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THE 'AT RISK' REGISTER: A STATISTICAL EVALUATION

BY

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THE 'AT RISK' REGISTER: A STATISTICAL EVALUATION

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In the past decade there has been considerable discussion about the policy of the early selective screening of children at high risk of suffering from handicapping conditions which are not apparent at birth.

This policy was advocated by Lindon (1961) and Sheridan (1962), who felt that universal screening of all infants was not practicable at that time. Sheridan in particular considered that it was essential to keep children 'at risk' under surveillance until their development was seen to be progressing entirely normally. They recommended that local authorities kept 'At Risk' registers of vulnerable children, and this recommendation was reiterated by the Sheldon Committee Report (Ministry of Health, 1967) and by a working group of the World Health Organisation (1967).

Nevertheless in 1967 Oppé and Walker, who reviewed the functioning of such registers in the U.K. and Scotland respectively, found that the detection rate based on selective screening was disappointing (Oppé, 1967; Walker, 1967). They attributed this largely to the difficulty of defining precisely the factors which put an infant 'at risk'. This tended to make the registers longer and longer, in some authorities comprising as many as 60% of all live births, thus negating the advantages of selective screening. Other authors confirmed the disappointing results of the 'at risk' policy and criticized the concept itself as being inherently unsound (Richards and Roberts, 1967; Rogers, 1967; Hamilton, Richards, Barron, Mackie, and Finlayson, 1968). Forfar (1968) also felt that selective screening was not a satisfactory substitute for universal screening but considered that the 'at risk' register should be retained as an additional safeguard.

The critics of the concept of selective screening based their arguments largely on the fact that no local authority has managed to achieve the goal forecast by Lindon (1961) namely, that the screening of a small group, 10 to 20% of all births, would identify the *majority* of those with 'invisible' handicaps. However, to our knowledge there has been

no serious attempt to assess the actual benefit of differentially devoting resources for the screening of children at different risks, as opposed to screening only the children at high risk. The former is a policy which common sense alone would dictate.

It is possible to construct a mathematical model of the functioning of a system of selective screening for handicap, based on certain assumptions, and in particular one which relates the amount of resources available for a child to the probability of detecting an 'invisible' handicap. Such a model can be used to calculate the optimum size of the group and the division of the resources between this group and the remaining children in a population, in order to detect the greatest number of handicaps for a fixed amount of resources.

In the following account we describe such a model and its use in conjunction with data from the National Child Development Study (Pringle, Butler and Davie, 1966).

THE SAMPLE

The Perinatal Mortality Survey (Butler and Bonham, 1963; Butler and Alberman, 1969) comprised about 98% of all births occurring in England, Wales and Scotland in the first week of March 1958, 17,418 births in all. The National Child Development Study (N.C.D.S.) was able to obtain data on the health, education and development of 92% of the children of the cohort still resident in Britain at the age of 7 years. It has been possible in 14,862 of these children to relate the data recorded at birth to that obtained at 7 years.

It is thus possible to ascertain the maternal and perinatal factors which are the best predictors of later handicap.

Since we had no information on family history or mothers' suspicions of retardation, these factors have not been included in this analysis.

SELECTION OF HANDICAPS TO BE PREDICTED

An attempt has been made to simulate the type of register most commonly used in local authorities,

namely, one designed to predict severe physical and educational handicaps for which early detection is highly important. A child was considered to be handicapped if he was suffering from one or more of the following: cerebral palsy, a severe hearing defect, blindness or partial sight, severe mental defect or multiple handicap. Children who died between birth and 7 years with one of these handicaps have also been included. Since in this particular instance the exercise was to predict handicaps which would not have been identified at birth, children with malformations visible at birth have been excluded from this analysis. The total number of children in this survey who fell into the category of 'unseen handicaps' was 167.

