

Health Consumers, Bio-citizens, or (Yet Another) Third Way? How NGOs Negotiate State and Individual Responsibility for Health in Croatia¹

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Abstract: Non-governmental organizations (NGOs) have become integral to health care in post-socialist transitional settings. This mandates attention to how such organizations address disparities in health and access to care that have accompanied privatization of services and growing economic inequalities in these areas. Central to their role is how NGOs represent those seeking care and, in particular, the models they invoke to advance both individual and collective claims on state and provider systems.

This paper examines health-related NGOs in Croatia in order to assess models of citizenship rights and health consumerism. The concept of bio-(logical) citizenship denotes a broad project of medically-based demands for state support and collective entitlements. Policies based on models of health consumerism promote rational and informed individual decision-making. These perspectives originally arose as part of anti-professional movements and more recently trace to neoliberal assumptions of individuals as self-managed consumers. Critical analysis has yet to unpack the different bases for these models and their possible relationship to sources of health inequalities.

Based on participant observation, interviews, and public documents, this analysis assesses the applicability of these models to Croatian NGOs addressing health and disability concerns. NGOs adopt diverse approaches, ranging from a focus on rights – including claims to care, support, or recognition – to those centered on personal responsibility and consumer choice. Contextual elements centrally shape the meaning of NGOs' claims and thus the nature of bio-citizenship and health consumerism in their practice. Factors unrelated to health or disability, including the security of institutionalized entitlements and connections with health professionals, appear influential to the framework(s) NGOs deploy. In terms of their importance to NGO missions, questions of social justice, distribution of health resources, and social inclusion eclipse identity claims based in either model. Moreover, notwithstanding the differences among them, NGOs remain subsidiary in a system increasingly affected by health disparities cutting across the categories of people they represent. For NGOs to play a role redressing this would require transformation of their organizational status and missions.

Keywords: NGO, Post-Socialism, Eastern Europe, Citizenship, Consumerism, Disability

Introduction

Now more than twenty years since their political transitions, post-socialist countries include civil society sectors encompassing diverse and dynamic actors. Within health care and disability-related services, Non-Governmental Organizations (NGOs)³ address disparities in health and access to care that have emerged from the privatization of services, state retrenchment, and growing economic inequalities. These organizations adopt different purposes,

strategies, and institutional logics, and their contributions to health and health care in transitional settings are critical.

This paper examines two models typifying the roles of health- and disability-related NGOs in Croatia. The models center on competing claims, of citizenship rights and of health consumerism. These models also draw on different logics, focus on divergent aims, and promote different actions. The first reflects a variation of the concept of bio-(logical) citizenship (Petryna 2002, Novas and Rose 2005), which denotes a broader project of medically-based claims to state support for sick and disabled populations. “Health consumerism,” in contrast, refers to the promotion of rational, informed individual decision-making in the context of a global market of biotechnology and health care (Sulik and Eich-Krohms 2008).

Croatian NGOs addressing health and disability concerns embody both of these models, but in ways shaped by Croatia’s history and that of its health care system. Those organizations emphasizing bio-citizenship press for extension of state and professional actions using rights-based discourses and claims. The nature of these claims varies, however: some NGOs press for state-mandated entitlements, others for social inclusion and yet others for enforcement of patients’ rights. In contrast, NGOs employing a health consumer model provide critical forms of support and information to individual care-seekers and act as intermediaries between patients and medical providers. These organizations thus seek to enrich formal care systems as well as enhance the consumerist abilities of care-seekers, but in the absence of a consumerist ethic similar to that in the West. Neither the age of NGOs, nor the specific health condition or disability addressed, differentiates those operating with a bio-citizenship framework from those addressing health consumer issues. Instead, factors unrelated to health or disability status, including other claims on the political arena, legacies of entitlement, and connections with health professionals, shape the approach adopted.

Across these approaches, NGOs remain bound by categories determined by the health professions and, as such, play a subsidiary role to formal providers and the state. They do not, and arguably could not, address the structural conditions underlying current disparities in health care. The privatization of health care has altered the distribution of health risks and access to care; where inequality used to exist on geographic and categorical bases (and to some extent still does), now the ability to obtain care in the private sector affects all categories of individuals. For NGOs to take a more proactive stance responding to this situation would require dramatic change in their financial and organizational structures, in short a transformation of the civil sector.

Rationale: The Third Sector and social citizenship

Since the 1990s, shifts in social welfare, particularly in transitional settings, have altered relations between individuals and the state, leading scholars to re-examine the concept of social citizenship (cf. Evers and Guillemard 2013). These policy changes center on neoliberal reformulations of the welfare state, but are not reducible either ideologically or programmatically to them. International trends that also affect social welfare sectors include increased instability of the labor market, the expanded role of consumer markets, increased social diversity and multicultural demands, and, of particular salience to the case of Croatia, the process of European unification.

