In all other aspects, serious deficiencies were noted. Up to 20% of approval letters did not mention the names of members of the EC attending the meeting.

The quorum was not met in four ECs although the problem may be larger as half the letters did not carry the names of those who attended the meetings and therefore could not be assessed. As per Schedule Y, a lack of quorum would invalidate the approval and the study should not have been initiated. Similar observations have been made in a study carried out in Pune (3).

Most approval letters did not mention the presence of a legal expert or social scientist /ethicist. The participation of legal experts and a social scientist or ethicist is crucial in the review of and decision making on projects. The legal expert is expected to look at legal requirements and issues related to provisions for compensation.

The other common observations included not mentioning the venue and time of the meeting, and not stating the method of patient accrual. Patient accrual methods (including advertisements, letters to colleagues or any other methods) must be reviewed by ECs as these have important implications for the ethical conduct of clinical trials. Several ECs did not state if documents such as the investigator's undertaking, the clinical trial agreement and insurance policy documents were reviewed. The insurance documents must be reviewed as per Schedule Y in order to ensure that the sponsor has given adequate cover to the research participant in case of research-related injury.

In this study, only one-third of ECs approached provided consent. The experience of the ICMR has not been different. In 2002, 35 of 71 institutions did not participate in the ICMR-conducted survey of ECs, even when the ICMR was the sponsor (4).

The study is limited by the small numbers involved, but it identifies important issues regarding the functioning of ECs. There is a need to train EC members and create a better awareness of regulatory requirements. There is also a need to evolve a mechanism to monitor EC functioning, which is crucial in ensuring the ethical conduct of research.

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# Considering ethics in community eye health planning: perspectives from an existing model

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## *Abstract*

*Despite the widespread acceptance of the principles of the Alma Ata Declaration of 1978 and the subsequent amendments, health for all has remained a distant dream in many parts of the developing world. Concerns such as the economic efficiency of health systems and their reach and coverage have dominated discussions of public health, with ethics remaining at best a shadowy set of assumptions or at worst completely ignored. Similarly, questions of ethics have been taken for granted and rarely addressed directly in the design of public health models across sectors and are rarely explicitly addressed. This paper uses the experience of the L V Prasad Eye Institute's (LVPEI) pyramidal model of eye healthcare delivery to explore ethical issues in the design and implementation of public health interventions. The LVPEI model evolved over time from its beginnings as a tertiary care centre to a network that spans all levels of eye care service delivery from the community through primary and secondary levels. A previously published analytical framework is applied to this model and the utility of this framework as well as the ethics of the LVPEI model are interrogated. An analytical and prescriptive framework is then evolved that could be used to build in and evaluate ethics in other public health delivery models.*

## Introduction

Among the most significant achievements of modern medicine is the possibility of making good healthcare available to all people at a reasonable cost. While this has been underwritten in large part by advancements in science and medical technology, no less important have been the political and social perspectives that inform contemporary societies. These perspectives have in turn led to the creation of equitable systems of distribution of goods and services. The distribution of basic material needs has been accompanied by the effort to make available key services such as education and health to all people.

Public health as policy and practice stems from a basic moral imperative: to create and use systemic resources and structures to help improve the quality of life, and relieve suffering from disease and disability through a societal rather than an individual approach. The health of societies and communities is central, shifting the focus of medical attention from the individual to the group. The public health approach therefore is based on an understanding of "the greatest common good" as opposed to the highly individualistic, patient-centred approach taken in medical practice.

Given that public health as a concept, policy and programme is based on what are largely accepted as communitarian and altruistic principles, there has been little separate scrutiny of its ethics. While clinical practice and research do receive attention on the basis of their ethical considerations, and while medical practitioners are in general guided by ethical frameworks, both absolute and situational, the context is somewhat different in public health. The difference arises not only from the wider range of application of policy and action, but also from the need to balance different (and sometimes differing) interests and stakeholder perceptions.

