitrarily defined) which continuously impede the child in its natural development. The handicap can be anatomical, biochemical or environmental. The study is not limited to the health services but also covers the utilization of allied health personnel and day-care institutions in the detection of handicap in children. Parents are closest to children and in many situations are the best observers. The education of the population in health problems and the parents' position in the early detection of handicap ought to be included in the study, but this has not been possible for lack of resources.

DENMARK

1. Demography

The population is around 5 million. The birth rate decreased from 15 o/oo in 1971 to 13 o/oo in 1976. Nearly 10% of the population is below the age of 7 years.

2. Health Services

The health services are public and financed from direct and indirect taxes. All services dealing with the detection of handicap in children are free.

In Denmark the general practitioner has an important position in the health services as a family physician. To a certain degree general practice is a private occupation, while all other health personnel are employed by the State, the country or the municipality.

¹ WHO Regional Office for Europe. The early detection and treatment of handicapping defects in young children: Report on a working group. Copenhagen, 1967.

3. Prenatal diagnosis

Up to now prenatal diagnosis has been supported by research foundations but since 1 October 1978 it has been a public activity. Expenses of genetic counselling and examinations are paid by the public.

There are three genetic centres and the aim is to reduce the number of places where amniocentesis is done. Six hospitals are recommended.

Today, genetic counselling and prenatal chromosome diagnosis are offered to pregnant women:

- if they are 35 years or older
- if a previous pregnancy has produced a child with a chromosome anomaly
- if the woman or the father has chromosome anomaly
- in other cases where the risk is high, for instance if the father is 50 years or more or if a chromosome anomaly has been found in the family.

For prenatal diagnosis of inherited metabolic diseases, genetic counselling is available for pregnant women who in a previous pregnancy had a child with a metabolic disease or an x-linked disease. After the genetic counselling it is decided if prenatal diagnosis is possible.

In the three Danish laboratories, 20 metabolic diseases can be diagnosed prenatally. The examinations are always done in two laboratories. If prenatal diagnosis is not possible in Denmark the amnion cells are sent for examination in two different laboratories outside the country.

For neural tube defects, every pregnant woman can be referred for genetic counselling and examination of alpha-fetoprotein in the amnion fluid if neural tube defect has been found in the woman or in the near family. Amniocentesis is done in the 14th to 15th week of pregnancy under ultrasound control. The results of examinations for chromosome anomalies are available 2-3 weeks later. If the amnion cells are examined for metabolic diseases the results are available 3-6 weeks after the amniocentesis. It has been estimated that 3 000 amniocenteses are performed each year, i.e. in 4-5% of pregnancies. In nearly 90% of cases the indication is that the woman is 35 years or more. In 1977, 1 257 amniocenteses were done. The frequency of chromosome anomalies in these cases was 1.1%.

4. Birth and the neonatal period

It is reported that 61% of babies are born in maternity wards, 27% in other wards, 11% in maternity homes and 1% at home. If the baby is born at home or in a maternity home, the mother is assisted by a midwife and a general practitioner or an obstetrician. The child is examined shortly after the delivery by the physician present. In a hospital ward a physician is present at the birth and examines the baby immediately after delivery and in most cases also before discharge from the hospital. In these wards an obstetrician is present and examines the child immediately after the birth. Most maternity wards are located in hospitals with paediatric wards. If this is not the case, a child specialist is assigned to the maternity ward as a consultant. This system means that all risk children are examined by a child specialist before discharge from hospital. In some hospitals all the children are examined by the child specialist before discharge, and if the maternity ward and the paediatric ward are located in the same hospital it is usual for a paediatrician to be called for every risk delivery, so that the child is examined by him immediately after delivery. The Apgar score is recorded in every case. In addition the child is at least examined for external malformations, hip dislocation and the development of icterus. In the birth notification 22 types of congenital malformations are listed which the midwife has to look for. As mentioned, in most cases a more comprehensive health examination is done by a paediatrician, obstetrician or a surgeon before discharge of the child. Healthy children born without complications stay an average of 5 days in the ward together with the mother for further nursing and observation. A few days after the discharge from the hospital the family is visited by the public health nurse who follows the child's progress in the next few months, and at five weeks the child can undergo a first examination by the family physician. The public health nurse receives a birth notification with several clinical data and the general practitioner receives a letter with relevant data if the

child is born at a hospital. If the child presents problems at birth or in the following days he is referred to a paediatric ward for further examinations and/or treatment. Most paediatric wards have facilities for short- or longer term outpatient care of children considered to be at risk in the neonatal period.

5. Screening for inherited metabolic diseases

5.1 Total screening

Today 99.99% of newborns are screened for phenylketonuria and for hypothyroidism. Guthrie's test is used to screen for phenylketonuria and has been used for several years. The examination is centralized in one laboratory. On average 5-6 new cases are found each year, i.e. 1 per 12 000 births. Screening for hypothyroidism started in 1978 and it is expected to show 15 cases each year. Guthrie cards are also used for hypothyroid screening. It is estimated that screening and treatment of patients in Denmark save society nearly 2100 000 per diagnosed case. Consideration has to be given to using the thinlayer chromatograph techniques instead of Guthrie's test, because they allow screening for several metabolic diseases at the same time and thereby decrease the expenditure for each detected case. In the near future it is contemplated to start screening for galactosaemia of which six new cases are expected to be found each year. It is estimated that in Denmark today three-quarters of the cases are diagnosed too late to be treated successfully. It has been decided not to introduce total screening for cystic fibrosis. A study has been done using examinations of the meconium. This test is not at the moment useful for total screening because there are too many false positive results. Instead, selective screening for cystic fibrosis is being introduced all over the country by analysis of the chloride content in sweat.

Experience has shown that it is important to centralize population screening. On the other hand, the population basis must not be too large if the organization of the screening procedures is to be kept intact. The 5 million population of the country should serve as a good base for one screening centre. Experience has also shown that it is important to inform the population about the different kinds of screening performed so that parents will be prepared if something abnormal is found in their child. It will also diminish anxiety in the cases of false positive results where a new examination is necessary. Information to the population is not yet systematically provided in Denmark.

5.2 Selective screening

In Denmark 80 of the metabolic diseases where the primary biochemical defect is well known can be investigated. Treatment is the consequence in very few cases where a diagnosis has been made, but it has a consequence for genetic counselling if the woman has a new pregnancy. It is estimated that 10% of children hospitalized in paediatric wards should be screened for inherited metabolic diseases. This is not done partly because of limited capacity and partly because the knowledge of these diseases is not yet widespread among physicians.