Based on their analysis of these developments, Johannson and Hvinden (2013) identify three models of social citizenship centered on different expectations regarding the roles of individuals, on the one hand, and states, on the other. The Socio-liberal model sees individuals

and states as mutually obligated to each other; a Libertarian approach emphasizes individual responsibility within a market context; and the Republican model stresses self-governance by users of programs. (Johansson and Hvinden 50 ff.) While actual welfare policies and programs are likely to be hybrids of these models, the ideological distinctions remain important for their adherents in welfare reform debates. For non-state collective actors, like NGOs, such models provide different discourses articulating the rights of their constituents: rights that may be state-mandated, exerted within the market, or invoked by inclusion in structures of governance. The rights of social citizenship can thus be claimed in different ways, towards diverse purposes. In what follows, each of these discourses will be evident in the ways Croatian NGOs make rights-based claims.

Researchers examining changes in health care systems in the late 20th and early 21st Centuries have documented developments similar to those in social welfare. While these analyses share some conceptual roots (in particular, Foucauldian notions of surveillance and governance) with those of social welfare, models here pertain less to transformations at systemic and global levels. Instead, analysts point more to the negotiation of state support by particular categories of people, particularly those with disabilities or health conditions thought to be related to state action or neglect. Citizenship here is not a stable characteristic, but rather an identity negotiated within a context of political and institutional transformation (Ecks 2005). Assessing conditions in Ukraine post-Chernobyl, Petryna (2002) found that impacts on health provided the basis for both collective campaigns and individual claims for state support, processes she termed “bio-citizenship.” Rose (2007) and Novas (Rose and Novas 2005) extended the term to encompass the shared identity and understandings of communities advocating for biologically based rights. This formulation sees the active undertaking of such actions as a form of moral obligation.

Social policies based on the concept of health consumerism developed around the same time as models of bio-citizenship and share with the latter a move away from citizenship claims based solely on membership in a nation state (cf. Rose and Novas *Op. cit.*). Health consumerism has, however, a longer history, tracing to Western consumer and anti-professional social movements of the 1960s and ‘70s (Sulik and Eich-Krohm *Op. cit.*). These earlier activists demanded increased state control of corporate actors, both those that had adverse impacts on health and those corporate entities providing health care. In the anti-regulatory era of the ‘80s and ‘90s, the notion of the health consumerism morphed from individual or collective entitlement into the promotion of individual responsibility for health and choice within a market-based or hybrid system of care. Globally, the consumer movement divided, to some extent along development lines, between a focus on individual consumer choice and an alternative attuned to collective commitments to justice (Hilton 2009, Khoo 2012). In terms of activism, however, consumerist models became eclipsed, and at times subsumed, by rights-based expectations of civil society participation as well as state accountability (Khoo *Op. cit.*, London and Schneider 2012).

There is good reason to interrogate the institutions that connect individual or collective actors with state or market forces within all of these approaches. This is, indeed, a key objective of the third sector: to mediate between the micro-level of lived experience and the macro-level of governance and opportunity structures. Efforts to promote civil development in societies transitioning from socialism relied on this mediating function as a way to instill civic norms and democratic practices, and to protect individuals from the ill effects of state retrenchment. Despite much attention to mixed systems of welfare, there has yet to be an explicit focus on how third

sector institutions, and specifically NGOs, address the “tensions, conflicts and ambiguities” that accompany new hybrid models and expectations at micro- and macro-levels (Johansson and Hvinden 2013, 52).

To illustrate the forms such mediation are likely to take, consider some fundamental contributions to civil society attributed to CSOs (Civil Society Organizations, the category encompassing NGOs and other civic associations): educating about conditions, services, and rights; improving skills for claims-making; providing arenas for “active citizenship;” articulating claims – material, political, and symbolic – and monitoring accountability; expressing grievances and advocating on both individual and collective levels; and acting as co-producers of services (Edwards 2004; Pestoff 2011). Most of these could serve their purpose within any model of social citizenship, for example, to advocate for rights within the Socio-Liberal approach, or to inform choice within a Libertarian one. For CSOs to provide services would serve access objectives within a Socio-Liberal model, an expansion of privatized options within a Libertarian model, and purposes of self-help in a Republican approach. Seeing how the assumptions of those models are actually expressed in CSO and NGO practice would thus shed light both on the experience of social citizenship today and on the significance of the third sector for specific issues like health inequality.

