

PUBLIC HEALTH GENETICS and SOCIAL JUSTICE



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Public Health Genetics and Social Justice

- „Justice is the first virtue of social institutions.”
(Rawls 1999)
 - Public Health = integration of genetics into Public Health
 - Public Health (Genetics) is performed by public or semi-public institutions
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- Public Health (Genetics) has to cope with justice



Task of Social Justice

- Against the background of scarce resources, **social justice** = claim toward social institutions to find a balance between liberty and equality while considering procedural fairness and the inviolable human dignity of every human being.



Content

1. Introduction
2. The right and the good
3. The Capabilities-approach in PHG
4. A justice based rule for the conflict: 'respect for autonomy' versus 'common welfare'



Preconditions for PHG

- The social accountability for technologies and procedures depends on different conditions
 - HTA
 - Ethical Criteria



The differentiation between the right and the good

- background: the modern society
- juridical and ethical norms = what people owe to each other as long as they want to live in peaceful coexistence
- ideas of goods = values and ends of individuals and societal groups



Ethical rules derived from the distinction between ‚right‘ and ‚good‘

- preference of the right over the good
- liberty is valid as long as it does not jeopardize the freedom of the other
- Obligations and prohibitions must be proven if they are not obviously prohibiting actions which endanger liberty
- the constraint of abuse is preferable to a general prohibition
- legitimacy of property
- recognition that the just conceptually and motivationally relies also on the good



Application of the differentiation to PHG

- also less effectual means cannot be impeded unless they are proven gross negligence, unfair competition or equitable fraud
- publicly accounted and recommended means of gene medicine can justly be questioned in terms of their performability, social acceptance and ethically or legal equitableness (Paul 2004)
- publicly promoted health literacy dealing with genetic information is of high ethical importance



The core criterion of social justice dealing with PHG

- In the framework of the constitutional state measures of PHG must be restricted to the necessary and the just of health care
- the necessary should be defined as a decent minimum (not a minimal minimum)
- Criteria that fail in applying social justice to PHG
 - utility
 - strict equality
 - equality of welfare
 - radical freedom



The key criterion of social justice dealing with PHG

- equality of opportunity
 - social structural view
 - brute luck view
 - with taken-for-granted-assumption (images of man)
- fair equality of opportunity only if enabling to real freedom
- key criterion: enabling people to live an integral, self-responsible life in order to take part in social communication (related to age or physical condition; respective to the social framework)
- capabilities-approach (A. Sen; M. Nussbaum; H. Pauer-Studer)



Supplementation by a network of just institutional elements

procedural
justice

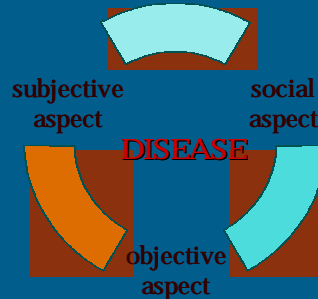
participation

compensational
justice

need

Formal
subject-oriented
criteria

1. sufferableness
2. urgency
3. influenceability
4. no closeness to consumption
5. effectiveness



Priority setting concerning
concepts of disease

1. All three aspects
2. Two, one of them the objective
3. Only the objective aspect
4. Subjective and social aspect
5. Only the subjective or the social aspect

justice
of efforts

semantical
transparency

efficiency
and
effectiveness

inter-
generational
justice

The key criterion of social justice dealing with PHG

- fair equality of opportunity = enabling to live a self-responsible life
- this implies
 - recognition
 - redistribution
- applying to PHG
 - recognition ⇒ vs. stigmatization and discrimination
 - genetic knowledge is special but not exceptional
 - redistribution ⇒ not widening health disparities



[Social justice in the likely conflict ,respect for autonomy' vs. ,common welfare'

- backgrounds: vs. free-rider-mentality; limited resources
- preconditions: HTA; efficiency, effectiveness
- rule: strong moral obligation if
 - avoiding serious diseases
 - promoting the individual development
 - avoiding high costs
 - not expecting social stigmatization
- weaker obligation if the criteria become less
- limitation to the moral sphere
- legal sphere = abandon a non-directive counseling



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Thank you for your attention!

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