Personal practice

Establishing a register of children with special needs

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The *Court Report* recommended that every health district should maintain a register of children with handicap.¹ These registers, however, rarely meet their stated objectives, cannot provide data readily, and even yield unlikely variations in incidence of conditions like Down's syndrome and spina bifida.²

The requirements of the 1981 Education Act and advances in desk top microcomputing have renewed interest in registers. O'Mahony *et al* reported their approach to setting up a register but they had only just started to record data, had not started to validate the data, and did not know whether the register was meeting its stated objectives.³

Northumberland health district has maintained for three years a computerised register of children aged 0–16 years with long term special needs. We report the thinking behind this register, the practical implementation and validation of the register, and the uses to which it has been put. We hope that this will promote discussion and help other districts to maintain more accurate and useful registers.

Thinking behind the register

The objectives of our register are to: (a) improve the care of individual children; (b) improve the planning of services for children; and (c) improve opportunities for research and epidemiology.

Northumberland had kept a manual register for 10 years but there was no clear policy about which children should be registered. We decided that the criterion for registration would be that the child had some 'long-term special need for multi-disciplinary help or review that can be better planned and performed by being recorded centrally. The need should arise at least in part from a physical, sensory or mental impairment or chronic illness'. In practice, most registrations are: (a) children with chronic illness; (b) children who are the subject of a 'Statement of Special Educational Need'; or (c) pre-school children who already need special educational provision or help from many professionals.

The following children are *not* placed on our register:

(1) Children with congenital malformations. Congenital malformations are already recorded by the Office of Population Censuses and Surveys and most do not give rise to long term special needs.

(2) Children 'at risk of a condition'—for example, deafness, cerebral palsy, non-accidental injury. The 'at risk concept' has been largely abandoned.⁴ If a health district retains it for a particular problem, names should be on a separate register with its own objectives and operational control.

(3) Children with common mild chronic conditions such as asthma, eczema, glue ear, hay fever, long sight. If the condition, by its severity or complex interaction with family factors, creates a long term special need then the child should be registered because of this need not because of the diagnosis in itself.

There are of course some children whom we are uncertain whether to register or not—for example, a child with a mild hemiplegia or a child who needs remedial reading help. Provided such grey areas are recognised, the validity of data about children who are always included or excluded is not affected.

'Diagnosis' is not a logical system of classification for it may describe a disease, medical problem, impairment, or psychological circumstance. Nevertheless the concept is very useful and we have developed a 100 category classification relevant to children with chronic problems. Each child may have up to six codes. For instance a child with Down's syndrome may be coded as Down's, fostered, complex heart disease, mental retardation, glue ear.

The concepts of impairment, disability, and handicap are more logical and consistent but the World Health Organisation coding system is complex.⁵ Moreover, it was not designed for children and does not take account of age or the effects of handicap on the family. We have recorded data

about impairment and disability as one research objective of the register.

Implementation

Northumberland health district has a population of 290 000 and is by area the second largest health district in England and Wales. The 4000 files of the existing manual register were examined by the community paediatrician and, using the agreed criterion for registration, 1700 children's names were placed on the new register. The data recorded about each child are shown in table 1. Coding by the paediatrician took about 100 hours and data entry by the clerical officer took about 90 hours. The time needed to add or remove children from the register and to keep up to date details of school, address, etc, is about 16 hours a year of medical time and 40 hours a year of clerical time.

The program is written in DBase 2 and runs on an Apricot PC/Xi computer. The cost in 1985 for computer, printer, and software was £3500. One of the authors wrote the program. Although it is useful if the same person has clinical and computer skills, it is not essential. It is essential, however, that the program is planned and tested by clinicians who work closely with the programmer. DBase 2 or 3 is a suitable data base because it allows data to be selected, changed, or analysed in any manner (maximum flexibility) but may be 'menu driven' for day to day running by clerical staff with no computer knowledge.

