

MPHP 439

Public Health Management & Policy

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Biosocial Citizenship:

Community Participation in Public Health

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November 30, 2009

Biosocial citizenship is a concept extrapolated based on two medical anthropology theoretical concepts, Rabinow's term of biosociality and Rose and Novas's term of biological citizenship. While human individuals are defined biologically by their specific phenotype and genotype characteristics, they are also defined socially through their own conceived sense of identity as well as the social interactions they are involved in. Biosocial citizenship refers to a special kind of defining the individual by taking into account the role of both biological and social features. Furthermore, biosocial citizenship addresses an individual's choice of group membership and the consequences of that choice.

Biological definitions of human individuals have historically focused on outer appearance: race and ethnicity are grouping categories based on such physical features. Another means to discern people based on their biology is to divide them into normal and abnormal groups: the healthy and the sick, the sane and the mentally ill. People can either self-identify as such, or be assigned to one of these groups through medical diagnosis. While the process of medical diagnosis aims to describe patients based on their conditions and hence suggests that health or sickness is a state of a person, health or sickness can also be regarded as social roles (Parsons, 1951).

Social definitions of people are descriptions such as your curriculum vitae or your MySpace profile. They are concerned with your place in your family, in your community, in your profession and in your culture. They have to do with how people describe themselves and with how they are described by others. Health condition becomes a social role when it affects social interaction. For example, a diabetic can have the disease but not be diagnosed. From the moment when the diabetic obtains this specific diagnosis, he or she is regarded differently in their social setting. Moreover, being a diabetic can become part of one's new sense of identity: a

diagnosed person may wish to associate with other diabetics. Groupings around a shared sickness are not new. Leper colonies and houses, for example, were widespread in the Middle Ages. In our age, however, new technologies allow people to communicate and connect at an unprecedented degree. Even people with rare conditions have the chance to relate to someone who shares their plight. Lepers in Middle Age Europe were severely marginalized. In contrast, today's citizens have the option to engage democratic governmental structures in order to advocate for better health care as well as raise social awareness of their condition in order to establish a positive and constructive social role for themselves.

Biosocial citizenship is about the role people play in their own health and sickness. It looks at how people take the way in which they are described by science and the medical system and transform that definition in order to negotiate their own identity. As will be related with the case of amyotrophic lateral sclerosis, this can be achieved by acting on the products of science: sponsoring new laboratory research and raising public awareness of one's condition can change the image that society has of an individual with the targeted sickness. Alternately, one can act to create a new social group, such as a disease-centered association.

Biosocial citizenship, like national citizenship, is something one is born into and at the same time something one has a choice about. Being at hereditary risk for cancer is not a choice; becoming involved in the cancer community is a matter of choice, will and commitment, or, to use a term to be addressed shortly, a matter of exacting one's agency. Also, like in the case of national citizenship, biosocial citizenship can be obtained by right of blood (having a physical condition or risk of disease) or right of soil (having a sustained interest in the condition). Family members and friends often associate with the disease group of their loved one.

The term of biosocial citizenship is highly relevant to public health. In discussing it, I will address how the concept responds to new challenges facing the efficient delivery of health care in a globalizing world. I will present the biological and social components involved in the framework of disease. Finally, I will how the politics of biosocial groups can inform health policy.

### **Globalization and public health**

The process of globalization is a major influence in all areas of human life nowadays. Concerted flows of people, goods and information travel across national borders and interact in the global sphere. What this unprecedented amount of networking and interaction creates is fast-paced change, change that concomitantly creates new possibilities and new risks to the human population of the globe. Such change is also reflected in the sphere of public health. Current advances in biomedical research and technologies positively affect the health outcomes of not only the citizens of countries where they occur, but also of the international community. This is made possible by increased communication and collaboration, which in turn allow for the more efficient and extensive applying of health care measures globally. On the other hand, the high mobility of pathogens across geographical borders has led to an increased risk from infectious disease (Lee 2002). Moreover, globalization is associated with growing urbanization in developing countries and added health risks due to industrial pollution, crowding, urban poverty and inequality (McMichael 2000).

New possibilities and new risks are continuously being crafted in the realm of public health. They stem not solely from epidemiologic risks and environmental exposure. They also have to do with changing human relationships and interactions. The community is a main locus

of globalization created change. More than ever, the field of public health needs to take note of how people act socially in order to better provide for their wellbeing. Public health is facing a complex challenge. It needs to turn its analytical gaze from studying a geographically bound population to working with an intermeshing global community. Variation at a population level can be studied through epidemiological and statistical means. Focal change at the level of the community, however, requires new study tools that can assess notions of social interrelatedness and agency.