When policies are framed on behalf of communities by powerful elites, varying considerations may apply. In recent times, debates on health have moved through a variety of frames, ranging from the purely medical to protectionist to economic and, finally, human rights. In the light of the millennium development goals, health has been seen as a basic human right, with governments holding the responsibility to ensure that this right is guaranteed through appropriate service delivery and education systems. In evaluating the implementation of such policies, criteria that apply range, correspondingly, across these same dimensions. Ethics has usually been taken for granted and only rarely been explicitly considered in both framing and implementing public health programmes, and even less so in evaluating them. In the past decade, some scholars have focused on the need to develop ethics frameworks for building and evaluating public health policies and programmes, but few look specifically at the context of developing countries. As Kass (whose framework is discussed in more detail here) notes: "it is in great part because...power is vested in public health by law that a code or framework of ethics designed specifically for public health is so very important" (1:1777).

This paper outlines ways of looking at public health programs and activities through an ethical framework, and applies one such framework to evaluating an eye health programme in India. In doing so, the authors seek to understand the utility of this existing framework and suggest modifications that might better suit ethical scrutiny of such programmes in developing countries.

## Situating ethics in public health

Several scholars from diverse fields have discussed the ethics of public health, contrasting these frameworks with the more established approaches to making ethical care decisions in clinical practice. Turoldo (2: 1197) notes that bioethics has "been...concerned with the relationship between doctor and patient in a clinical context or, alternatively, with the rights of individuals involved in biomedical research." The clinician-patient dyad is governed by similar social principles as other human interactions. The guiding principles that frame the work of individual doctors in private or government practice include such aspects as honesty, transparency and appropriateness of care, apart from a focus on providing the best possible care in a manner that best suits a particular patient. The variables that need to be considered are individual differences that could lead to differing expectations and experience in the clinic (3). Practitioners therefore are able to evaluate the ethicality of their actions and decisions within this dyadic space, as long as they are adequately informed and are mindful of the needs and expectations of the patient.

The movement of health work from the clinic to the community necessitates a shift or an expansion from principles that guide the underlying moral reasoning of medical practice, which are primarily based on notions of efficacy, respect for autonomy, beneficence and non-maleficence, to a larger framework that takes into account social and environmental concerns (4). These might include factors such as the precautionary principle, social cohesion and individual and community resilience. The degree and nature of accountability also differs between interactions with individuals and the larger group, whether a small bounded community or the population of a state. Emanuel and Emanuel (5) describe different models of accountability that may be applied to public health planning and evaluation based on professional, economic and political criteria.

While debates on ethical principles in public health are relatively recent, model frameworks have emerged that seem to offer ways of approaching the planning, monitoring and evaluation of programmes that are aimed at communities and larger populations. As Roberts notes, there is "good reason" to pursue ethical analysis in public health, as such an analysis may "promote the identity and function of public health, address some of the shortcomings of utilitarianism, and help to combat the threat that public health faces through lack of political will in many parts of the world." (6:1556). It is generally accepted that there is a need for a distinct set of principles-a framework as it were-that guide public health work, considering the larger implications and the associated responsibilities that such work carries. In addition, the distance separating the policymaker/planner from the implementer and, finally, the recipient community (in contrast to the closeness of the individual medical practitioner and his/her patient) necessitates a more rigorous approach to conceiving and running these programmes.

Ethicists and public health specialists have approached the question from different angles, making suggestions that range from a rationing approach (7) to one that balances private and public interests in a contextual manner (8). Other approaches to evaluation appeared to be more in the nature of justifications for public health activities, emphasising economic or productivity losses and gains (using outcome measures such as disability adjusted life years or quality adjusted life years). It is our position that, given that public health is in essence an activity based on a deep sense of morality, of acceptance that societies have a shared responsibility to ensure the health and well being of all, we cannot restrict our judgments of efficacy to narrow economic or social criteria. We need to include in our evaluations an ethical component as well. This ethical component must be clearly spelt out and integrated into, or become an addition to, existing evaluative criteria.