The district receives information about children who may need to be registered from neonatal units, hospital discharge summaries, hospital outpatient letters, health visitors, and the local education

authority. To keep the register up to date, a list is sent every year to each school doctor to confirm or change the school which the child attends. Also, when an examination is undertaken for the 1981 Education Act, the doctor completes a form for the computer.

Validation of data

Validity of data may be defined as 'An expression of whether data actually represent what they purport to'. 'Item validity' is the accuracy of individual items such as date of birth, address. 'Case validity' is the extent to which the cases agree with an independent external set of cases.⁶ We shall discuss our approach to establishing case validity.

Children with mild impairments may not have been ascertained or may be judged too mild to warrant registration. Children with more severe impairments should always be registered, but how confident can a district be that it learns about all these children from hospital letters, requests from education departments, etc? Each district must establish the case validity of its register before it can be used for planning, research, or epidemiology. We have studied groups of children who should always be registered and for which there was already an independent register or for which it was easy to obtain an independent list. Table 2 shows the numbers of children on the external and Northumberland registers, the overlap, and the total number of children. For more severe impairments our register is as, or more, comprehensive than external lists. For less severe impairments such as diabetes we are not so comprehensive. For impairments such as epilepsy we do not know the validity.

For preschool children there are few independent data sets with which to compare a register. We suggest as a measure of validity the number of children, unknown to the register while preschool, who become the subject of an educational statement before age 6 years. During the last three years in Northumberland there have been only five such children, two with speech, two with learning, and one with behaviour problems.

The comparisons to assess validity were made in 1987. Since then validity has improved and the register is now known, for example, to include all children at special schools or the subject of an educational statement.

Uses to which the register is put

A register must 'live'. The more it is used and the more this use is reported back to professional staff, the more accurate and comprehensive the register

Table 1 *Data recorded about each child*

Unique computer number
Surname
First name
Address
Date of birth
Sex
County district
Family doctor
School
School doctor
Free text description of child's main diagnoses
Coding of above diagnoses
Coding of impairment
Coding of disability
Medical provision—for example, paediatrician
Educational provision—for example, preschool teacher
Therapeutic provision—for example, physiotherapist
Family provision—for example, attendance allowance
Date of educational statement

Table 2 Comparisons of the Northumberland register with independent lists of children in certain groups

Group of children	External list	No on external list	No on Northumberland register	No overlapping	Total
Duchenne muscular dystrophy	Regional muscular dystrophy register	8	8	8	8
Cerebral palsy births 1975-80	Regional cerebral palsy study	30	34	28	36
Registered blind or partial sight	Social services register	26	27	26	27
Fitted with hearing aids	North East audiology register	74	90	72	92
Spina bifida	North East spina bifida clinic	16	16	16	16
Cancer under treatment	Regional cancer register	33	26	26	33
Severe mental retardation, age >5 years	Education department	164	158	158	164
Moderate mental retardation, age >5 years	Education department	448	424	424	448
Attending language unit	Education department	16	16	16	16
Children eligible to apply to Family Fund	Family Fund register	128	202	126	204
Diabetes mellitus	Specialist diabetic nurse's list	60	57	46	68

Table 3 Examples of uses to which the register is put

Individual care

The names of preschool children are brought up for review by the preschool panel for children with special needs. One function of this panel is to inform the education department of preschool children likely to have special educational needs. Preschool children with certain problems are notified to the community dental service. Information is sent to each school doctor about children with special needs in ordinary and special schools.

Planning

Information to the principal educational psychologist enabled him to apply successfully to the Department of Education and Science for funds for a 'Portage scheme'.^{*} Information to a specialist health visitor and social worker helped them assess the need for and subsequently introduce a parents' support group for families with handicapped children. Information to the social services department helped them plan further developments in their respite care service for families with handicapped children. Information to the Spina Bifida Association enabled it to plan voluntary services in Northumberland.

Research and epidemiology

Evaluation of the health surveillance programme of preschool children in Northumberland requires regular details of children with congenital deafness, severe cerebral palsy, language delay, and mental retardation. A regional study of cerebral palsy received information about children with cerebral palsy. Three separate national studies of congenital rubella, autism and deaf-blind children received information about such children. The Family Fund in York compared its register with the Northumberland register and reported the proportion of children with severe handicap who applied to the fund. A working party of the British Paediatric Association received a report on the prevalence of disabling conditions in childhood in Northumberland.