The term of agency is central to the scope of this chapter. As employed in current medical anthropology literature, agency stands for the ability and capability of an individual to exert his or her free will. Agency entails the power to act on one's beliefs and achieve one's goals. As opposed to a passive bystander, the individual endowed with it is an agent of change. While traditionally public health involves action by health care agencies, institutions and policy makers on a population of receiving individuals, this role undergoes a partial reversal under the impact of globalization. Instead of being passive receivers of care and letting themselves be structured according to top-down policy goals, populations self-shape into risk communities and individuals enact action to improve their health according to their personal goals through a bottom-up approach to public health. This chapter explores theoretical models and applied concepts that reflect the need to focus public health towards community involvement in policy making.

### **Popular epidemiology and environmental risk**

One concept employed to address social agency in the crafting of public health epidemiology is that of popular epidemiology. The term was coined by the sociologist Phil

Brown as a result of his analysis of a community response to toxic waste induced disease in Woburn, Massachusetts (Brown, 1987). In the mid 1980s, residents of Woburn raised awareness to the fact that their children were suffering from leukemia at rates higher than previously perceived. The affected families polled together to link the cases of infantile leukemia to their drinking water supply and its contamination with industrial waste carcinogens.

Despite frequent complaints of local residents about the bad taste and bad odor of water, a well as documented high concentrations of organic compounds in local water wells, local and state officials dismissed the concerns of Woburn residents. Community efforts led by actors such as parents of leukemia-affected children and a local pastor, Reverend Bruce Young, reached the attention of the media and persuaded the City Council to request the CDC to investigate. The CDC report was inconclusive, but the media hype attracted the interest of scientists from The Harvard School of Public Health. Their study linked the incidence of leukemia to the consumption of water from two specific local wells. Later, investigations at local industrial sites revealed buried chemical wastes.

Woburn is a valuable example of how the concerted action of a lay community led to the communication of health risk to scientific experts and government officials. From this example, Woburn extrapolates the concept of popular epidemiology as: “the process by which laypersons gather statistics and other information and marshal the knowledge and resources of experts in order to understand the epidemiology of disease” (Brown 1987). Popular epidemiology does not only constitute gathering of data in order to explain the etiology of a condition. It also entails taking an active part in crafting the practices employed to deal with the condition. It involves social movements and challenging the assumptions of traditional epidemiology.

While the model of popular epidemiology is very useful in providing a path for community input into public health initiatives, its applicability is limited in a couple of ways. First, it is grounded in a definition of disease as a physical insult on the human body by a biological pathogen or a nocive environmental factor. While this definition is still current and accounts for a large amount of experienced disease, the modern definition of disease has been extended to include other deviations from health. Lack of health and disability have often been linked to social components. These, as well as the physical and biological contributors to disease, need to be addressed altogether. This aspect will be further detailed in the next section of this chapter.

A second limitation of popular epidemiology is its view of community as a spatially bound entity. Traditionally a community is defined as an interacting group of people sharing the same physical location and history. The effects of globalization on breaking geographical boundaries and fostering globe-spanning communication, coupled with recent advances in biomedical science, have led medical anthropology theorists to imagine new forms of communities: social groups assembling out of their own impetus, and not because they share a locality; social groups forming a coalition according to common interests and goals; communities creating together a group identity based on their shared biological and health attributes, as opposed to their common historical heritage, culture or nationality. Later in the course of this paper I will explore two new concepts of community - biosociality and biological citizenship - which follow from these ideas. Not only have they been theorized, but they have also been shown to take shape and occur around the world as predicted.

### **Biological and social factors in disease**

Scientifically, public health thinking and problem solving approaches have derived from an epidemiological model. This model is based on the tripartite agent-host-environment paradigm and on a biomedical definition of disease.

The widely accepted definition in the domain of public health equates disease to a physiological dysfunction of the human body. Brown (1996) debates the question of what disease is and how to unambiguously assert what disease implies. First of all, disease is a failure of normal bodily functions and a departure from the state of health. Moreover, disease could imply an abnormal variation in the structure or function of any part of the body (Anderson 1985 in Brown 1996) This would translate as any sort of handicap or disability. At the level of a specific afflicted individual, disease can be observed as a static state. When moving from the level of the individual to an ecological perspective, disease and its causation can be perceived as an interactive process between a host and an environmental insult such as a pathogen. Put into an evolutionary biology frame of thinking, disease is “very simply that alteration of living tissues that jeopardized their survival in their environment” (Jaques May 1958 in Brown 1996). The agent-host-environment paradigm highlights the interactions between an agent of infection that causes pathological alterations in its human host and the physical environment in which agent and host are brought together.

Disease involves a departure from the state of health. Another fundamental epistemological issue in public health is how to define health itself. Health could be seen merely as absence of disease. That however is not a sufficient characterization of this particular state and also makes for a tautological definition of both health and disease. A refinement of the previous statement concerning health would be that it represents an absence of infection, handicap or

disability. Still, in today's world absence of infection does not equate good health. The World Health Organization developed a holistic definition of health that goes as follows:

“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”<sup>1</sup>

It is the goal of achieving health as a state of well-being that calls into attention a key factor missing from the agent-host-environment paradigm. Bodily, but also mental and social wellbeing can not be obtained and maintained without a significant contribution of the human social environment.

