ECONOMIC ASPECTS OF THE PREVENTION OF DOWN'S SYNDROME (MONGOLISM)

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### INTRODUCTION

Developments in chromosome analysis in recent years have led a number of people to suggest "screening" programs for the detection and prevention of genetic disorders. In particular, Stein et al. (1973) have outlined the case for the progressive introduction of a comprehensive program to eliminate or, at any rate, to reduce the incidence of Down's Syndrome (Mongolism). The program would involve the detection of the genetic abnormality in utero by amniocentesis and chromosome analysis, combined with the offer of an abortion to those women found to be carrying an affected fetus.

In this article, in the correspondence which followed it, in the document emanating from the WHO Scientific Group (1972), and in the recent work by Milunsky (1973), reference has been made to "economic" aspects of such a program. In particular Stein et al. and Milunsky have claimed that the program would certainly "pay for itself" for mothers over thirty years old, in the sense that the savings in future institutional care of Mongoloids would more than offset the cost of the scheme. The WHO working party suggested that for mothers over thirty-five years of age, the cost of the program would be less than half the savings it engendered.

Since the medical participants have not feared to tread in this area of "economic" costs and benefits, the rest of us perhaps may be excused the wish, if not to rush in then, at least to sidle in also. In particular, it was not always made clear in the works cited already whether the calculations made were expected to apply to all countries or only to the US and, if only to the US, whether conclusions drawn from the US case might need to be altered for other countries. The analysis in this paper confines itself to the situation in the UK.

# THE ECONOMICS OF SCREENING--SOME ETHICAL AND ECONOMIC CONSIDERATIONS

Screening programs are, in principle, capable of being regarded as any other investment project. They usually require an initial capital outlay and incur continuous running expenses. In return they generate a series of effects which can be thought of as benefits or returns and which accrue over time. Well-tested techniques exist for dealing with this kind of problem and for deciding whether the investment is a "good thing" or not.

In practice, however, this approach has its limitations. These have been summarized by Pole (1968) as follows: "Economic considerations are bound to play a part in determining what screening programmes are put into effect, but can only operate within a framework of valuations which have an obvious moral content and of constraints which are likely to be ethical, political, and administrative as well as financial and medical." In short, many of the costs and benefits of screening programs are such that there is no technical way of expressing them in terms of a single dimension which would be generally acceptable. Although one can attempt to set out the various factors in terms of a "balance sheet" there is no useful apolitical way of totting both sides up.

Should one therefore carry out any "economic" analysis of such programs at all? The customary justification for analysis in these circumstances is that since one element in any decision to proceed with a screening program is its impact on the

use and availability of resources--largely a matter of "fact", and establishment of the "facts" can at least narrow down the area of uncertainty. This view has, however, been attacked.

The nature of the criticism is best summed up by Wiseman (1963): "I am uncomfortable about the notion that better information about one part of an indefinite whole must always make for a better understanding of that whole: it seems at least possible that it might make for difficulty in taking a balanced view of the relative importance of the things that have been quantified and those that have not (the socalled intangibles)." The first part of this argument resolves itself ultimately into a matter of fact: do the decision makers find the type of information provided by an economic analysis helpful or not? To a large extent this will depend on the nature of the decision and the quality of the information—not to mention the character of the decision makers!

The second part of the argument, especially as expounded more recently by Draper (1974) seems to involve the belief that dangerous toys should be kept out of the hands of children, doctors, health administrators, and politicians, who cannot be trusted to put such economic information into its correct perspective alongside medical and moral considerations. Obviously, we shall tend to differ about whether we find this essentially paternalistic attitude attractive.

In any case, whether economists take a vow of abstinence or not, people will hold and air opinions about the economic aspects of screening programs and it seems sensible that these opinions should be based on explicit assumptions and calculations rather than on implicit ones.

At the beginning of the section I drew a comparison between screening and investment. A major similarity is that screening involves an outlay now in order to achieve a benefit in the future. It is, I think, clear that if two outlays of equal size x promised, on the one hand, a benefit of size y in five years time, and on the other, a benefit of size y in 100 years time then, on the whole, we should be inclined to choose the first. This is not simply because we shall not be alive 100 years hence. One could always sell the right to appropriate the benefit to someone else. Forests are planted even though their planters may never live to see them felled.