^{*}The Portage scheme is a home visiting service for parents of children with special needs who are under 5 years of age. It encourages home based teaching of appropriate developmental skills.

becomes. Reporting back also helps professional staff to understand how they might use the register for their own planning or projects.

Table 3 gives examples, under each objective, of uses to which the register is put. Some are local and each district will have its own requirements. Others should occur in every health district. For example, every district should monitor its preschool screening programme and will require details of profoundly deaf children to do this. All districts must also ensure that the education department is informed early of preschool children likely to have special educational needs.

Discussion

Some district registers record more data about each child than we do. We have restricted our data because:

- (1) A small amount of accurate data which can be kept up to date is preferable to a larger amount of less accurate data. We also think it is not good clinical practice or use of resources to arrange regular examinations of children mainly to keep a large data set up to date.
- (2) Our register was up and running within six months and has data on children 0-16 years

with special needs. Districts which record more data will usually enter only *new* children as they present. It is therefore 10 to 15 years before the full benefit of the register is realised.

(3) Large data sets tend to include more subjective information about unmet need and the extent to which social factors contribute to a need. Subjective information is essential in clinical practice but is less useful for epidemiology, research, or planning purposes.

Why use a computer at all? Could not a manual system be just as good? For each individual task a manual system is good but when many tasks are performed on a regular basis, each task needs a separate subregister to be maintained or a separate manual search made of the main register. Further, any data or text for regular circulation need to be typed each time. Finally new requests for data for planning or research require lengthy manual search and analysis. We believe that it is these constraints on regular or unforeseen analysis and reporting that have made district registers so little used and thus so inaccurate.

An important reason therefore for introducing a computerised system is to have readily available data. Facilities for this must therefore be available from the outset. Eventually the National Child Health Computing System may provide the flexibility needed for local input/output and analysis of data, but at present it does not. 'As child care is primarily a local concern, the best computer option will usually be a small local system with sound operational control on a locally co-ordinated basis'.⁷ Microcomputers are now as fast and advanced as necessary to run a register of children with special needs.

We hope that districts will be encouraged to establish and use registers because they should be of immediate benefit to them. We also hope that districts will be encouraged to report and publish their developments to help us all to understand better the concepts of impairment, disability, and

handicap and the practical difficulties of recording useful data about them.

Conclusion

Registers of children with special needs are held by health districts but little attention has been paid to their objectives, criteria for registration, or validity. The registers are therefore not used or trusted. Our register has clear local objectives and operational control and has run for three years. The small amount of data recorded about each child is kept up to date and used to improve opportunities for individual care, service planning, research, and epidemiology. We have argued that a simple computerised database is more appropriate than either a manual system or a more complex computer system. The uses to which a register is put must be regularly reported to the staff who contribute data so that the relevance of the register is appreciated and its accuracy thereby maintained.

References

- ¹ Committee on child health services. *Fit for the future*. London: HMSO, 1976. (Court report.) (Cmnd 6684.)
- ² Balarajan R, Weatherall JAC, Ashley JSA, *et al*. A survey of handicap registers for preschool children in England and Wales. *Community Med* 1982;4:315-24.
- ³ O'Mahony MC, Allsop M, Heath C, *et al*. The register of children with special needs—an approach. *Public Health* 1987; 101:9-15.
- ⁴ Richards IDG, Roberts CJ. The 'at risk' infant. *Lancet* 1967;ii:711.
- ⁵ World Health Organisation. *International classification of impairments, disabilities, and handicaps*. Geneva: World Health Organisation, 1980.
- ⁶ Stone H. A method for the validation of data in a register. *Public Health* 1986;100:316-24.
- ⁷ Dodge JS. The use of microcomputers for child health services. In: Macfarlane JA, ed. *Progress in child health*. Vol 2. London: Churchill Livingstone, 1985.

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