SELECTION OF 'HIGH-RISK' CRITERIA

The high-risk criteria were selected after a series of analyses which related maternal and perinatal variables to the probability of having one of these handicaps. The definition of the groups within each variable was planned so that they could easily be reproduced, with a view to making the classification of a baby an administratively feasible proposition. It could be argued that more extreme groups and a finer categorization would provide a better prediction of handicap risk. This may be true, but it would certainly complicate the classification of any particular baby, and, furthermore, considering the perinatal factors in combination should effectively identify these narrow risk categories.

The following five maternal and perinatal variables were analysed; parity, social class, method of delivery, birthweight, length of gestation, and neonatal illness. When the *joint effects* of these variables were analysed the statistically significant predictors of handicap were parity, method of delivery and neonatal illness. These variables are grouped as follows:

- Parity** (a) Parity 4 and more ('adverse' group)
(b) Parity 0-3
- Method of delivery** (a) Breech, face or shoulder delivery, internal version, or delivery by an untrained person ('adverse' group)
(b) Remainder
- Neonatal illness in first week of life** (a) Convulsions, cyanotic attacks, cerebral signs, hypothermia, jaundice (serum bilirubin 15 mg./ml. or more), Rh incompatibility or serious illness ('adverse' group)
(b) Remainder.

The total number of children for whom information was available on all these variables was 12,083.

This analysis is described in Appendix I.

RESULTS

As a result of the above analysis the probability or risk of handicap (as defined above) can be predicted for each combination of the groups of the above variables. Table I shows the combinations of parity, neonatal illness and method of delivery ranked in decreasing order of the probability of a handicap being present at 7 years. As one would

TABLE I
COMBINATIONS OF PERINATAL VARIABLES FOR THE PREDICTION OF SEVERE PHYSICAL OR MENTAL HANDICAP IN DECREASING ORDER OF RISK

Rank No.	Perinatal Groups			Predicted Risk %	Cumulative %	
	History of Neonatal Illness ¹	Parity	Adverse Method of Delivery ¹		All Livebirths (12,083)	All Predicted Handicaps (167-0)
1	Yes	4+	Yes	14.19	0.1	0.2
2	Yes	0-3	Yes	8.06	0.2	1.0
3	Yes	4+	No	6.94	0.3	2.0
4	No	4+	Yes	4.74	0.9	4.0
5	Yes	0-3	No	3.80	2.4	8.0
6	No	0-3	Yes	2.57	5.9	14.6
7	No	4+	No	2.19	13.2	26.3
8	No	0-3	No	1.18	100.0	100.0

¹See above for details

expect, the highest risk of handicap was in the small number of fifth or later born children who were delivered in an abnormal fashion and were noted to be ill in the neonatal period; the lowest risk was in those in whom none of these drawbacks was present.

It is possible to divide the population into two groups, of high and low risk, at any point in this table. Figure 1 presents the relationship between the size of the 'high-risk' group and the proportion of all the handicapped children to be found in that group. Thus choosing a group comprising 1% of all births at highest risk of handicap would include just over 4% of all children with severe physical and mental handicaps (excluding, of course, those with visible malformations). On the other hand, choosing a high-risk group comprising 10% of all births would include just over 20% of all children with severe physical or mental handicaps. It seems unlikely, even if we had been able to include cases with a family history of defects or with signs suggestive of retardation, that we would have been able to include the majority of all handicapped children on a register comprising 20% or less of all births. Nevertheless, it is clear that the perinatal 'risk' criteria we have chosen do have a predictive value.

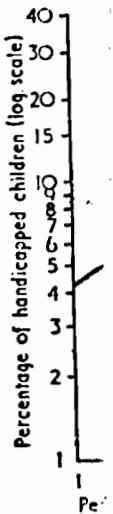


FIG. 1.—Percentage of group

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Figure 2 demonstrates a further important principle, namely, that the allocation of *all* available resources to the high-risk group (curve C), although optimal when the overall detection rate is very low, is not a sensible plan when more than about 20% of the handicaps are detected in an undivided population. In practical terms, only in an area where the resources are so slender that less than 20% of handicaps can be detected in an undivided population is it worth concentrating *all* resources on the children in the high-risk group.