Background on Civil Society and Health Care in Croatia

Although some civil initiatives arose under late socialism, it took the dissolution of Yugoslavia and the beginnings of democratic statehood for an independent civil society sector to begin to re-appear in Croatia (Bežovan and Zrinščak 2007). The Croatian war of independence and subsequent climate of state-building and nationalism initially discouraged the growth of a domestic third sector, as well as the extent (and perhaps quality) of foreign technical assistance for civil society development (Coury and Despot Lučanin 1996, Stubbs and Zrinščak 2009). Democratization opened the possibility of independent civil initiatives, but there was distrust of CSOs both within the government and among the general public (Bežovan and Zrinščak 2007, Croatia 2007). While there was a similar situation in other post-communist countries, due to its state-building agenda and late Europeanization, democratization in Croatia proceeded more slowly than elsewhere (Stubbs and Zrinščak 2009).

Dialogue between the state and civic associations improved in the first years of the 2000s, increasing the visibility and legitimacy of civil society. Notwithstanding some fluctuations since then, conditions for civic associations have generally remained favorable, and Croatia is more similar to Central European countries like Slovenia, the Czech Republic, and Poland in terms of the strength of its civil society, than to countries that have experienced stronger authoritarian rule (like Serbia, Georgia, or Ukraine) (Celichowski 2008). Still, participation by citizens in CSOs remains low, CSOs are mainly found in urban areas, and the government has yet to create systematic mechanisms for consultation with civil society actors (Bežovan and Matančević 2011).

Parallel to civil society expansion, and of particular importance to the Croatian NGOs examined here, reforms of health care since independence introduced market forces, privatization, and centralized state control. Privatization first involved the introduction of health insurance supplemental to that of the state; in short order, laws enabled private practice in both primary and specialty care as well as privately owned medical practices and health institutions. Co-payments for care were introduced within both the public and private sectors. At the same

time, the state centralized health care financing, health insurance funds, health policy, and health services, placing them more directly under state governance than had been the case within the semi-autonomy of Yugoslav republics and self-management (Mastilića and Kušec 2005).

Since these developments, there has been growing inequality in health and health care within Croatia. Shortly following the initial health care reforms privatizing care, a two-tier system emerged, with private services for those who could afford them and public programs for those who could not. Lower income people reported more difficulties in accessing services, and many more reported burdensome copayments for specialists and prescription drugs, compared to higher income individuals (Mastilića and Kušec 2005). Preventive services and home visits aimed at vulnerable populations declined due to cuts in provider reimbursements (Chen and Mastilića 1998). Almost a decade later, a population health survey found significant differences among income groups in their self-reported health status. Over fifty percent of the low-income group rated their health as “poor,” compared to roughly eighteen percent of those with high incomes. Moreover, among all those with self-rated poor health, low income individuals used significantly less specialist care than those with higher incomes (Mastilića and Kušec 2005). Increased income inequality has also occurred, fueled in part by the differential impact of the costs of care (Kunitz 2004). By 2006, a representative sample survey found significant differences among income quartiles on all health indicators (including self-perceived health, satisfaction with health, and long-term illness or disability) and four indicators of access, including distance to care and its cost (Šućur and Zrinščak 2007).

In short, although these data cannot be taken as causal evidence, they paint a picture of continued adverse health effects since the reforms and privatization of care of the early 1990s. Disparities known to exist under the former system – in particular, regional and urban-rural differences – have remained (Chen and Mastilića 1998; Šućur and Zrinščak 2007). Now there are also clear socioeconomic disparities in health outcomes, access to care, preventative approaches, specialty care, out-of-pocket payments, and the receipt of care in public versus private systems.

Health-Related NGOs and Croatian civil society: Empirical findings

The analysis that follows draws on long-term, immersive connections with the Croatian civil society sector, beginning during the war that dissolved Yugoslavia (see Dill 1992). Empirical research in 2001 included interviews and observations of health-related NGOs offering self-help groups in Croatia and Slovenia; follow-up with these and other organizations took place during 2003, 2005, and 2007 (Dill and Coury 2008, Dill and Fink 2003). A 2005 multi-method study with leaders and board members of thirty health- and social welfare NGOs assessed multiple dimensions of the situation of the third sector and its leadership (Dill, Zrinščak and Coury 2012).

In 2012, systematic examination of the Croatian National Register of NGOs established sub-categories of those with health- and disability-related missions (Dill 2014). Excluding professional associations, trade unions, and individual members of federated organizations, this analysis identified roughly 500 separate NGOs. Web-based research and interviews with NGO members and experts on the sector then provided basic information on the mission and activities of those organizations that had remained active. Participant observation and in-depth interviews took place (then and in brief research visits each year subsequently) with a subset representing different conditions and constituents (e.g., specific physical diseases and disabilities, psychiatric

conditions, hospice providers, and parents' and other family groups). Observation of NGO "fairs," conferences and state-sponsored "NGO Day" events provided further information on specific NGOs as well as contextual material for this analysis.

