



Child Health Information Development



**Developing child health information for
Tyne and Wear Service Providers**

Child Health Information project reports

Report Title	Date	Web Address
Low Birthweight Report	Aug 2001	http://www.ncl.ac.uk/plerg/Research/CHI/Low Birthweight Report.pdf
Cerebral Palsy First Report	Sep 2000	http://www.ncl.ac.uk/plerg/Research/CHI/Cerebral Palsy Report.pdf
Smoking Prevalence Report	Jun 2001	http://www.ncl.ac.uk/plerg/Research/CHI/Smoking Report.pdf
Severe Injury Report	Jan 2001	http://www.ncl.ac.uk/plerg/Research/CHI/Severe Injury Report.pdf
Teenage Pregnancy Report	Sep 2001	http://www.ncl.ac.uk/plerg/Research/CHI/Teenage Pregnancy Report.pdf
Quality Protects Report	Dec 2001	http://www.ncl.ac.uk/plerg/Research/CHI/Quality Protects Report.pdf
Consultation Comments Report	Dec 2001	http://www.ncl.ac.uk/plerg/Research/CHI/Consultation Comments Report.pdf
Meeting Report	Dec 2001	http://www.ncl.ac.uk/plerg/Research/CHI/Meeting Report.pdf
Cerebral Palsy Second Report	Dec 2001	http://www.ncl.ac.uk/plerg/Research/CHI/In-depth Report.pdf
Interim Report	Feb 2002	http://www.ncl.ac.uk/plerg/Research/CHI/Interim report.pdf
User Interface Report	Mar 2004	http://www.ncl.ac.uk/plerg/Research/CHI/User Interface Report.pdf
Cerebral Palsy Qualitative Study	Mar 2004	http://www.ncl.ac.uk/plerg/Research/CHI/Cerebral Palsy Qualitative Study.pdf
This Report	Mar 2004	http://www.ncl.ac.uk/plerg/Research/CHI/Final report.pdf

Executive Summary

- ◆ Information on the health of local children is considered by service planners and providers to be incomplete, inaccessible, and of little utility.
- ◆ A development project, funded by Tyne & Wear HAZ explored this issue by focusing on six exemplar topics. Birthweight, teenage smoking, severe injury, cerebral palsy, teenage pregnancy, and the health of looked after children across Tyne & Wear were the subjects of separate reports, a set of consultation exercises and some further extension projects.
- ◆ The conclusions from this process are that in the North of England:
 - Child growth data where available are unused and almost uninterpretable. The minimum requirement is comparison to relevant growth charts. Fetal growth and preterm birth both show strong social gradients which cannot currently be monitored with routine data.
 - We know very little of our children's exposure to important health risks. There is an urgent need for continuous representative risk monitoring by local sample survey. The feasibility of an omnibus health risk survey delivered by Internet questionnaire to children in schools has been demonstrated and a pilot study is in progress.
 - Analysis of non-fatal injury frequency using the UK government's indicator is seriously misleading. As with other acute health events a minimum severity case definition is essential for analysis of health records. A new indicator based on "severe fracture" admissions is currently in use in the European CHILD project (and by CHAI?).
 - Participation of children with cerebral palsy in ordinary life situations is hardly recognised as a legitimate health outcome. All children with severe chronic disability should have their participation established. The degree of participation of local children with cerebral palsy has been shown to depend on where they live. Detailed studies have clarified current local barriers to participation, the methods to describe disability-friendliness of localities, and a variety of techniques to identify children with unmet service needs.
 - Relatively good information is available on teenage pregnancy. However we know little of the longer-term outcome for children who conceive when under 16 years of age (approximately 1% of girls).
 - The health of looked after children – a second highly vulnerable minority – is almost undocumented. A means should be found to monitor their health careers in some detail (approximately 1% of all children).
- ◆ Other important sources of local child health data, such as the perinatal mortality/ fetal abnormality/ child cancer registries, and the universal records on immunisation and screening coverage are under-exploited.
- ◆ It is possible to offer Intranet access to anonymized raw and value-added data on local child health to naïve users – data quality is unlikely to improve until a wider set of such users appreciate their utility.
- ◆ The overall recommendation is that there should be an Observatory of children's health at a regional level, linked to the Public Health Observatory and with a remit to collate existing data, add value by analysis and linkage to evidence for effective interventions, commission new surveillance methods (such as an omnibus or panel questionnaire survey) and conduct R&D on new indicators, data utility and user access methods.

