

DISCUSSION PAPERS

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**Routine Data Collection And Monitoring of
Health Services Relating to Early Childhood
Development: A Two-Nation Review Study**

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OVERVIEW

Monitoring of health services can serve two major functions: providing information for performance management as well as for evidence-based policy-making. The means by which monitoring is carried out and the balance that is struck between these functions vary according to the situation of different countries. This paper reviews monitoring processes and the availability of data relating to early childhood development in the cases of Germany and the United Kingdom. The discussion centres on pre-requisites for successful routine data collection: a national framework, a national database and making data available publicly.

*This paper contributes to IRC's ongoing exploration of the assessment of child well-being. Sandra Eismann is a staff member of the Healthcare Commission in the United Kingdom. She was recipient of the James Mayes Award in 2007/2008 and was in residence at the Innocenti Research Centre at the time that the work reported here was conducted.

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About UNICEF IRC

The UNICEF Innocenti Research Centre in Florence, Italy, was established in 1988 to strengthen the research capability of the United Nations Children's Fund (UNICEF) and to support its advocacy for children worldwide. The Centre, formally known as the International Child Development Centre, has as its prime objectives to improve international understanding of the issues relating to children's rights, to promote economic policies that advance the cause of children, and to help facilitate the full implementation of the United Nations Convention on the Rights of the Child in industrialized and developing countries.

The Centre's publications contribute to the global debate on children's issues and include a wide range of opinions. As a centre for excellence, Innocenti also collaborates with external partners and often seeks contributions and inputs from children's rights specialists from a range of disciplines

The Centre collaborates with its host institution in Florence, the Istituto degli Innocenti, in selected areas of work. Core funding for the Centre is provided by the Government of Italy, while financial support for specific projects is also provided by other governments, international institutions and private sources, including UNICEF National Committees

ROUTINE DATA COLLECTION AND MONITORING OF HEALTH SERVICES RELATING TO EARLY CHILDHOOD DEVELOPMENT: A TWO-NATION REVIEW STUDY

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1. Introduction and Background

This paper examines monitoring systems relating to early childhood development in two European countries, Germany and the United Kingdom. For present purposes, early childhood refers to the period from birth until the child enters school; broadly, the period from zero to five years of age. Considerable research in early child development has been done with regard to pre-school education and care (see e.g. reviews by Carneiro and Heckman, 2003, and OECD 2006). This analysis focuses particularly on the collection of routine data on health service provision in Germany on the one hand and in England and Wales on the other, comparing and contrasting and discussing approaches to strengthen their effectiveness.

Routine data collection and the use of monitoring information can (1) facilitate performance management, identifying areas of concern and means to improve outcomes; and (2) it can inform policy decisions by supporting evidence-based – a shift from opinion-based – policies (Segone 2008).

The early childhood years are the key formative period of an individual's life (Shonkoof and Meisel 2000). Early childhood factors are a major influence, for example, on the quality of life in adolescence and on mental health in adult life. Research in neurology has shown the impact of early childhood experience on brain development (Kotulak 1996). Early childhood development can be described as a life-long determinant of health (WHO 2008a). Shortfalls in stimulation and in impressions experienced in childhood cannot be compensated for at later ages: they represent a major missed opportunity.

Health is an important component of early childhood development. It is cited explicitly in the Convention on the Rights of the Child: 'the child shall be entitled to grow and develop in health' (United Nations 1995). By focusing on health this paper does not suggest that health in isolation is important for early childhood development, nor does it suggest that health services should work in isolation. In doing so the child would be deprived of other services outside health or other professional services, which could be available, such as the community. Health is among the key elements of an multidisciplinary approach to early childhood development.

Health is generally an area where public investments are expected to yield high returns. For example, low-cost interventions such as immunizations for young children can prevent deaths and/or high costs to individuals and society in later life. It was estimated in 2002 that immunizations against pertussis saved around 450 million DM in treatments costs annually in Germany (Meyer et al., 2002).

At the national level, the UK Department of Health supports health care delivery and the improvement of performance by a range of means including monitoring (Department of Health 2008). Scholars such as Bevan (2007) for example have argued for better data collection to improve the quality of

hospital care. The German Federal Ministry of Health states that it needs continuous data about its health system to inform its policy decisions (Bundesministerium für Gesundheit 2008). In turn, international data comparisons allow benchmarking, the demonstration of achievable outcomes and the highlighting of areas of success as well as for improvement.

