A New Approach to the Care of Handicapped Children

The Milroy Lecture 1979

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The history of the attitudes of communities towards children born with severe physical deformities or mental handicap has been identified by Gliedmans and Roth (1976) as following four main reactions in chronological order: extermination; segregation; second class citizenship within the community; the granting of equal rights as citizens.

Extermination is still practised in some primitive societies, but in western cultures, the spread of Christianity and, in particular, the formation of monasteries with their infirmaries produced a more caring attitude towards those unable to fend for themselves.

Corbett (1978) has described the formal introduction of the policy of segregation of the mentally handicapped in Britain during the nineteenth century, including the opening of the four major asylums, the Eastern, the Midlands, the Western Counties, and the Royal Albert Asylum at Lancaster, between 1845-1870. Segregation was official government policy confirmed by the Mental Deficiency Act of 1913.

During the next 66 years this policy was increasingly questioned. The report of the Mental Deficiency Committee of 1929 is worth mentioning for its prophetic words about special neighbourhood day schools for the mentally handicapped:

'If the majority of children for whom these schools are intended are to lead the lives of ordinary citizens with no shadow of a certificate and all that that implies to handicap their careers, these schools must be brought into closer relation with the public elementary school system and presented to parents not as something both distinct and humiliating but as a helpful variation of ordinary school'.

Despite this report the reality remained very different and it is to be hoped that the Education Act of 1977 and the Warnock Report of 1978 will lead to effective action.

The Mental Health Act of 1959 gave official approval for the policy of reduction of institutional care and the provision of increased social, educational and training services in the community. A further step was taken in 1971 when, in response to pressure from many quarters including parents of handicapped children, the Education of Handicapped Children Act made it obligatory for education to be available to all children irrespective of the nature of their handicap or whether they lived in hospitals or in their own homes. It is one of the main purposes of this lecture to emphasise that insufficient attention (and therefore resources) has been given by our health services to the effects and demands that such social changes would have on the care that is now provided by conventional primary health and hospital services.

My central theme is that the major steps that have to be taken by and for the handicapped to achieve equality of rights as citizens are social in nature and have implications for all sections of our community. The medical, health and educational needs of the handicapped are demanding, but even the best services can be largely nullified if there is a failure by society to recognise that the unmet needs of the handicapped and their families at the present time are primarily social in origin.

It is against this background that I describe some investigations in Exeter, which started in the area of medical and health care. I report the work of many colleagues (especially that of Dr Joyce Rubisow). We had three initial objectives: the identification and measurement of all handicap in children; to describe the use made of statutory and voluntary services for the handicapped; identification of the unmet needs of handicapped children and their families.

Identification and Measurement of Handicap

Our first objective was to identify all handicapped children (where the handicap was of pre- or perinatal origin) in a defined population of births, and to attempt to measure the extent of the functional handicap present in each child.

It was first necessary to define the meaning of the words defect, disability, and handicap. Medical diagnoses do not of themselves indicate the extent of functional handicap.

We have done our best to make accurate medical diagnoses in our cohort of 7,000 births, but I shall concentrate upon the prevalence of functional handicap which we identified. We have studied all children born to
the residents of the small city of Exeter during the years 1967-71. Although the social class distribution of the population of Exeter does not differ from that of England and Wales as a whole, the perinatal and infant mortality rates, as in much of southern England, were significantly lower than in the country as a whole; indeed, the infant mortality rate aggregated for the years 1967-71 was closer to that of Sweden than that of England and Wales for 1971 (Table 1).

Table 1. Perinatal and infant mortality rates.

|                      | Stillbirths and first week deaths per 1000 total births | Deaths under 1 year of age per 1000 live births |
|----------------------|--------------------------------------------------------|-----------------------------------------------|
| England and Wales (1971) | 22.4                                                   | 17.5                                          |
| Exeter (1967-71)       | 20.5                                                   | 14.1                                          |
| Sweden (1971)          | 22.2                                                   | 12.2                                          |

This more favourable survival rate cannot be attributed to a smaller proportion of low birth weight infants nor to a lower proportion of illegitimate births (Table 2).

Table 2. Percentage of low birth weight and illegitimate births.

|                      | Infants with birth weights below 2500 g | Illegitimate births |
|----------------------|----------------------------------------|---------------------|
| England and Wales (1970) | 6.8%                                   | 8.7%                |
| Exeter (1967-71)       | 6.8%                                   | 9.1%                |

From the children surviving from this birth population we improvised our own classification of defects and the extent of functional handicap which we believed to be of pre- or perinatal origin, as shown in Table 3.

