Public bioethics: a proposal

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Abstract

Public bioethics: a proposal

Bioethics is at risk to become an academic discipline unconnected to yearns of citizenship, which is of particular concern in less developed regions lagging behind due to the impact of globalization, social and economic inequities, scarcity of resources, and lack of public policies to protect suitably people. This article proposes a public bioethics approach to public health problems, medical care, biomedical research, and environmental issues, and safekeeping private sphere by biopolitics colonization. This paper suggests the development of a public bioethics based on four pillars: comprehensive social participation, democratic deliberation, development of protective ethics aimed at empowering citizenship, and structured pragmatism proposal yielding structures and programs targeted to meet community's needs, as well as the empowerment of excluded, channeling these actions through the establishment of strong national bioethics commissions.

Key words: Bioethics. Public participation. Social inequity



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Critics of bioethics realized conceptual rigidy, thematic insufficiencies, and perspective narrowness 1, claiming for the need to revise its fundaments and to change its perspectives under penalty of seeing it turning into applied ethics lacking social meaning ^{2,3}. Los(Bio)ethics principles necessarily fail in providing solution to practical dilemmas, while anymore possible achieve consensus...silencing the reasonably moral and debate4. Voices like those of Castoriadis, Maldonado, and others consider that bioethics has diverted in punctual problems intricacies at cost of not attending major conflicts of a humanity submersed in iniquities, marginalization, social and ecological non-adaption ^{5,6}. These critics suggest that biopolitics provides a more suitable view for the social dimension of bioethical issues. but they do not consider the inherent risks of colonization of private space from a biopolitics that historically has been more destructive than affirmative 7.

Biopolitics reflections shown in English languagespeaking publications that go to the extreme of tolerating and even justifying holy wars and acts of social applications of genetics, of the neuroscience, and of political movements that stimulated academic nanotechnology ⁹ despite its inequity potential and thought of the region, but whose presentation depriving neglected diseases¹⁰ resources. Ethical surveillance instruments of research proposals own to our region, such as the ethics with humans like Helsinki Declaration are stripped of of liberation, the bioethics of protection or normative strength and discredited as irrelevant¹¹. The bioethics interwoven in human rights, all bioethical discipline requires reinforcement and presented to some extent in the 'Diccionario strengthened against these attempts of diverting ethical Latinoamericano de Bioética' (Latin American language, and seeing it re placed by a biopolitical Dictionary of Bioethics) 14, did not achieve to utilitarianism that threatens above all precarious enter the international debate. developing countries.

If bioethics understood as reflections on human bioethical deliberation in accordance acts, carried out in freedom and responsibility, in with the autochthonous culture, and function of its contribution to harmonic adaptation pertaining to issues that concern our of human being to its social and natural societies. It is a priority to develop own environment, the need of a greater compliance of the stance in face of the social evils that afflict our discipline remains in need, bringing it closer to citizenship problems of social relevance and focusing its attention inequities, toward less developed world 12,13.

On Latin American bioethics

evolution of bioethics generates special concern cultural colonization, conservative morality, because it hides and justifies damages and ill- considering that interpretation of certain values practices that marginalized and powerless and norms depend on cultural beliefs, and populations are submitted, on the grounds of a modifying the level of changes in social debate monopolized by Developed World circumstances, political and economic, including academics, which grants scarce space for the availability of resources¹⁵. dissenting voices who try to expose and deliberate on problems and yearns of poorer nations.

torture *, as well as to celebrate the achievements and There is, certainly, wealthy history of social and of required exceeds the limits of current work. Bioethical

It is urgent to fulfill the regional task guiding and cause deep sanitary which are the cause and consequences of weakness and disempowerment. It is equally unpostponable to reinforce own language in face of our ecological reality, harmed by several factors with historical prevalence - economic From a Latin American perspective, the uncritical dependence, social segmentation in classes,

> Immersed in historical vicissitudes, social turmoil, ethnical tensions, as well as economic dependence and bankruptcy, the region is in permanent seek of a significant ethics to respond promptly to moral

conflicts of people and life communities in Latin relevance in its concern with the reality of our America 16. Biomedical research, techno-population. Immersion in the social reality is scientific transfer, knowledge management precisely what academic bioethics has not and mercantilization, professional formation served, having limited itself in the empirical to and brain losses, are just few issues that lighten the origin and validity of ethical yearns require agreements more than sterile and uncertainties of the social practice within polemics. Latin American bioethics has as biomedical scope 19,20. task to defend the autochthonous and prepare a armor against every colonizing This text intends to introduce in the debate attempt, including the academic, for which the notion of public bioethics, based in a perspective new perspectives must be developed.