Country Comparison – UK and Germany

Both the United Kingdom and Germany are developed countries with per capita GDP (US\$) of 33,238 for the United Kingdom and 29,461 for Germany (World Bank 2007). The UK has a population of approximately 60,512,000 of which some 3,467,000 are under 5 years old, while Germany has a population of about 82,641,000 of which 3,548,000 are under 5 years old (United Nations 2007).

The United Kingdom and Germany both signed the Convention on the Rights of the Child upon its introduction in 1989. In a recent UNICEF review, the countries ranked similarly in the area of child health and safety, in the middle among developed countries with Germany ranked at 11 and the UK at 12. (The United Kingdom's performance in health and safety was its best among all the dimensions used to assess child well-being.)

Detailed examination indicates that the UK fares worse than Germany in all the health and safety dimension relating to early childhood development (namely, infant mortality, low birth weight and immunization rate). While Germany ranks between 10-17 in these areas, the United Kingdom ranks at 20 or below, among 25 OECD countries included in the study (UNICEF 2007).

In both countries health services are offered free of charge or at minimal cost for the user at the point of access. Services are financed either through public funds or by private insurance. A general view is held in both countries that all citizens are entitled to the same level of public services. It is worth noting, for example, that both countries provide broadly-based home visit services, such as midwifery. A further similarity is that the delivery and to some extent the design of health services are devolved to the regional levels.

2. United Kingdom – Governance and Data Availability in Health

The United Kingdom is a constitutional monarchy consisting of England, Wales, Scotland and Northern Ireland with individual legislatures. There is a bicameral Parliament in Westminster, a Scottish parliament in Edinburgh, a Welsh Assembly in Cardiff and a Northern Ireland Assembly in Belfast.

England, Scotland, Wales and Northern Ireland have separate healthcare systems, but are subject to a common standard: "...all areas of the United Kingdom are entitled to broadly the same level of public services" (HM Treasury, 1979). Within

the UK Government, the Department of Health (headed by the Secretary of State for Health) is responsible for health and for the management of the National Health Service (NHS) in England. Responsibility for health and the management of the NHS in the other three constituent countries falls to the Department of Health, Social Services and Public Safety in Northern Ireland, the Scottish Health and Wellbeing Directorates and the Welsh Assembly Government. The four health systems have similar features, as Health Authorities have major responsibility for pursuing population-based public health strategies within a national framework, while health services are commissioned and provided at the local level.

The NHS is largely funded through general taxation, with an element of national insurance contribution. All persons normally resident in the United Kingdom are eligible for coverage under the NHS. Most services are free at the point of use for the patient, with some co-payments required for services such as dental care. UK taxpayers can choose to purchase private health insurance, but they still contribute to the NHS via general taxation.

Primary care services are mainly provided by General Practitioners (GPs), who normally are contracted self-employed professionals. UK residents register with a GP, who can refer patients to specialist services. Patients usually have no direct access to specialist services, other than for example attending Accident and Emergency departments. Individual patient records are normally held with the GP.

Practice nurses, health visitors and midwives also provide primary care services. Practice nurses usually work in a GP practice; they promote health activities and provide vaccinations. Midwives focus on women's health during pregnancy and childbirth. Health visitors (HVs) concentrate on visiting families with babies and very young children in their homes. They offer advice and are generally concerned with the prevention of ill health and with health promotion.

Hospitals offer secondary and tertiary care, most providing outpatient as well as inpatient services. They are not-for-profit organizations but they are expected to generate income through service contracts with purchasers.

Health Service Provision in England

The Department of Health is responsible to lead the NHS. It sets standards for the health sector, secures resources and issues guidelines for payments and for the distribution of funds. The National Service Framework for Children, Young People and Maternity Services sets out eleven standards of care for children, with a focus on the integration of services.

Ten Strategic Health Authorities (SHAs) are responsible for developing improvement plans for their local health services, and for managing the performance of local NHS trusts. Primary Care Trusts (PCTs) organize the provision of primary care services and purchase secondary care. They are allocated a fixed budget, thereby requiring choice about the services to be provided for their local population. The PCTs commission healthcare services from hospitals, GPs and others.

Acute NHS trusts provide hospital services; mental health NHS trusts provide specialist mental health services. Care trusts combine health services and local authority functions. Foundation trusts provide services as in the above cases, but

they control their own budgets and are not under the authority of SHAs.

Health services are monitored and inspected by the Healthcare Commission, an independent body. The Commission inspects health care provision in accordance with national standards and other service priorities in England, reporting directly to the Westminster Parliament on the state of health care in England and Wales.