6. Health surveillance

6.1 General practitioners

Since 1946 every child has been offered nine routine preventive examinations at preschool age. Three of them are offered in the first year of life, two in the second year of life, and the remainder once yearly. Because of the general practitioner's central position in the Danish health services, he performs nearly all the examinations. Only a few children are examined at child health stations staffed by a paediatrician. The examinations done up to now have had a somatic oriented action. Initially the aim was to reduce infant mortality and prevent serious physical diseases. Subsequently the aim was to check as early as possible on a broader spectrum of somatic handicaps, and behavioural and learning problems. However, experience in recent years shows that there has been a marked decrease in the occurrence of somatic diseases among children. For any general practitioners the examinations have therefore been boring routines. Today psychosocially caused handicaps among children are found to be a considerable problem and many are not detected until the child begins school. In this light a new approach to routine examinations of children will be introduced at the end of 1978. This new approach is not intended to expand the examinations but to redirect the priorities. In the first two years of life the examinations of the child's physical health condition and motor development are still of great importance. After this it is recommended that the physical part of the examinations be done only if it is required. Instead, greatest importance will be attached to evaluation of the sense organs and psychosocial

development. It is also recommended that the general practitioner devote a good deal of time to orienting himself through dialogue with the parents and observation of the child's behaviour. The new examinations are briefly as follows:

- 5-weeks examination: history of pregnancy and birth, somatic aspects, relations between parents and the child;
- 5-month examination: the child's use of its sense organs, motor development, the child's contact with its surroundings;
- 10-month examination: use of sense organs, motor development, interaction with the surroundings;
- 15-month examination: motor development, development of independence;
- 2-year examination: independence, development of vocabulary and speech;
- 3-year examination: psychosocial development;
- 4-year examination: sight (sight test), vocabulary and speech (speech test);
- 5-year examination: hearing (audiometry), fitness for school;
- 6-year examination: fitness for school.

If the examinations show any abnormality or if the physician suspects an abnormality there are excellent possibilities of referral for further examinations. The different institutions for care of handicapped persons (sight, hearing, speech, mental function) are being developed to offer intensive ambulatory examination and observation of children. Besides this, general practitioners can refer to specialist physicians and psychologists, and physicians can cooperate with public health nurses and day-care institutions for further observation of children.

The routine examinations are offered to the public. They depend on voluntary participation and physicians have considerable liberty in administering the system. A weakness of the system is that by no means all families take up the offer to have their child regularly examined. Experience shows that if children are not examined in the first 2-3 years of life they will later have development problems in more than half of cases. However, the utilization rate is gradually increasing. For all age-groups the rate of utilization was 80% in 1976. In 1968-69, when total utilization was 72%, the distribution in age-groups and geographic areas was studied. It was found that utilization was nearly 100% for the 5-week examination and that it gradually decreased thereafter to 50% for the 6-year examination. The utilization rate was lowest in the capital and rural municipalities. Experience shows that a great part of the children who do not attend come from families with poor social conditions (e.g. single mothers, immigrant families) or have mothers who do not dare to ask for permission from their jobs to accompany the child. Others do not bring their children because they are well examined elsewhere or because they do not regard it as meaningful to have an apparently healthy child examined. It is now recommended that physicians call in all the children who do not attend as expected.

The effectiveness of the examinations has not been evaluated, but it is known that some children reach school age having problems with the sense organs or psychosocial handicaps which have not been detected in the examinations. It has been discussed whether it would be valuable to introduce intense screening of 4-year-old children. The aim would be to have all children examined, possibly at home. This idea has risen partly because not all children are examined in the last years before school age and partly because there still are good possibilities to treat developmental problems at 4 years of age. It is held that the screening should be a real test of speech, hearing, sight and psychosocial development. The argument against an intense screening at 4 years is that each age offers different possibilities to examine a child, so that a yearly examination allows a better evaluation. There have also been arguments against testing in the true sense of the word. It is said that general practitioners are not educated to test children and that the parents are not motivated to have their children tested.

6.2 Public health nurses

Since 1937 there have been public health nurses. Since 1974 the public health nursing system has been compulsory for all the municipalities. It is estimated that the requirement is of one nurse per 8 000 population. Today the nurses are found nearly all over the country. Less than 1% of families refuse visits of the nurses. The system was originally introduced to control morbidity and mortality in the first year of life. Since then it has gradually changed. As infant morbidity and mortality have decreased while development, social and psychological problems have increased, the system has changed and emphasis is now also placed on detection and treatment of the latter problems. Originally children received a number of visits in their first year of life. Now the nurses visit children as required. It is up to them, in cooperation with the family and the general practitioner, to decide how often a child has to be visited and when the visits can stop. It is also up to the nurse to decide which children are at risk. In those cases she can continue to visit after the first year of life. The changes in the system have come about slowly. Most children are still visited an average of 9-10 times in the first year of life; however, only 3% of children of 1-6 years are visited although it is estimated that 10-15% are at risk. The nurses examine the neonatal reflexes and the motor skills at the different ages. Psychological development is checked as well as the child's reactions to stimuli, and speech. The height, weight and head circumference are measured. The observations are compared with the information the nurse gets from the parents.

There is no general principle concerning the place of public health nurses in the primary health services. It is obvious that cooperation between the general practitioner and the nurse is important, but in the large municipalities this cooperation is difficult because of lack of client identity. It is also stated that cooperation can be impeded by the fact that the nurses are employed by the public whereas general practitioners work in a private capacity. Apart from their work with general practitioners, the nurses cooperate with social workers and school health nurses, and with day-care institutions, and county paediatric hospital departments. Usually the nurses contact general practitioners if they find problems. But their right to make their own referrals for further examinations is increasing.

In 1974 a screening examination (the Boel test) was introduced by the nurses, with every child being examined between 7 and 9 months. This screening has quickly spread to other municipalities. The screening comprises a hearing test, a sight test and a development test to evaluate the child's motor development and interaction with the surroundings. The screening gives information about the selective attention which usually develops at about 6 months. Without the ability for selective attention a child has difficulty to learn language and communicate with the surroundings. The screening can also reveal psychomotor and psychological deviations, in which early detection is of decisive importance for treatment. Experience in Copenhagen shows that abnormalities are found in 5% of children. In nearly all these cases the abnormalities are confirmed at specialist clinics. The experience also indicates that parents are interested in the screening and do not view it as a test.

After discussions on the value of screening for 4-year-olds, the nurses in the municipality of Copenhagen undertook a project for screening 150 children aged 3 years and 10 months in the autumn of 1978. It was decided that in this screening, sight would be tested, motor development evaluated, and pronunciation, vocabulary and understanding of language examined. Through conversation with the parents and observation of the child the psychological and social conditions would be evaluated. The parents would be informed in advance about the screening and all abnormalities would be discussed with them. Experience of screening of 4-year-olds in Sweden shows that it is difficult to follow up those children with abnormalities and that the same problems are often found again when a child starts in school. In the Copenhagen project it was decided that the nurses would follow up the children even if an abnormality was found, and that they could call for appropriate assistance from other parts of the health or social services.

7. Day-care institutions

An average of 10% of children of 0-2 years in the country go to infant day nurseries and 35% of children of 3-6 years to kindergartens. The variations between different geographic areas are large. The costs of running the day-care institutions are met partly by the parents using them and partly by the local social authority. Up to 1975 all children in the day-care institutions were regularly seen by a physician. This system was abolished partly because of the existing routine examinations by private practitioners and partly for economic reasons.

As mentioned earlier, attendance for the routine examinations is not high for children of 3-6 years. In Copenhagen it is estimated that one-fifth of children in day-care institutions require an examination by their family physician, but this could not be done either for practical reasons or because the parents were not motivated. The teachers who work in infant day nurseries are trained in hygiene, illness and social medicine so as to enable them to observe and describe symptoms of illness and know when to recommend calling in medical personnel. Teachers in kindergartens are not trained in these matters to the same extent but they have lessons in psychology, psychiatry and social medicine. Although a few years ago the personnel in day-care institutions was reduced by 10-20% for economic reasons, the teachers play an important role in the early detection of handicap by virtue of their experience and education. However, they lack supervision and counselling by medical personnel. A proposal has been made to introduce a consultant system, under which the teachers would make the primary observations and call in a consultant if necessary.