Many health-related associations in Croatia pre-date their current status as civic organizations, having been established during the socialist period by physicians wishing to involve patients and communities in their own health care. Over four decades ago, public health physicians founded self-help groups for people with diabetes, hypertension, and other conditions; remnants of these remain active as NGOs (Dill and Coury 2008). The current director of the WHO "Healthy Cities" initiative reported that it was likewise initiated by public health physicians in the decade before independence. Interviews with NGO leaders revealed that physicians founded currently active NGOs for people with breast cancer, alcohol dependency, bipolar disorder, and needs for palliative care, among others; even patients' rights NGOs were founded and remain led by physicians.

It is difficult to verify the numbers, membership, and impact of health- and disability-related NGOs related to health and disability due to issues in the data currently available. Of over 42,000 non-governmental associations listed in the National Register, roughly 1500 fall into a health-related category, but the definitional boundaries of that categorization make it of limited analytic use. For example, professional associations of health care providers, self-help groups for people with alcohol dependency, and chapters of an international breast cancer advocacy organization are all included in the same category. "Membership" may encompass only active board members, participants in single events, dues-paying individuals, and/or individuals who join in order to get public benefits such as transportation passes.⁴

As noted, there are roughly 500 separate health- and disability-related NGOs listed in the National Register, apart from trade unions, professional associations and individual members of coalitions of associations. Most of these NGOs address specific diseases or disabilities (close to one-quarter are disability-related), rare diseases, patient's rights, and issues of specific groups, such as parents of sick or disabled children, war veterans, or ethnic minorities.

Health-related NGOs, and particularly those concerned with disabilities, are acknowledged as a relatively influential part of civil society in a recent CIVICUS survey of CSO representatives and external policy experts (Bežovan and Matančević 2011).⁵ CSOs have become service providers in nursing homes and elder care, alcohol and substance abuse treatment, care for deinstitutionalized populations (such as the mentally ill and developmentally disabled), and rehabilitation programs. Other examples of CSOs addressing health-related issues come from the green movement, self-help, mutual support, voluntary associations, multi-purpose advocacy and service organizations for people with disabilities or particular medical conditions, church-sponsored charities, and a panoply of INGO-supported programs and health initiatives. In all of these, CSOs mobilize volunteers and communities, convey information, provide public representation of issues, and develop local knowledge as well as community capacity for care delivery.⁶

NGOs and the State: The importance of legacy

Many health- and disability-related NGOs in Croatia are privatized reformulations of state-controlled initiatives from the Yugoslav era; that is, as laws permitted the registration of civic associations, some entities formerly organized and run by the state were registered instead as separate organizations formally under the direction of private leadership and boards. They

remained largely dependent on public resources, however. The state, in these cases, was less hollowed-out as a provider in the health care sector, than repositioned, with less direct control over these organizations. In the 1990s these older groups were joined by a plethora of new associations, some representing people with diverse illnesses and disabilities and their families, while others formed around issues, such as rare childhood diseases, infertility, and eating disorders, formerly dominated (or neglected) by state -controlled professionals and institutions (Dill and Coury 2008). NGOs formed since Croatian independence largely originated among urban, relatively educated populations with connections to professionals and formal institutions such as state bureaucracies or ministries. From their beginnings, many NGOs in the health sector have had medical or public health professionals as leaders, consultants, and participants.

Thus, many health-related NGOs parallel formal systems of care: they are structured around the same diagnostic categories, institutions, and populations, and their missions and activities incorporate medical understandings and goals. NGOs are not, however, contractual providers of state services; this requires different registration and regulatory requirements. Instead, the services they provide are supplementary to formal care, such as, health screenings, rehabilitative therapies (music therapy, therapeutic horseback riding), psycho-social support, and adaptive training (sign language, independent living skills). Other programs include recreational activities, educational placements for health occupation students, financial and medical support for patients, and individual as well as collective advocacy. Policy experts acknowledge NGOs as having a substantial impact on health and disability issues, despite lacking an overall system of consultation by the state. (Bežovan and Matančević 2011)

While legally separate from the state, Croatian NGOs are not, strictly speaking, independent of it. The state retains its dominance in social welfare and in the health care system, for example, by being the sole source of primary health insurance. Even since Croatia's joining of the EU, NGOs have remained largely dependent on precarious programmatic and project funding from the national governmental level.⁷ To date, EU funding has provided a buffer against variability in the provision of state funds, but remains primarily programmatic, cross-subsidizing the ongoing work of NGOs rather than increasing their organizational autonomy (Dill 2014).