To bioethics will not be certainly, an hegemonic role in this citizenship as are the community bioethics and social project of existence, nevertheless, that based in common morality, which received it must fulfill its builder's task that attention only marginally. A summary of these contributes to the soundness of the initiatives shows how a gap persists to be building, in consonance with some filled between bioethics as discipline and the attempts to develop a regional ethical fulfillment of its social relevance. discourse. The danger for an applied ethics is to fall into the instrumentalism that characterizes pragmatic Community bioethics and common bioethics, which provides prima facie principles aiming at **morality** creating decisional trees with algorithm features, which arises special interest to approach techno-scientific Community ethics developed itself in the issues, but attending to socially more relevant issues only 20th Century as a response to large marginally, such as sanitary rights, the role of the State in migratory currents that, by inserting providing social services, particularly in health themselves in societies that shelter them, sector, the search for therapeutical agents for endemic attempt to assimilate without losing their diseases, and accessibility to medicines 17,18.

as shown by its deplorable Gini index, understanding feature, it may not represent the entire civil that bioethics gets closer to sociology to recover

similar to that developed in the social sciences under the title of public sociology. There are few granted, initiatives to develop an applied closer to

cultural fitness, avoiding dissolutive assimilation, as well as marginalizing Socioeconomic inequity characterizes Latin America discrimination. Given its focal and local society as it has a guiding north to safeguard its own idiosyncrasy without harming the governing culture, values and moral 21.

In its turn, to highlight the relevance of common These digressions, as polemic theoretical moral is an ethical proposal that has been subjects of the academia, make common moral understood very diversely. Every human a corpus of precepts invariable for some, being shares, from its socialization and contextual and socially constructed for others, opening based in moral disposition²², transcendental ethics understood necessary condition to begin communication and action 23. People have Public Sociology some fundamental perspectives, which Ch. Taylor designates as the horizons of meaning, M. Burawoy's proposes, in his Presidential which provide meaning and coherence to its Message read ethical stances ²⁴. Of ethics, one speaks Association of Sociology, in 2004, the return from a stance, not from a void, and this toward a public sociology engaged in stance is given through which, from turning public issues of our private tradition. and history, circumstances of a society, structures decolonization of the private space and the companionship, the meaning of the recovery of its limits in face of the pertaining and the will of cohesion or public space²⁹. Private concerns transcend change 25.

philosophers, is inherent to every human in life in relation to abortion, the Alcoholic as much a gregarian, is invariable, and has Anonymous, the association that defend as basis to maintain the moral principle of minorities. These groupings lead to a fragile not harming 26. The common moral, for others, is existence, threatened to be destroyed by the an initial proposal susceptible to be changed because market, colonized by the means, hindrance d every ethical proposal, as fundamental as it may be, by bureaucracy 30. has to undergo justification and compatibilization with other equally valid perspectives 27. The relationship of Public sociology presents itself as a complementary common moral, expressed in specific moral way to develop discipline, along with other three convictions or intuitions, with ethical theories is more traditional variants: professional sociology, analyzed through the philosophical ethics and, policy sociology, and critical sociology. One perhaps, particularly by bioethics²⁸. In this sense, tends to differentiate descriptive sociology principialism changed its approach, from adopting the language of the prima facie distinguished by the philosophical postulate – that may be validly questioned speech for proposing its normative by other postulate – and presented with idealism... within specific contexts, which avoids pro tanto feature, that is valid within a given scope and circumstances.

a the door for doubts on what is identified as common as really is attaining to yearning of citizenship.

before the American the tribulations, to understood be social area by seeking recognition and support, yielding public groups around a common This common moral, according some interest, as movements like pro choice and pro

> the prescriptive, this later

descriptive speech 31. The distinction questioning, and sociology of bioethics that relies between sociology for sociologists and public in ethics to unravel sociological issues 35. sociology for non-sociologists, although not Sociology collects empirical data on beliefs exempt of criticism 32, is also comfortably and values given in society, providing extrapolated to bioethics, in search of a evidences that become part in formation of contribution to renews and correct some moral opinions 36. To make reflections on deficiencies in current bioethical speech, bioethical issues from a macro-sociological providing a questioning proposed synthetically and sociopolitical standpoint has been by the question: to whom does bioethics undertaken by global bioethics, with a speech speak?