Excluding the children in Group 1, this result shows that 3.3 per cent of the surviving children had a handicapping disorder of a greater or lesser degree and that 1.1 per cent had a severe handicap; the latter figure is in close agreement with those found in other population based studies (Rutter et al., 1970; Bradshaw, 1975; Neligan et al., 1976; Kushlick and Cox, 1973; J. R. Bradshaw unpublished observations; D. Pomeroy, unpublished observations; France, 1971). It is lower than that found in surveys of older children, largely because such handicaps as minor degrees of mental subnormality, and behavioural and psychiatric disorders do not become evident until mid-childhood and are not represented in our study of children under five years of age. Our survey does not include children in whom we believed the cause of handicap to have originated after the perinatal period.

Finally, in this preliminary description of prevalence of handicap, I wish to draw attention to the influence of birth weight (Brimblecombe et al., 1978; Rubissow et al., 1979) and of social disadvantage in the families of these children (Tables 4 and 5).

Table 3. Exeter Survey 1967-71: Functional classification of handicapped live births surviving beyond 28 days of life. (No. = 6,897).

| Group | Description                                                                 | No. |
|-------|-----------------------------------------------------------------------------|-----|
| I     | Congenital defects unlikely to cause handicap or totally corrected by surgical or other treatment during the first year of life (appropriate sample of group) | 81  |
| II    | Defects or disabilities giving rise to handicap in the first years of life, which were totally corrected by the age of 5 years | 45  |
| III   | Children with a mild or moderate persistent handicapping disorder likely to cause some functional restriction at school and in adult life | 105 |
| IV    | Severe permanent handicapping disorders                                    | 77  |

Subgroups

A. Severe mental subnormality 29
B. Severe locomotor disorder 11
C. Chronic illness 16
D. Severe sensory or language disorder. Severe emotional or psychiatric disorder 21
Total 308

Table 4. Exeter Survey 1967-71: Birth weight related to neonatal deaths and to persisting handicaps (No. = 6,897).

| Birth Weight | Percentage of all Neonatal Deaths | Percentage of Group III and IV Handicaps |
|--------------|----------------------------------|----------------------------------------|
| Less than 2500 g (6.8% of live births) | 61% | 18% |
| More than 2500 g (93.2% of live births) | 39% | 82% |

Table 5. Exeter Survey 1967-71: Infant mortality (England and Wales 1975-76) and persisting handicaps (Exeter 1967-71) related to social class.

| Social Class | Infant Mortality per 1000 live births England and Wales 1975-76 | Handicap Groups III-IV per 1000 live births Exeter Survey |
|--------------|---------------------------------------------------------------|----------------------------------------------------------|
| I            | 10.2                                                          | 22.6                                                    |
| II           | 11.1                                                          |                                                        |
| III          | (i) 11.8                                                     | 23.0                                                    |
|              | (ii) 13.7                                                   |                                                        |
| IV           | 16.3                                                         | 27.1                                                    |
| V            | 23.0                                                         | 41.1                                                    |

It is clear that the adverse effect of low birth weight so predominant in relation to neonatal mortality, although still significant, has a much less marked association with persistent functional handicap identifiable in the first five
years of life. On the other hand, social disadvantage shows a similar correlation with functional handicap to that seen in infant mortality rates. This emphasises yet again the social origins of handicap so well documented by Professor Butler and his colleagues in the National Child Development Study.

Use of Statutory and Voluntary Services

Our second objective was to describe the use made by families with a young handicapped child of the statutory and voluntary services compared with the use made by a control group of families from the same population. The controls were obtained from the birth notification register of Exeter City and in each case was a child whose birth date was within a month of that of the index case and who was of the same sex and place in birth order in a family of the same size and social class as the index case.

Primary Health Care

As seen through the eyes of the families, the service provided by their family doctors and the health visitors attached to their practices was extremely varied, the variation depending on the nature of the handicap and the individual practice. For some families, the family doctor and health visitor emerged as the key figures they looked to for advice, help and support for all the problems presented by their handicapped child. In other instances the contacts between families with handicapped children and their doctors differed little from those made by the control families without a handicapped child. Many families with a handicapped child had been diverted at an early stage to one or other branch of the hospital service, to which they turned for help for their child's particular handicap. Our detailed evidence on these subjects has been published elsewhere (Rubissow et al., 1979). We concluded that—

1. The organisation of group practice health centres is in many instances inappropriate to the special needs of families with a handicapped child. This was for many families a cause of stress and anxiety.