8. Registers

Denmark is preparing to establish a register of all congenital malformations in order to join the International Clearinghouse for Birth Defects Monitoring Systems. The registration will be based on birth notification and reports of 5-month examinations by general practitioners. It is estimated that 90% of anomalies are found at the age of 5 months. In the birth notification the midwife must, by law, report every case of malformation seen at birth or shortly after. Later on the intention is to complete the register and to follow up children with different malformations. This can be done by taking the nationwide electronic data on all diseases investigated and/or treated at hospitals and by visiting institutions for care of handicapped persons.

It has for many years been the physician's duty to report all handicaps for which it is considered that the growing child and the family will need help from institutions. Such handicaps include:

- speech defects including harelip, cleft palate
- blindness and severe sight defects (0.05% of Danish children have severe sight handicap and 3% have one-sided defects)
- deafness and severe loss of hearing
- mental defects (the incidence is not known for sure but it is estimated to 1-1.5%).

Supported by grants from foundations, a register of cerebral palsy was established in 1967. Through reports of some institutions and regular visits to other institutions in different parts of the country, the register has been built up. Today the registration of cases of cerebral palsy detected since 1950 is nearly complete in the eastern half of the country. At the moment the aim is to perform the registration nationwide. Among 7-year-olds, 2 cases of cerebral palsy per 1000 children are registered today, 90% being congenital (pre or perinatal) and 10% postnatal. The register shows that in the beginning of the 1950s, 2.6 new cases were detected per 1000 live-born children; and at the end of the 1960s, 2.0 new cases were detected. It is stated that the 20% decrease in frequency of cases is primarily due to the increased activities for treatment of perinatal complications.

SPAIN

1. Demography

The population is around 35 million. The birth rate is decreasing. 45 years ago it was 24 o/oo and now is 18 o/oo. The proportion of children below the age of 7 is estimated at 15%.

2. Health services

Today 85-90% of the population is covered by social security. This means that every service under the health system is free for this part of the population. In the primary health services each family has a general practitioner and a paediatrician. The paediatricians are responsible for children aged 0-7. Generally the general practitioner and the paediatrician do not work under

the same roof. Some 5 000 physicians have the right to call themselves paediatricians. To be a paediatrician today requires 3 years of paediatric training. The coverage of paediatricians varies greatly from province to province, from one per 500 children in the best equipped areas to one per 4 000. There is a considerable private health sector related to primary, maternity and hospital services.

The running of the health services was the responsibility of different ministries until about a year ago, when the Ministry of Health and Social Security was created. Thus today the immediate task is to build up a general picture of the health services, to coordinate activities and to plan new initiatives.

3. Prenatal diagnosis

Techniques like amniocentesis, cultivation of amnion fluid cells, chromosome analysis and diagnosis of inherited metabolic diseases can be performed, but the capacity is low. Moreover, prenatal diagnosis has very few consequences because abortion - even for medical reasons - is not allowed. Prenatal diagnosis is therefore done in few cases. Another problem was that family planning was impeded by the law. The use of contraceptives was not accepted until recently, when the law was changed.

There is one main genetic centre in Madrid to which children with all kinds of handicap are referred from the whole country. In this centre chromosome analysis can be done and genetic counselling given. The centre started a year ago. Spread over the country there are 20 minor genetic units usually connected to a paediatric ward, maternity ward or laboratory.

The first step in setting up 15 family planning centres has been taken. The aim initially is to train personnel which later on can work in the 75 family planning centres due to be established.

4. Birth and neonatal period

It is estimated that 60-70% of children are born at public hospitals under the social security system. On average, newborns are discharged from the hospitals two days after the delivery, together with the mother. All children are examined by a paediatrician or an obstetrician before discharge. 20-30% are born in private maternity wards where the standard varies. Approximately 10% are born at home. The mother usually does not receive instructions on nursing and feeding the child during the two days' stay at the hospital. There is no systematic recording of pregnancy, delivery and state of the newborn, but it is planned to establish a record on each child.

Neonatal services have been introduced in many hospitals spread over the country but real neonatal units exist at only three hospitals today. One of the leading hospitals, La Paz in Madrid, has one of the largest maternity wards in the world with 30 000 deliveries per year. At this hospital assistance is given by a midwife if the pregnancy has been normal and the mother is healthy. In risk deliveries, the mother is assisted by an obstetrician and a paediatrician. Each child is examined by a paediatrician before it is 8 hours old. All risk children and children with identified problems can be referred to a neonatal unit. At this hospital the first and only social paediatric unit in the country is located; it attends to all children with recognized problems both physical, mental and social. The children are examined at the age of 5 weeks, 5 months, 10 months, 30 months and then at 2, 3, 4 and 6 years. A urine sample for amino acid screening is collected from each child before discharge from the hospital. On this occasion a nurse completes a short questionnaire on the family. This questionnaire is used to identify all children expected to be at risk, who are then examined regularly in the social paediatric unit. The unit uses a comprehensive record with somatic and socioeconomic data on the whole family.

To a small (unknown) extent, it is possible to follow up risk children at hospitals in the rest of the country, but usually they are referred to the primary health services.

5. Screening for inherited metabolic diseases

5.1 Total screening

Examinations for inherited metabolic diseases started 10 years ago but for the first time this year they have been officially accepted as part of the health services and are financed by social security.

Today, there are four groups for total screening. The chromatography technique is used and therefore the children are not only screened for phenylketonuria, but at the same time for all other aminopathies. The 4 groups comprise half of the 600 000 newborns in the country. Blood as well as urine samples are examined. The samples are collected around the 15th day. By this time nearly all children have been discharged from the hospital and the samples have to be collected by the parents. They are given a description of the sample collection technique and told what the children will be examined for. Only 40% of parents send samples to the laboratories. The possibility is now being discussed of taking the samples at the hospitals the day the child is discharged (second day).

5.2 Selective screening

Besides the laboratories for screening for aminopathies there is a centre for glycogenesis, a centre for lipidosis, a centre for mucopolysaccharidoses and a centre for endocrine diseases. Each of these centres covers the whole country.

6. Health surveillance

As mentioned, primary health services are provided by general practitioners who are responsible for parents and children over the age of 7, and paediatricians who are responsible for children of 0-7 years. In Spain routine preventive examinations of children of preschool age are not carried out. The family goes to the paediatrician if there are health problems with the child; and the predominant problems are still infectious and nutritional diseases. Public health centres for children of preschool age are usually open 1-2 hours daily and, on average, a paediatrician has to see 50 children per hour. Outside these two hours a day there is no paediatric care in the primary health services for children that get sick, and parents are expected to consult general practitioners. However, many apply directly to the hospitals which are usually open even for patients that do not have a reference from a physician in the primary services.

It is contemplated to introduce routine preventive examinations, one of the reasons being that many not previously detected handicaps are found in children starting school. It is estimated that 600 000 children in a population of 10 000 000 below the age of 13 have a mental subnormality.

A visiting health nurse system does not exist.