Health Service Provision in Wales

At top level, the Minister and Assembly members of the Health and Social Service Committee are responsible for health and social services in Wales. Three NHS Regional Offices are responsible for implementing health policies and monitoring services in their respective geographical areas.

At the local level, Local Health Boards, whose coverage areas correspond to the boundaries of 22 local authorities, are responsible for providing and securing primary and community healthcare services. They receive a large portion of the NHS budget for Wales, and then commission NHS trusts, GP practices and other organizations to provide primary and secondary services to their respective populations. The Boards are also responsible for developing long-term health sector strategies.

In Wales as in England, other key actors include NHS trusts and General Practitioners. A further element is the Community health councils, which act on behalf of patients who receive NHS services. The Councils are independent statutory lay organizations with rights to information about, access to, and consultation with all NHS organizations.

The Healthcare Inspectorate Wales is a department of the National Assembly; responsible for inspecting and investigating the provision of health care by and for Welsh NHS bodies. NHS Healthcare organizations are required to formally submit their declaration and self-assessment returns to Healthcare Inspectorate Wales. The Inspectorate is responsible for testing and validating the returns against a range of data sources.

As in the case of England, the National Service Framework for Children, Young People and Maternity Services in Wales, published by the Welsh Assembly in 2005, provides a framework for services to these groups.

Routine Health Service Data Collection in England and Wales

The "NHS Numbers for Babies" (NN4B) System enables midwives to request a unique NHS number for every infant shortly after birth. This number allows for a common link to be made immediately with different services, helping to increase coverage of screening programmes. (Previously, Registrars of Births and Deaths issued NHS numbers at the time of civil registration, which was sometimes as late as six weeks after birth.)

All babies born in England and Wales are covered by NN4B. Each newborn is assigned a unique NHS number by the Central Issue System (CIS) and printed in the maternity unit on the birth notification form. In the NN4B dataset, information on the birth, the mother and the healthcare professionals supporting the newborn is all recorded. The data

are kept for about 6 months in the CIS system, but are not routinely published (Hilder et al., 2005).

Local child health databases have been developed to assist NHS trusts to administer child immunization and health surveillance programmes. These databases, whose information is largely based on returns from GPs and nurses, have primarily been developed to support local services administration. For each child a record is created at the electronic trigger of the allocation of the unique NHS identifier.

These local datasets are usually not analysed nationally, except in two cases. Babies' birth weights are passed to the local registrars of births and deaths, who forward them on to the Office for National Statistics (ONS) to be analyzed in conjunction with the data recorded from parents at birth registration. ONS provides primary care trusts and strategic health authorities with information based on anonymized birth and death records in their areas. Secondly, if the child has a notifiable congenital anomaly a form containing relevant data is sent either to the National Congenital Anomaly System, run by the ONS, or to a local anomalies register where this exists.

In Wales, a National Community Child Health Database (NCCHD) has been developed, consisting of anonymised records for all children born, resident or treated in Wales and born after 1987. It brings together individual local Child Health System databases, which are held locally by NHS Trusts. The information is published in StatsWales, a free online publication of the Welsh Assembly Government.

In England, computer-based child health information systems have been used since the 1960s. Currently the data are recorded using multiple systems and recording procedures. The databases are not necessarily linked to Primary Care Trust boundaries; PCTs may operate in areas covered by more than one child health database, or they may be part of a wider area covered by a single child health database. Children's records are initiated by birth notification. If a child moves to a different area, a health visitor (HV) will enter their data into the new child health system.

A central actor in routine data collection on children in England and Wales is the UK National Screening Committee (NSC), which develops policies for screening and organizes monitoring programmes. These include the following:

1) **Newborn Blood Spot Screening** analyses a dried blood spot taken from babies' heels, usually by a midwife or nurse, and screened in a laboratory for irregularities. The midwife should inform the GP and HV and record information in the personal child health record. (The personal child health record database has several monitoring purposes, in addition to recording consent from families or carers.) The NSC collects the data centrally and monitors performance and data quality, publishing a data collection and analysis report (UK Newborn Screening Centre 2007). For the past two years, the publication has excluded Scotland. Wales and England are included, although data availability and completeness differs between them. (for example, no data was received for Wales for standard 3 – completeness of screening coverage – in 2006/07.) The report presents an overview of UK performance (excluding Scotland), and gives locally-specific performance information to Directors of Public Health.