Two public health theorists, Schwab and Syme (1997), challenge the old epidemiological paradigm and call for an integration of the social dimension of the human environment in a successful public health approach to health. They believe that a new paradigm has developed in public health, a paradigm characterized on one hand by a socio-ecological, or population level approach, and on the other hand by community participation. They argue that community participation challenges the objective, yet reductive truths of science and brings forth the own truths of the community, which are intertwined with social factors. Crowley and Hunter 2005 support this position and advocate for putting back the public in public health.

This position centered on social factors and community involvement has been championed in theoretical developments in anthropology. The eminent anthropologist and physician Arthur Kleinman speaks of the notion hinted at in the above paragraph of local truths and local biologies, shaped and determined by particular networks of social relations and of cultural meanings (Kleinman 1997). In public health literature as well it has been more recently

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<sup>1</sup> <http://www.who.int/about/definition/en/print.html>

recognized that “the social environment is associated with disease and mortality risks, independent of individual risk factors.” (Yen and Syme 1999). An ecosocial framework for epidemiologic theory is valuable in studying the social determinants of the health status of a population and implementing prevention programs. The question remains how to address the second approach to a new theory of epidemiology evidenced by Schwab and Syme: community participation.

So how does a public health policy maker achieve this lofty goal of community participation? As hard as it has been to state this goal, effectively accomplishing it is undoubtedly harder. How does one foster community involvement in the production and application of biomedical knowledge? How does one get all members of a population engaged, even those who have no scientific expertise? How does one translate their voices back into the bioscience jargon, so that they can be effectively utilized in implementing new public health measures?

One extensively explored means to achieve all of the above steps has been to access the community through the means of a mediating agent: civil society. The term of civil society stands in opposition to the governmental fraction of society. Policy makers and public health officials are part of the governmental section of the political scene. They are elected or appointed to take action based on civilians’ needs. Civil society, composed of all non-governmental organizations (NGOs) and institutions is a mediating segment which can update the governmental one on the interests and will of citizens. This political interplay is further detailed below.

### **Vertical and horizontal action**

Traditionally, the domain of public health has been rooted in a specific political paradigm. Public health measures are designed to serve the interests of the general population through the directed action of centralized agencies and institutions. Research regarding health care issues and concerns is commissioned through governmental organizations. Legislative initiatives and other decision making processes are initiated by political bodies. This is what has been termed a vertical hierarchy of power. The power to instate health research, prevention and disease control is enacted from the top of the political ladder down towards the simple citizen.

With the advent of the new era of globalization definitions of citizenship are shifting. Flows of people and flows of information, as well as technological progresses challenge the old boundaries of national citizenship. The stage is open for a new type of citizens to take shape. More informed, more connected individuals exert their own agency to improve their health and the health of their peers. This sort of action originating at the grassroots level is termed a horizontal venue of advocacy and power.

Community participation emphasizes the agency of small groups over the structural force of institutionalized venues of power. Beck provides a new concept for viewing power stemming from non-traditional venues. He defines subpolitics as a “form of politics outside and beyond the representative institutions of the political system of nation-states” (Beck 1996, in Holzer 2001). What this refers to are familiar, but unconventional venues of power such as NGOs and other forms of civil society. Achieving community participation is a particularly challenging goal, since it leaves the policy maker struggling to grasp the driving forces of subpolitics.

While vertical forms of power are grounded in a politically based form of citizenship, horizontal power is grounded in social association. Social membership is commonly based on

perceived factors of risk. Local communities can come together to respond to new perceived health threats. New communities can be formed around previously singular health conditions. Such forms of organization are the subject of the following sections of the present chapter. Specific examples of groups whose identity is centered on a biological trait will be described. The particular social health-related functions that they accomplish will be detailed, such as the ways they network, communicate, manage stress and, most importantly, assert their political agency and influence traditional medical structures of power.

### **Sclerosis and the negotiation of care**

The case of amyotrophic lateral sclerosis, or ALS, is particularly relevant to the above discussion of how to interject and intertwine community involvement with public health initiative. Amyotrophic multiple sclerosis involves the gradual degradation of motor neurons in the brain and the gradual loss of muscle function in the patient's body. It is usually diagnosed in men between the ages of 40 and 60. No known cure is available for the condition. Symptoms are managed rather than treated. The factors causing and triggering the disease are also not well determined, but heredity seems to play a role.<sup>2</sup> Amyotrophic lateral sclerosis is a diagnostic of disability. It is also a rare condition, affecting only one to three people out of 100,000. As such, it is not the object of conventional public health campaigns since it does not affect a majority of the US population and cannot be prevented or treated through medication.