7. Day-care institutions

It is not known how many children use day nurseries and kindergartens, but day-care institutions are a growing phenomenon in the big cities. Today, establishment of day-care institutions is not under control, but it is the plan to demand that a certain number of the personnel be trained in nursing before a new institution can be opened.

8. Registers

As earlier mentioned, one of the main problems for the new Ministry is to build up a general picture of the health problems in the country. As a first step, the group working on congenital malformations is now financially supported by the Ministry. Spain has been associated with the International Clearinghouse for Birth Defects Monitoring Systems for two years and will be a full member from January 1979. The aim is to collect data about morphologic malformations in 10% of all newborns, preferably from hospitals with a relatively small number of newborns where it can be guaranteed that each will be examined by the same paediatrician and/or obstetrician before discharge. The observation is extended up to 72 hours. Consideration is limited to malformations that are morphologic and clinically diagnosticable with an acceptable degree of certainty. Figures for the first two years in which the project has run, with nearly 50 000 children being examined, show that prevalence of malformations was 14.36 o/oo. Data on clinical signs of Down's syndrome are collected from the same population. The prevalence of the syndrome diagnosed in this way is 1.66 o/oo. In the project each malformed child is matched with a healthy child and background data on the mother and the father are collected so that epidemiological studies can be done later on.

CZECHOSLOVAKIA

1. Demography

The population is around 15 million, with an estimated 13% below the age of 7 years. The birth rate, which has varied in the last decades, is now approximately 18 o/oo and slowly decreasing.

2. Health services

The health services are public and financed by taxes. All health personnel are employed by the public. Every service in the health system is free. Paediatrics has a prominent position and priority is given to prophylaxis in the primary services; the care of children of 0 to 15 is the responsibility of the community paediatrician and the paediatric health nurse. On average, there is one community paediatrician per 1 340 children and one paediatric health nurse per 700 children.

3. Prenatal diagnosis

Prenatal diagnosis has been done since 1971, with amniocenteses totalling about 800-900. There are three centres, including two in Prague. Amniocentesis and amnion fluid analysis take place in the same hospital. Amniocentesis is done in the 16th-17th week. Results of the analysis can be expected 4-6 weeks later. In all cases an analysis of chromosomes and alphafoto-proteins is done in the three centres. If an inherited metabolic disease is expected the analysis is generally done outside the country. Two different laboratories are now used in each case.

In only 16% of cases was the amniocentesis indicated because of high age of the mother. A review of the first 400 prenatal examinations shows that 71% related to chromosome-dependent defects, 9.7% to sex assessment, 14.8% to alphafotoprotein and 4.5% to congenital metabolic diseases. Pregnancy was interrupted in 4.5% of cases and the diagnosis was confirmed in each case.

Capacity is limited and amniocentesis cannot be offered to every pregnant woman at risk, but the hope is that this will be possible in 5-6 years.

Fetoscopy is done to a limited degree at a centre in Prague, and ultrasound examinations are done at 10 centres in the whole country.

4. Birth and neonatal period

Nearly all children are born at hospitals with an obstetric as well as a paediatric department. At least one of the paediatricians is trained in neonatology. Paediatricians are called in all complicated deliveries and if there are problems with the child after birth, it is referred to the paediatric department. In all cases the Apgar score is registered. Every newborn baby is seen daily by a paediatrician until discharge on the 5th day after birth. Every child is examined by a neonatologist before discharge. A test of sight and hearing is included in this examination. To detect hip dislocation every child is examined clinically and by X-ray. The community paediatrician receives a report on each child.

In some of the regions in the country there is now a systematic selection of all children that can be considered at risk, according to the history of pregnancy and delivery. In these cases neurologic screening is done by a neonatologist before discharge and risk children are followed up by the neonatologist at a polyclinic for such children connected to the hospital. The neonatologists participating in the programme have attended a course in child neurology in Prague. The idea is to establish risk centres in all districts of the country.

Based on the results of a long-term follow-up study of nearly 1 000 risk children born in Prague, efforts are being made to develop a neurologic screening examination which will give optimum reliability using as few neurologic tests as possible.

It is calculated that approximately 15% of newborn children are at risk.

5. Screening for inherited metabolic diseases

5.1 Total screening

Screening for phenylketonuria has been done for several years and has been compulsory from 1975. In the Czech Republic there are three centres; two use Guthrie's method while that in Prague uses paper chromatography and can therefore systematically examine for all aminopathies. The procedure is to obtain the blood sample on the fifth day after birth, and the screening is repeated in the fifth week using urine which the paediatric health nurse obtains from the child. In certain areas of the country the frequency of _____ is high (1 to 6 000-7 000) and in Prague every pregnant woman is screened for this condition. Screening for galactosaemia and hypothyroidism was also attempted but has been abandoned for lack of resources.

5.2 Selective screening

The capacity is limited. There is one centre in the country for glycogenesis, lipidosis and inherited hematologic diseases, while several laboratories can analyse amino acids and mucopolysaccharides.

6. Health surveillance

6.1 Community paediatricians

The community paediatricians have to follow the children in their geographic area from the age of 0 to 15. At present there is one community paediatrician per 1 340 children, but the aim is to reduce the ratio to one per 1 100 children. The community paediatrician works primarily in the child health centre which is located in the area concerned. Besides this he does home visits in cases of acute illness or non-attendance for routine preventive examinations. The community paediatrician is also the school physician for the area and carries out examinations regularly in the creches and kindergartens.

As soon as possible after the birth (ideally within 14 days), the first contact between the child and the community paediatrician is established. The child goes for his first visit or, in the case of non-attendance, the physician visits the home. On average, the community paediatrician has 22.77 contacts with children in the first year of life, of various types: extended preventive including routine examinations and counselling (3.75), short preventive (10.27) and curative (8.75). At the age of 7-8 months, a hearing test is done. At 1, 3 and 5 years a comprehensive examination is done. Between 1 and 5 years the paediatrician has an average of 9.92 contacts: i.e. comprehensive preventive (1.07), short preventive (1.25) and curative (7.60). Hearing, sight and speech are tested. Every child has a record which gives details of the examinations for guidance of the physician. Children who need special attention from the health services (dispensary care children) have to be seen by the community paediatrician at least three times yearly.

If the paediatrician has detected abnormalities or if he is in doubt, he can refer to the child for further examinations at a polyclinic, of which there is at least one in each district (about 100 000 population) connected to the paediatric department at the district hospital.

As opposed to vaccinations, routine examinations are not compulsory; and every child attends for them regularly. There are special problems in the case of gypsy families and the separated families. If the child does not attend for the examinations, the family is visited by the public health nurse who encourages attendances. If a family does not act on the advice, it is the physician's duty to visit the family. Furthermore, state allowances to women who take leave from their jobs to care for their children in the home on the attendance for prophylactic examinations in pregnancy, prophylactic examinations of children and vaccinations of children. The community paediatrician has the duty to report in these cases.

6.2 Paediatric health nurses

These nurses have special training in paediatrics. There is one nurse per 700 children. She works closely with the community paediatrician and the base for her work is the chief health station. She assists the paediatrician in the station and also visits families for both curative

and preventive care. The nurse visits the family immediately after the mother and child have been discharged from hospital and one of her jobs is to evaluate family situation, housing conditions, etc. The nurse always visits the family before the comprehensive examinations at the age of 1, 3 and 5 years. On these occasions she performs a simple test of sight and hearing. The nurse makes an average of 4.3 visits in the first year of life.