In seeking within the literature a framework that would help us evaluate the community eye health programmes run by L V Prasad Eye Institute, an eye health system that works across levels of care, from advanced tertiary to community, we identified two analytical approaches that appeared at first to be suitable. Both seemed to provide a broad frame while allowing the development of focused questions related to programme evaluation from an ethical standpoint. The first of these, described by March Roberts and Michael Reich in The Lancet (9), is based on a consideration of three philosophical approaches, utilitarianism, liberalism and communitarianism. The authors suggest that any ethical investigation of a programme must first select one of the three philosophical foundations and the ensuing analysis must proceed based on the assumptions generated by the selected approach. The three approaches, in their discussion, emanate from a consideration (or emphasis) on the consequences of policy (utilitarianism), the rights of individuals and groups (liberalism), and the structure and future of communities (communitarianism). They also extend the framework to take into account newer thinking in health ethics introduced by feminism (ethics of care) and postmodernism (relativism). While the approach suggested by Roberts and Reich is intellectually rich and promises to introduce rigour into discussions of ethics, it does not lay out an analytical framework that can be applied in a pragmatic fashion to a functioning programme. Hence we moved to the second framework, one developed by Nancy Kass and described in detail in the *American Journal of Public Health* (1).

The selected framework takes forward an approach initially suggested by Beauchamp and Childress in 1979 (1) and directs enquiry in six steps. Kass emphasises that the framework is not a code of practice but an analytical tool, "designed to help public health professionals consider the ethics implications of proposed interventions, policy proposals, research initiatives and programs." (1:1777). The framework moves through a close examination of goals, processes, burdens and benefits to looking at issues of fairness and sharing of costs and burdens. Clearly, all the questions are not evenly relevant to all types of public health interventions, and they will need to be applied with different levels of emphasis and detail. The six steps are outlined, and we apply them to an interrogation of L V Prasad Eye Institute's community interventions, which is described in the next section.

## The L V Prasad Eye health pyramid

L V Prasad Eye Institute (LVPEI) started as an advanced tertiary centre in 1986 with the vision of creating excellent and equitable eye care systems for all those in need, regardless of ability to pay. It soon became clear that a significant number of socio-economically disadvantaged patients came from rural areas, travelling long distances to obtain free eye care. Despite LVPEI making high quality care available at no cost to the poor, it was still not reaching people in remote rural areas, for whom travel to the city was expensive and difficult.

In the early 1990s outreach activities in eye health were synonymous with cataract and screening camps. Many eye care organisations used this as their main community outreach strategy. Despite the popularity of this approach, a study from rural south India revealed that a high proportion of persons who could benefit from attending the outreach services did not participate in the services (10). Moreover, this approach did not ensure follow-up at an individual or even community level. This led to the idea that a permanent facility located within reach of communities would be more likely to provide accessible care on a continuous basis.

Supporting this idea is the fact that all the barriers reported in the literature for utilisation of eye care services may be grouped into three major categories: accessibility, affordability and availability (11-13).

Reliable population-based epidemiologic data regarding vision and ocular morbidity, as well as those related to people's perceptions about visual impairment and eye care, are very important to establish service delivery systems that address needs in a relevant and efficient manner. The Andhra Pradesh Eye Disease Study was designed and carried out by LVPEI in order to gain an understanding of the eye disease burden in the state's population (14). The study showed a high prevalence of blindness in the rural areas of Andhra Pradesh, at 2.4 %; nearly 80% of this blindness was treatable or preventable (15).

Based on understanding gained from this study, LVPEI planned its rural outreach programme, beginning with the establishment of secondary level eye facilities in rural areas. These centres, staffed by an ophthalmologist and support staff, would primarily address the major causes of blindness such as cataract and refractive error and identify other potentially blinding conditions such as glaucoma and retinopathies for which referral could be provided to the tertiary centre. After a few years of service it was realised that refractive error correction was the greatest need in the communities. Data published by the World Health Organization and others also revealed that uncorrected refractive error was the leading cause of avoidable blindness in developing countries (16-18).

LVPEI realised that uncorrected refractive error, among other things, could be effectively addressed by a para-medical worker trained in refraction and basic eye screening. This led to the development of a special cadre of technicians dubbed "vision technicians". Subsequently LVPEI set up primary eye care centres called Vision Centres, within a 50 km radius of the secondary centres. Each vision centre serves a cluster of 10-12 villages and uses community volunteers who raise awareness, conduct door-to-door screening and refer all those who require eye care services to the vision centres. At the primary level screening is done to identify all potentially blinding conditions and refraction and spectacle services are offered. Only those who require further attention are referred to the secondary level for further treatment.