We are dealing with the complex phenomenon of time preference. How should next year's benefits be valued compared with this year's, and what about benefits in five years' time? A discussion of this issue would take us far afield. What I have done is to use the procedure which H.M. Treasury suggests for public expenditure projects, namely a 10% discount rate. This means that the value of a benefit or cost decays at a rate of 10% per year in real terms (i.e. in constant prices). The longer the benefits or costs are delayed the lower their value. The extent of this reduction for the purposes of planning the community's activities must be a social (and, ultimately, political) decision.

The notion of discounting future costs and benefits has important implications for screening. The effect of screening relates to the particular cohort screened, and the benefit or cost accrues over the lifetime (or potential lifetime) of the cohort screened. The cost (however defined) of the present mentally handicapped population, for example, is irrelevant to a decision about screening to prevent or alleviate mental handicap. What is relevant is how such costs might be expected to occur over the lifetime of the affected cohort. The importance of this consideration will, I hope, become clearer later.

### THE ECONOMICS OF DOWN'S SYNDROME: TWO OBJECTIONS

Objections to carrying out an economic analysis of an amniocentesis/abortion program come under two headings. The first relates to the ethics of abortion. A "prevention" program to eliminate or reduce the incidence of Down's syndrome would

involve the offer of an abortion to those mothers discovered after amniocentesis and karyotyping to be carrying a Mongoloid child. Many people find the notion of legal abortion--especially in the form of an organized program--abhorrent and may consider arguments about economic gains and losses irrelevant, if not reprehensible. Of this group of people, some would still hold this opinion even if caring for the population of Mongoloids were to absorb 100% of our national resources. For the remainder there is, presumably, some point between one penny and 100% of our national resources at which ethical objections would weigh less heavily than the economic burden implied by these objections. For the former group there is no point in reading further. Members of the latter group will, I hope, be interested in being able to weigh the economic considerations in the balance with other more exalted considerations.

There is a potential second group of objectors whose line is, perhaps, best exemplified by a passage from Stein et al.(1973): "But is a detailed estimate of money cost required? The lifelong care of severely retarded persons is so burdensome in almost every human dimension that no preventive program is likely to outweigh the burden."

The problem with this argument is that it appears not to be true. The number of nurses working in mental handicap hospitals in England and Wales rose from 10,000 to 15,000 between 1959 and 1969. Despite occasional instances of illtreatment there is no reason to believe that these nurses find the "lifetime care of severely retarded persons so burdensome in almost every human dimension," or they would clearly not be willing to do the job. As for the parents of Mongoloid children, there would appear to be conflicting views on the extent to which they find the burden of caring for their children intolerable. But even if it were true that the burden was an intolerable one from the parents' point of view this is not altogether germane. Since the "community" is to provide the resources for a screening program, the question to be decided is whether "the community" regards the burden borne by the affected parents as intolerable. This is clearly a rather different question from that of whether the parents themselves find it intolerable. The evidence, from the UK at least, would appear to be that either 1) the community does not regard the burden as being so great that the resources necessary to provide complete lifetime institutionalization for all Mongoloids could not be better spent elsewhere or 2) parents do not regard the lifetime care of severely retarded persons as so burdensome that they would prefer to institutionalize their children, since only about 10% of Mongoloid children are currently institutionalized.

However, even if Stein et al.'s statement were self-evidently true--namely, that the burden of caring for Mongoloids far outweighed the cost of any prevention program--this, in itself, does not constitute an argument for not computing this cost. For it may well be that when the cost of "any" prevention program is taken together with possible clinical and ethical objections, not to mention the political "cost" of getting such a program accepted, the combined forces of the various negative factors outweigh the "great" benefits. Unless we know the resource costs and benefits we cannot make an overall judgment on the value of the scheme. For these reasons, I consider it to be a worthwhile task to trace out as fully as I can the resource implications of such a prevention scheme for the UK.