Policy, legal, and financial frameworks established by the state have created different opportunity structures affecting NGO resources and missions. Some NGOs benefit more than others from legacies of prior organization and connection to the state. A clear example of this type of legacy comes from NGOs that deal with physical as opposed to mental or intellectual disabilities. Associations of people with physical disability pre-date Croatian independence: associations for disabled veterans formed following the Second World War, and other organizations for people with physical disabilities followed. Incorporated into the structures of Yugoslav self-management, these associations held both social and political legitimacy. Those that still exist -- notably NGOs for people with physical disability and, among those, particularly associations of veterans -- operate with "legacy missions"⁸ that are reliably represented in policy discussions and government-sponsored committees relevant to sector development.⁹ While it is beyond the scope of this research to assess the extent of their state funding, they are considered relatively unassailable in terms of state support,¹⁰ and social policy has favored their constituents.¹¹

In contrast, NGOs dealing with issues of intellectual, developmental, and mental health disability operate in a context dominated by a legacy of institutionally-based care, affecting both their relations with the state and the resources available to them. While there has been strong

program development by such associations, social policy has stalled around achieving community-based care. The government has committed itself to deinstitutionalization, but a strategic plan to achieve it has been slow in forthcoming. Charges of human rights abuses in institutions are mounting, and in general social integration of people with these forms of disability is poorly developed.¹² NGOs in this field thus struggle for state support and adopt agendas based on lower expectations of what the state will provide than those held by associations with legacy missions.

NGOs, “Rights” and “Health Consumers”

In the course of this research, analytic focus on “rights-based” discourses emerged from interviews regarding the relatively recent legislation on patients’ rights, as discussed below. This in turn prompted attention to the ways in which diverse NGOs did, or did not, exert claims grounded in the rights of their constituents. Since relations with the state, and in particular legacy missions, had been found to affect many aspects of NGO activity (Dill 2014), we compared material on NGOs that differed in those areas. To rule out factors related to longevity, founder effects, and the specific constituents or conditions addressed, we compared NGOs that differed on those dimensions. “Consumerism” had also been important in prior analysis of the relations between health professionals and patients (Dill 2014). Unlike its development in the West, health consumerism in Croatia, particularly among health-related NGOs, does not involve contesting the dominance of physicians and other health professionals, although consumer behaviors, such as seeking second opinions, are becoming more common. Given the current scholarship assessing both health consumerism and rights-based claims of biocitizenship, these contrasting categories became the foundation for our analysis.

To define NGOs in terms of missions related to rights *versus* those with a consumerist orientation, would, however, greatly over-simplify the practices of most NGOs in the health arena. Prior analysis identified multiple areas of effort that exist in combination for the majority of associations dealing with health and disability issues (Dill, 2014). These include offering services such as health screenings, rehabilitative therapies (e.g., music therapy, therapeutic horseback riding), psycho-social support, and adaptive training (e.g., sign language, independent living skills). These services may complement public service systems, as in the provision of a mobile mammography unit reaching areas uncovered by public services, but with the screenings themselves paid for through public service. More often, services are supplementary to those of the health care and social welfare systems, offering programs to individuals who would not be eligible under public auspices or types of activities that simply are not offered otherwise, such as summer camps and other forms of recreation. NGOs intersect with formal sectors in more collective ways, as well; examples include field placements for students in different health occupations, or parents’ groups that raise funds for new care facilities for sick children.

Beyond service provision, NGOs provide information, education, advice, and referrals for care to both members and the public at large. As well, they offer concrete personal support, for example, by providing funds for lodging for parents of hospitalized children or securing medicines not covered under the public formulary. Advocacy occurs at this individual level and also collectively, as NGO representatives provide testimony and written commentary on proposed legislation and are included in policy formulation committees on an ad hoc basis. Use of public campaigns and media are other advocacy mechanisms, though demonstrations are uncommon.

NGOs thus fall along a continuum between an approach focused on “rights” – including claims to care, support, or recognition – and one centered on personal responsibility and consumer choice, with considerable overlap in-between the two approaches. As an example, *Krijesnica* (“Firefly,” <http://www.krijesnica.hr/h>), “an association for helping children and families facing malignant diseases,” lists many service activities on its webpages alongside lobbying and advocacy.¹³ Most health- and disability-related NGOs would include some such combination, with great variation in the exact activities as well as the emphasis given each type of approach. Still, case examples can illustrate some distinctive forms each model within the continuum assumes in the current Croatian context.