The work in the child health station is evaluated continuously. The numbers of contacts are counted regularly for comparison between the different regions and districts. The regional paediatrician and the district paediatrician regularly check the quality of work in the local child health stations. In a comprehensive study of the population's assessment of the social and health services, mother and child health care was rated highest.

7. Day-care institutions

Every child is offered the possibility to attend day-care institutions at preschool age. From 6 months to 3 years, 13-14% of the children use the crèche. Later, 75% of children use the kindergartens. Teachers in creches are nurses with special training in pedagogy and psychology while those in kindergartens have pedagogical training. In creches and kindergartens there are regular examinations of children by the community paediatrician.

8. Registers

Every child has a record which follows it to adult age. At one year a child who needs special care by the health authorities has to be reported to the central authorities (for dispensary care). After the age of one year, every child in this category has to be reported regularly. Dispensary care is also provided to 13% of children aged 1-6 years. The registration covers children considered to be at risk because of social conditions in the family.

Since 1975 every child with a handicap such that it needs special social, health and teaching care has been registered; 2% of children aged 1-8 years are in this category. The group is divided into five subgroups dependent on severity: those who need constant care at institutions (0.23%); those who can lead a social life outside institutions but under special conditions (0.21%); those who will grow up with a permanent disability (1.02%); two subgroups of those who have a handicap which can be corrected by treatment (0.37% and 0.18%).

The group is also subdivided according to the type of handicap: physical handicap (0.40%); sense organs and speech (0.25%); mental diseases (0.55%); two subgroups of chronic diseases and genetic diseases (0.80%).

Congenital malformations have been registered since 1965. Since April 1975 the registration has been monitored and the country participates in the International Clearinghouse for Birth Defects Monitoring Systems seventeen types of anomalies are registered. The registration period is from birth to one year and it is estimated that 80% of all congenital malformations have been detected in this period of life.

USSR

1. Demography

The population is around 250 million with an estimated 12% below the age of 7 years. The birth rate is approximately 18 o/oo and slowly increasing.

2. Health services

The health services are public. All health personnel are state employed. All services in the health system are free. Paediatrics has a prominent position in the services. In the primary sector, the care of children of 0-15 years is the responsibility of general paediatricians and paediatric nurses. In cities, the first link is the children's outpatient clinic where the general paediatrician and the paediatric nurse work as well as paediatricians trained in different specialties. In rural areas the first link is composed of the rural physician, medical assistants (feldshers), paediatricians in rural ambulatory aid clinics and the outpatient departments of local and central district hospitals.

3. Prenatal diagnosis

Pregnancies are divided into risk or non-risk cases. If inherited diseases are suspected, the pregnant woman is referred to a network of genetic centres where genetic counselling is given and decisions about amniocentesis are made. Amniocentesis takes place at highly specialized hospitals, at least at regional level. Indications for this procedure are for instance, chromosome defects in a previous baby, hemolytic diseases, and immunologic diseases. To a certain degree, amniocentesis is also recommended if the mother's age is 35 or over but only for primiparae. The amnion fluid is examined for alpha-fetoprotein if neural tube defects are suspected, and at the All-Union Research Institute of Obstetrics and Gynaecology, 17 different inherited metabolic diseases can be detected prenatally. At this Institute, which attends to many risk pregnancies, amniocentesis is done in approximately 3% of cases.

Abortion is free up till the 12th week of pregnancy. Thereafter a commission has to decide if an abortion is indicated for medical reasons.

4. Birth and neonatal period

Children are born at maternity homes or in the obstetric and gynaecological departments of hospitals. Pregnancies are divided into risk pregnancy or non-risk pregnancy. The maternity hospitals are staffed by midwives and are located in rural areas. Only normal deliveries take place at maternity homes. The obstetric and gynaecological departments are staffed by obstetricians, midwives and paediatricians trained in the care of newborn babies. Specialized departments for women with different kinds of complicated pregnancies (e.g. diabetes mellitus, cardiovascular diseases, endocrinological diseases) exist in towns or at regional or district level. The pregnant woman is assisted by a midwife if the delivery is normal; in the case of complicated deliveries an obstetrician and a paediatrician are called. The child is examined immediately after birth either by a paediatrician or an obstetrician. Usually the child is referred to the neonatal care unit two hours after the delivery. Here the child is seen daily by the paediatrician till discharge from the hospital on the 6th or 7th day. The neonatal care units are equipped to observe and treat children in the first days after the delivery. If further observation or treatment is necessary the child is referred to a paediatric department. At least once before discharge a neurologic examination is performed if the child is born at a hospital staffed with paediatricians; and at least one of these has training in child neurology.

Immediately after discharge from hospital a form is sent to the polyclinic which has to follow the child's progress.

5. Screening for inherited metabolic diseases

Total population screening is not performed for any metabolic disease. In selected areas, total screening for phenylketonuria, galactosaemia (and hypertension and joint diseases in children) are performed. Therefore, screening for inherited metabolic diseases is generally selective. In the smaller republics there is at least one teratological laboratory; and in the larger ones there are several.

6. Health surveillance

Outpatient care for children is ensured from the moment they are discharged from the maternity home until they reach the age of 15. This care is provided by the children's outpatient clinics which function on a territorial basis. An independent paediatric "locality" is set up when there are 800 - 1 000 children living in a given area. In each locality there is a paediatrician and a paediatric nurse, who carry out prophylactic measures for children at home and therapeutic measures for all children in the locality. Each district has several children's outpatient clinics, one of which functions as the centre clinic for the whole district. At this clinic there are paediatricians specialized in a variety of medical and surgical areas. Children from other clinics are referred to the clinic if examination by a specialist is required.

A link between pregnant women and the children's outpatient clinics is established from the 32nd week. A trained nurse is assigned the task of visiting the home when the mother is still pregnant. The visiting nurse checks the living conditions of the future child, and acquaints the expectant mother with methods of preparing for the child and feeding. The children's outpatient clinic is notified of the discharge of the mother and the newborn from the hospital. In the first

days after discharge the local paediatrician, accompanied by a paediatric nurse, pays a visit to examine the infant. During the first month the nurse makes at least two further visits. From the second month, children staying at home are visited once by the paediatric nurse and examined once by the paediatrician at the outpatient clinic. In the second year of life, the child is visited four times in the home by the paediatric nurse and examined four times in the clinic, twice in the third year of life and thereafter once per year till the start of school at the age of 7 years. At each visit to the clinic the physical status and the neuropsychological development of children are checked. The examinations are standardized, and at the same time the procedure is kept under constant surveillance and changed according to new knowledge. Once a year a routine blood count, urine examination and feces examination are made.

Besides the preventive examinations done by the paediatrician and paediatric nurse, each child is examined at least once by a neurologist, twice by an ophthalmologist and three times by an orthopaedist during the first year of life. Thereafter children are examined by an increasing number of specialists each year. At the examinations in the 5th and 6th year, and immediately before start of school, children are examined by physicians representing all specialities included in the preventive programme, and other specialists are called if necessary. If a health problem is found the child's progress is followed carefully both by the local paediatrician and by a specialist. Before the start of school a special form is filled out and this follows the child during his school attendance. In the rural areas the organization of health surveillance is slightly different. Children are seen initially by the local physician and his assistant. The system is administered by the paediatricians of rural ambulatory aid clinics and the outpatient departments of local and central district hospitals.