Although the NSC issues central guidance for newborn screening, the actual service provision and data collection coverage varies within the UK. For example, screening for sickle cell disease (SCD) is currently part of the routine programme in England, but not in Wales. Screening for medium chain acyl CoA dehydrogenase deficiency (MCADD) is to be offered to all newborn babies in England by March 2009, but in 2006/07; data for MCADD was recorded for only about half of the English areas; the condition is not part of the screening programme in Wales.

(2) The NSC recommends the universal **Newborn Hearing Screening Programme** (NHS Scotland 2003). This test is now offered in all regions in the United Kingdom; 2006-2007 was the first year in which this screening was offered universally in England. The hearing test is usually carried out at the maternity unit before mother and child leave hospital, or otherwise the midwife or GP can arrange for it to be done later. The programme database is linked to birth registrations. In the year 2006-2007, 98.8 per cent of all new births recorded were offered screens, and 94 per cent of these were completed. However, for those screens that were completed, over 5 per cent were incomplete. A quality assurance programme has been established to improve data quality.

The Newborn Hearing Screening Wales (NBHSW), established in 2003, offers screening to all babies born to women living in Wales. Trained newborn hearing screeners are responsible for screening babies in the hospital or the community and for recording clinical test data. NBHSW is responsible for management, quality assurance and evaluation of the screening. It has set several standards to monitor performance, as well as the effectiveness of the programme in identifying hearing loss and providing treatment. Results are presented, per trust, in the annual report by the NBHSW. An information system transfers data into the core Child Health System. In 2006-2007, virtually 100 per cent of eligible babies were offered screening, and 79 per cent of babies received the screening test within the first week of life. A recent report highlighted that screening rates are lower in areas where hospital screens are not offered or in midwifery led units where babies are frequently discharged before screening is undertaken (Minchom et al, 2007).

(3) Third, the NSC issues standards based on best practice for a **newborn and infant physical examination** (NHS Antenatal and Newborn Screening Programmes, 2008). (The present proposal clearly refers to England, and it is unclear whether and how it will be applicable to Wales.) The standards set out a detailed newborn examination, in addition to a brief examination at birth, which is to be carried out within the first 72 hours; and finally a follow-up examination at 6-8 weeks. The newborn examination is to be carried out in hospital, while the examination at 6-8 weeks should be carried out by GPs or community paediatricians together with health visitors.

The guidance includes standards to measure performance, such as the percentage of babies offered screening. Primary Care Trusts are responsible for commissioning a comprehensive service for the physical examination, as well as for monitoring and measuring performance outcomes.

(4) Information on routine immunization in the UK is managed through COVER (**Coverage of Vaccination Evaluation Rapidly**). GPs, nurses or health visitors usually administer vaccination, and records are held in local child

health databases. COVER provides data on quarterly vaccination coverage statistics for children in the UK aged up to five years, published by the Health Protection Agency. Data is collected from the Welsh administrative regions as well as from the central Welsh National Community Child Health Database (NCCHD); and from Primary Care Trusts in England. Gaps exist; for the period from July until September 2007, 15 of the reporting 144 PCTs were unable to provide data (HPA, 2007).

For Wales, published data is provided at the SHA level and aggregated; the assembly government uses the information to monitor the performance of Local Health Boards and NHS Trusts. For 2007-2008, targets included update rates for routine childhood vaccinations.

(5) Another relevant routine data collection programme is the **Confidential Enquiry into Maternal and Child Health (CEMACH)**, for England, which collects a standard dataset of all maternal and perinatal deaths and reports annually on mortality trends. Additionally, a triennial report on maternal deaths gives details on case studies into those deaths. The programme monitors changes in rates, causes of death and risk factors. For their data collection CEMACH depends on the voluntary support of many clinicians. CEMACH also provides information to individual health providers, which enables them to benchmark their mortality rates with other providers.

(6) The **National Neonatal Audit Programme (NNAP)** collects information in pre-identified areas of concern, aiming to identify good clinical practice. This national database enables users to audit their own practice to in comparison to other providers of similar care. The Healthcare Commission funds the project, with a current commitment for 2 years. A defined neonatal dataset is collated via a web-based system. NNAP covers England, and beginning in 2008, Wales.

(7) The **National Congenital Anomaly System (NCAS)** is run by ONS. The main function of NCAS is health surveillance. Notification is made of congenital anomalies for live and stillbirths on a voluntary basis by local community trusts or health authorities. Additionally, regional registers such as the Congenital Anomaly Register and Information Service (CARIS) in Wales provide information to NCAS. The programme covers England and Wales. Data are available on anomalies categorized by a number of variables including mother's age, month of birth, sex and birth weight. Data is published annually by the ONS, at health authority and postcode level.