Even though the incidence of ALS is low, its impact on society as a whole is larger than the number of cases documented in the country. ALS affects the families of individuals diagnosed, on top of the individuals themselves. The mysterious nature of the condition is a

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<sup>2</sup> <http://www.mayoclinic.com/health/amyotrophic-lateral-sclerosis/>

heavy burden on loved ones trying to make meaning out of the prospect of loss they are facing. As early as 1985, family members of ALS patients rallied together to take action and co-funded the ALS association, a non-profit organization with the mission of fighting the disease on every front. The association first served the purpose of fundraising in order to provide additional money for biomedical research into the cause and treatment of the condition. In time, it also became a nucleus for providing support and services to people whose lives had been affected by ALS. Today, the association addresses four central aspects to managing and improving care to ALS patients: research, advocacy, patient and community services and public education and awareness.<sup>3</sup>

In terms of research, the ALS association directs a comprehensive, global program encompassing over 100 research projects. Funded work looks into all aspects of the disease and addresses all hypotheses of ALS pathogenesis issued up to date. According to the association's research philosophy, study ideas come from small teams of researchers, directly from the investigator's minds. The association also supports a post-doctoral fellowship focused specifically into research on ALS, thus further promoting the unfettered opportunity of conducting focused and directed work under no financial or institutional pressure. Moreover, the association holds annual workshops where scientists can propose new ideas and develop common insight into the condition. All of the above initiatives have the role of circumventing the traditional regulation of laboratory science through governmental and academic institutions. By facilitating a focused, accelerated environment of research, the ALS association is attempting to build a faster bridge between lab science and clinical results.

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<sup>3</sup> <http://www.alsa.org/>

Also, the association is de-commercializing the process of laboratory research by disengaging the production of scientific knowledge from the production of pharmaceutical products. In the microenvironment fostered by the ALS association, scientists need not depend on the funding of pharmaceutical companies and need not adjust their research to fit the profit goals of one or another company. Similarly, by being detached from academic or governmental drives, scientists need not focus as strongly on the definitions of success of those particular institutions: publishing and catering to the majority, respectively. In this way, science is put at the direct service of those immediately affected by ALS. Once this unique form of lab science knowledge is obtained, clinical management and drug development are also engaged into the process of providing more immediate and informed care. The association can thus translate the agency of patients and concerned family members into directed action.

The association's role does not stop at attempting to find cures faster than waiting for the conventional routes of power to take action. It also performs its own advocacy, advancing the promotion of policy and regulations to facilitate ALS patients' access to care and benefits. Moreover, through its now nation-wide chapters, the association provides patient and family support in various locations throughout the country. They provide information, resources and referrals to doctors and community services, in an effort to provide hope and improved quality of life to ALS sufferers. Through their signature fundraising walk, held biannually in numerous cities, the members of the association create new networks of people brought together by a shared health concern and a common biological tie. Thus a new community is crafted, a type of community that transcends physical boundaries and relates through the means of biology and not culture.

Another non-governmental organization addressing amyotrophic lateral sclerosis is ALS-TDI, a Cambridge, Massachusetts based research institute attempting to develop effective therapeutics that stop the progression of ALS<sup>4</sup>. Although the goal of ALS-TDI is strictly research oriented and does not have the outreach and educational components that the ALS association boasts, this sister organization also aids in the crafting of a transnational, global ALS community through the powerful story that stands behind it. ALS-TDI is centered on the persona of Stephen Heywood. Son of son of MIT mechanical engineering professor John B. Heywood and MIT engineering graduate James Heywood, Stephen led a simple, quiet life as a carpenter until his diagnosis with ALS in 1998, at the age of 30.<sup>5</sup> The diagnosis was an urgent incentive to his brother to start researching the condition in order to better understand what Stephen was going through. Upon realizing how little was actually known about ALS and how dire the life prognosis stood, James Heywood employed his brother Stephen as a catalyst for biomedical research, in hope of finding a cure for him before it would be too late.

While Stephen was gone in late 2006, leaving his tight-knit family behind, he remained a source of inspiration and hope to ALS sufferers around the world. His story was publicized in the novel *His Brother's Keeper*, written by the Pulitzer Prize winning author Jonathan Weiner, and also in a documentary film, *So Much So Fast*, which premiered at the 2006 Sundance Film Festival.<sup>6</sup> His public image as a beloved son and brother, as well as a husband and a dad, raised sympathies and helped to further catalyze the ALS community.<sup>7</sup> Through the art created around him, Stephen Heywood became a role model for all patients and families dealing with the burden

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<sup>4</sup> <http://www.als.net/>

<sup>5</sup> <http://www.cbsnews.com/stories/2000/04/17/60II/main185037.shtml>

<sup>6</sup> <http://www.boston.com/news/globe/obituaries/articles/2006/11/28/>

<sup>7</sup> <http://web.mit.edu/newsoffice/2006/obit-heywood.html>

of the disease. Here is a first-hand testimony of Stephen's story's effect. It appears among the entries on the ALS-TDI family page, where the Stephen Heywood fund is publicized.