To begin with, rather than having a unitary focus on constituent’s rights, there are several variations in NGOs’ rights-based claims. Some older NGOs, particularly those noted as having “legacy missions,” are intent on maintaining the entitlements already accorded their constituents. Associations for disabled veterans center their mission on the maintenance of members’ rights, generally achieving success in this, as already described. NGOs representing individuals with particular disabilities, the successors of formerly state-run associations, similarly emphasize categorical benefits for their members. The *Udruga Slijepih Zagreb* (Zagreb Association of Blind Persons, founded in 1947), while offering many educational and recreational services for members, maintains a focus on legal rights. A “legal advisor” (*Pravni Savjetnik*) section on its website lists the benefits available to members as well as the rights of blind people regardless of membership. The Association also supplements social welfare programs by offering adaptive technology and certification for free transportation tickets, in essence extending the entitlement claims of blind people as citizenship rights. The Association’s rights-based emphasis is further evidenced in activities such as a workshop for representatives of leaders from country-wide associations for the deaf and the blind, entitled “Advocating for change in public policy in the local community” (<http://www.udruga-slijepih-zagreb.hr/index-s.html>). Similarly, one of five workshops in the association’s NGO Open Days program was “And the blind and deaf people have a right to watch television” (advocating for enhanced audio descriptors). Even a demonstration of gardening for people without sight focused on the lack of provision of “comfortable and quality accommodation” in the city’s gardens and plants.

Other organizations with a rights-based agenda work more from the rhetoric of inclusion than that of entitlement. Predictably, these encompass organizations representing people with disability, including those for people with intellectual disabilities. *Inkluzija* (the “Association for Promoting Inclusion”) gives as its mission, “to promote the development of a society in which people with intellectual disabilities have equal opportunities, their contributions are valued, and their human rights are respected.” Several programs of this association focus on transforming care from its current institutional base to community settings. One such project involves a partnership with the Ministry of Social Policy and Youth and the Centre for Adult Education “Validus” in a three-year, Open Society Institute-funded project; others center on creating subsidiary adult education centers throughout Croatia (<http://inkluzija.hr/eng/about-api/>). The “Association for Self-Advocacy,” *Udruga za Samozastupanje* (<http://www.samozastupanje.hr/>), which often allies itself with *Inkluzija*, identifies an even broader set of claims in a lecture for students at the Faculty of Education and Rehabilitation Sciences:

The majority of persons with intellectual disabilities are being deprived of legal capacity. That is why we can not (*sic*) realize many of the rights that are written in

the UN Convention of the Rights of Persons with Intellectual Disabilities. For example:

- We can not get married
- We can not get a job
- We can not run for president of our association
- We can not vote in our association
- We can not decide where and with whom we want to live.

http://issuu.com/damyan/docs/voice_of_self_advocates_winter_2013)

Non-disability-related CSOs, like *RODA (Roditelji u akciji*, “Parents in Action,”), also assert claims for rights using the discourse of social inclusion. *RODA* was founded in 2001 by parents objecting to cuts in maternity leave benefits; it is now focused on the rights of pregnant women, parents and children. Most recently the organization has advocated for parental leave commitments and other health care rights, including the right to medically-assisted conception (Evers and Ewert 2012). Recent postings have included a call for parents to “make intercession for the right to be with their child 0-24!” as well as a detailed listing of state-mandated rights in referrals for hospital treatment (<http://www.roda.hr/article/category/u-akciji>). A further example of claims-making in the health care system comes from *HUCUK, Hrvatsko udruženje za Crohnovu bolest i ulcerozni kolitis* (Croatian Association for Crohn’s Disease and Ulcerative Colitis), which is drawing media attention to the limits on their constituents’ access to therapy that come from purchasing expensive biologic drugs from hospital coffers rather than a dedicated fund for expensive drugs within the national health insurance program (<http://www.index.hr/vijesti/clanak/pacijenti-obiljeli-od-crijevnih-bolesti-omogucite-svima-jednaku-dostupnost-bioloških-lijekova/748066.aspx>, posted 5/18/14).

What unites these examples are calls for the state to recognize the specific rights of the represented group, for inclusion in decisions about how care should be provided and funded, and for the removal of barriers to the type of care being promoted. These claims are both more specific and grounded on a different basis than those of “entitlement;” they call for categorical as well as individual inclusion in the process of care rather than an extension of state-provided support *per se*.

Yet a third version of claims-making also centers on participation in health care, but with a more generic focus on patients’ rights. *Hrvatska udruga za promicanje prava pacijenata* (The Croatian Association for the Promotion of Patients’ Rights) advocated for five years for an “Act for the Protection of the Patients’ Rights,” which was finally enacted late in 2004 (cf. Babić-Bosanac and Dzakula 2006). Beyond detailing rights to health care, respect for dignity, informed consent, refusal of care, and so forth, the act specifies obligations of users as well as providers of care, defining the provision of services as contractual in nature (see <http://www.pravapacijenata.hr/eng/pdf/stradovi/Law.pdf>). While this legislation has yet fully to impact health care provision, informed consent procedures are gaining force in institutional settings, and respondents in several organizations noted that requesting a second opinion (another of the provisions of the legislation) has become common among younger generations of patients. While this association is widely credited with the enactment of this law, other patient’s associations (e.g., *Udruga Hrvatskih Pacijenata*, based in Zagreb) promote patients’ rights through direct advocacy (e.g., writing letters to the parliament regarding particular cases or treatments), media campaigns, and public education.