There are no great problems regarding attendance for routine examinations. The family is informed by letter. One of the physicians in the clinic is responsible for checking the attendance. If a child does not attend, the paediatric nurse visits the family and requests that the child be brought at another date. Eventually the child can be brought to the clinic by the nurse. In many families both parents work full time and the clinics are therefore open in the early evening and also on Saturdays.

7. Day care institutions

Preschool children can attend day nurseries, nursery-kindergartens and kindergartens. More than one-third of the children attend preschool establishments. Before a child can start in a day nursery he has to be examined by a special commission which decides if he is healthy and when it would be appropriate for him to start. The nurseries are staffed by nurses but the services of pedagogues are also available. From the age of 3 years, children can attend kindergartens staffed by pedagogues.

In each locality there is a special team of paediatricians and paediatric nurses responsible for the children attending day-care institutions and schools. The routine examinations of children attending these institutions are performed by this team. They work independently but in cooperation with the children's outpatient clinic in the area.

UNITED KINGDOM

1. Demography

The population is around 50 million, with 6% below the age of 5 years when school starts (9% is below 7 years). The birth rate is around 12 o/oo.

2. Health services

The health services are public and all provisions for the detection of handicap are free. The resources, structure and function of the services can vary from area to area. But at the primary level, curative and preventive care of children is generally the responsibility of general practitioners and the preventive services. General practice is a private occupation, while nearly all other health professions including those in the preventive services are public.

3. Prenatal diagnosis

Several centres examine the alphafetoprotein level in plasma for every pregnant woman in the 16th-18th week of pregnancy. Before the blood sample is taken the age of the fetus is determined by ultrasound scanning. If the alphafetoprotein level has increased, the examination is repeated. If the second examination also shows an increase, amniocentesis is done under ultrasound control. If the alphafetoprotein level in the amnion fluid is also too high, abortion is recommended. The whole procedure takes 2-3 weeks. It has not yet been determined whether this procedure should be generalized for total screening of all pregnant women, because there are still unsolved problems. In some of the abortions, recommended because of high alphafetoprotein level, the fetus has apparently been normal; and on the other hand children have been born with neural tube defects, where the alphafetoprotein level was normal. Moreover, it is calculated that amniocentesis increases the risk of spontaneous abortion by 1%. It is also being considered whether blood samples for alphafetoprotein examination should be taken routinely, or if the pregnant woman should be invited for an examination and thereby have the possibility to decide for herself if she wants to participate.

There are reasonable possibilities for chromosome analysis. Amniocentesis is offered if the pregnant woman is 40 years or more and consideration is being given to lowering the age limit to 35 years. Amniocentesis is also offered if there is a family history of chromosome defects. Chromosome analysis is centralized at area or even regional level but there is not yet ultrasound equipment at all centres. It appears, however, that amniocentesis without ultrasound assistance does not raise the number of complications. The results of examinations for chromosome anomalies are available 3-4 weeks after the amniocentesis.

There are 12 laboratories dealing with inherited metabolic diseases, each able to examine for different diseases. In all, 37 of the 60 possible metabolic diseases can be diagnosed prenatally in the country. Often, but not always, the examination is duplicated at another laboratory, and even laboratories outside the country are used. It is being considered whether chromosome examinations should be done in all cases of amniocentesis or neural tube defects and inherited metabolic diseases.

Fetoscopy to detect visible defects in the fetus is done at four centres. At one or two centres, the necessary technique has been developed to take blood samples from the fetus for detection of thalassaemia, hemophilia and muscular dystrophy.

4. Birth and neonatal period

It is reported that 90% of babies are born at maternity units, 7% at general practitioners' units, 1% at private hospitals and 2% at home. By no means all maternity units are located in hospitals with paediatric departments but there is a trend toward this. Usually the newborn baby is examined shortly after birth by the general practitioner, an obstetrician or a paediatrician, depending on where the delivery takes place. If it is a hospital with a paediatric department, usually a paediatrician is called in complicated cases and all children are examined by a paediatrician before discharge. As a minimum, all children are examined for congenital malformations including congenital dislocation of the hip and for phenylketonuria between the 6th and 14th days. About 60% of all newborn babies are observed and/or treated at a special care baby unit and 1-2% at intensive care units. From district to district a varying number of children, who present problems at birth or are suspected to develop handicaps, are followed up on an ambulant basis by the paediatric department. Others are referred to the district handicap team or a general practitioner.

5. Screening for inherited metabolic diseases

5.1 Total screening

All newborns (99.99%) are screened for phenylketonuria. The Guthrie method is used, but some centres use paper chromatography and therefore at the same time screen for other aminopathies. In a few areas all newborns are screened for other metabolic diseases such as hypothyroidism.

5.2 Selective screening

Twelve laboratories deal with nearly all inherited metabolic diseases. An index shows what kind of analyses the different laboratories can perform.

6. Health surveillance

6.1 General approach

There is no general approach for the whole country. Usually the preventive services are run by a local authority child health clinic, while the curative services at the primary level are run by general practitioners.

6.2 Local authority child health clinics.

The units are staffed by clinical health officers and health visitors, employed by the community. Their functions relate not only to children but also, for instance, to the elderly. The tasks in relation to children are, first of all, assessment of development and vaccinations. The personnel can only give advice, not treat. On average, there is one child health clinic per 20 000 population, but the numbers of clinics, medical officers and health visitors depend on the resources the local authority devotes to health services. It is stated that most of the clinical health officers do not have satisfactory training in child health and also that the child health clinics are shorthanded. The ages for developmental checkups varies much from place to place, but many clinics try to see the children at the 6th week, between the 7th and 10th month, at the 18th month, and at 2 1/2, 3 1/2 and 4 1/2 years. In general parents are given a booklet with information on the surveillance programmes. At some places the child is invited by letter, and at others the family is informed verbally of the next visit. The clinics are open daily, so that parents always can contact them if they have problems with their child. Attendance is far from 100%, being approximately 80% for the examinations before the first birthday, a little more than 70% for the 1-year examination and less than 30% for the examinations in the 2nd to 4th years. A study of 1 878 children showed that 35% of children who did not attend for the routine examinations (and were therefore visited at home) were at risk compared with 22% in the study population. At 6 months, 45% of high-risk children who did not attend for the examination were suspected to have problems compared with 13% in the population as a whole at this age.

6.2 General practitioners

The vast majority of general practitioners do not participate in routine preventive examinations of children connected to their practice. There are two principle reasons for this: they are not paid for this kind of service, and most have no training in child health. Nevertheless, there is growing interest among general practitioners in developmental surveillance. Many - especially parents - feel that it is unsatisfactory that the preventive and curative services at the primary level are divided between child health clinics and general practitioners. This attitude has also been stated on official side. It is recommended that the general practitioners gradually take over the developmental services, and that general practitioner paediatricians be trained who would be responsible for children in the primary health services (Committee on Child Health Services: Fit for Future, London, HMSO, 1976 - Court Report).