2. The continuing complex and specialised needs of some handicapped children were more than the resources of a family doctor and health visitor could possibly be expected to provide. This applied both to routine daily needs and to emergency services.

3. If a severely handicapped child is to be cared for at home rather than in an institution, the family, while still requiring the usual services of a family doctor and health visitor for ordinary purposes, also requires additional community-based services designed to cater for the special needs of their handicapped child and their family.

The out-patient hospital services for handicapped children in Exeter in the early seventies revealed their emphasis on curative medicine, in that the Group II children, whose handicap was remediable, were offered the highest number of out-patient clinic visits; the children with irremediable handicaps were seen less frequently (Table 6).

The parents' criticisms of hospital services followed all too familiar lines. The highly unsatisfactory experience of seeing different doctors each time they visited an out-patient clinic was depressingly frequent. Consultations were often unsatisfactory to the parents because they felt they had been given insufficient information. Sometimes the parents were told their child was too difficult to examine when they themselves realised that the reason was that the child had become upset by a long wait in uncongenial surroundings. It is of interest that there were few criticisms of in-patient services.

Fewer of the handicapped children attended a health authority child health clinic than the control population of children. Often the reason was that the family had been directed at an early stage to a more specialised service. Other families described their distress and reluctance to take a handicapped child to a well-baby clinic because of their own feelings and of the distress they felt it might cause to other mothers. The design and inaccessibility of clinics was sometimes a cause for comment. Difficult bus journeys for a mother with a new baby and a handicapped child, and clinics with two exits, in which it was difficult to keep an effective watch on an active toddler while nursing a handicapped child, are examples of some of the problems.

Typical examples of other health problems mentioned by parents were the inaccessibility of chemists' shops from housing estates for the filling of prescriptions, and no home telephone for emergencies such as an epileptic seizure when the mother was alone in the house with the child.

Our study showed that one-third of the families with a handicapped child had had contact with the social services department compared with 6 per cent of the control families. As with the social services, the involvement of the voluntary agencies concerned with

Table 6. Exeter Survey 1967-69 only. Hospital services. 180 children. First five years of life. (The figures in brackets refer to controls.)

|                      | Hospital Clinic Visits | Admissions | Total days | Days per child | Laboratory investigations |
|----------------------|------------------------|------------|------------|---------------|--------------------------|
|                      | Total                  | Per child  |            |               | Total                  |
|                      |                        |            |            |               | Per child              |
| All groups           | 2013 (185)             | (1)        | 1.8 (0.2)  | (1.6)         | 4160 (258)             | (1.3)                  |
| Group I              | 6                      |           |            |               |                         |                        |
| Group II             | 17                     |           |            |               |                         |                        |
| Group III            | 10                     |           |            |               |                         |                        |
| Group IV             | 14                     |           |            |               |                         |                        |

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handicapped children varied with the severity of the handicap (Table 7).

Table 7 indicates the refractory period during the first five years of life between the identification of handicap and the contact with the appropriate voluntary agency, especially with the Group IV children. It may indicate the need for health service professionals to be more fully informed about the availability of voluntary agencies so that parents can at least be offered the opportunity, which they can take up if they wish, to use these services. It may also indicate the reluctance of some parents to recognise and acknowledge that their child is handicapped or to appreciate or want the type of help that is available to them.

Table 7. Exeter Survey 1967-71: handicap and contact with voluntary agencies (No. = 308).

| Severity of Handicap | Cases | Controls |
|----------------------|-------|----------|
| Group I              | 5%    | 6%       |
| Group II             | 6%    |          |
| Group III            | 15%   |          |
| Group IV             | 57%   |          |

Unmet Needs

However admirable the health and educational services provided for handicapped children may be, for many families these services can never provide more than a partial contribution to their needs. It is not possible to tabulate the information that we obtained from the narrative accounts of parents regarding their unmet needs. To a large extent what follows must be a subjective selection. In summary the following major areas of need emerge.

1. There is a need for more information about the nature of the child's handicap communicated, not at one or two consultations, but over whatever period of time and at whatever pace may prove to be needed by that particular family, and communicated by a professional person who not only has the necessary knowledge but who over this period develops a genuine personal relationship with the family so that real communication between them can occur.