Sociology and bioethics

Current literature spreads many bridges conflicts 37. In its turn, nations requesting between sociology and [bio]ethics. Dew external aid are concerned in how these proposes an observation of Durkheim's thought that programs threaten their autonomy and saw biology as having as goal its practical effect on autochthonous 38,39. medicine and therapeutics...sociology having similar goal in its practical effects on society 33. From this, Toward a public bioethics the author sees contemporary public health as replacing religion in the role of organic social Similarly to sociology, it is possible to detect solidarity through its concern with social inequities, four ways to develop the bioethics discipline: sanitary behaviors, and populational health a) The academic turn around of perspective that shall influence over social health bioethics, which yielded criticism both and disease determinants, inclusively on clinical by the recurrent sterility of its speech practice in terms of justice and equity. The and by its excessive dedication to evaluation of sanitary impacts presents one of public issues of scarce social relevance, sociology applications, producing texts where provoking the suggestion of replacing closeness with bioethics in undeniable 34.

Sociologists interested in the interaction of their epistemological instrumental stance, including to sodiscipline with bioethics have stressed the called experts in bioethics requested in advisory to difference between sociology in bioethics, which

updating a decontextualized and universal utilizes the social science to answer bioethical that remained just as mere proclamation, recognizing itself as impotent to face holistically the circumstances disadvantaged nations and their many social

bioethics by biopolitical perspective; b) The professional bioethics, which adopts an the legislative power, testimonies given in legal suits, participation in committees, and evaluation of programs, documents, or teaching plans; c) Critical bioethics also exercised in academic grounds, where nourishes discussions, for

example, on the validity of several principles in of what could be designated as public face of neo-fortuitism, or ethical normative that bioethics, whose development must be should govern bioethics in research with humans; synergetic with the academic, professional, and d) As an applied ethics, bioethics cannot and critical ways mentioned above. In a stop keeping a close contact with real public ethics, it will be necessary to biomedical situations required to be deliberated, consider social reality, the values, and and with the necessities and interests of agents institutions of citizenship as empirical affected when involved procedures, clinical practices and education in coherent arguments and opinions health professions.

These tasks cannot be dealt with in the deductive mode from above – applying norms elaborated by the theory nor **Four components for a public** have had general acceptance in using the inductive method **bioethics** of empirical bioethics, which has the risk of falling into the naturalist fallacy by deriving a normative speech from the A. Sen states, in his writings, that a part that only description of governing moral stances in society. There there can be empowerment of people in the has been much discussion if bioethics should conditions of effective democracy, when the public develop the deductive mode from theory- top hand took needed measures to ensure primary down - or in inductive way, from the empirical goods for all. In his more recent work, where experience and socially governing moral Sen clearly recognizes that presented concept of convictions— bottom up — 40. Beauchamp's democracy proposal is that an applied ethics inevitably will emphasizes that representative democracy, is make eclectic use of both paths, exerting what defined by the voting and election acts, is the he designates coherentism, and which is the exercise of the public reason by free and most appropriated for a bioethics built from the equal people 42. Going beyond and recognizing conjunction of social reality and a moral that democracy has diverted into a elites deliberation.

The task of linking an ethical deliberation the deliberative democratic forms. bioethical reflection with a social reality that requires guidance and advisory in decision- The proposal to develop a public bioethics relies making would correspond to the exercise

research data that nourish deliberation, to develop relevance and quality about the collected empirical evidence 41.

comes from John Rawls. democracy as announced by Schumpeter, one should struggle for participative and

in four pillars that ensure its conceptual solvency and at the same time point to a strategy for its effective insertion amidst civil society: participation, deliberation, protection, and pragmatism.