#### INCIDENCE OF DOWN'S SYNDROME

Table 1 summarizes the salient features of the incidence of Down's Syndrome. It can be seen that the condition has an overall incidence of about 1 in 600 but that this incidence rate rises greatly with maternal age. Although the incidence is tending to fall with a fall in the number of children born to mothers over 40, prevalence is apparently tending to increase due to increased survival rates among Mongoloids. The hereditary element is not very important in the incidence of the condition. The evidence about survival rates is somewhat conflicting. Stein et al. quote a number of studies to the effect that 54% of children with the syndrome had died before the age of 7. Kushlick, however, found that two-thirds were still alive

at 15 (1974) while Neligan (1974) reports a survival rate at 5 years of over 80%. Since most deaths occur within the first year the differing rates are somewhat confusing. While it is possible that they may reflect the phenomenon of increasing survival noted earlier, the differences seem rather too large to be explained in this way.

Children with Down's Syndrome comprise about 30% of severely mentally handicapped children (IQ  $\leq$  50). In the Wessex survey (1973) higher-grade Mongoloids comprised just over 3% of the mildly sub-normal (50  $\leq$  10  $\leq$  70).

Table 1. Estimated age-specific incidence of Down's syndrome, numbers of live births, and estimated numbers of affected infants with percentages, in England and Wales, 1970.

Maternal age (years)	Incidence/1000 live births (estimated)	No. of live births	No. of affected infants (estim.)
all ages	1.67	784486	1312 (100.0)
under 20	0.9	80975	73 (5.6)
20-24	1.0	289209	289 (22.0)
25-29	1.1	238228	262 (20.0)
30-34	2.0	114086	228 (17.4)
35-39	5.0	48323	242 (18.4)
40-44	15.0	12756	191 (14.6)
45 and over	30.0	909	27 (2.1)

Figures in parentheses are percentages.

Source: Wynne Griffith, 1973.

# AMNIOCENTESIS AND KARYOTYPING

The detection of a Mongoloid child in utero depends on a technique known as amniocentesis which consists of the aspiration of amniotic fluid from the uterine cavity. This is usually done at 14-16 weeks and can be performed normally on an outpatient basis under local anaesthetic. It is, however, thought to be desirable that the placenta should be located by the use of ultrasonic equipment (1973).

The subsequent chromosome analysis to detect the presence of an extra chromosome (the normal genetic characteristic of Down's syndrome) is a laborious process taking two to three weeks for culture and analysis. Antenatal diagnosis of fetal chromosomal abnormalities is still very much an art rather than a routine procedure. Stein et al. claimed a 95% culture success rate per pregnancy, including repeat cultures the need for which can normally be ascertained after a few days, but this has been disputed by others. There would appear also to be differences of opinion concerning the likelihood of significant technical improvements involving computer technology. The specificity and sensitivity of the test is very high.

The risks to the mother and fetus attendant upon amniocentesis are a matter of dispute and are currently the subject of a Medical Research Council project. Estimates of the risk of inducing abortions range from 3% to virtually mil.

In general, before amniocentesis is carried out to detect genetic abnormalities an undertaking is obtained from the mother that she will consent to an abortion in the event of such an abnormality being discovered.

#### HOSPITAL RESOURCES REQUIRED FOR AMNIOCENTESIS

Amniocentesis is normally carried out as an outpatient procedure under local anaesthetic. The resources demanded would clearly depend on the size of the program, the participation rate of mothers, the number of repeats required, and the rate at which the procedure can be carried out.

An upper bound to the possible manpower implications of an amniocentesis program can be given using fairly extreme assumptions. If the amniocentesis program were to cover all pregnancies in England, which we shall assume to number 700,000 a year, if all mothers participated, if one procedure in three had to be repeated, if the procedure required a consultant obstetrician, and if each obstetrician carried out four procedures in a session, then such a program would require the services of about 470 whole-time consultant obstetricians. In 1972 there were just over 500 whole-time-equivalent consultant obstetricians in England.

If the size of program and the participation rate were held constant but a repeat rate of one in ten and a work-rate of six procedures per session were assumed, then the number of whole-time consultants required would be about 280. A lower participation rate would, of course, reduce the number of doctors required but would concomitantly reduce the number of cases detected.

It becomes clear that a program to provide amniocentesis for all pregnant mothers, even using the second set of assumptions above, would imply farge increases in medical manpower. Probably for this reason, a phased introduction of such a program has been suggested by Stein et al. (1973) and by Bain and Sutherland (1973). Given the highly age-related incidence of the condition, the program would initially cover mothers over the age of forty and would gradually be extended to younger age groups.