The Child Health Information Project (funded by Tyne & Wear HAZ)

With the institution of the Tyne & Wear Health Action Zone, the opportunity was taken to develop a study of key indicators of health of children in Tyne & Wear. The objective was to identify gaps in both the range of information available and the processes by which it is made accessible and useful.

Six exemplar issues were chosen, after consultation, to answer the question “**How healthy are children in Tyne & Wear?**” For all children: -

- ◆ Their growth and development
- ◆ Their exposure to known health risks
- ◆ Their experience of acute ill health
- ◆ The extent of morbidity amongst those with severe long-term health impairments.

In addition, two identifiable groups of health vulnerable children are included: -

- ◆ The 1% of girls aged 13-15 years who become pregnant each year
- ◆ The 1% of youngsters who, at any one time, are being ‘looked after’ by Local Authorities

Other aspects of child health were not chosen as exemplars because data sources were too sparse (eg pre school screening coverage, breast feeding) or were already relatively well developed (eg perinatal mortality, cancer).

For *growth and development*, the chosen focus was on birthweight, otherwise there are no satisfactory local data to assess children’s physical growth (eg height and weight) nor are there any data at all on achieved norms of psychomotor development.

For a common *risk to children’s health* where there are at least some local data, the chosen exemplar was tobacco smoking in secondary schoolchildren. There are some data from similar sources (ie self completion questionnaires) on children’s nutrition and other health related behaviours.

Acute ill health events, which lead to emergency hospital care, are what many would describe as ‘serious illness’ in childhood. One of the commonest reasons for acute admission of local children to hospital, and the most dangerous (ie with the highest fatality risk) is severe unintentional injury. Other common causes of urgent hospitalisation amongst children, such as acute respiratory problems (bronchiolitis etc) are also important.

To demonstrate the *chronic morbidity* of children with long-term health impairments, we have used data from a local, long-running survey of children with cerebral palsy. This is the only source of comparable data across Tyne & Wear for any type of disability in childhood.

For teenage pregnancy, the principal source is the centrally collated, anonymized dataset on conceptions (ie completed pregnancies plus therapeutic abortions) compiled by the Office of National Statistics (ONS). Similarly, for looked after children, the principal set of comparable data across Tyne & Wear are the published national returns from local Health and Social Services Departments.

Following the completion of the six exemplar reports and a series of consultation exercises based upon them, an interim report made recommendations for further work on population health risk survey methods, development of indicators of child disability-friendly environments and the exploration of ways to allow constructive access to raw child health data by naïve users.

The following section contains the summaries from each of the six exemplar reports, a synthesis of common themes and more detail of the follow up projects. Full accounts of each stage of project are given in separate reports [see web addresses on page 2 of this document].