It is worth remarking that, as is intuitively clear, dividing into three or more risk groups will give a better detection rate than dividing into only two groups. The additional gain from using all eight risk groups (Table I) is small, however, and does not seem worth a practical recommendation.

Table III shows the actual optimal division of resources between high and low risk groups as calculated from our data. This shows that the

TABLE III
ALLOCATION OF RESOURCES TO OPTIMUM GROUPING FOR 'AT RISK' REGISTER BASED ON TWO GROUPS

Percentage of Handicaps Detected in an Undivided Population	Ratio of Resources per Individual in High-risk Group to Resources per Individual in Low-risk Group ¹
10	∞
20	8.6
30	4.4
40	3.1
50	2.5
60	2.0
70	1.7
80	1.5
90	1.4

A value ∞ indicates that no resources are allocated to the low-risk group.

¹Using the groupings of 1-7, 8 of Table I.

proportion allocated to the high-risk group should fall progressively as the basic detection rate rises.

DISCUSSION

It is now universally accepted that the earliest possible diagnosis and treatment are essential in order to prevent, or at least to minimize, the handicapping effects of a disability and to make the most of the assets a child possesses. It is also generally agreed that it should be the responsibility of the local health authority to seek out young children with handicaps, or potential handicaps, and it is important that this task is performed as efficiently as possible.

The aim of this paper has been to demonstrate that, in economic terms alone, it is worth while to divide live births into high and low risk groups, and to differentiate between these groups in the amount

of resources to be spent per head in searching for 'invisible' handicaps. It has been shown that only in areas where the detection rate is exceedingly low is it worth concentrating *all* resources on the high-risk group. In all other areas, it is preferable to devote a proportion of the resources to the remaining children, a proportion which should increase as the basic detection rate rises.

Although it is impossible to lay down uniform rules we can give some examples of our recommendations. From the present data it appears that an optimally sized high-risk group, using *birth data alone* as predictors, is about 13% of live births. These comprise fifth or later-born children, those who were delivered abnormally, or those whose condition caused concern after birth. Amongst these would be about 26% of all children with 'unseen' handicaps. In an authority who had been detecting only about 10% of such handicaps early—say in the first year—the detection rate could be increased by 50% simply by devoting *all* resources available for this exercise to this high-risk group. Where 30% of the handicaps had been detected early, this could be increased by 10% by allocating the resources in a ratio of four to one in favour of the high-risk group.

This is a difficult concept to put over for it is impossible to define closely the resources available. These may take the form of home visits, of examinations in clinics, or of special screening tests. If we take home visiting, in the example above, we would recommend that the high-risk children should be visited four times as often as the remaining children; in the case of examinations in welfare clinics, we would recommend that appointments be given four times as frequently. The allocation of resources in areas with other detection rates can be obtained from Table III. We recognize that there may be certain constraints on the relative amounts of particular resources required to detect different handicaps, for example of the special senses. In addition one might want to give more weight to detecting certain types of handicaps early, in particular, hearing. We are currently working on a generalization of this model which distinguishes between different types of handicap and different resources required to detect them.

It is obvious that, in order to achieve the best possible use of resources, a continuous review of the existing situation is necessary. It must be emphasized that our results are based on certain assumptions concerning the relationship between resources allocated and the probability of detecting a handicap for children at different risks (see Appendix for details). These assumptions, albeit

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reasonable, have not been empirically verified. It is hoped that a longitudinal study now being planned in one local authority ('Combined Obstetric and Child Health Project', London Borough of Hounslow) will enable this to be done. It would also be valuable if Medical Officers of Health were to keep accurate records of the handicaps detected at different ages, and of the resources used.

We must stress that with the present data it was not possible to include other known high-risk factors, such as family history or maternal rubella, which a medical officer of health will obviously want to include in relevant cases.