2. Families need to achieve independence and self-reliance in dealing with their child's handicap by acquiring the essential skills, confidence and courage needed to help their child achieve his full potential.

3. More support for the family is needed. Families with handicapped children feel themselves to be isolated. In this isolation, the strains arising from conflict between the parents, the difficulties of meeting the needs of their handicapped child as well as those of the non-handicapped siblings, and above all the gradual erosion of courage and strength that results from the continual day and night care of a dependent handicapped child may otherwise lead them, exhausted and bitterly humiliated, to seek institutional care for their handicapped child.

In summary, our study suggests that if a handicapped child is to remain at home with his family and if the family is to experience a satisfactory quality of life, an additional resource is needed in the community, not as a substitute for existing services (with the exception of long-stay institutions) but complementary to all other existing community services and working closely with them.

The New Approach

The Family Support and Treatment Unit

Over the last decade we have developed in Exeter a prototype family support and treatment unit which is called Honeylands (Brimblecombe, 1974, 1976a, b, c, 1977, 1979; Rubissow, 1976; Pugh and Russell, 1977; Goddard and Rubissow, 1977; Goddard and Rayner, 1978; Rayner, 1978a, b; Burden, 1978), whose purpose is to make it possible for parents to adjust right from the start to having a handicapped child at home in their family and to enable them to sustain and make appropriate adjustments to maintain their normal family and social relationships. A survey of the number of mentally handicapped children aged 0-16 years of age in permanent institutional care in England and Wales (National Development Group for the Mentally Handicapped, 1978) in 1976 showed that 9 per 100,000 total population of persons of all ages were receiving permanent institutional care. The number in the Exeter Health Care District, which has a total population of 300,000, was considerably smaller (Table 8).

Table 8. Numbers of mentally handicapped children aged 0-16 years in permanent institutional care (1976).

|                          | No. per 100,000 population of all ages |
|--------------------------|---------------------------------------|
| England and Wales        | 9.0                                   |
| Exeter Health Care District | 2.3                                  |
| District X               | 7.5                                   |
| District Y               | 6.0                                   |
| District Z               | 8.1                                   |

With reference solely to children whose predominant handicap is mental retardation, these figures indicate that if the Exeter figure was replicated throughout England and Wales, the number of children from 0-16 years of age in permanent institutional care would be reduced from over 4,000 to under 1,000 in total. Such an assumption needs to be qualified by comparison with the health care districts that are contiguous to Exeter; in these three districts the numbers are also below the national average although considerably higher than the Exeter figure. It is clear that the numbers of children in institutions in rural south west England are less than in other parts of the country. Even so, the gross figure for Exeter, namely only 6 children for a total population of all ages of 300,000, brings much closer to reality the
disappearance of long-stay mental subnormality hospitals for children and the practicability of their replacement by small family group homes.

It is not suggested that the presence of Honeylands, our family support and treatment unit, is the sole reason for this difference. There are many other reasons, including the well-developed educational and social service facilities available in the Exeter district, but it is believed that the direct contribution of Honeylands has been substantial.

Honeylands does not cater solely for the needs of families with severely mentally handicapped children, but for all young children with handicaps of any kind. It is essentially a resource centre in which all the professions are represented (doctors, psychologists, speech, occupational and physiotherapists, teachers, nurses, social workers and voluntary helpers) and jointly financed and administered by the health service local authority educational and social services and by relevant voluntary agencies. Once a child has been identified as handicapped, and as soon as the parents through the help of the doctor or other professional person who has been working with them are ready, the family starts to visit the family support unit. From the start, one member of the team becomes the named person who will be responsible for ensuring that the needs of the particular family are met. This individual may come from any of the disciplines represented. Throughout any period of multidisciplinary assessment at a Child Development Centre and afterwards, the named person works as a confidante and advocate for the family. A treatment plan is worked out by the therapeutic team in discussion with the parents and the named person to ensure that it is practicable and workable at home. The named person makes regular home visits at which the home treatment plan is discussed and practised. The local health visitor and other members of the primary health care team advise and are consulted. At any time when problems arise the parents and named person refer back to Honeylands for further advice from the professional expert within whose discipline the difficulty lies. At medical consultations the named person is available to help as an advocate for the parents, should this be needed. Because of its health service participation, Honeylands is a part of the paediatric unit of the district general hospital; 24-hour emergency medical care is available. As a result, much of the primary emergency medical treatment is provided at Honeylands with the agreement of the individual family doctors.