Growth and Development - Low birthweight

- ◆ Birthweight is a key indicator of the health of babies. Perinatal and infant mortality and morbidity are strongly associated with birthweight. Low birthweight also shows a steep social gradient. Improvements in birthweight and reductions of inequalities in birthweight are integral parts of Government health targets.
- ◆ Birthweight is really a measure of size at a specific age since conception. If gestational age (GA) is also recorded it is possible to use normative growth charts to estimate relative fetal growth across populations.
- ◆ It is then also possible to see if the duration of pregnancy is changing (spontaneously or due to inductions).
- ◆ Interventions to increase birthweight may operate by improving fetal growth, or by increasing duration of pregnancy.
- ◆ There are three potential sources of such data concerning all babies: birth tapes from ONS (registrations), local child health systems (notifications), and maternity hospital data (obstetric/neonatal HES mds).
- ◆ Birth tapes do not include GA, maternity HES data are not returned by all hospitals, and local child health systems data are not standardised, aggregated, or accessible.
- ◆ In Tyne and Wear over the last 20 years there have been wide local variations in the proportion of births that are low birthweight (< 2.5 kg) or very low birthweight (< 1.5 kg). Newcastle has rates of low birthweight that are 15% higher than those in Gateshead – a situation that has developed since the mid-1980s.
- ◆ There is a general increase in low birthweight rates during the 1990s specifically affecting the more disadvantaged social groups, thereby increasing the social gradient, especially for very low birthweight babies.
- ◆ These two factors combined mean that those Local Authority Wards with significantly high rates of low or very low birthweight are concentrated in the socially deprived areas, particularly in Newcastle.
- ◆ Analysis at ED level (approximately 200 households) shows that some of this excess can be located to quite small areas distributed across the whole of Tyne and Wear.
- ◆ To show the potential for analysis of fetal growth rather than birthweight, data extracted from the child health systems south of the Tyne were used.
- ◆ When the data are mapped, several Local Authority Wards are seen across Gateshead and South Tyneside where there is poor fetal growth. Again, these Wards are concentrated in socially deprived areas, but now include places where crude birthweight based indicators do not reveal a problem.
- ◆ There are also important differences over time, with a gradual decrease in the proportion of slower growing babies between 1980-1990.
- ◆ The explanation for the paradox, that fetal growth is improving while low birthweight rates are increasing, appears to be that the proportion of babies born preterm is increasing, especially in mothers from socially deprived areas.
- ◆ It is proposed that future analyses of birthweight should be based on much improved data collection, to include accurate information on GA at birth – preferably collected in both maternity HES and child health data systems.
- ◆ A protocol for further work on fetal growth and length of gestation in relation to social deprivation is being developed with NPEU (Oxford), Napier University and ISD (Scotland).

Health risk prevalence – smoking in secondary schoolchildren

The consequences of the massive increase in cigarette smoking by both sexes since the 1940s is seen in our current waves of adult cancers, heart and respiratory diseases.

This legal addiction has its origins in childhood and once established is extremely difficult to reverse. Furthermore, passive and active smoking in childhood has immediate effects on children's health due to low birth weight, sudden infant deaths, asthma, meningitis, and ear infections.

This report examines what we know about this threat to our children's health in Tyne and Wear. The results are as follows:

- ◆ There is no regular and representative data source by which to accurately compare smoking rates amongst Tyne and Wear children over time or between places.
- ◆ National and local surveys show that Northern children smoke 15% more than the national average.
- ◆ By age 15, over 30% of children in Newcastle, Sunderland and Gateshead are smokers (either regular or occasional) and this has changed little in recent years.
- ◆ In South Tyneside, by contrast, a recent survey has found rates of smoking have fallen by almost 50% since 1995. For North Tyneside there is no smoking survey data.
- ◆ Although average smoking rates amongst 11-15 year olds appear to have fallen slightly since 1996 (nationally and locally), this obscures continuous increases in the rate of smoking amongst 12 year olds from 6% (1994) to 11% (2000). This may presage a further expansion in teenage smoking.
- ◆ Most teenage smokers acquire the addiction between age 13 and 14 years, and girls smoke 25% more than boys.
- ◆ At age 14 years (year 10) most child smokers obtain their cigarettes from shops and report little difficulty in these illegal purchases.
- ◆ A significant proportion of cigarette supply is from 'bootleg' sales through mobile shops, ice cream vans, and door sales.
- ◆ More than 50% of current teenage smokers want to give up smoking, but most think that they will need nicotine patches or cessation clinic support to achieve this.
- ◆ Across Tyne and Wear, 2/3rds of teenagers, whether or not they smoke themselves, live in households where at least one adult smokes.
- ◆ In Gateshead (the only District to conduct a fully representative survey) there are wide variations in smoking prevalence rates according to the Local Authority Ward of residence.