The ONS monitors congenital anomaly rates to detect increases, and will alert health authorities if necessary. The analysis is undertaken quarterly, and the relevant health authorities are informed of any increase.

In Wales CARIS is funded by the NHS Wales. It uses the Child Health Databases for information, and is also connected to the Welsh NHS Administrative Register (NHSAR) to validate administrative information. Feedback to clinicians is given on a quarterly basis to CARIS coordinators as well as through CARIS annual reporting. At the end of each calendar year CARIS data is transferred to the EUROCAT register, part of a European surveillance programme.

(8) **The UK Collaborative Network of Cerebral Palsy Databases, Registers and Surveys (UKCP)** is a collaborative

network of cerebral palsy registers and surveys in the United Kingdom which works together for the purposes of research and exchange of information. At present there are 5 registers recording children with CP in the United Kingdom, such as 4Child, covering around 15 per cent of England and Wales as well as Northern Ireland and Scotland. The regional registers use multiple data sources for verification. Data completeness varies over time and across locations, as registers were set up at different times with some collecting data retrospectively and others focusing on newly diagnosed children (Surman et al., 2006). UKCP monitors data quality including validation and makes the data available for research.

(9) The local register **Child** collects data on children with cerebral palsy, sensorineural deafness or severe vision loss born to residents in certain parts of England. Paediatricians are contacted for clinical information when children are aged 3 and 5 years. The register is used to monitor trends and variations in prevalence rates of these three conditions.

(10) **Dental data** for children are collected in England and Wales as part of a rolling programme of annual national surveys. The survey, commissioned by the different UK health departments, has been carried out every 10 years since 1973 in England and Wales. The latest data are available for 2003. Dental specialists examine the sampled children in selected schools. Parents are further asked to provide background information on the dental health of their children. The overall report on the UK and the 4 constituent countries is published on the DH website.

In Wales, the dental public health team and the Welsh oral health information unit collect dental data annually. The information is provided to the Welsh Assembly Government and is used to inform the development of health and wellbeing policy. The latest targets released by the Welsh Assembly Government include two targets on oral health for 5 year olds.

(11) The **General Practice Research Database (GPRD)** has since 1987 collected anonymised longitudinal medical records from over 460 practices covering about 5.5 per cent of the UK population (GPRD, 2008). GPRD data is used by government departments and others for research purposes. However, the overall data are not routinely published, nor are datasets from specific research.

Routine Data Collection Specific to England

To assess progress towards the health improvement targets set by the Department of Health, two proxy indicators have been established: mothers smoking at the time of the delivery and mothers initiating breastfeeding. These data items form part of the Priorities and Planning Framework which is used by each Primary Care Trust to state how they intend to decrease the percentage of mother smoking at delivery and the percentage of mothers initiating breastfeeding year-on-year. PCTs submit data quarterly to DH, which publishes it on its web page. The number of maternities is validated with ONS data. The Healthcare Commission also uses these two performance indicators in its annual assessment of NHS organizations.

The Hospital Episode Statistics (HES) database contains details of all admissions to NHS hospitals in England (Hospital Episode Statistics online, 2008a). It is run by a company on behalf of the NHS Information Centre for Health and Social care. It records finished consultant episodes including clinical information such as diagnosis (using ICD-

10), and administrative information such as waiting time and others. The data is collected locally by the healthcare providers, and sent to the Secondary Uses Service (SUS). SUS forwards the information to the commissioning bodies and to HES. The data are then cleaned and validated, and made available in the HES data warehouse. Some information is publicly available on the website, while other items are provided to NHS organizations and selected other partners for further analysis.

The HES data is also linked to ONS, to include information on the date of death. If a woman gives birth in a hospital, this is recorded in Maternity HES, which might not be linked with other HES databases. For example, if a mother or baby is ill and is transferred to an intensive care unit, the case would be recorded as a separate episode in HES (Hospital Episode Statistics online 2008b).

The Neonatal Critical Care Minimum Dataset has been mandated to be collected within the Commissioning Data Sets from 1 April 2007. It aims to provide information for payment by results, commissioning services, national policy analysis and others. The dataset covers all patients in Neonatal Intensive Care Units and those receiving critical care in a maternity or Neonatal Transitional Care Ward. It includes demographic information as well as on critical care activity. Similarly, the Paediatric Critical Care Minimum dataset is designed to cover all patients in a Paediatric Intensive Care Unit or other defined units where the critical care activity is greater than 4 hours. The dataset collection has been mandatory since 1987. Implementation of the new data collection is primarily a responsibility of individual providers.