The evolution of the pyramidal model took over two decades and each tier was added based on an identified need. The secondary centre along with a complement of 10 vision centres together make up what is called the "Village Vision Complex", serving the needs of more than 100 villages. The impact of this model is assessed every five years through rapid assessment surveys to determine changes in the prevalence rates and level of service uptake by communities. The most recent survey reports showed a significant reduction in the visual impairment in the service areas in the last 10 years (19), apart from establishing the cost-effectiveness of such community-oriented permanent facilities (20).

LVPEI has continually expanded its capacity to meet the emerging needs of the communities with which it works. Currently the rural centres are beginning to look at diabetic retinopathy, glaucoma and children's eye health. Awareness and screening programmes are organised to screen high-risk groups in the villages so as to offer interventions at an early stage to prevent or reduce blindness due to these conditions.

In summary, the LVPEI approach to public health has been largely reactive, with the design and implementation of the system following experience in the field. While this has ensured that needs that surface are addressed as quickly and efficiently as possible, it has not allowed for a reflective space that might more critically consider aspects outside what may be immediate and obvious. As such, ethics is one of those dimensions that is too easily assumed but not actively and consciously examined.

## Turning an ethical lens on the LVPEI model

In applying Nancy Kass' suggested framework to an ethical examination of the LV Prasad Eye Health Pyramid, we have confined ourselves to the six main questions she raises. Each of these questions throws up several sub-points to be addressed, and some are relevant to the activities and intentions of the eye health interventions, others not. We begin by examining the LVPEI model along these six dimensions, as exhaustively as possible, and go on identify additional dimensions of analysis not included in Kass' model. We conclude by offering an expanded framework for ethical analysis that might be more suitable for building a public health ethics for developing country contexts.

### *1. What are the public health goals of the proposed programme?*

According to Kass, the goals of a public health programme cannot be articulated in terms of simple numerical targets from a provider's standpoint, but must define the desired outcomes in terms of reduction of morbidity and mortality. Furthermore, Kass notes that community development outcomes of public health programmes must not be incidental to the programme but must be part of the plan.

The LVPEI Eye Health Pyramid has as its broad single goal: the reduction of the prevalence of avoidable blindness in the targeted areas (as opposed to "reaching a certain number of people"). This means that all activities under the rubric of community eye health are designed not only to screen and treat a certain number of individuals, but also to ensure that interventions result in sight restoration or prevention of vision loss. Going further, curative and preventive programmes are supplemented by rehabilitation programmes for those whose vision loss can neither be cured nor managed. One of the key factors responsible for leading to this approach is that the institute's community health interventions were based on data from an epidemiological study (14). This study provided inputs to a focused, outcome-oriented community eye health plan. Further, while the Andhra Pradesh Eye Disease Study provided "big picture" data, ongoing studies to check progress and other emerging issues have pointed us toward more targeted interventions, for instance focused on children, and persons with chronic conditions (diabetes).

A second goal of LVPEI's interventions is to improve access to quality eye care among marginalised rural and urban populations-access defined both in terms of reach and cost.

In terms of community development indicators such as greater employment, LVPEI's interventions address this in two ways. One, staff for rural centres are drawn from the local community and two, those who have had sight-restoring or sight-enhancing treatment now have access to greater employment opportunities.

### *2. How effective is the programme in achieving its stated goals?*

Success of our programmes is measured in two main ways: (1) number of people who have been able to access the services, either in the community or at the hospital/clinic and (2) number of people who have made use of services. More recently, the second parameter has been modified to include the number of sight-restoring surgeries. There is an ongoing system to monitor these goals, with cataract surgical rates, the number of door-to- door screening programmes conducted, and the number of spectacles distributed or number of patients referred. In terms of increasing access to eye care services, LVPEI's goals have been achieved by locating eye care centres in remote rural areas thus reaching populations that have so far been denied access to such services.