In addition, Honeylands is constantly available for family support. It is open day and night throughout the year. The atmosphere is informal and no one wears uniform. The child can come whenever the parents wish and for periods they themselves select—for the day, for the night, for weekends or for longer periods, depending upon their needs. Most parents decide to have a regular arrangement so that they know in advance that their child will spend two days a week or alternate week-ends on a regular basis. They know that they can also call upon Honeylands at any time (day and night throughout the year in any type of medical or social crisis or emergency). This support is available from the time the handicap is identified and will continue for as long as the family feel that it is needed.

As well as forming relationships with the staff, parents meet other families who have children with handicaps similar to their own. Often they may learn as much from other parents about practical solutions to their problems as they learn from the professional staff. There are both formal and informal discussion groups among parents and staff to consider particular problems. There are social occasions in the evenings, which fathers are particularly invited to attend. The parents are key members of the policy committee that has been formed to plan future developments at Honeylands.

Despite this type of provision there are some families who are not able to cope at all with a handicapped child on account of social or psychological reasons. No pressure is placed upon them to do so; instead it is found that many foster parents are prepared to take handicapped children into their families knowing that as foster parents they will receive the same service, including family support, as is provided for natural parents.

As children reach school age they start to attend the school most appropriate to their needs but they and their families continue to make use of Honeylands at weekends and in school holidays to whatever extent they wish to do so. By this time the parents have the sort of easy contact with Honeylands normally accorded to relatives and close friends.

It is the opinion of independent assessors who have evaluated Honeylands that the lives of the families of children who have used Honeylands in this way have advantages over those of families with a handicapped child in a control population where such a service does not exist. The risk of marriage breakdown is diminished, the siblings are enabled to live more normal lives, the social life of the family is less impaired and the handicapped children themselves appear to have achieved better developmental progress than has apparently been achieved by many of the control group of handicapped children in which a family support unit is not available. Evaluation is an extremely difficult technique in that the modalities susceptible to measurement are often not those we most need to measure. Professor Jack Tizard (1978) has commented that 'in practice the variance in treatments is usually much greater than the variance in services; in general it would be nearer the truth to say that any model of service can be made to work and that what is of crucial importance is not the service model but the manner in which it is operated'. The purpose of Honeylands is to provide families who have handicapped children with the insight, skills, courage and the essential support they need right from the start. I am sure that Professor Tizard is correct when he says that it is the quality of service that matters and that the model through which this provision is made can vary and be adapted to local needs. Honeylands is a prototype that is adaptable, and similar resource centres developed in other areas may well find that variations appropriate to their own local needs may be required.

Finally, and I hope in the spirit that Dr Milroy in-
tended, the social welfare of handicapped children and their families remains the most crucial component of any new approach. In our society the handicapped still meet the following reactions in their daily encounters with non-handicapped people:

1. 'Stranger'
2. Failure of interaction
3. Ignorance
4. Power

Handicapped children or adults appear different or foreign, they represent something unknown from which many of us turn aside, partly through fear and partly because we do not understand them. This leads to a failure to interact and to their isolation from normal society. Their responses and gestures when we do approach them may seem inappropriate and may mask their own desire for involvement. All this compounds our ignorance of their real needs and of their potential to participate both in work and social activities. A vicious circle is created; the more they are isolated, the less is their chance to overcome their handicap and the greater the likelihood of atrophy rather than development of their potential. The nineteenth century model of segregation inevitably led to domination and power over the handicapped by those who supervised their daily lives.

Now, as part of the new approach, all this is beginning to change; modern technology has begun to provide communication and life support systems for the handicapped, which greatly facilitate active participation in normal daily activities and at the same time lessen dependence upon other people. In the total analysis, however, the contribution of medical and other professional technologies can never be more than individual component parts of what is basically a new approach by society as a whole to the care of the handicapped in which the new medical approach can have a catalytic effect upon all community services, such as architecture, town planning and transportation. The new life style must incorporate the implicit right of equality of citizenship and the opportunity for further education and appropriate employment, and it calls for a response from each local community to become involved in the care of the handicapped in its own locality. One of the most hopeful signs in this respect is the concern of young people who, in my experience, are far more aware of this responsibility than was my own generation as teenagers or young men and women.

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