The Quality Management and Analysis System (QMAS) is a national IT system linking GP practices and PCTs. It supports the Quality and Outcomes Framework (QOF), according to which GPs are paid. The system describes whether maternity and child health surveillance services are offered. Most children in England are registered with a GP, who in turn enters data into QMAS. The data is sent to the commissioning PCT; practices are financially rewarded according to QOF. Additionally, QMAS allows comparison between different practices against national targets detailed in the General Medical Services contract. Information is also published by the Health and Social Care Information Centre

The National Child Measurement Programme (NCMP) weighs and measures children aged 4 to 5 years when they enter school, recording height and weight in order to assess overweight levels (The Information Centre for Health and Social Care, 2008a). The Department for Health and the Department for Children, School and Families are responsible for the programme. The data is collected in schools and submitted to PCTs. The Information Centre collates the data nationally, and makes it available to SHA, PCT and national levels. In autumn 2008 an assessment was initiated by the Healthcare Commission on the quality of data in this collection process by PCTs.

Finally, a national children's services dataset is currently being developed. It aims to make data already collected more accessible for secondary analysis (The Information Centre for Health and Social Care, 2008b). The data, to be taken from clinical records, will be used to monitor the implementation of standards as detailed in the National Service Framework. At national level, the Department of Health and the Healthcare

Commission will use the data to audit service quality and coverage.

3. Germany – Background Information and Data Availability in Health

Germany is a federal republic consisting of 16 Bundesländer (federal states). While the German constitution does not specifically mention health, it requests that living conditions shall be of equal standards in the Länder.

At the federal level, the Ministry of Health is responsible for supervising compliance of organizations with the statutory health insurance schemes (i.e. the federal associations of physicians and sickness funds). It also has a supervisory role for non-governmental institutions, such as the Federal Centre for Health Education, the German Federal (Social) Insurance Authority (Bundesversicherungsamt) and the Joint Federal Committee. The latter can issue directives for sickness funds, physicians and hospitals, and which are binding in law.

The Länder governments are responsible for public health services and maintaining a hospital infrastructure. Some Länder have devolved responsibility for community public health services to local government. Public health tasks include health promotion and the clinical examination of school children.

The German healthcare system is characterised by decentralization and autonomous decision-making; shared among the Federal Government, the Länder and identified civil society organizations.

At a corporate level, the health insurance system includes organizations providing and purchasing services. Physicians' and dentists' associations, which are affiliated with the statutory health insurance, are on the provider's side, while the sickness funds and their associations are on the purchaser's side. These organizations have the status of quasi-public corporations and are based on mandatory membership. The Social Code book sets the framework of this delegation of state powers to corporate bodies. The physicians' association must provide health services as defined by both legislation and contracts with the sickness funds. (Hospitals usually contract individually with sickness funds.)

On the purchasers' side, sickness fund associations raise contributions from their members and determine what contribution rate is necessary to cover expenditure. They negotiate prices, quantity and quality assurance measures with providers on behalf of all members of the sickness funds.

The Social Code book states that service providers are themselves responsible for quality management. They have the legal obligation to maintain and improve the standards of service they provide. However, this is not aggregated to national level.

Most people in Germany are covered by health insurance, mainly in the statutory health insurance scheme but some in private systems. Statutory health insurance is the major source of financing health care. Germany traditionally has no gate-keeping system: patients have access to generalist doctors as well as specialists. Apart from a minor patients' contribution, the health insurance company pays the costs associated with healthcare. Most of the preventative screening programmes and health check-ups for children and adults are included in

the sickness funds' benefit packages and are carried out by office-based physicians.

Immunization

The Communicable Diseases Law Reform Act from 2000 provides a legislative framework for immunization procedures in Germany. It sets out responsibilities for the different bodies in the healthcare system, including the mandating of a federal commission, the German Standing Vaccination Committee (STIKO), which recommends an immunization schedule and vaccination practices in a reference guide published annually.

As required by law, the Robert Koch Institute publishes the recommendations. The Länder governments then issue public recommendations for vaccinations based on them. The Federal Ministry of Health has special powers in certain circumstances. For example, it can require sickness funds to pay for individual vaccinations or even mandate individual vaccinations, and require recording and transmission of anonymised data about vaccinations given. Legal guarantees for compensation have been implemented for the vaccination programme recommended by STIKO, in case people suffer permanent damage through vaccination.