However, it is now becoming clear that for the model to be effective access is achieved not only in terms of reaching people where they are, nor only in referring to appropriate levels of care, but in ensuring that such care is available to them and that all barriers to access are addressed. Persons diagnosed in the community setting, with conditions that require care at the secondary or tertiary level, need to be supported in order to obtain care at those levels. In this aspect, the Pyramid has not been entirely effective. More needs to be done to ensure that people who travel from rural areas to the city or larger rural towns are supported through the process of accessing care. A public health programme cannot be said to have achieved its goals on objective measures and numerical outcomes alone; it must have built into it accountability on "soft factors" particularly when dealing with vulnerable populations who are only now beginning to understand their rights of access to such services.

Kass raises issues of data adequacy and completeness, suggesting that programmes should be based on hard data. We feel that often needs arise that cannot be substantiated by data, or that do not correspond in a strictly linear fashion to resource allocation. Data on outcomes and impact may also not always justify the continuation of a programme while soft factors (such as improving awareness and healthcare-seeking behaviour) may in fact do so. Notions of sustainability therefore need to be expanded so that programmes are not judged on hard data alone. Kass does not comment on this aspect of public health programmes.

### *3. What are the known or potential burdens of the programme?*

In this step, Kass recommends a careful evaluation of burdens and risks to the populations that are targeted by the intervention, including risks attached to privacy and confidentiality issues, those arising from reporting conventions, distribution of resources, and justice/self-determination.

With the LVPEI community eye health interventions, the question that always arises is: do we emphasise eye care over general healthcare? How do we talk about eye care when even basic primary health is not available to the population we are dealing with? Our rural programmes are mindful of this conflict, and address the issue by ensuring that we have linkages with other organisations that can help with general healthcare and with conditions not addressed by our own work.

Cultural and tradition-based conflicts are minimised by having community workers drawn from the targeted groups, and surveillance measures are taken in an atmosphere of caring rather than blame.

Health education and promotion is an essential part of all community programmes, aiming to reduce the disease burden proactively rather than reactively.

One realisation that has come about (and a criticism that is made of such interventions in general) is that learning that happens at the community level is rarely fed back into policy making at higher levels. LVPEI's community level work has generated a certain sense of what systemic changes can help reduce the burden of diseases, but little advocacy has been undertaken to feed this back into national or state level policy in eye health.

### *4. Can the burdens be minimised? Are there alternative approaches?*

The questions raised by Kass force one to look closely at the burdens imposed on potential beneficiaries as a result of a new programme being introduced. Are there invisible costs to the community that need to be weighed and addressed before going ahead with an intervention? Have planners and implementers sufficiently considered all the alternatives before settling on the most appropriate choice?

The LVPEI model was evolved after previous approaches were found to be inadequate in terms of meeting both stated and presumed community needs and perceptions. The alternatives that existed earlier-the camp surgical and screening approaches-had not succeeded in ensuring either reach or quality of service to communities in need. The Vision Centre model therefore can be said to place the least burden on communities in terms of direct and indirect costs of accessing and availing of eye care. This question does, however, force an ongoing consideration of burdens imposed on beneficiaries as a result of the programme's existence.

### *5. Is the programme implemented fairly?*

Kass points to concerns such as fair distribution of services, the extent of responsibility taken by the programme implementers to help create better living conditions and access to broader social services and facilities (housing, sanitation, etc.). The LVPEI programmes in rural areas are made available free of cost, and are available to all, regardless of ability to pay. In design, they are also sensitive to differences of social standing and issues of caste and gender. In fact, they have succeeded in reaching more women and children than have previous interventions. As compared to the camp approach, where eye care professionals were taken into the community and services provided for a fixed period of time, the permanent set-up created by the LVPEI network allows a measure of familiarity with both the provider as well as the system. This is expected to encourage more disadvantaged communities to make use of the facility, as there are no constraints of time or seasonality.

The vision technician (VT) is expected to build a relationship with other community service providers to become an advocate for development in several areas, though this is not a key requirement of his or her work. We recognise that the VT has the potential to become a community development advocate. However, this is not consciously integrated into the programme or the training.