Several research groups are studying developmental surveillance. One, the Ashford Developmental Paediatric Research Group, recommends that the child be seen in the home as soon as possible after discharge from hospital, then in the clinic at 7 months, 12 months, 2 1/2 years and 4 1/2 years, with selective screening at 3 years. The Group use an effective appointment system and has achieved a low non-attendance rate of 3-4%. In a study of the surveillance programme, the Group found the following annual percentages (for all children in the practice under 5 years) of referrals to specialist agencies: ophthalmology, 3.0; audiology, 1.5; speech therapy, 2.7; developmental paediatrics, 0.7; general paediatrics, 0.15. Only the experience in detecting hearing loss was disappointing because the procedure used (standard Stykar test) gave a high false positive rate.

6.3 Health visitors

Health visitors are highly trained nurses who traditionally have special responsibility for families with young children in a given geographical area; but they also have other responsibilities. Many are attached to child health clinics, but it is more and more common for them to be

attached to a general practitioner or a group practice. This is a development which is recommended on many sides because it is considered essential to build up primary health care teams. But at the same time these changes mean that the health visitors spend less time in child care. Therefore it is recommended to train a group of child health visitors who would work with the general practitioners/paediatricians.

Today, the woman and the child are visited by the midwife in the first 10 days after discharge from hospital. Then it is the duty of the health visitor to visit the family after a short interval. Thereafter, how often the health visitor visits the family and her duties vary from district to district. In some districts she performs developmental screening or sight and hearing tests and makes referrals to the child health clinic if she observes deviations.

6.4 District handicap team

The health authorities have been advised to build up handicap teams in each district, and in some districts such teams are already established. They usually consist of a consultant community paediatrician, a nursing officer, a social worker, a psychologist and a teacher. The primary functions are to examine and assess individual children with complex disorders and to arrange and coordinate their treatment, and also to participate in the detection of handicaps whether by examining children suspected to have a handicap or by giving advice or organizing courses for professional staff in the district.

6.5 Risk registers

Based on risk factors in pregnancy, labour and the neonatal period the majority of health authorities established risk registers in the 1960s because it was stated that most of the defects in children (about 70%) could be detected early if resources were concentrated on a small proportion of the infant population (20%). It is now recommended that the health authorities cease to use risk registers because they have not proved satisfactory in practice. It has been difficult to define the risk factors precisely. The majority of individual pregnancy and labour risk factors, commonly used as items for entry in the risk register, have proved to be poor predictors. Many risk registers were enormous with many normal children included; and at the same time children who were not entered were ignored and many handicaps were found among them.

7. Day-care institutions

Provisions for children under the age of 5 include day nurseries, nursery schools and play groups. Day nurseries run by social departments are for children from 3 months to school age. The personnel have two years of training, including observation of the development of the child. Day nurseries are primarily for children of parents who are both working outside the home, but are also for handicapped children and children who need stimulation. The day nurseries are usually visited regularly by a clinical medical officer, e.g. once or twice monthly. The children are examined approximately every 6 months. There are not many day nurseries. The majority of children in day-care institutions attend either nursery schools or play groups. These institutions are for children of 3-5 years. Nursery schools give priority to education. Usually they are visited regularly by a health visitor.

8. Registers

A voluntary system of notifying congenital malformations in babies in England and Wales was set up in 1964. Now the United Kingdom is a member of the International Clearinghouse for Mental Defects Monitoring Systems. Malformations observed at birth or up to 7 days after birth are included. The notification system is linked to that for statutory notification of birth to local health departments.

Three types of analysis are made by computer each month for surveillance: (1) numbers of each type of malformation reported are presented as tables; (2) a test for statistical significance is used to compare numbers of babies observed with each malformation in each area health authority with the number expected if the national incidence of the malformation concerned in that particular month applied to that authority; (3) to ensure that such changes are not due solely to improved methods of case-finding and to distinguish real from random increases in reporting, numbers of each malformation reported by each area health authority are compared with the average number previously reported in that area. In 1977 the reported incidence of babies born with congenital malformations was 216 per 10 000 births.

To study the influence of the environment on the health of the human population, the health committee of the EEC appointed an epidemiological committee. The committee considered whether it was possible to monitor health using malformations as an example. The idea would be to produce incidence figures. The analysis would be an ongoing cohort study for the period from conception to school age. It was decided first of all to study the information systems in 15 areas of the EEC, four of which are in the United Kingdom.

Conclusions

The United Kingdom and Denmark have low and decreasing birth rates, 12-13‰, and the proportion of children at preschool age in these countries is also small (9 - 10% below the age of 7) compared with Eastern and Southern Europe where 12 - 15% of children are at preschool age and the birth rate is approximately 18‰.

The organization of health services varies greatly in the five countries. Spain is the only country with a considerable private sector. To be a general practitioner in the United Kingdom and Denmark is a private occupation, under public control in many respects, while nearly all other health personnel in the primary health and hospital sectors are employed by the public.

In Czechoslovakia and the USSR preventive and curative services are highly integrated in an extended primary health system, but the care for children and adults is separate. In Denmark prophylactic measures and curative services for all age-groups are in the hands of the general practitioner who functions as a family physician. In the United Kingdom prophylactic measures usually are entrusted to a local authority child health clinic and curative services to general practitioners.

Care of the children in the primary sector is the responsibility of paediatricians in Spain, USSR and Czechoslovakia and of general practitioners in Denmark and the United Kingdom. In the USSR and Czechoslovakia there are paediatric faculties where medical students are instructed in paediatrics from the beginning of the training.

Prenatal diagnosis seems to be a valuable tool in reducing the frequency of cases of children born with handicaps and presumably in saving families and children from an unhappy life. In Denmark it has been calculated that the expenditure for each amniocentesis and amnion fluid examinations is about US\$ 2000. However, screening for inherited metabolic diseases saves more than ten times the cost of the procedure by avoiding the birth of heavily disabled children.

But the organization of prenatal diagnosis is still changing because there are many unsolved problems. Some are ethical and religious. In Spain, for instance, prenatal diagnosis does not serve its purpose because abortion is forbidden. Another problem is that it is a heavy responsibility for parents to decide if they want abortion or not. Nor has the problem of supplying adequate information to the public concerning prenatal diagnosis been solved.

There are also technical problems, including the number and nature of complications after amniocentesis and the fact that there is still a small but important number of false negative and false positive results.

There is also the question of whether the indications for amniocentesis are correct. In the United Kingdom where the number of congenital malformations is monitored, a decrease in the occurrence of Down's syndrome has not been observed up to now. In a Danish study the same frequency of chromosome anomalies was found among fetuses with increased risk as among fetuses with no increased risk.

Nearly all deliveries in the countries visited take place at hospitals, and most of the risk pregnancies are attended at hospitals with paediatricians on the staff. This means that nearly all risk children could therefore undergo an examination by a paediatrician immediately after delivery, in which the major handicaps would be found. However, not all the complicated deliveries in the United Kingdom, Denmark and Spain take place in hospitals where it is possible to call a paediatrician immediately after the birth. It is the opinion of the author that this should be the aim.