Participation

kernel of deliberative democracy, it is not possible to rights - who are citizens - and the excluded forget how the attempts to convene civil society have who are the marginalized, the expelled, and been difficult, frustrating, and not fruitful. It has been the -. Secondly, it is indicated that confirmed from several perspectives that, by having humans are not equal or, better still, they scarce saying in the course of the public affairs, are while constituting a community but citizenship has lost the interest in the participative no while structured as society. Society instances and in manifesting through vote, preferring requires labor division, the distinction between alienation of politics, and turning back to private life and producing and controlling, the inequity that arises personal interests. Thus, the neoliberal stance is since labor now is recognized as source of assets reinforce based in classics like A. Smith and as measure of its value. Concluding, [S] and Tocqueville: well understood, the doctrine of equality is the community law, society own interest is the best moral theory of our times, belongs to inequality 45. such as points Hardin when he quotes Tocqueville in his article 43. Citizen's stagnation in If power differences and their popularization are private life and the display of professional inherent to every social order, it will be sterile to politics in public space constitute possibly a struggle for equality. And it should be sought an spontaneous evolution in developed countries, ethical way for tolerating power inequalities, but they are altogether inadequate for people requiring that the most powerful to protect the fragile, where inequity and disempowerment governs. at least in the path that the later will have to pursue Real citizen participation and civil society's in order to integrate society, and to project his life political strength need to be reinvented, and for others inside fair institutions 46. Thus, the strengthened, and by all means abandoned importance of a protection ethics replacing the under the pretext that a genuine democratic unattainable pursue of an unreal justice 47. participation is difficult to implement 44.

Protection

It is important to use two digression that increasingly more notorious and the socioeconomic derive, in their essence, from contemporary gaps are deeper, both inside societies and in the French thought, but whose seeds are global context. The mismatch between the rich and present already in previous writings by the poor increases, and the possibilities of a State Simone Weil and Hanna Arendt. It is pointed

that human rights speech is not absolutely universal, as it establishes a divergence By rectifying that citizen participation is the between those who effectively have claimable

Justice is a utopian ethical desideratum whose iterative proclamation attempts to hide that in all times, but more accentuated now, inequities are power that

equity is increasingly less probable toward citizenship. serves considering the governing economic and political globalization. Elster's idea, quoted by Miller, is Deliberation that the car of procedural justice should not be put before the horse of the substantive justice 48. Aristotle Several contemporary philosophers indicate that justice appropriate rational method for decision-making does not mean equality regarding distribution of economic unpostponable under uncertainty conditions, which resources, the important is from a moral perspective is not has been updated to exercise practical reason as the each has the same, but that each has enough 49. The most suitable way to solve bioethical issues and concept of justice remains empty without dilemmas whose feature is having empirical political strength while not specified and one information reflects, even if critically, on equalitarianism, Deliberation in ethics accepts both arguments justice in inequality, complex justice.

speech of empowerment and social support develops in However, this tolerance of intuitive arguments order to reduce special vulnerabilities - susceptibilities - have gone to extremes of allowing biased and to achieve that people develop competences to stands or based in dogmatic assertions that are structure their lives in freedom 50,51. In view of the not correctable by opposing ideas, the so-called difficulties in applying the definition and specifying a wisdom of repugnance or the reasons of the principle of justice that could inspire political action, it was heart is an example 52,53. Arguing with doxastic suggested to develop a bioethics based in an ethics of elements in complete lack of attention of protection that proposes empowering the destitute in order epistemic aspects and formal logic, bioethical to strengthen their presence and management capacity, argumentation becomes sterile because Allowing them to achieve the exercise of autonomy to where there is not contrasting elements by which every human being has the right. Autonomy free argumentative exchange, one loses the of social constraints is transcendental for capacity of the effective participation in the task of civil agreements. It is necessary to avoid false society. The empowerment under the guidance popularizations, hasted generalizations, to of an ethics of protection constitute the most make naturalist fallacies since, despite acceptable path to gain participation spaces

describes deliberation as the and axiological propositions. based in data and events – epistemic elements -, as judgment of values that incorporate Based in these uncertainties and discrepancies, the opinions and emotions - doxastic elements -. convincing presenting our argumentation as objective, it must be based in previous opinions, indoctrinated values and cultural presumptions...which could reinforce our prejudices by justifying them as substitute of reasons instead of developing a sound