### *6. Are the benefits and burdens of a programme fairly balanced?*

This dimension of ethics has to do with the level to which the identified burdens are distributed across the community, whether attempts have been made to minimise them and whether the expected benefits justify these burdens. In applying this stage of analysis to the LVPEI model, we find that with eye care, in the way it is practised within the model, there are no burdens that fall upon the community. If one considers such factors as location and planning of screening programmes as potential burdens, then the following issues may require to be accounted for:

- Level of access to services because of specific location-is the clinic equally accessible to all sections of society (within reasonable limits)?Do the timings take into account the work cycle and living patterns of all cultural and social groups in the village? The answer to both these questions would be in the affirmative. Although LVPEI vision centres are determined based on a combination of donor availability and suitability for the purpose of eye care, their location so far has been convenient to the community at large. Also, the working hours keep in mind the rhythm of life in the village.
- Screening programmes are timed to suit community needs: door-to-door surveys are done early in the morning and late in the evening so that a maximum number of family members are present in the home. School screening programmes are scheduled so as to not conflict with high-pressure points in the school calendar, thus avoiding or minimising the burden on participating school teachers, administrators and children.

We have found through our continuous monitoring that the benefits accrued so far have been evenly distributed across the community, and particularly favour those groups hitherto not reached by health care programmes.

## The framework and the model: ethical enough?

Overall, the LVPEI system appears to score quite well when looked at through the framework of ethics. It is able to answer to all the six dimensions of analysis, making it clear that the assumptions of the plan were in fact ethical, even though these were not explicitly built into the planning process. However, the analysis also makes clear that we need to go beyond the assumptions if the programme is to answer all ethical considerations in a rigorous manner. The framework proposed by Kass allows the LVPEI model to emerge with a high score, but also throws up some gaps-both in the ethical framework and in the eye care model.

The six dimensions or steps of analysis offer an extremely detailed framework, but there are significant overlaps and redundancies, as also significant gaps. When the model-which assumes relevance across specialisations-is overlaid on a specific area of healthcare, it would seem that the model does not offer enough flexibility across health scenarios, being more suited to more general healthcare interventions such as sanitation, maternal and child health and, perhaps, communicable diseases. Eye care represents a very small piece of the public health puzzle, and is relatively simpler, though not without areas of ethical concern. In fact, its assumed simplicity and straightforwardness keep us from seeing the possible ethical concerns, and to that extent the model is certainly useful in making them explicit.

The specific gaps that strike us following this analysis are:

- The model offers no guidance on stakeholder identification. This is a necessary first step in order to determine the fairness of distribution of benefits and burdens of a programme;
- The questions are too focused on data-based outcomes but do not sufficiently point to quality and other soft factors that are often implicated in project success and ethical functioning; and
- There is no way to identify inter-sectoral connections and their strength-the lack of such cross sectoral cooperation is often a failing of public health programmes.

We find that certain additional criteria could be applied to the ethical analysis of public health service programmes:

- quality;
- continuity of care;
- identifying and defining stakeholders;
- sustainability;
- non-competition and collaboration

The framework suggested by Kass is certainly exhaustive; but could be expanded with these additional criteria and reorganised as a series of shorter, more pointed questions to allow for greater applicability across health care contexts. We suggest a revised framework incorporating these additional criteria, presented as a list of questions to be addressed during the planning and again during the evaluative phase of a public health programme. This revised framework, which admittedly draws greatly from Kass' original work, is presented in the Table.

## Conclusion

Public health is an area of activity that impinges directly on people's lives and well being. While it is in essence a morally driven activity, it could benefit greatly by an explicit consideration of ethics in the planning, implementation and evaluation phases. Medical practice has for long had a tradition of ethical inquiry, and its practitioners and policy makers are routinely schooled in its ethical traditions. The same cannot be said of public health practice. In recent years, ethicists and public health researchers have debated various frameworks that could be applied to the planning and practice of public health. In this paper, we have reviewed one such framework and have applied it to the public health programme in eye health. We found the framework useful in a preliminary ethical analysis of the L V Prasad Eye Health Pyramid. However, our analysis made evident several ethical concerns that were not addressed by the framework under consideration. We therefore suggest an amended framework that incorporates several additional questions that public health planners and programme managers can incorporate as evaluative criteria in ethical analysis of programmes. The expanded framework includes issues related to responsibility, accountability, quality, stakeholder analysis and sustainability, all of which are important analytical categories in evaluating programmes aimed at creating healthy communities.