Vaccinations are offered by office-based general practitioners, paediatricians and health offices. Each vaccination is recorded in a vaccination card, which remains with the child/parents (and, in consequence, does not facilitate easy monitoring). Immunizations are not recorded centrally and regional databases do not exist. Practitioners are not required to actively approach their patients about their vaccination status. Each vaccination requires active engagement and cooperation on the part of the parent. However, all children are screened before they enter school.

Preventative Health Check Ups

Children in Germany have a right to 9 preventative health check-ups before they enter school. When the mother leaves hospital with the newborn child, she received a booklet in which these should be recorded, that should be brought by the caregiver every time the child visits a paediatrician. The costs of all check ups, if done within the recommended timeframe, are paid for by health insurance.

Guidance issued by the Federal Joint Committee for the early detection of diseases in children under the age of 6 years was last amended in 2008 (Richtlinien des Bundesausschusses der Ärzte und Krankenkassen, 2008) It sets out the 9 preventative health check ups, including their recommended timing and recording process. The guidance covers comprehensive physical examinations as well as the bloodspot test. Some conditions screened for in the bloodspot test are the same as in the UK (PKU and MCADD), while some others are not offered in the United Kingdom (e.g., hypothyroidism, adrenogenital syndrome).

Laboratories are responsible for the quality assurance of tests undertaken. They have to submit quarterly reports (including details on recall rates, test results and timeliness of testing) to the association of physicians, which passes the report on to the sickness funds and the Federal Joint Committee.

As with the immunization schedule, there is no national database containing uptake or results for all children covered by this initiative.

The proportion of children undertaking health check-ups cannot be reliably estimated because the total number of births is not available. Aggregation is also difficult in relation to laboratory results, as parents can freely choose office-based physicians. School entry examinations are the only time when all children in an area are screened, if they go to school.

Some Länder made the 9 preventative health check ups mandatory, mainly for child protection purposes. For example, the Bavarian government passed legislation in 2007 making the check ups mandatory. Proof of checkups has to be provided when enrolling the child into childcare or school and when claiming child-raising allowance.

School Entry Examination

Children have to be examined before they enter school in order to confirm they are physically and mentally healthy. Health officers or physicians undertake the examination. At this point, the vaccination status of the child is recorded and sent to the Robert Koch Institute via the supreme health authority in each of the Länder (Communicable Diseases Law Reform Act 2000).

The local authority of Unna in North Rhine Westphalia analysed the uptake of preventative health check ups, based on information from the booklet of each child undergoing the school entry examination. It found that while almost all children had the first check up, only 86.5 per cent had the ninth.

The data and analysis on the health status of children allows local planning of services. The local authority in Unna found in the analysis above that children born abroad or from migrant families are less likely to undergo the recommended health check ups; this information can now be incorporated into their local planning and outreach of services.

KiGGS – The German Health Interview and Examination Survey for Children and Adolescents

KiGGS is a comprehensive, nation-wide interview and examination survey, covering 17,641 children and adolescents in 167 communities representative of Germany (KiGGS 2008). The survey was carried out by the Robert Koch Institute between May 2003 and May 2006, commissioned by the Federal Ministry of Health. Topics relating to early childhood include oral health, breastfeeding, and immunization status. The study aims to assist policy makers, establishing a baseline for monitoring health issues for German youth and assisting health needs prognosis. For example, its analysis of data relating to oral health show different patterns for different social and cultural groups, which calls for differentiated preventative actions.

Hospitals and medical practices are obliged by law to have internal quality management systems in place. Since 2005, hospitals have had to publish quality reports every two years which contain data about their service spectrum, qualifications of the personnel, the number of treated patients, type and quantity of surgical procedures as well as the outcomes of services.

4. Discussion – Availability of Data and Monitoring of Health Services Relating to Early Childhood

A range of approaches are suggested to organize the monitoring of health services at national level, to provide information for performance management and to support evidence-based policymaking. For example, WHO proposes a health matrix network, which increases “the availability, accessibility, quality and use of health information vital for decision-making at country and global levels” (WHO 2008b). The OECD calls for national database to inform policy decisions (OECD 2006). A national database would be a prerequisite for international benchmarking, and could thus nurture government responsibility and accountability.

At local level, information collected through routine collection can identify gaps and areas for improvement, if the information is disaggregated appropriately. For example, a PCT that knew which wards had low immunization rates could focus its efforts there. It could subsequently compare its performance to that of a neighbouring PCT, or to other benchmarks in order to gauge how well it is doing.

Three criteria are seen as critical for the development of routine national health data collection.