“Darlene - 1/30/2009

Just yesterday, I saw the documentary "So much, so fast" on CBC in Canada. It was such an incredibly touching story. Stephen Heywood appeared to be one of the most upbeat, caring, loving people. I cried at the end when I found out he is no longer with us. Condolences to your entire family and upon seeing the documentary, I know that even though he was only with you a short 37 years, it was a wonderful 37 years. I think it is great that you are bringing awareness and research in a different way than is traditional for ALS.”<sup>8</sup>

Remarkably, the impact of Stephen Heywood's example of living his life while giving hope to others is not restricted by geographical and communication boundaries. It reached Canada, as it has South America. The following testimonial speaks for the power of shared ALS identity to foster initiative and empower members of the community to take action against the disease and assert their agency:

“Maria Rosales - 11/20/2008

Hi, I am from Chile, South America. My father has ALS since 2002, at this moment he is using bipap at night, and he only moves his head, he is 54. I am the oldest of 4 sons, 3 girls and a boy. I am 28 and my youngest brother is 16. Now I am trying to start a non profit foundation, for those patients that are not as lucky as we are, because we have the money to give him the best quality of life that is

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<sup>8</sup> <https://stephenheywoodfund.alscommunity.org/>

possible at this moment, but as you can imagine, we are a developing country and here people live more or less depending the money and also, they can not afford all the equipment necessary to maintain in a good shape their loved ones. So best luck to all of you and keep fighting this disease...we can do it may be not for the ALS people of today but for all the people that will be tomorrow, and to remember all our loved ones that have passed away. Sincerely, Maria de los Angeles Rosales”<sup>9</sup>

Wide outreach of Stephen’s story is also achieved through his obituary profile on the patient support website Patients Like Me<sup>10</sup>. Stephens profile shows his clinical prognosis and the progression of his disease, his treatment course and the progression of his symptoms from the onset of the disease to the day he deceased. Patients Like Me, a now popular address where people afflicted with any condition can connect, share stories, learn from each other and provide support, has grown out of Stephen’s saga. It was founded by his brother James (founder of ALS-TDI) and his brother Benjamin (director of Patients Like Me) in 2004, in order to spread awareness of ALS and provide help and shared experiences to other ALS sufferers. Today, it hosts a plethora of parallel communities centered on more prevalent as well as rare diseases.

So how does a sense of community, of a shared identity and a need to support one another, arise among ALS sufferers and their families? The cultural anthropology theorist Paul Rabinow conjectured in 1996 upon a new form of identity that would be shaped out the modern day awareness of one’s biological characteristics, predispositions, genetic make-up. This was contrasted to the old evolutionary biology model of sociobiology, coined by E O Wilson, which

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<sup>9</sup> <https://stephenheywoodfund.alscommunity.org/>

<sup>10</sup> <http://www.patientslikeme.com/patients/view/40>

sets out to explain animal and human social behavior. Sociobiology claimed to show that social behavior is determined by the evolutionary drive of the species, as coded in an individual's gene. Rabinow hypothesized that the revealing of a person's genetic make-up, made feasible by the Human Genome Project, would foster a sense of solidarity among people sharing the same genes. This new form of social identity would be particularly visible in the cases of individuals with a genetic predisposition towards a certain disease: they would seek each other and share experiences. This new concept was termed biosociality: instead of genes acting as a biological determinant, they would act as a cultural determinant, causing new social identities to coalesce through an interplay of shared genes and shared perceived risks or interests. Rabinow's theory of biosociality is further expounded on below.

### **Biosociality and genetics**

One source of empowerment for individual community stems from the modern processes of globalization. The impact of globalization on health has redefined spatial, temporal and cognitive boundaries of local communities. With the advent of new powerful both health technologies and communications technologies, communities have been restructured in terms of their defined identities, their notions of perceived risk, as well as their possibilities for social networking. The Berkeley anthropologist Paul Rabinow discusses how there has been a transition from the dogma of sociobiology to a new form of personal and group identity. Sociobiological theories based in evolutionism have attempted to explain cultural classifications as deriving from biological truths. They have supported racial and gender differences as based in nature as opposed to culture. Rabinow argues that thanks to such biotechnological advance such as the Human Genome Project, individuals will be faced with the revelation of a new identity: that of biological health risks:

“In the future, the new genetics will cease to be a biological metaphor for modern society and will become instead a circulation network of identity terms and restriction loci, around which and through which a truly new type of autoproduction will emerge, which I call ‘biosociality’” (Rabinow 1996)

Rabinow argues that through the use of computers, individuals that share certain traits will group themselves together in a nonsubjective way that decontextualizes them from their physically proximal social environment. Such virtual groups will be able to share experiences, lobby for their disease, educate their peers and their children, adapt their home environment to their health necessities and so on. Rabinow claims that in the face of this new form of bio-identity, termed biosociality, former cultural classifications such as gender, race and age will gradually lose their power.