**Table: A suggested framework for ethical analysis of public health programmes**

| **Suggested criteria for an ethical evaluation for public health programmes** | **Points present in the Kass framework** |
|---|---|
| *Issues of responsibility*<br>* How is responsibility for the programme and its outcomes distributed?<br>* How is authority for the programme and control its outcomes distributed? | No |
| *Who are the stakeholders in the programme?*<br>* Identify by group<br>* List involvement type | Not explicit, implied |
| *What are the benefits of the programme?*<br>* Economic<br>* Social<br>* Cultural | Yes |
| *How are these benefits distributed?*<br>* Across gender<br>* Across social groups<br>* Across economic classes<br>* Across cultural categories | Yes |
| *What are the risks of the programme?*<br>How are they distributed? | Yes |
| *How accessible is the service or the facility?*<br>* Location<br>* Social barriers<br>* Cost | Not explicit, subsumed under burdens |
| *What is the type and level of accountability of programme implementers?*<br>* To community<br>* To other stakeholders<br>* To internal groups | Not explicit |
| *What measures of quality will be applied and why?*[1]<br>* Qualitative measures<br>* Quantitative measures | Not explicit |
| *What measures are taken to ensure programme continuity?* | Not explicit |
| *How are the following patient/beneficiary factors provided for?*<br>* Freedom of choice<br>* Privacy and confidentiality<br>* Cultural and social aspects | Yes |
| * Measure of impact<br>* Economic<br>* Social<br>* Health outcomes<br>* Policy | Yes |
| *How is sustainability built in?*<br>* Programme level<br>* Staffing<br>* Financial<br>* Other (programme-specific factors) | No |

[1] *The "why" is the specific ethical dimension here, to ensure that measures of quality are those that are not only universally acceptable but that they have specific relevance to the program under review.*

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# Impact of UNCRPD on the status of persons with disabilities

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## Abstract

*The sanctity of human life is a fundamental human value and the medical profession has been ethically charged with respecting and enhancing the value of all human beings' lives. However, disability-selective abortion has been perceived as an acceptable health intervention to eliminate disabilities, and is provided for in law as well as in policies and healthcare programmes related to disability. Advanced medical technologies are being utilised not to maximise the lives of persons with disabilities but to prevent the birth of disabled people by medically terminating foetuses diagnosed with disability. Evidently, disability is seen as undesirable per se by society, and life with disability as not worth living.*

*The disability rights perspective argues that such laws, policies and programmes deny persons with disabilities the right to life and thereby discriminate against them. They violate the United Nations Convention on the Rights of Persons with Disabilities that recognises the inherent human dignity of all human beings and treats persons with disabilities on an equal basis with all other human beings.*

*This paper examines the question of whether disability-selective abortion as a prevention strategy diminishes the value of persons with disabilities, in the context of the right to life and dignity of life accorded by the UNCRPD to persons with disabilities. This is discussed in the context of a selected summary of international and Indian policy and law on this subject.*

## Introduction

The sanctity of human life is a fundamental human value recognised by all societies, their social institutions and legal systems. The medical profession is one such social institution which has been ethically charged with respecting and enhancing the value of life of all human beings. It is assumed that the ethics of protection or preservation of human life should be applied equally to all without discrimination. Healthcare interventions are intended to promote the health of human beings and thereby to protect human life.

Yet in the healthcare system's approach to disability, disability-selective abortion is perceived as an acceptable health intervention. Laws, health policies, and healthcare programmes focus on the strategy of prevention of disability through prenatal diagnosis and disability-selective termination of pregnancy. Healthcare programmes related to prenatal care have routinised prenatal screening for foetuses with disabilities. The law has sanctioned its use and the subsequent termination of such foetuses. This unquestioned acceptance of disability-