From the outset, **a national framework is needed that sets out a coherent approach to data content and its use.** It must be noted that no clear European or globally agreed policy seems to exist giving a standard perspective on the nature and content of early childhood health services in economically advanced countries. Yet coherent policies and frameworks are important. Coherent policies can lead to coherent service provision leading to coherent data collection allowing data to be combined and analysed at national level. If such frameworks can tie in with existing international recommendations, it could pave the way for internationally comparable data on benchmark indicators. Germany seems to be in a good position to establish a comprehensive national health information framework, building for instance on existing legal provisions for immunization and child health check-ups.

While existing guidance in Germany, e.g., for immunization services, follows internationally recommended standards, the United Kingdom rarely refers to international recommendations. A number of UK monitoring programmes, along with a range of policy decisions, have on the other hand been devolved to constituent countries. As has been seen, some routine screening projects cover England, Wales and Northern Ireland such as CEMACH, while others cover only England and Wales (NN4B), or only one of these. A comprehensive national data collection system on early childhood health seems less feasible in this context. Attempts have been made to introduce consistency, for example with the establishment of the National Screening Committee. However the force of such mechanisms remains limited.

Second, **a framework setting out clear roles and responsibilities increases data quality and value.** In England, birth certificates are a legal requirement; the informant is responsible for the accuracy of the information and faces legal penalties for providing false information. For health data, ONS undertakes consistency checks; and reports that it believes the data supplied is generally correct due to the legal requirement (Office for National Statistics 2004).

Following establishment of a national framework, a national database would be needed to collect data. The two countries studied differ in this respect. Germany on one hand does not

have comprehensive routine data collection for early childhood health but instead relies on retrospective data collections such as the school entry examination or the KiGGS study. Information from such sources may be relevant to advise on larger policy decisions involving the interpretation of overall past trends. Such sources do not allow pinpointing of specific geographical locations in anything approaching real time. Nor do they provide information that can advise on health system performance for individual children, e.g., in the area of child protection; yet it is recognized that when the child reaches school age it might be too late for appropriate interventions. At present, for example, there is no mechanism in Germany which provides assurance that all children born are provided with health check-ups.

Existing local child health databases, on the other hand, offer a foundation for this purpose in England and Wales. A national system could be readily envisaged covering all children, as the local databases already contain a record of each child born. The challenge is then to link these files with other existing local, regional or national databases; currently, different data systems are not well connected and information from one system rarely feeds into another. For example, GPs and health visitors have locally held records but these are usually not connected to the local child health systems. (As a practical matter, current individual child health databases often use distinct IT solutions. In 2005 in the South East region, for example, it was found that 49 PCTs used 24 different IT systems, with 10 different types of software. Not all of these included newborn screening data (Hilder et al., 2005).) Even within a given facility, information systems serving similar purposes may not be linked, as in the case of separate systems for HES data and maternity HES data. The ‘National Programme for IT’ had been intended to replace local NHS databases with a single large national database. At the time of writing, however, the future of this programme was uncertain (House of Commons 2007).

A national database should provide up-to-date and comparable information, and identify trends and areas of concern. As a prerequisite, the information collected needs to be timely and coded in the same way. Guidance as suggested above represents some first steps toward this end.

Third and finally, **health monitoring information should be well catalogued and made publicly available.** The research for this review encountered numerous barriers to finding accurate and clear information about data being collected in the different country settings, and to learning how the data can be accessed. A particular limitation in England and Wales was unclarity over how specific initiatives (such as the screening programme) apply in different constituent countries. In addition, -- assuming that privacy and other relevant safeguards can be met -- there is wide inconsistency over access to childhood health data. For example, the General Practice Research Database in England and Wales appears to provide a good base for research, yet its database is not easily accessible.

In Germany, hospitals are required to have a quality management system, but it is not clear how this information would be made publicly available. Generally, it was more challenging to find information from local monitoring systems in Germany, access to which is captured by sickness funds for purchasing purposes.

To summarise, despite broad similarities in their overall social, economic and political situations, Germany and the United Kingdom differ significantly in the design and operation of their routine data systems on early childhood health. Equally, while common principles may be identified for effective routine data systems, distinct steps are required in the two countries to put these into practice.

The importance of this issue is that if such data were routinely collected, it could be used productively at the national level, and contribute to debates at the international level, to strengthen policy decisions regarding health services for early childhood development.

If comprehensive databases existed in Germany and the United Kingdom, future research could try to establish the reasons and factors in the different outcomes for children between them. This in turn could be a great lever for improving health outcomes for young children across the two countries.

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