While biosociality is a powerful concept, it only partially applies to the case of ALS discussed above. Yes, heredity is a part of the ALS risk factors, but is not the sole liaison between ALS sufferers. While shared genetics do play a role in the formation of disease-centered communities, other risk factors as well as the shared experience of illness and ailment also play a part in bringing separate people together. The following concept expands on biosociality to create a model of the sense of biological belonging that is even more relevant to the modern global world.

### **Biological citizenship**

A more recent concept, developed by the British sociologists Nikolas Rose and Carlos Novas, elaborates on Rabinow’s term of biosociality. Rose and Novas expand the category of civic involvement in the process of developing health research and health care to go beyond the

commonalities of genetics and to include other forms of biological risk as well. Biosocial groupings are defined as “collectivities formed around a biological conception of a shared identity” (Rose and Novas 2003). Groups organized around specific medical classifications have existed for quite some time. However, Rose and Novas argue that it is the increasingly specialized scientific and medical knowledge of one’s condition that makes such groups into increasingly significant actors in the sphere of decision making about their own health.

Individuals are crafting new classificatory identities for themselves, such as the child with attention deficit hyperactivity disorder, the woman with pre-menstrual dysphoric disorder or the person pre-symptomatically ill because of a genetic susceptibility to Huntington’s disease. Rose and Novas claim that such individuals with a biological sense of identity are particularly apt to actively engage biological explanations and form new relationships with figures of scientific and medical authority such as personal physicians or laboratory researchers. Furthermore, these individuals are said to be redressing a sort of “democratic deficit” (Rose and Novas 2003) by actively shaping their scientific and technological futures. Some forms of activism include campaigning for better treatment, ending stigma or gaining access to services.

### **Rotterdam**

One vignette exemplifying the activism of biological citizens in shaping their own medical future is that of Rotterdam intravenous drug users (IDUs) and the AIDS epidemic. Regular injection of intravenous drugs poses several health risks, of which the most common and dangerous are the development of abscesses at injection sites and the transmission of infectious diseases such as hepatitis B or AIDS. National policies regarding the social and health services provided to drug users and their moral status as national citizens also vary. The US policy has

historically been hostile to IDUs both in legal and sociopolitical terms. Existing drug laws pose a threat of long term imprisonment to the street user. The Netherlands, on the other hand, sports a more user friendly drug policy.

Friedman describes how, in the early 1980s, before HIV had gained prevalence in the country, the Dutch government oriented its drug policy towards harm reduction. Social services designed to keep IDUs from penury, malnutrition, homelessness and bad health were implemented. Drug users had access to essential living resources support from church groups (Friedman 2007). This proved of utmost relevance to forming social relationships that were to result in political mobilization. In January 1981, a group of Rotterdam heroin injectors organized in an advocacy association called the Junkiebond. In reaction to a state proposal for forced detoxification of heroin users, the Junkiebond put together a booklet detailing the human rights that drug treatment agencies had to abide by in relating to their junkie patients. Also, hundreds of users were mobilized to demonstrate over drug policies.

Remarkably, the Junkiebond also raised awareness to the health risks of syringe sharing and developed an underground needle exchange program to protect against hepatitis B transmission. The initiative soon spread and dozens of other cities in the Netherlands took up formal and informal junkiebonden groups. Although the Junkiebond was viewed with distrust by local agencies, the national health ministry decided to support and fund the junkiebonden. In 1985, when HIV entered the Rotterdam IDU community, the local health authorities and drug treatment facilities did not pick up on the threat. However, the Junkiebond quickly reacted by extending its needle exchange program from individual users to dealers themselves. By 1986, it put together and published the first HIV prevention brochure for IDUs in the Netherlands – *Junkies Blood*. This was done without any support from local authorities and institutions. The

Junkiebond also attained extensive media coverage of their efforts. Fortunately, the national Ministry of Health responded to these calls by funding underground needle exchanges and implementing official ones on a large scale. From 1987 and until the end of the 1980s, needle exchanges were operational in 60 Dutch cities (Friedman 2007).

The micro-social responses of the Junkiebond to the health risks of active IUDs in general and HIV spread by means of contaminated syringes in particular had a strong impact on formal policy responses. They set the path for the response of national and local authorities and worked with the media to muster public support and acceptance. HIV prevalence was stabilized at 12 percent of the junkie population, as compared to the much higher rate observed in New York City. There, although awareness of a new epidemic existed among drug users and efforts were made to use clean syringes to curb the rate of infection, documented levels of HIV prevalence by 1987 were as high as 50-60% (Friedman 2007).