In summary, there is rapid and widely sanctioned addiction of Tyne and Wear children to tobacco between the ages of 12 and 15 years. We have only intermittent information on this, the most likely killer of our future adults. Illegal sales of cigarettes are commonplace, and only a minority of schoolchildren live in houses where adults do not smoke. There are worrying signs that there may be yet further growth in smoking in the next generation of teenagers, as well as local pockets with very high smoking prevalence rates in childhood.

Acute Morbidity - Severe Injury

Injury is the commonest cause of death in children and young people, at least three times as common as cancer. Between 1979 and 1996, there were 700 injury deaths in young people under 20 years of age in Tyne and Wear (approximately one third of all deaths in this age group). Government strategies have targets to reduce both fatal and non-fatal injuries. However, we have no clear picture of the true frequency of injuries.

This Report illustrates how routine hospital admission data can be used to fill this gap. Two types of 'severe' non-fatal injuries are identified from amongst the 100,000 injury admissions over the last 20 years amongst young people in Tyne and Wear – 16,400 severe fractures and 18,200 'serious' injuries of any type where the length of stay in hospital exceeded 3 days. The results show that:

- ◆ Data quality has greatly improved since 1995 and it is now possible to use hospital admission data to examine details of the causes of injuries.
- ◆ Across all three Tyne and Wear Health Authorities, the rate of severe fracture injuries has increased by about 50% over the last 20 years.
- ◆ The proportion of these severe fractures, which lead to hospital stays of more than 3 days, has declined from 80% to 30%.
- ◆ During the same period, the rate of injuries of any type requiring a hospital stay longer than 3 days has decreased by more than one third (Government's 'serious injury' definition).
- ◆ This decline in 'serious injury' admissions is an artefact of reducing length of stay, and does not mean the frequency of injury is falling.
- ◆ There is a marked concentration of both severe fractures and 'serious' injuries in young people from socially deprived areas in all Districts.
- ◆ Severe fracture rates are nearly twice as high in boys as girls, with an increasing difference as they get older.
- ◆ Severe fracture rates are highest (about 1% each year) amongst boys aged 10-14 from the most socially deprived areas.
- ◆ There appears to be a particular concentration of severe fractures in South Tyneside.
- ◆ The only obvious excess cause of these injuries is 'falls from skating and skateboarding'.
- ◆ These differences between Districts are not present in the 'serious injury' (> 3 days LOS) analysis.
- ◆ For children < 5 years of age, fractures are the second commonest cause of such prolonged hospital stays after burns.

Injuries from blunt trauma, leading to severe fractures among young people are increasing. These are particularly concentrated amongst 10-14 year old boys in socially deprived areas, and there is a largely unexplained excess in South Tyneside. Other types of 'serious' injury, which require long hospital stays, are burns (< 5 years), intracranial injuries (5-9 year olds), open wounds (boys > 10 years), and poisoning (girls > 10 years). It is impossible to be certain how the frequency of these other injuries has varied over time or by place, as there have been major changes in the lengths of hospital stays, which may differ between injury types and by place of treatment.

Children with Chronic Disability - Cerebral palsy

Cerebral palsy is one of the commonest causes of physical disability in childhood. Very little is known about the daily lives of these children as they grow up, but the Lifestyle Assessment Questionnaire (LAQ) used in the North of England survey of cerebral palsy (NECCPS) is a potential source of useful data.

- ◆ About 30 children are diagnosed with cerebral palsy each year in Tyne and Wear. Data from LAQ were extracted for the 126 children born between 1991 and 1994.
- ◆ The LAQ includes questions about children's participation (or handicap) in terms of physical independence, mobility, schooling, social integration etc.
- ◆ The typical pattern for local children with cerebral palsy is that problems of physical independence and mobility seriously interfere with participation. A consequence of this is poor social integration for the child and family.
- ◆ There are important variations in the patterns of participation between children, which might indicate areas suitable for intervention. For instance, some families have disproportionately large economic problems.
- ◆ Levels of participation amongst children with cerebral palsy seem to vary between locations. (Eg Newcastle children with cerebral palsy report greater physical independence and higher levels of social integration).

A second more detailed qualitative study was then undertaken in Newcastle. This was to explore ways that such information might be made useful or usable by those responsible for the planning and delivery of services relevant to children with cerebral palsy. The report on this exercise is summarised below.