To move farther in the direction of “consumer-citizenship” (Johansson and Hvinden 2013:39 ff.), arguably would require more of a health care marketplace, or rather, less state dominance and monopsony, than exists in Croatia at present. Those NGOs with more of a consumerist orientation are thus seeking not so much the enhanced exercise of choice of health consumers, as to enable individuals more fully to take responsibility for their health, to be involved in their health care, and to be educated patients.

This form of health consumerism is not a recent phenomenon: during the 1960s-1980s, physicians and nurses in primary care clinics formed self-help groups for people with hypertension, diabetes, alcoholism, and other conditions. The objectives of such groups centered on peer education, health maintenance, and mutual support (Dill and Coury 2008). The Yugoslav Cancer League also founded “clubs” for patients treated for a variety of cancers, designed to assist with psychosocial rehabilitation and provide social support as well as patient education. While professionally facilitated, all of these groups and clubs were governed by members. Those that survived the war and transition of the early 1990s became registered as NGOs, and their numbers were increased by many newer self-help groups serving individuals with a wide variety of conditions. These NGOs reflected a consumerist orientation by encouraging self-care and mutual support, in essence helping patients become better health care consumers as seen within a medical model. Their work is still done in alliance with that of health care institutions.

The evolution of the Croatian chapter of the European breast cancer advocacy organization “Europa Donna” (ED) illustrates how this type of consumerist approach must be understood in the context of transformations in Croatian society and health care.¹⁴ Founded as an NGO by a small group of physicians, ED subsumed the cancer clubs for women who had breast cancer surgery, securing the cooperation of medical institutions by framing this as a form of voluntary psychosocial support. ED could not, however, make the same claims on the official system that it had when the clubs were more integrated within state-provided health care; instead, it competed with other NGOs for meeting space and financing. In the early post-war years, ED was somewhat disadvantaged by the suspicion with which the nationalist state viewed international connections. Moreover, the international organization of which ED was a part did not provide it with material resources and required local chapters to pay dues. Thus, ED gained neither legitimacy nor financial autonomy from the state through its status as part of an international organization. In the mid- to late ‘90’s, ED conducted fundraising campaigns to provide mobile mammography units to underserved areas. While the screenings were covered by state funds, ED paid for their operation, thus extending the formal care system. As mammography became more widely available, the organization shifted its focus to ensuring quality standards for oncology in treatment of breast cancer. This mission is in line with that of ED’s international federation, but it is possible in Croatia only because of ED’s medical leadership and its history of collaboration with the health care system. ED also continues to operate in “club” mode, with a physician as its national leader and activities and meetings run by members in chapters throughout Croatia.

Other NGOs that take a consumerist approach have reached into the emerging corporate sector for support. For example, during the last four years, a new NGO – *Sve za Nju* (“Everything for Her”) has created a center for psychosocial support for women with breast cancer and connected with the Avon company to sponsor fundraising walks much like those held in the West. *Sve za Nju* publishes monthly on-line newsletters focused on patient education as well as a series of monographs adapted from materials from the American Cancer Society (*Edukativne knjižice ženama oboljelima od raka I njihovim obiteljima* – “Educational booklets

for women with breast cancer and their families,” including one on “diet and exercise during treatment” and one entitled “message of hope”). With sponsorship from a drug company (Roche) and a telecom server (VIP), *Sve za Nju* has most recently developed a “Breast Test” app for mobile phones, which includes a timed reminder and instructions for doing a monthly breast self-exam (<http://www.svezanju.hr/projekti/266-promocija-kampanje-breast-test.html>).

Cancer-related NGOs like ED and *Sve za Nju* are not alone in adopting a consumerist approach supplemental to the formal health care system. Clubs for Treated Alcoholics also began with the sponsorship of formal health care institutions, but with lay management of the clubs themselves (Marušić and Maravić 2008).¹⁵ The objectives of one such club illustrate how patient education and reinforcement of a medical treatment agenda are core to its mission:

- Continuation of treatment and resocialization of alcoholics and their families
 - Establishing harmonious relations in families of alcoholics, which were consistent affected by alcohol
 - Development of the principle of self-help and mutual assistance among members and their families with the goal of abstinence
 - Ongoing education of all members and their families in order to be more familiar with their disease and its treatment methods
 - Helping members who have difficulty in treatment, especially in case of recurrence, and helping through friendly visits to families to continue treatment
 - Explaining the problem of alcohol dependence and active inclusion of in the local community
 - Promotion of cultural, sporting and other activities that will facilitate and strengthen abstinence of the members
- <http://www.info-marija-bistrice.hr/index.php/en/associations-clubs-societies/clubs/178-club-of-alcoholic-in-treatment-bistrina>

In short, consumerism among Croatian health-related CSOs has not developed as a challenge to professionalism so much as a supplement to it, with a primary focus on the agency and responsibility of patients. The groups discussed here exhibit a high degree of professional involvement, even if their formal leadership is non-professional. None of them completely rejects professional control or refutes a biomedical approach. While NGO members might voice private dissatisfaction with treatment by particular providers, or with the intransigency of public medical institutions, the stance of these NGOs towards medicine has been predominantly one of partnership, seeking collaborative relations with health professionals and the institutions and corporate elements of the health care sector.