## **ACT UP**

In New York City, large scale outreach targeting the spread of HIV among at risk populations began in the late 1980s. Although the intravenous drug users did not have a public voice in the process, there was another high risk population that made demands on authorities and institutions to obtain adequate services and treatment for AIDS sufferers. The New York LGBT community founded the organization ACT UP in 1987. ACT UP, or the AIDS Coalition to Unleash Power, defines itself as "a diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis."<sup>11</sup> On one level, ACT UP worked by organizing dramatic street demonstrations to garner the attention of the media and attract public

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<sup>11</sup> <http://www.actupny.org/>

support and awareness. On a second level, ACT UP negotiated with government officials, public health policymakers, medical personnel, researchers and pharmaceutical manufacturers to speed up treatment and care efforts.<sup>12</sup>

A second branch of the organization was soon created in Boston. Their agenda included demands for a compassionate and comprehensive national policy on AIDS; a national emergency AIDS project; intensified drug testing, research, and treatment efforts; and a full-scale national educational program within reach of all. The organization held die-ins and sleep-ins, provided freshman orientation for Harvard Medical School students, negotiated successfully with a major pharmaceutical corporation, affected state and national AIDS policies, pressured health care insurers to provide coverage for people with AIDS, influenced the thinking of some of the nation's most influential researchers, served on the Commonwealth committee that created the nation's first online registry of clinical trials for AIDS treatments, distributed information and condoms to the congregation at Cardinal Law's Confirmation Sunday services at Holy Cross Cathedral in Boston, and made aerosolized pentamidine an accessible treatment in New England.<sup>13</sup> The organization not only managed to combat stigma associated with the disease and give AIDS patients public faces and voices. They also impacted the enactment of public health measures on all level, from creating and directing scientific research to making the products of that research available to the ones in need.

In closing, I will briefly address some of the factors that make for successful crafting of biosociality and biological citizenship, as well as equally successful efforts to integrate the goals of biological communities into the sphere of national and international health. In the case of the

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<sup>12</sup> <http://www.actupny.org/>

<sup>13</sup> [http://www.lib.neu.edu/archives/press\\_releases/#act](http://www.lib.neu.edu/archives/press_releases/#act)

Dutch Junkiebonds, efficient access to social services as well as supportive legislation played a major role in the successful implementation of the health goals of a marginalized risk group. Access to knowledge and sufficient living resources appear to have a definite positive effect on community mobilization and involvement in health policy. In the case of ALS-TDI, although the key advocates in efforts to fight ALS were very well educated, resource-rich individuals, it was Stephen's charisma that created a strong, human bond among fellow patients on top of his brothers' tech-saviness. Ultimately, I believe that for the public health to succeed to bring in successful community involvement in addressing novel health issues, it needs to act both by mandating efficient social services and supporting and acknowledging the human connective agency that creates a new sense of biological community out of the isolation and suffering of disease.

## **Digital Communities developed around Health Conditions:**

<http://www.patientslikeme.com/>

A collection of online forums serving neurological conditions, mood disorders and HIV/AIDS.

<http://www.healingwell.com/pages/>

A resource directory linking organizations and support groups on a variety of on a range of diseases, disorders and chronic illnesses or general health concerns.

<http://www.inspire.com/groups/rare-disease/>

The NORD Rare Disease Support Community connects patients, families, friends and caregivers for support and inspiration.

## **Online Patient Empowerment Resources**

Patient Empowerment at About.com (<http://patients.about.com>)

Overview to challenges in navigating the American healthcare system targeted to empower patients. Includes patients' rights, healthcare consumerism, patient safety, medical decision making and patient advocacy.

Patients Are Powerful (<http://patientsarepowerful.com>)

Nonprofit advocacy organization offering a variety of patient rights services such as HMO challenge sample letters and free legal advice in all areas of medical malpractice.

Patient Advocate Foundation (<http://www.patientadvocate.org>)

Patient Advocate Foundation is a national non-profit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability relative to their diagnosis of life threatening or debilitating diseases.

Every Patient's Advocate (<http://EveryPatientsAdvocate.com>)

Provides information and practical suggestions to help you take responsibility for your own medical decisions, and partner with your doctors to attain the best outcomes possible for your medical situation.

National Resource Center on Psychiatric Advance Directives

(<http://www.nrc-pad.org>)

Psychiatric advance directives (PADs) are relatively new legal instruments that may be used to document a competent person's specific instructions or preferences regarding future mental health treatment, in preparation for the possibility that the person may lose capacity to give or withhold informed consent to treatment during acute episodes of psychiatric illness. The site provides state by state resources to help consumers and their families complete their own PADs in advance.