It may be argued that the expense involved in the administration of such a system cancels out the benefit gained. This is a question to which no complete answer can be given here, except to remark that this is likely to be true only where there is already at present a high basic detection rate.

This analysis has gone some way to explain why recent papers from very efficient local authorities have expressed disenchantment with the 'risk' concept. It is clear that the more successful a local authority is at the detection of handicaps (so that its detection rate lies at the higher end of the horizontal scale in Fig. 2), the less a risk register has to offer. However, in areas with few resources per head, the keeping of a risk register and selective screening of these children is still the best policy.

It seems to us that it would be a great pity if a lack of understanding of the potential benefit to be gained from keeping risk registers were to preclude their use. We see this case as being two-fold; first, in Sheridan's view, as a mechanism for following high-risk children until their development is seen to be progressing normally (Sheridan, 1962); and, secondly, in order to make possible an intelligent allocation of resources allowing for differential risk. We feel that, far from discarding this policy, one ought to consider extending it, for it is possible to predict not only children with severe handicaps, but also those with milder handicaps of predominantly educational importance. The extension of this approach to other forms of handicap is now being investigated, and the results will appear in a forthcoming publication of the National Child Development Study.

It is worth pointing out that other areas of medicine pose similar problems, for example, screening for malignant disease of the breast or cervix, or for diabetes. An approach similar to the present one could be fruitful.

SUMMARY

The aim of this paper is to evaluate the maximum benefit to be gained by the differential allocation

of resources, for example, screening tests, in the search for 'unseen' handicaps amongst young children. Longitudinal data from the National Child Development Study have been used. A mathematical model is proposed to determine the allocation of resources among groups of children at different risk of handicap, such that the maximum number of handicaps is detected. It is shown that there is always a benefit from differential allocation of resources, particularly when the amount of resources per head of population is small.

We should like to thank the Medical Officers of Health and their staff, without whom this study would not have been possible; the National Birthday Trust Fund and the Directors and Steering Committee of the National Child Development Study for permission to publish results of the Study; and the following for helpful criticism: Professor N. R. Butler, Mr. M. J. R. Healy, Dr. M. L. Kellmer Pringle, Dr. S. V. Leff and Professor R. C. M. Pearson. This work was supported by the National Fund for Research into Crippling Diseases (E.A.), and by a grant from the Nuffield Foundation to the Department of Growth and Development at the Institute of Child Health (H.G.).

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APPENDIX I

THE PREDICTION OF SEVERE HANDICAP AT 7 YEARS

This analysis relates the probability of handicap to a function of perinatal variables.

The grouping of the perinatal variables is as follows (see text for details):

- 1. Neonatal illness (a) Ill during first week of life
(b) Not ill during first week of life
- 2. Parity (a) Parities 4 and over
(b) Parities 0-3
- 3. Social class (a) Social class 5 } Registrar
or no male } General
head of house- } (1951)
hold
(b) Social class 1-4
- 4. Method of delivery (a) Breech, face, shoulder, in-
ternal version, or un-
attended delivery
(b) Remainder
- 5. Birthweight-
gestation (a) Less than 2,500 g. or less
(completed weeks) (b) Over 2,500 g. and over 42
weeks
(c) Over 2,500 g. and 37-42
weeks

The definition of handicap is given in the text.