- ◆ Fourteen families of Newcastle children born 1991 – 1994 with cerebral palsy responded to a postal survey.
- ◆ Their use of relevant services was related to their participation (LAQ) scores.
- ◆ There are several children with very limited participation in terms of economic burden, mobility, physical independence and social integration, who make almost no use of relevant services.
- ◆ Managers of 14 local services relevant to children with cerebral palsy were interviewed. They were asked how they planned and monitored their services.
- ◆ All of these 14 service managers wanted (but did not have) estimates of the numbers of potential clients and their 'degree of disability' in order to plan services. In the absence of these estimates, services rely on referrals or direct requests, but cannot otherwise identify any potential clients with unmet needs.
- ◆ Some respondents were very interested in the use of LAQ profiles of clients (eg housing and welfare rights) but the data were not sufficiently specific for others (eg Education felt it did not define 'level of need', while Transport would prefer to know 'journey purpose and mode'). Therapy services saw potential uses of the LAQ profiles, but felt under pressure to ration, rather than expand services.
- ◆ Whilst three of the 14 services undertook user surveys and eight gauged outcomes in terms of individual fulfilment of professionally assessed 'needs', there was little formal evidence base for service effectiveness.
- ◆ There was general appreciation by Local Authority (but not Health) staff that physical, social and attitudinal environments matter in promoting participation. On the other hand, there are no structured measures of quality or performance in achieving disability friendliness within services or across whole cities.

Vulnerable Children - Teenage pregnancy

In Tyne and Wear, there are about 1200 teenage pregnancies (conceptions amongst girls under 18 years) each year. This represents a rate double that across the rest of the country, and at least ten times that in the Netherlands. In some parts of Tyne and Wear, virtually no 15-17 year old girls become pregnant, but in several socially deprived Wards, more than 12% of 15-17 year olds are pregnant each year. In secondary schools in these Wards, one-third of all girls will become pregnant at least once before they leave school.

It has been argued that primary prevention of pregnancy for teenagers is not a major public health priority and that the focus should be on social and educational support for these vulnerable mothers. However, pregnancies before the age of 18 are unplanned in at least three-quarters of cases. One third of these conceptions result in therapeutic abortion. For those pregnancies that are completed, the mothers are much more often supported by their parents than by their partners, their education usually ceases, and 40% of them will experience clinical depression in the first year. Furthermore, their babies will suffer even poorer health outcomes than those of older mothers in similarly socially deprived circumstances.

About one-quarter of these pregnancies (250 each year in Tyne and Wear) are amongst girls under the age of 16 years. These are children having abortions or bearing their own children. The scale of morbidity represented by these figures is important, and is now subject to intense central and local public sector activity.

From an information perspective, teenage pregnancy is a positive exemplar. Not only are there accurate and confidential data concerning conceptions, births and abortions, but also most Local Education and Health Authorities have invested in regular (albeit unrepresentative) self-completion questionnaire surveys in secondary schools that yield important information on relevant risk factors and attitudes amongst young people. Furthermore, there are standardised data available from the National Teenage Pregnancy Unit on the availability of local contraceptive/family planning services, and their accessibility to young people.

Nevertheless, the conception rate amongst women under 18 years of age has not noticeably fallen, and there are significant information gaps. We have no reliable data source on contraception use, and we know almost nothing about the fathers of these pregnancies. Information on services is not clearly linked to an evidence base of what works in avoiding unwanted pregnancy, and we have little systematic data on the local health outcomes of this vulnerable group of teenage mothers and their babies.

Vulnerable Children - Quality protects

In 1998, the 'Quality Protects' programme set mandatory national objectives for services for children and young people in the 'looked after' sector. Amongst these objectives was Objective 4.2 'To ensure that children looked after enjoy a standard of health and development as good as all children of the same age living in the same area'.

Earlier research studies had shown that children who are looked after away from home have greater levels of health need than their peers, yet are less likely to receive adequate health care. A number of Performance Assessment Framework Indicators are now published about the implementation of quality protects.