In 1971 mothers over forty accounted for 1.7% of all live births although this proportion is falling. On the other hand they accounted for an estimated 16.7% of all Mongoloid births. If we take 1.5% as our best estimate of the proportion of the 700,000 births which will be accounted for by mothers over forty, such mothers will be responsible for 10,500 births. Of these, about 170 might be expected to be Mongoloids. What this will mean in work load is more difficult to estimate. Ammiocentesis would need to be carried out by the sixteenth week of pregnancy in order to permit an abortion to be carried out by the twentieth week. The proportion of potential mothers over forty who will have come in contact with a medical agency by the sixteenth week is unlikely to be anywhere near 100%. While this factor is important it should be stressed, on the other hand, that a reduced participation rate principally affects the absolute level of costs and benefits. The ratio of costs to benefits is largely unaffected by such a transformation.

With this in mind an estimate of the hospital cost of an amniocentesis program for the annual cohort of mothers of age 40 and above in a proportion of 700,000 mothers is given below. The detailed estimates on which it is based are described elsewhere. The estimates assume a participation rate of 100% and should be appropriately scaled down for lower rates. They also include an allowance for subsequent abortions.

Table 2. Estimated annual clinical cost of an amniocentesis program for mothers aged forty years and above.

Work rate Repeat Rate	4 per session	6 per session
One in Three	£196,000	£125,000
One in Ten	£164,000	£114,000

The foregoing calculations do not include the costs to the patient of attending for the amniocentesis. The size of such an element would depend on the number of centers carrying out the program within a given region and on whether one chose to attribute a cost to the patient's time travelling and at the hospital. A larger number of centers would reduce travelling time and costs but might lead to rather higher unit costs at each center if capital and equipment were under-utilized and if the fewer cases to be handled provided less scope for technical improvement. It might also involve a higher risk of inducing abortions.

A similar scheme for mothers in the 35-39 age group would be about four times as expensive as that for mothers of forty and over, since births to mothers between 35 and 39 might be expected to account for about 6% of all births. Economics of scale, however, might reduce the cost of this larger program.

The above calculations have also ignored the high abortion rate for older mothers. To the extent that older mothers who currently abort might, under an amniocentesis program, be screened before doing so, the cost of the scheme would be higher. The fact that a proportion of older mothers may currently seek an abortion from fear of bearing a Mongoloid child (a fear which would be removed by a screening program) provides a further complication.

# LABORATORY RESOURCES REQUIRED

Chromosome analysis on the scale implied by a comprehensive screening program has not hitherto been carried out at any center in the UK although its practice is rapidly increasing. This increases the problem of estimating the cost of such a procedure.

The detailed estimates of staffing and other requirements which have been made are outlined elsewhere. Chromosome analysis is a highly labor-intensive procedure. It is possible that there may be significant technical improvements in the future. The possibility of such technical improvement is only relevant to a current decision, however, to the extent that the implementation of a large-scale chromosome-analysis service would be likely to hasten such technical development. If technical development is likely to proceed autonomously at an unchanged rate, then for present purposes it can be ignored. If technical development is likely to be hastened by the presence of a larger-scale service commitment, the calculation then becomes much more complex.

In Table 3 the costs of a laboratory program to detect Down's syndrome in the annual cohort of mothers over the age of forty is set out. It is assumed that a service on the scale implied (around 1,000 analyses a year at each regional center) would require purpose built accommodation.

Table 3. Annual laboratory costs of a screening program for mothers 40 and above.

REPEAT RATE	COST
One in Three	£820,000
One in Ten	£750,000

Once again the cost of extending the scheme to the population of mothers between 35 and 39 would be a sum about four times as large as that for those over 40.

To summarize, there are various assumptions one can make about the operation of an amniocentesis/abortion program for the prevention of Down's syndrome. On the assumptions outlined above the minimum annual cost of such a scheme for mothers of 40 and over would be £850,000. The maximum figure would be about £1 million. These estimates do not include patient costs. A similar scheme for mothers aged 35-39 would cost at present between £3.4, and £4.0 million, assuming no economies of scale. These cost estimates are based on a participation rate of 100% among mothers and need to be appropriately scaled down for lower rates.

