Case 43

Evaluation research on a disability rehabilitation programme

Child-rights groups in a poor democratic country in South Asia have successfully campaigned to make elementary education for all children between the ages of 6 and 14 years a fundamental, justiciable right. The campaign included several groups working in the area of disability, and the resulting law on Right to Education clearly states that it applies equally to all children, including disabled children.

A massive nationwide programme was launched to bring all children aged 6-14 years into the education system. It provides US$ 100 a year for each disabled child. This money is to be disbursed to voluntary organizations to set up appropriate, community-based settings to provide relevant and accessible services for disabled children. Although the programme's primary aim is to improve access to education, organizations can include other service components, such as health (including medical care) and rehabilitation.

Money is allocated between districts based on the recent census, which has, for the first time, covered disabled people. However, since the census data are 5 years old and do not include children whose disability was diagnosed more recently, each organization is also given a one-time grant to survey disability in its area using the same protocol as the census.

The government appoints a well-known public-health expert (who specializes in child health) to evaluate the performance of the programme 3 years after it was launched. A district which is regarded as a model is selected for the study. This evaluation suggests that the programme is efficient and innovative, the commitment of the organizations is evident, and user satisfaction is very high. The district administration is keen to use this study to promote the success of the programme and make it a model for scaling up in the rest of the country.

However, the expert evaluator, who has clinical experience as a paediatrician, is concerned that the evaluation shows that unusually few severely disabled children have been included in the programme. However, repeat surveys using the standard census protocol (including some conducted specifically to check the accuracy of the data collected by the organizations), have yielded similar results.

The expert designs a new protocol, with several probing questions. A pilot survey with this protocol in four poor urban and rural blocks reveals that many severely disabled children (most of whom are bedridden, and unable to care for themselves or communicate verbally), have not been enumerated in any of the surveys or the census. The expert asks some postgraduate medical students to assess these children. They find that the children are being fed and cared for by their parents, but that they do not get medical care or rehabilitation services. Most of them are severely malnourished (e.g. teenagers who weigh less than 15 kg) and several have untreated chronic ailments (including tuberculosis, epilepsy, asthma, and heart defects).

The expert conveys his finding to the programme's district collector, who says that the programme is only obliged to extend services to children identified by the census. Moreover, because the programme already includes more children than the target which is based on the census statistics, their needs exceed the available budget. This administrator appeals to the expert to be more pragmatic, and to refrain from creating a controversy which would not only discredit the programme but also the census, which is the basis on which most government programmes are planned. He points out that inclusion of disabled children would divert resources away from children with better chances of leading productive lives. However, he expert argues that he has a responsibility to reveal that the research data are systematically biased.

Questions

1 The researcher feels a responsibility to reveal the truth, which is a key ethical concern for research as an enterprise of knowledge creation. Would he be justified in insisting that the information should be made public, even though no action (in terms of services or care for the severely disabled children) might result from it?

2 Should the design of this evaluation study have been reviewed by an ethics committee? Why or why not?

3 Who is most at "risk" during the conduct of health systems evaluation studies? How can the "risk" to health care professionals be decreased during the conduct of these evaluations?

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