An acceptable model to describe these types of data is one where a logit transformation of the probability of a handicap is related to a linear function of the perinatal variables (see also Butler and Alberman (1969), chap. 3),

TABLE
FITTED CONSTANTS AND ANALYSIS OF VARIANCE
TABLE

(All chi square values are adjusted for the other factors)

Source	Fitted Constant	Standard Error	D.F.	χ^2
Overall	-1.538			
Neonatal illness				
a-b	0.571	0.170	1	8.5**
Parity				
a-b	0.318	0.111	1	7.2**
Social class				
a-b	0.010	0.121	1	0.0
Delivery				
a-b	0.383	0.135	1	6.7**
Birthweight-gestation				
a	0.136			
b	-0.088		2	1.5
c	-0.048			

Test for 'goodness of fit' of model: $\chi^2 = 31.5$, d.f. = 31

Significance levels

** 0.001 < P < 0.01

Otherwise 0.05 < P

$$1/2 \log \left(\frac{p_i}{1-p_i} \right) = \alpha + \beta_i;$$

where p_i is the probability of handicap in the i^{th} group, and β_i is a linear function of the independent (perinatal) variables. Results are presented for a 'main effects' model (Table). Tests for first order interaction effects were all non-significant at the 5% level.

The analysis uses the maximum likelihood procedure described by Dyke and Patterson (1952).

APPENDIX 2

Following the analysis in Appendix 1, we can divide the population of children into categories (or groups) on the basis of the perinatal variables, each category associated with a specified risk of developing a handicap (Table I). We now turn to the problem of using the information for the purpose of utilizing available population screening resources in the most efficient manner in order to identify children who will subsequently be handicapped. We do not here discuss the nature of the resources available, but, for example, they may consist of the manpower available for developmental screening tests. Nor do we discuss the utilization of different types of resources, although this is undoubtedly important. Instead, in order to obtain a simple solution to the problem, we assume a certain fixed quantity of one type of resource which can be divided in any manner among the population of children.

If we are not able to divide the children into risk categories at all, it is clear that we ought to divide our resources equally among all children. Suppose now that we have S defined categories of children with associated risks of handicap p_1, \dots, p_S . Let the expected number of handicaps in the i^{th} category be n_i and the total number of children in the i^{th} category be T_i so that $p_i = n_i/T_i$. Also let the total population = T and the total number of handicaps = H . Let $a_i = T_i/T$. Suppose, further, that we assign resources R_i to each individual in the i^{th} category.

Since the total amount of resources is constant,

$$\sum_{i=1}^S T_i R_i \text{ is constant or, equivalently, dividing by } T,$$

$$\sum_{i=1}^S R_i a_i \text{ is constant} = Q \text{ say.}$$

The criterion we use to determine the optimum allocation of resources is that of those children who will subsequently be handicapped (those with an 'unseen' handicap); we maximize the number who can be detected using these resources.

In order to make this allocation we must have some knowledge of the relationship between the amount of resources devoted to a child and the probability of detecting the latent handicap. Again, we shall assume a simple relationship, which, as well as leading to simple equations, may be expected to bear some resemblance to reality.

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Suppose then that the probability of detecting a latent handicap = $g(R_i)$, where g is independent of which category the child falls in. Then the expected number of detected handicaps in the i th category will be this proportion of the number in the category and the total expected number detected will be

$$C = \sum_{i=1}^S n_i g(R_i) = T \sum_{i=1}^S p_i a_i g(R_i)$$

With Q constant, C is a maximum or minimum when $\frac{\partial C}{\partial R_i} + \frac{\lambda \partial Q}{\partial R_i} = 0$ λ is a Lagrange multiplier

$$\text{or } p_i \frac{\partial g(R_i)}{\partial R_i} + \lambda = 0 \quad i = 1, \dots, S \quad (1)$$

A possible choice of g is $g(R_i) = 1 - e^{-R_i}$ with R_i measured in appropriate units.

This choice of g can be motivated as follows.

Suppose the resources devoted to an individual (R) are used in discrete amounts (e.g. a unit amount is one screening test) and the probability of one unit amount failing to detect a latent handicap is q . Then for x units of resource failing to detect a handicap = $q^x = q^{aR}$ where a is a constant. Therefore the probability of detection = $1 - q^{aR}$, which is equivalent to $1 - e^{-R}$ if the unit of R is suitably chosen.