The proportions of Tyne & Wear children in the looked after sector are about 30% higher than the rest of the country with just under 1% of all under 18s being looked after at any one time. About 2,000 children in Tyne & Wear are currently looked after of whom 450 have been looked after continuously for more than four years.

Children in the looked after sector move around between placements frequently, with about 20% having three or more placements per year (the government target for this is less than 16%). Most are placed with foster parents (about 65%) and a further 10-20% in community homes. Many of these children are in care due to abuse or neglect, and their numbers increase as children get older, with the largest group now being 10-15 year olds.

Insofar as they are known, the outcomes for these children are relatively poor. For instance, 70% leave full time education with no GCSE or GNVQ equivalents (versus less than 10% of their peers).

Of health outcomes, very little is known, and only four routine indicators are required by central government, (% with complete primary immunisation, % having routine dental checks, % having annual health assessments, and % who had a comprehensive health assessment when they entered the looked after sector).

On these criteria, Authorities in Tyne & Wear show some variation, with between 60 and 90% of children looked after fulfilling the first three of these criteria. This compares to about 95% of children who are in the non-looked after sector, who will have had complete primary immunisation and dental checks.

What is most striking about these data is, first, their sparsity - this is all that is known routinely about the health of this group of children. Second consultation with a number of local professionals suggests that it is very difficult to generate reliable information about the health of children in the looked after sector for a number of reasons.

- ◆ There is not always clear transfer of information from Social Services to Health Authorities concerning the identity of children in the looked after sector to allow their health to be monitored.
- ◆ Although there is information about resident children who attend hospital or who have been offered immunisation through Community Child Health services, it is rarely known which are in the looked after sector.
- ◆ The records, which are held about all children as they make contact with health services, do not have a unique identifier. Thus linkage to a separate confidential database of looked after children cannot be made.
- ◆ The situation is complicated by the fact that this vulnerable group of children is transient and highly mobile; with many children entering, leaving and changing care each year.

To deal with this, most local Health and Social Service departments have set up collaborative arrangements to ensure that there are regular health assessments for these children. Information systems are being developed, based on these individual personal records. Compiling more comprehensive records by linkage to other useful data systems is theoretically possible but unlikely until logistic and ethical issues are clarified.

General Themes from the Six Exemplar Reports

Four major themes emerged from the initial exercise of producing the exemplar reports.

Even for these relatively well-documented exemplar issues there are still important weaknesses within the original data and their conventional interpretation (many being incomplete, misleading and sometimes inappropriate).

Not all children are equal in the requirement for information about their health (often it appears that the most health vulnerable children are those about whom we know least).

These exemplars were confined to available data. We know almost nothing about the frequency of the commonest conditions leading to acute hospital admission, while for most children with disabilities there is simply no reliable and representative source of information.

Existing sources of data about children's health are often underused and poorly coordinated. Although the situation has greatly improved with the advent of Public Health Observatories there is still no coordinated research, analysis and presentation of the many potentially available indicators. Identification of unequivocal child health outcomes, their linkage to the evidence base for effective interventions and their dissemination in an accessible form are all poorly developed.

For the most part therefore we do not know 'how healthy are children in Tyne and Wear' or if this is changing over time. When this fundamental purpose of data collection about child health is not met we can hardly aspire to understand the local causes of poor child health nor to develop and evaluate better services to tackle them.

A set of consultation exercises was used to flesh out these conclusions with a wide group of child health professionals and public service planners. A number of high priority issues was then identified for further study.

Further work on the Child Health Information Project completed since 2002

1 *A pilot project has looked at methodologies for improving access to and facilities for analysis of two existing datasets (HES data on injuries, birthweight data from ONS). [Lead, Dr Philip Lowe]*

Access to data is part of the key to developing it's utility. Several important and available datasets relevant to children's health are hardly used at a local level. We wished to explore methods of dissemination and multi-level access, which allowed both naïve and adept users to interact with the raw data. It is this process of direct exploration which could drive better-informed data collection. A simulated user interface for Internet access to anonymized raw health datasets was assessed by six potential users. The method - combining common language queries, automated graphs, maps and histograms, and intelligent links to relevant evidence base sites - was widely welcomed (<http://www.ncl.ac.uk/plerg/Research/CHI/User Interface Report.pdf>).