## SAVINGS IN INSTITUTIONAL CARE

An amniocentesis/abortion program for mothers over 40 might expect to prevent about 170 live Mongoloid births, assuming 100% participation by mothers. To estimate the consequences of this for institutional care one would need to know how many of these children will be institutionalized at what stage in their lives. This requires not simply information about the present state of affairs but a prediction as to likely trends in care over the next fifty years—clearly a tall order!

There has been a tendency in the various articles and letters about screening programs to discuss the "institutional" costs of the trisomic population in an obscure and ambiguous way. In particular it has not been made clear that the relevant "institutional" costs are those that would be caused by a particular cohort of Mongoloids. It is often not clear whether, for example, Stein et al. and the WHO working party are referring to the costs of institutionalizing all Mongoloids or to the costs of institutionalizing that proportion of future cohorts who, given the present or projected provision of institutional places, are likely to be institutionalized.

The first assumption does not conform with what actually happens, in this country at any rate. The second requires a forecast of rates of institutionalization—rates which are probably largely determined by the extent of public provision of hospital and residential places.

For the purposes of this study I have made the following assumptions about the expected average lifetime experiences of a current cohort of Mongoloid births in the absence of an amniocentesis program:

- Assumption 1. Fifteen per cent of Mongoloid children die before one year; ten per cent of those left alive are institutionalized for life; and thereafter half of the remainder are institutionalized at age 15 and the other half at age 25.
- Assumption 2. The same as Assumption 1 except that twenty per cent are institutionalized for life.

- Assumption 3. The same as Assumption 1 except that one-third of children die before first year.
- Assumption 4. The same as Assumption 2 except that one third of children die before first year.

These assumptions are made with references to the work of Kushlick (1974) and of Neligan (1974). The important point to note is that under all of the assumptions most of the "savings" in institutional care do not occur for fifteen years after the birth of the cohort. It is this delay which makes the use of a "discounting" procedure imperative.

In estimating the "savings" from the reduction in the need for institutional care I have used as my basic estimate the current cost of a patient-year in a mental subnormality hospital to which I have added a capital cost allowance to give an average figure of £1,500 per year per patient. To the extent that Mongoloids present particular problems this may be a slight underestimate. To the extent that Mongoloids present fewer problems or might be accommodated in community residential accommodation the figure may be somewhat lower. The allowance for capital cost reflects the fact that hospital and residential places for the mentally retarded are in short supply (at zero price!). For the sake of simplicity have assumed that all places are provided by the public sector and have not tried to incorporate the role of the private and voluntary sectors.

It is not very realistic in a cohort analysis of this kind to assume that expenditure will remain constant in real terms (it is likely, of course, to rise dramatically in money terms!) This is for two reasons: firstly, if the country becomes richer higher standards are likely to be desired for the care of the mentally subuormal and are likely to be implemented; secondly, labor-intensive sectors like the care of the mentally subnormal, where wages probably account for 90% or more of hospital expenses, are likely to become relatively more expensive as labor productivity increases at a faster rate in the rest of the economy. This latter effect may, however, be offset by a move away from hospital-type care.

With these effects in mind I have estimated expected lifetime "savings" in institutional care for a current cohort of Mongoloids under two assumptions:

- (1) That expenditure remains constant in real terms--the first two effects being offset exactly by the third.
- (2) That expenditure rises at a real rate of 5% per annum.

Table 4 gives the results for the various assumptions.

Table 4. Lifetime costs of institutional care for one year's cohort born to mothers of age 40 and above (discounted at 10% per annum).

	Zero Real Growth in Expenditure	5% Real Growth in Expenditure
Assumption 1.	£567,000	£1,200,000
Assumption 2.	1732,000	£1,539,000
Assumption 3.	1470,000	£ 976,000
Assumption 4.	£611,000	£1,248,000

If the amniocentesis program were extended to mothers in the age group 35 to 39, the savings attributable to this extension would be about one-eighth greater than the above figures. Once again it should be stressed that these calculations assume 100% participation by mothers and a "success" rate of 100%.