In Czechoslovakia and the USSR nearly all newborns are examined at least once by a paediatrician before discharge from the hospital. This is far from the case in the other countries where the majority of the healthy newborns are examined by a midwife or an obstetrician. One criticism of this procedure is that it does not take advantage in the period immediately after birth of the opportunity - which does not recur until school entry - to perform a thorough

and comprehensive health examination. In the United Kingdom it is recommended that every child be examined between the 6th and the 10th day after delivery by a paediatrician who is trained for the purpose, and that the results of the examinations should be the basis of a health record on which the child's subsequent progress is charted. But it has not been shown whether routine examinations of healthy newborns by paediatricians gives more useful informations compared to examinations performed by obstetricians or general practitioners. The move from home deliveries to hospital deliveries has now culminated; and a new trend has been observed in Denmark and the United Kingdom. A small but growing number of women want to deliver at home or to deliver through ambulant services and return home after a few hours. This has to be recognized in the planning of care for newborns and these children should be visited by community paediatricians at least once.

Today approximately 3 000 so-called syndromes have been described in paediatrics. Of these the primary biochemical defect is known in approximately 600 cases. Diagnosis allows successful treatment in only a very few cases; but it is important for genetic counselling, if the woman has another pregnancy.

There are a few inherited metabolic diseases where early diagnosis is of vital importance because early treatment is decisive for the result. This applies to phenylketonuria, hypothyroidism and galactosaemia. In many countries all newborns are screened for phenylketonuria and in Denmark newborns are also screened for hypothyroidism. In other countries selective screening is performed for the above mentioned diseases. In Denmark it has been calculated that each examination for phenylketonuria costs nearly \$1, i.e. about 60 000 per year for all newborns. However, in each case of successful diagnosis and treatment, society is saved nearly \$100 000.

New techniques in the discovery of inherited metabolic diseases have been introduced. Using paper chromatography it will be possible to examine each blood or urine sample for different diseases at once and thereby reduce the expenditure per diagnosed case. There still exist a number of problems. In particular, it is the opinion of the author that if an acceptable system of treatment for the conditions revealed does not exist, carrying out the diagnoses could be more harmful than taking no action.

It is also a problem that the different methods used still give false positive results. This can cause much anxiety in a family until the diagnosis has been invalidated. One of the reasons for this is that the public is not sufficiently informed about the routine examinations of newborn babies.

The organization of health surveillance varies greatly from country to country. In most countries the preventive and curative systems are integrated; only in the United Kingdom are they separated. It is the opinion of the author that the curative and preventive services should be integrated because they are so closely related. In the integrated system, the primary health team (the physician and the visiting health nurse) have a better general view of the child's development and the total situation, and parents are not confused by the involvement of too many different personnel in the care of the child.

It is difficult to know if the primary health services should be divided in a service for children run by general paediatricians and one for the adults run by general practitioners (as in the USSR, Czechoslovakia and Spain), or if they should be integrated in the hands of a family physician as in the United Kingdom and Denmark. In the first case it should be ensured that those dealing with children are properly trained and motivated in child health. In the latter case it should be ensured that the physician has a better general view of the total family situation. If the last system is preferred, it should be ensured that the family physician is able to use paediatricians as consultants.

It is important that the physicians and visiting health nurses be well trained in the surveillance programme. The organization of health services in Czechoslovakia and the USSR seems to ensure this, and the visiting health nurses in Denmark and the United Kingdom seem to be well trained to fulfil their task in health surveillance. The same could not be said about the general practitioners in Denmark, United Kingdom and Spain where it is up to each physician to decide how well trained he wants to be in this area.

It is also of great importance that the health surveillance programme be adjusted to new technical and psychological knowledge and to changes in disease patterns. It is the opinion of the author that, based on experience and scientific studies, a schedule for the programme as well as instructions on the examination technique be elaborated for application by all health personnel involved in the health surveillance of children. Again it seems that this is better ensured in Czechoslovakia and USSR than in the other countries, but it has to be mentioned that the health authorities in Denmark have just made new recommendations for routine preventive examinations. These recommendations are based on changes in disease patterns and therefore emphasize the psychosocial situation of the child, the development of sensory organs and psychomotor development.

In Czechoslovakia many studies are under way to establish risk registers based on risk factors in pregnancy, labour and the neonatal period. However, in the United Kingdom the health authorities have had 10-15 years of practical experience with risk registers and it has been so disappointing that their use has been discontinued. Instead, every child should be included in a thorough health surveillance programme. The number of health examinations and the ages for these examinations vary greatly from country to country. The surveillance programmes in the USSR and Czechoslovakia are characterized by a large number of preventive contacts with children especially in the first year of life and the programme in the USSR also uses a great number of specialists. To the author it is not evident that this approach will give significantly greater security in detecting handicap compared with programmes involving a smaller number of examinations at appropriate ages. What is important for the effectiveness of health surveillance programmes is the possibility of referring children with suspected or obvious handicap for further examinations and assistance by specialists.

In Denmark and the United Kingdom, attendance for examinations is a problem. Experience shows that those who do not attend for routine preventive examinations are those who really have the problems. In the USSR and Czechoslovakia this is not a great problem because the preventive services are more intensive with greater outreach. In Czechoslovakia, economic measures are also used to reduce the frequency of non-attendance, in that allowances from the State depend on attendance for routine examinations. However, it has been shown both in Denmark and the United Kingdom that the frequency of non-attendance can be reduced to a few percent if the examinations are done properly and appear meaningful to parents; if families are invited by letter; if the physician cooperates with the visiting health nurses; and if parents who are both working outside the home are given the possibility to meet their children after working hours.

It seems that the evaluation of the health surveillance programmes is sparse in each country. It is the opinion of the author that effectiveness in detecting handicaps, utilization of the programme and parents' opinions about the health examinations should be studied continuously.

In Czechoslovakia and the USSR all day-care institutions are public. In Denmark most of the institutions are public, but a sizable minority of children have to be placed with private child minders. In the United Kingdom, many children are cared for in private homes and in Spain there are few day-care institutions. In the public institutions the personnel have approved training, including some instruction in the observation of child development, hygiene, illness and social medicine. In public institutions in the USSR, Czechoslovakia and the United Kingdom, children are examined by the physician and/or a visiting health nurse. This arrangement does not exist in Denmark.

It is the opinion of the author that public day-care institutions are a good tool in the early detection of handicaps. This is one of the reasons why priority should therefore be given to developing such institutions as an alternative to child minders, and every child in an institution should be regularly examined by a physician or visiting health nurse.

Precise registration of handicaps entails many difficulties. A well known problem is that diseases can be difficult to define. Another problem is that there are so many persons involved in reporting the detected handicap. Above all, the reporting has a voluntary element and the same interest and skill cannot be expected to be equally distributed in a whole country. Thus registration requires careful and strict organization.

The greatest experience has been gained in the registration of congenital malformations, because the organization of deliveries in most countries allows a physician and/or midwife to see nearly every child in the first days after delivery; and major handicaps are thereby detected and recorded.

There is less experience in the registration of complex diseases like cerebral palsy and psychosocial disabilities in which, among other things, the development of the child and changes in the surroundings make it difficult to decide when a manifest handicap exists. The registration of these conditions is nevertheless of the greatest importance in discovering causal relations and thereby preparing the way for real prevention.

Monitoring of handicaps, especially congenital malformation, has been introduced in several European countries. This procedure is of value in detecting changes in frequency of reporting rather than in estimating the absolute incidence of malformations. Data collection systems have been found useful for many purposes in addition to monitoring, e.g. planning of services for disabled children, tests for a suspected relationship between toxic substances in the environment and congenital malformations, case control studies, monitoring of the effects of changes in therapeutics, case-finding.