2 *A feasibility study has been undertaken of an Internet based survey to obtain questionnaire data directly from school-aged children. [Lead: Neil Hamilton]*

Survey data collected direct from children are a vital but under-developed source of information on children's exposure to health risks (eg smoking, diet, exercise) as well as on their experience of health events and use of health services. On-line Internet questionnaires, with very rapid data aggregation and confidential feedback might now replace traditional methods. Some types of detailed contextual data important to the understanding of health events (eg location and activity at the time of injury) are easily introduced as conditional questions in such a computer-assisted survey instrument. Other types of denominator data to calculate exposure-specific risks (eg the safety of football versus rugby) could be the subjects of appropriate questions to (samples of) the non-injured population. A feasibility study has been completed (<http://www.maria.org.uk/hrbqrept.pdf>). The pilot of a live Internet based survey instrument funded by Tyne & Wear HAZ, Northumberland NHS Care Trust and Northumberland LEA will be reported in mid 2004.

3 *A set of in-depth studies has explored appropriate methods for describing the circumstances of children with cerebral palsy for service planning and monitoring. In particular, we examined direct measures of the contextual factors which may determine participation. [Lead: Brenda Welsh]*

A number of publications describing the results of this work are in press or to be submitted shortly.

Study 1 has shown that higher levels of participation amongst children with cerebral palsy are associated with residence in certain districts. This is not attributable to variations in case-mix or functional capacity of the children. Participation of children with disability is partly a product of the environment. [Dev Med and Child Neurology 2004; 46: 292-298]

Study 2 found that defining and measuring potential environmental determinants of participation for children with cerebral palsy still needs much further development and proposals are made as to how this might be done. [Dev Med and Child Neurology 2004; 46: 299-304]

Study 3 confirmed the importance of the environment for the participation of children with cerebral palsy. Not unexpectedly, physical elements of the environment were prominent as the children had moderate to severe cerebral palsy with significant mobility limitations. The social environment, in particular the supporting role of parents, was crucial for participation. There is a need for an instrument to quantify the environment with a view to influencing policy and advancing the participation of children with cerebral palsy (<http://www.ncl.ac.uk/plerg/Research/CHI/Cerebral Palsy Qualitative Study.pdf>). [A paper based on this work has been submitted to Disability in Society].

Study 4 showed that local environmental barriers for children with cerebral palsy can be identified and related to their participation using simple survey methods. [For submission to Public Health].

Confidential copies of these draft papers (studies 3 and 4) may be obtained from Dr A Colver (allan.colver@ncl.ac.uk).

Recommendations

Local practitioners in child health should have immediate access to information on a range of health outcomes:- acute and chronic morbidity, growth and development, exposure to prevalent health risks, coverage with effective prophylaxis, and child disability friendliness of the local environment.

Growth and development are crucial indicators of child health. Fetal weight and child height should be related to accurate norms. Gestational age at birth must be linked to birthweight records.

Local health risk prevalence (eg diet, smoking, injury risk etc) should be monitored by sample surveys (for school children by Internet questionnaire).

A series of indicators of acute morbidity frequency based on routine hospital (and ambulatory care) statistics should be developed and evaluated.

Children with chronic health related morbidity beyond a specified severity should be actively identified and their participation described. Local environmental barriers to their participation (and that of their families) should be identified by client survey and in collaboration with responsible agencies.

Girls who conceive as children and all children in “looked after” placements should be recognised as high risk groups requiring active and sensitive health monitoring.

All local population related surveys, registers and routine data concerning children’s health should be managed and developed as a primary responsibility of an intelligent NHS.

The overall recommendation is that there should be an Observatory of children’s health at a regional level, linked to the Public Health Observatory and with a remit to collate existing data, add value by analysis and linkage to evidence for effective interventions, commission new surveillance methods, and conduct R&D on new indicators, data utility and user access methods.