#### SAVINGS IN TRAINING COSTS

We have here assumed that all children receive some form of training from age 5 until age 15 or until they are institutionalized, in addition to what they would receive in their institution. We have used Section 6 fees paid by Local Authorities to Special Schools as a first measure of the cost of such training. For one local authority this averaged £700 a year per pupil in 1973.

Table 5. Lifetime training costs of annual cohort born to mothers age 40 and above.

	Zero Real Growth in Expenditure	5% Real Growth in Expenditure
Assumption 1.	£450,000	£778,000
Assumption 2.	£440,000	£758,000
Assumption 3.	£354,000	£609,000
Assumption 4.	£348,000	£593,000

The "costs" of the 35-39 cohort would again be about one-eighth greater than this.

#### HOSPITAL AND FAMILY COSTS

A cursory analysis of the data provided by Neligan did not indicate a very-great inpatient cost imposed by Mongoloid children who survived their first year. Only seven of the eighteen survivors examined appeared to have had an inpatient episode in their first five years and in general the episodes were not of long duration. Possibly this reflects a reluctance among pediatricians to admit Mongoloid children to acute wards. I have not allowed for home care or outpatient episodes.

The cost to those families who keep their Mongoloid children at home is difficult to estimate. I have used Family Expenditure Survey figures to estimate the cost of rearing a child--in this case the difference in average annual expenditure between a family with one child and a family with two children. Using 1972 data this amounts to £250 a year or about £300 in 1974 prices. Assuming a real rise in expenditure of 3% a year, the discounted value of family expenditure for an annual over-forties cohort, under various assumptions ranges from £283,000 for Assumption 4 to £406,000 for Assumption 1. Due to lack of data no attempt has been made to allow for the extent to which the presence of a Mongoloid child reduced the "employability" of the mother or father.

To summarize: it is possible to make a number of assumptions about the expected lifetime profile of a current cohort of Mongoloid births and about the trend of expenditure both public and private. This gives us a range of estimates of the discounted lifetime costs of an annual cohort. For mothers of forty and over, assuming a 100% participation and success rate (which would need to be scaled down for lower assumed rates), the values extend from £1.2 million using Assumption 3 and a zero real growth in expenditure to £2.7 million with Assumption 2 and a 5% real growth in expenditure. This compares with a cost of between £850,000 and £1.0 million. For the cohort of children born to mothers aged 35~39, the maximum "savings" figure is about £3.0 million, as against a cost of between

£3.4 million and £4.0 million.

#### CONCLUSIONS

The purpose of this paper was to trace out as fully as possible, using existing data, the resource consequences of an amniocentesis/abortion program for the prevention of Down's syndrome under a number of plausible assumptions. Implicit in an exercise of this kind is the belief that information of this kind is useful when taken together with medical and social data (and a person's own value judgments) in coming to a conclusion about the advisability of such a program.

There are some particular points which I wish to stress, however. The first is that under no set of assumptions in the paper is the resource cost of an amniocentesis/abortion program for the 35-39-year-old group of mothers in the UK less than the resource "savings" engendered by such a program, a result which conflicts with the assertions of Stein et al. and the WHO working party.

Much of the explanation for the different results lies in the apparent failure of the other studies to apply a discounting procedure to effects which occur over the lifetime of the affected cohort. However, this is not the full explanation. The cost quoted by both Stein et al. and Milunsky (1973,1973) for an amniocentesis/chromosome analysis in New York (\$150) would appear to be rather below the estimated current cost of such a procedure in the UK even allowing for intervening inflation, while the cost of caring for Mongoloids is, apparently, much higher in the US. This is simply another instance of the danger of applying results derived in one national context to quite different countries and societies. It should be stressed again that the analysis in this paper does not imply that a screening program should not be extended to mothers in the 35-39 age group in the UK; clearly such a decision depends on many other factors, clinical, ethical, social than could be considered here. The sole implication is that, on the basis of the data and assumptions used in this paper, such a program would not "pay for itself."

The second point is to stress the crucial role playing in the analysis by the discounting procedure. This is a procedure which is often difficult for non-economists to come to terms with and yet it is one which they implicitly use in their everyday lives. If a project promises returns in the future in exchange for present sacrifices, then some means of valuing these delayed effects in relation to present burdens must be found. The use of the Treasury-recommended discount rate for public expenditure projects seems to me the most reasonable rate to use in a project calling largely for the expenditure of public money.