Argumentation, valid and consistent regarding subordinated to the sovereign power, but involved moral values 54. It is necessary, in order to aimed at fomenting the common good bioethical deliberation be representative of social share by all. yearns and rationally convincing, to submit it to certain validation criteria own of a logic applied to Pragmatism ethics - that differs it from analytical logic 55 -,to develop sound arguments - coherent, Pragmatism, as the fourth element of a public proportioned, specific - but refutable and bioethics, stands out while a path to reach correctable 56.

Bioethics has two fundamental tasks in Crucial conviction of pragmatism is that public reasoning: a) to place in citizen agenda agreements require flexible, modifiable topics from the private space that attain to the postures and, therefore, free of unmovable world of people's life, which are been convictions and absolute principles 58, but a threatened by biopolitical violations of the floating pragmatism should be avoided, short of personal and intimate space of people; b) to principles and of all conceptual specificity. It is advise on the appropriate use of practical reasoning necessary to request a structured pragmatism, based in in order to deliberation respect the public non-common moral and from where it is possible to deliberate interference in the private realm, the plural also in structure way those issues that concern the validation of diversity, the respect of and by people, community and that require clarification in their unknown including the non-maleficence mandate in respect factors and advised in their indecisions 18. to the other, and related with the common good. All this should happen with equity in the exercise of Public bioethics contribution to parity participation of autonomy and in accessing the primary goods citizenship in the decisions that ordain and structure needed to develop each individual's life project. its society bases in education and in extension. B. Brecht had said it already, bread proceeds Bioethics shall be incorporated and spread moral and, in the present, equitable provision of in communication media and proclamation primary goods has to be assured at time of scenarios in search for shelter in the bioethical deliberation, a mandate in which political world, the legislative, in working protection seems more realistic than an utopia of benches, focal groups, associations and iustice.

The ultimate end of deliberation is to strengthen citizenship participation in the elaboration of public policies that are not

community agreements necessary for the fluidity and ethnicity of the social functioning 57.

diverse nature civil movements: programs against family violence, associations of the sick, of the disabled, of the excluded due to ethnical reasons. In the educational, bioethics should be brought

seek its insertion in the most primary mechanism of this type are explicitly considered in the levels of education: schools, capacity building institutional 59. programs, education of multipliers as are teachers, workers. and managers. initiatives are needed to introduce bioethics regarding bioethical issues were created in 1974 as school assignment and to establish a in the US with ad hoc feature and a specific basic curriculum in professional training. It agenda. These Commissions have been means institutionalizing bioethics teaching and to diversely draw programs of pedagogical action at the obscurantists and reason for polemic if they several levels of citizenship formation.

Objectives of the National Bioethics Commissions (NBC)

The pragmatic requirement of disciplinary flexibility, appropriateness. conceptual historical coherence, and social contingence are difficult to achieve through the political and social structures and institutions, currently governing in our western societies. In an opinion about the political scenery in Chile, but likely valid for other Latin American nations, one points that looked from institutions' perspective, what happens is that political parties are not capable today to comply fully with their traditional role articulating and aggregating social demands and represent them in the Parliament and before the Government...Perhaps the first step in this direction is the establishment of pre-legislative advisory commissions or pre-formation governmental initiatives with participation of all affected sectors or stakeholders in the respective topic, of politicians from diverse tendencies, delegations, and domestic and international experts that enjoy needed status and

down from the academic Olympus to accreditation. The moment may come when

Concrete The first Advisory Commissions to the President evaluated from pioneers fulfill their role of being a open forum at the service of a public bioethics 60. These controversies, and the strong politicization attributed to them, have prevented that Presidential Commissions to constitute a stable institution for bioethics deliberation.

> France was the first nation that understood the need of a permanent instance to develop a relevant and sound bioethical speech, inspired in rational deliberation, plural, socially outreaching, capable to develop an advisory disciplinarily sound, when it created the National Bioethics Advisory Committee, which acted as model for the establishment of the National Bioethics Commissions in over one hundred nations, and the functioning of Unesco Assisting Bioethics Commissions (ABC). The importance and actuality of the topic reflects in 'Ethically speaking', a periodical publication of the European Commission that provides information about the activities of the National Bioethics Commissions 61.