(1) gives a maximum when

$$R_i = \log p_i + B'$$

where $B' = Q - \sum_{i=1}^S a_i \log p_i$

The maximum is

$$C/T = p_0 - B \exp \left(\sum_{i=1}^S a_i \log p_i \right) = p_0 - B \prod_{i=1}^S p_i^{a_i} \quad \text{for a unit population} \quad (2)$$

where $B = e^{-Q}$, and where p_0 is the proportion of handicaps in the population.

A further constraint on the above equations is $R_i > 0$ for all i , since negative resources cannot be allocated. If Q is small enough then some values of R_i , for the smallest values of p_i , may be negative. In the special case of interest where $S = 2$, then $R_2 < 0$ when $B > (p_2/p_1)^{a_1}$ and where this occurs C is maximized by setting $R_2 = 0$, thus allocating all resources to category 1. The new value of C , say

$$C'' = p_1 a_1 (1 - B^{(a_1)}) \quad (3)$$

We cannot determine C completely unless the value of B is known. Consider the case when there is only one risk category so that no classification is attempted. Then $S = 1, a_1 = 1$.

Using (2) we obtain

$$C' = \frac{C}{Tp_0} = 1 - B \quad (4)$$

This is the proportion detected of the total number of handicaps.

In practice, C' will have different values in different situations and Fig. 2 presents results for a range of values of C' from 0.1 to 0.9 (see text).

We may also use (4) to estimate the proportion of handicaps detected if the amount of resources Q is changed to $Q' = dQ$. The proportion of handicaps detected in an undivided population is then

$$D' = 1 - (1 - C')^d \quad (5)$$

From a practical point of view it is probably not feasible to use all the risk categories, assigning different resources to each one. The simplest solution is to take just two categories or possibly three.

There are $S-1$ ways of constructing two categories such that all the cells in one category have a higher risk than all the cells in the other. For each of these divisions, using the results of the previous analysis, we obtain estimates of the risks in each category, and equations (2) and (3) have been used to estimate the expected number of detections. Table II shows these divisions and the associated expected number of detections. The optimum division is chosen as that one which gives the largest expected number. So long as the expected number has an absolute maximum for positive values of the resources, this division will be the same for each value of C' . Where the solution implies allocating zero resources to the low-risk category the division may be, and indeed is, different for different values of C' . Where this occurs, however, the difference between the expected proportion detected, using this division and using the division obtained where the resources are positive, is small for values of $C' > 1.0$, and the latter division is always used. Table III shows the relative allocation of resources for the optimum division into two categories.

These divisions into two categories may be conveniently summarized by relating h_i (the proportion of all handicaps in the i th category) to a_i (the proportion of the total population in the i th category).

Since for any one division the proportion of all the handicaps

$$h_i = \frac{n_i}{H} = \frac{n_i}{T_i} \cdot \frac{T_i}{T} \cdot \frac{T}{H}$$

then $\log h_i = \log p_i + \log a_i + \log (T_i/H)$

Figure 1 shows $\log (h_i)$ plotted against $\log (a_i)$ for some of the divisions into two categories.

of handicap in the i th group, the independent (perinatal) seated for a 'main effects' first order interaction effects at 5% level. maximum likelihood procedure (1952).

DIX 2 Appendix 1, we can divide categories (or groups) on variables, each category associated with a handicap. The problem of using the available population in the most efficient manner who will subsequently be discuss the nature of the sample, they may consist of developmental screening and utilization of different methods is undoubtedly important. A simple solution to a fixed quantity of one divided in any manner.

the children into risk we ought to divide our children. Suppose now that children with associated Let the expected number be n_i and the total number be T_i so that $p_i = n_i/T_i$ and the total $T = \sum T_i$. Suppose, $a_i = T_i/T$. Suppose, R_i to each individual in resources is constant, entirely, dividing by T_i , line the optimum allocation of children who will use with an 'unseen' who can be detected we must have some between the amount of the probability of detection, we shall assume a as leading to simple some resemblance to