Lastly, this study has confined itself to an analysis of the proposal to detect Down's syndrome. It is sometimes suggested that the sample of amniotic fluid could be used to detect the presence of other fetal irregularities such as spina bifida. Whatever the merits of this argument it should be noted that the actual amniocentesis procedure forms a comparatively small part of the total cost of detecting the presence of Down's syndrome.

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214 DISCUSSION

#### Comments of the Discussant, Mr. Thrall

The Glass study, Mr. Thrall pointed out, showed that cost-benefit analysis could exclude as well as justify a contemplated project. In this case, Mr. Glass had shown that the savings in institutional care, which others had claimed would more than repay the expenses of screening for Down's Syndrome, simply failed to do so. Mr. Glass had considered a broad range of alternative assumptions and had found that the saved institutional costs approximated the screening costs only for the population of women over forty.

Nevertheless, Mr. Glass realized that institutional savings were not the only benefit in reducing the incidence of Mongolism. The screening project might, after all, in weighing other benefits, be justified. Mr. Thrall felt that Mr. Glass had appropriately not embarked upon such an exercise. The values that would have had to be imputed to those benefits should be the values of the decision makers themselves. Lacking entry, to their minds, the modeller should not impose his own values upon the analysis.

The choice of discount rate for a study of this type is, as indicated by Mr. Glass, thorny. This area of systems methodology is currently undergoing careful scrutiny as to facile extentions of basic techniques to problems in which they were not relevant has brought discounting into disrepute. The use of discounting in valuing whale populations is a case in point. Assessing through discounting the future benefits from screening for Down's Syndrome is fraught with danger. Mr. Thrall suggested that a way around this might be to examine the steady state results of an assumed long-term adoption of the policy. In this way, costs and benefits could be compared for the same year. It was pointed out that this scheme effectively implies a discount rate equal to the population growth rate.

### Points on the Evaluation of Screening

Conference participants offered a number of thoughts on topics in the evaluation of screening prompted by Messrs. Glass and Thrall:

- a) that a kind of ethical paralysis sets in when people shrink from the thought of comparing the ineffable benefits of screening for Down's Syndrome with cold, hard lucre;
- that a recent evaluation of screening for phenylketonuria expressed output in terms of function years and found that the best screening is genetic rather than bio-chemical;
- c) that the cost of screening depends critically upon the level of personnel thought capable of performing the amniocentesis; and
- d) that the reduction of Mongolism may have vast unknowable externality benefits--invisible to the affected families themselves--making benefit estimation a nugatory exercise.

### Response by Mr. Glass

The possibility of ethical paralysis was conceded by Mr. Glass. His own analysis represented an attempt to resolve questions about the monetarily measurable benefits whose enumeration might subsequently aid the inevitable religious and ethical debates.

He took issue with one off-hand reference to his work as cost-benefit analysis. The facile deduction sometimes is made that any appearance of the dollar or pound symbol indicates cost-benefit analysis. Mr. Glass stated that the disparaging remark applied to certain cultures appeared to him valid for cost-benefit analysis: that it had passed from a state considered primitive to decadence without any inter-

DISCUSSION 215

vening phase.

Mr. Glass defended his use of discount rates as the best of presently available analytic alternatives. He warned, however, of a danger: that the presentation of alternative discount rates to evaluate proposed and competing projects might enable the decision maker to select first the project he finds personally most appealing and then to choose as the appropriate rate that justifying his project. Discount rates should be determined without reference to specific contemplated projects and should reflect the social attitude toward the future.

# Presenting Analysis

One participant felt that the Glass paper had skirted a danger run by all difficult and delicate analysis: that it is overwhelmingly likely to be misunderstood. To be as clear as possible, analysis ought perhaps to be divided in two parts. The first should compare monetarily quantifiable benefits with costs to obtain net benefits—which may be negative. The second part should enumerate those benefits whose valuation requires discretionary judgment which, as Mr. Thrall argued, can be assigned only by the decision maker.

Mr. Glass said that he had attempted to provide the first part in this suggested estimation of net benefits. He did not consider himself competent to embark upon the second exercise of enumerating such benefits as the social externalities.