The NBC, by articulating the interaction of society with the public power that pays attention to its needs and worries, shall be

democratic participative desideratum according to the emancipating communicative reason, and the which legitimacy will proceed to legality. domination of private space by the public sphere 62. Comprised by a sufficient number of members to Macro-political forces such as globalization, ensure its multi-cultural and plurality, NBCs work the as a double funnel, open in one side toward civil market hegemony, and debilitation of the society, and in the other to the State. The national States are leading to where large double front features of a NBC has populational sectors live in insecurity, been characterized as its function of uncertainty, and non-protection 63. expertise in one hand, and its task of setting a deliberation agenda (agenda- Medical care, public health, ecology, and scientific setting) in the other. In the relationship policies issues are primary concerns of bioethics that between the Commission and civil society should leave the self-referencing shelter of academia. should prime education, consultation, and The proposal to develop a sound public the debate. The outcome of participative bioethics which, in analogy to public deliberation allows the NBCs to study and sociology, assist priory issues that interest design of clarifying documents that advise and affect civil society, does not mean not the formulation of public policies targeted attending rigorous academic reflection over to foment the common good aimed at those issues that required finish knowledge citizens' empowerment and emancipation, and normative accuracy: regulation of French NBC model, designating itself as such, works as a programming of minimum curricula both public bioethics instance that may be school, undergraduate, and for working nations where deliberative feature of their democracy is for health policies and programs, or to purify still too fragile and where bioethics is the market of medicine. This institutional measure principialists and doctrinaires convictions. original inspiration of been a bioethics for

understood as the assurance of the ethical and growing tension of double nature: colonization of entrepreneurial trans-nationalization,

> without research and management of Committees, the professionals, designing of specific arguments from bioethics should keep alert and turn to its pertinent agendas of public policies.

Final considerations

Bioethics vertiginous development has produced a hypertrophy of its academic features and a distancing from issues of the world of life that really concern citizens affected by a

Resumen

Bioética pública: una propuesta

La bioética se encuentra en riesgo de volverse un disciplina académica desligada de las inquietudes de la ciudadan a, lo cual es especialmente preocupante en regiones de desarrollo atrasado, por el impacto de la globalización, las inequidades socioeconómicas, la escasez de recursos, y la falta de políticas públicas que protejan adecuadamente a la población. Este artículo propone una bioética pública que aborde los problemas de salud pública, atención médica, investigación biomédica, ecología y resguardo del espacio privado de su colonización por la biopolítica. Se sugiere entroncar la bioética pública en 4 pilares: participación social amplia, deliberación democrática, desarrollo de una ética de protección que se proponga empoderar a la ciudadan a, y la propuesta de un pragmatismo estructurado que genere instancias y programas destinados a enfrentar las necesidades de la comunidad y a fomentar el empoderamiento de marginados y despose dos, canalizando estas acciones a través de la creación de robustas Comisiones Nacional de Bioética.

Palabras-clave: Bioética. Participación comunitaria. Inequidad social.

Resumo

Bioética pública: uma proposta

A bioética está em risco de tornar-se uma disciplina acadêmica desligada das inquietudes da cidadania, o que é especialmente preocupante nas regiões de desenvolvimento atrasado pelo impacto da globalização, nas iniquidades socioeconômicas, escassez de recursos e falta de políticas públicas que protejam adequadamente a população. Este artigo propõe uma bioética pública que aborde os problemas de saúde pública, atenção médica, pesquisa biomédica, ecologia e resguardo do espaço privado pela colonização biopolítica. Sugere-se embasar a bioética pública em quatro pilares: participação social ampla; deliberação democrática; desenvolvimento de uma ética de proteção que se proponha a empoderar a cidadania; e a proposta de um pragmatismo estruturado, que gere instâncias e programas destinados a enfrentar as necessidades da comunidade bem como fomentar o empoderamento dos excluídos, canalizando essas ações mediante a criação de comissões nacionais de bioética fortes.

Palavras-chave: Bioética. Participação comunitária. Iniquidade social.

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