**Top US Health Charities from Charity Navigator (<http://www.charitynavigator.org>)**

National Organization for Rare Disorders

Danbury, CT

*Out of the darkness into the light*

The V Foundation

Cary, NC

*For cancer research*

Brain Tumor Society

Watertown, MA

*Leading through research and support*

International Fibrodysplasia Ossificans Progressiva Association

Winter Springs, FL

*Supporting families dealing with Fibrodysplasia Ossificans Progressiva*

Fisher Center for Alzheimer's Research Foundation

New York, NY

*Dedicated to funding research into the cause, care and cure of Alzheimer's disease*

Hemophilia Association of New Jersey

East Brunswick, NJ

*Making life easier*

Children's Organ Transplant Association

Bloomington, IN

*Providing fundraising assistance for children and young adults needing life-saving transplants*

Pulmonary Hypertension Association

Silver Spring, MD

*Improving the lives of those affected by pulmonary hypertension*

National Ovarian Cancer Coalition

Dallas, TX

*Raising awareness and promoting education about ovarian cancer*

National Foundation for Infectious Diseases

Bethesda, MD

*Education, prevention, research*

Kidney Cancer Association

Evanston, IL

*We're here to help*

American Skin Association  
New York, NY  
*Public support for research, education, prevention and cure of skin disorders*

Aplastic Anemia & MDS International Foundation  
Rockville, MD  
*Fighting bone marrow diseases through patient support and research since 1983*

Living Beyond Breast Cancer  
Haverford, PA  
*Empowering all women affected by breast cancer to live as long as possible with the best quality of life*

American Lung Association of the District of Columbia  
Washington, DC  
*Improving life, one breath at a time*

National Multiple Sclerosis Society, Connecticut Chapter  
Hartford, CT  
*Join the movement*

American Brain Tumor Association  
Des Plaines, IL  
*Sharing knowledge, sharing hope*

American Association of Kidney Patients  
Tampa, FL  
*The voice of all kidney patients*

Organization for Autism Research  
Arlington, VA  
*Research and resources that help families today*

PKD Foundation  
Kansas City, MO  
*For research in polycystic kidney disease*

Glaucoma Research Foundation  
San Francisco, CA  
*Funding innovative research to find a cure for glaucoma*

National Breast Cancer Foundation, Inc.  
Frisco, TX  
*Help for today . . . hope for tomorrow*

## References:

- Brown, P  
Popular Epidemiology: Community Response to Toxic Waste-Induced Disease in  
Woburn, Massachusetts  
Science, Technology, & Human Values, Special Issue on the Technical and Ethical  
Aspects of Risk Communication 1987, 12: 78-85
- Brown PJ, Inhorn MC, Smith DJ  
Disease, ecology and human behavior.  
In: Medical Anthropology, Contemporary Theory and Method (Revised Edition)  
Praeger, New York, 1996
- Crowley P, Hunter DJ  
Putting the public back into public health  
Journal of Epidemiology and Community Health 2005, 59 :265-267
- Friedman S, de Jong W, Rossi D, Touzé G, Rockwell R, Des Jarlais D, Elovich R  
Harm reduction theory: Users' culture, micro-social indigenous harm reduction, and the  
self-organization and outside-organizing of users' groups  
International Journal of Drug Policy, Volume 18: 107-117
- Gibbon S and Novas C  
Biosocialities, Genetics and the Social Sciences. Making biologies and identities.  
Routledge, New York, 2008
- Holzer B, Sorensen MP  
Rethinking Subpolitics: Beyond the `Iron Cage' of Modern Politics?  
Theory Culture Society 2003 20: 79-102
- Holzer B, Sorensen MP  
Subpolitics and Subpoliticians  
Arbeitspapier 4 des SFB 536 Reflexive Modernisierung, Munchen, July 2001
- Kleinman A  
A Critique of Objectivity in International Health.  
In, Writing at the Margin. Discourse between Anthropology and Medicine.  
University of California Press, 1997
- Lee K, Fustukian S, Buse Y  
An introduction to global health policy.  
In, Health Policy in a Globalizing World, p.3-17  
Cambridge University Press, 2002

McMichael AJ

The urban environment and health in a world of increasing globalization: Issues for developing countries.

Bulletin of the World Health Organization 78: 1117-1126

Nichter, M

Global health: Why cultural perceptions, social representations, and biopolitics matter  
University of Arizona Press, 2008

Novas C, Rose N

Biological citizenship, In Global Anthropology, Blackwell, 2003

<http://www.lse.ac.uk/collections/sociology/pdf/RoseandNovasBiologicalCitizenship2002.pdf> (accessed April 2009).

Parsons T

The Social System. New York: Free Press, 1951

Pearce N

Pearce responds.

Am J Public Health. 1997, 87: 2051–2052.

Rabinow P

Artificiality and enlightenment: from sociobiology to biosociality

In: Essays on the anthropology of reason

Princeton University Press, 1996

Schwab M, Syme SL.

On paradigms, community participation, and the future of public health.

Am J Public Health. 1997, 87 :2049–2052.

Yen IH, Syme SL

The Social Environment and Health: A Discussion of the Epidemiologic Literature

Annual Review of Public Health 1999, 20: 287-308