Discussion

Neither the life stage of NGOs nor whether they pre-date the transition from socialism differentiates those operating with a bio-citizenship framework from those addressing health consumerist issues. Their specific missions and, for the most part, the identities of their constituents also fail to determine the orientation of particular NGOs towards these models. Instead, factors unrelated to health or disability status, including other claims on the political

arena and connections with health professionals, appear influential to the approach adopted. The division between NGOs focused on entitlements and those advocating goals of inclusion does fall, to some extent, along the lines of age, as those that are older are more likely to have “legacy missions,” compared with those founded more recently. This has less to do with chronology, however, than with the extent to which institutionalized entitlements are still politically protected. In terms of newer projects, a focus on “inclusion” has been promoted by external funders, as well as EU standards, but without any ability to mandate inclusion on a programmatic level, as the barriers to community-based care demonstrate. There is some preliminary indication that newer, disability-related NGOs with higher income members and ties to state ministries are more likely to push forward rights-based claims. Those lacking such connections are neither rights- nor consumer-oriented, however, but rather, more likely to promote activities enhancing the quality of life (e.g., arts and crafts activities or recreational outings).

Consumerist approaches reflect the continued state monopoly as the primary insurer of health care, as well as the professional dominance of physicians in the health care system. As far as it goes, then, consumerism supplements professional medical agendas, for example, by providing patient education and encouragement to follow professionally prescribed regimens. It is too early in the use of private care to predict whether increased competition will promote change in the direction of health consumerism, but the fact that the same primary providers have both public and private practices will, at the least, dampen consumerist tendencies. At present, rather than seeking care from competing private providers, patients are more likely to combine the use of public and private sources, for example using private sources to get examinations yielding diagnoses that can then be used to shorten the waiting time in the public system. Claims for “consumer rights” and choice have thus expanded and are likely to continue to expand, but not necessarily alongside a consumerist ethic similar to that in the West.

Inequalities in access to care are increasing the importance of NGO activities, even as the organizations themselves remain subsidiary actors in the health care system. Despite the retention of universal health care entitlements through public insurance, access to care has become problematic for those who cannot afford to seek diagnosis or treatment through the private sector. Privatization has distributed health risk and inequality of access to care on different bases than formerly; where geographic or categorical sources of inequality used to pertain (and to some extent still do), now the ability to afford care in the private sector cuts across all regions and categories of individuals as a potential deterrent to health.

NGOs, in contrast, have retained a categorical basis; that is, they represent and advocate for categories of people defined by diagnosis, condition, identity, or status. Health-related NGOs thus fill an increasingly important but subsidiary role to that of the state: offering access for individuals in exceptional cases of need for things the state does not supply and increasing the visibility of categories that might otherwise elude state attention. This is the case whether they evolved out of parts of state systems reconfigured into non-state organizations, or arose following state transformation. In either event, the role of health-related NGOs remains largely residual: they can extend state auspices, they can correct market deficiencies on the level of individuals, but they do not address issues of poverty or other structural conditions underlying current disparities in health care. No health-related NGOs were found to have an agenda specifically addressing such issues, and respondents from diverse backgrounds reported that NGOs serving poor or marginalized populations seldom tackle issues in the health care arena. Arguably, to set a more proactive advocacy agenda in health care would require a change of organizational structure and mission for NGOs, both individually and as a part of civil society.

While these findings might be taken to support the claim by Rose and Novas that “collectivities organized around specific biomedical classifications are increasingly significant.” (2005: 442), *bio-citizenship per se* is not necessarily the motivation or focus of the collective efforts reported here. Other issues in the foreground for these NGOs include questions of social justice, nationalist politics, social inclusion, and provider/patient relations. Indeed, the “*rejection of biology is a salient organizing feature for some*” (Plows and Boddington 2006:5), such as those seeking social inclusion. These differences appear critical for the goals sought and practices undertaken, as well as relationships with state, professional, and corporate actors.

Disability-related NGOs provide a particularly trenchant example of this fragmentation of objectives. While some represent members as disabled citizens entitled to social provision, others press more singularly for access to care, and yet others seek inclusion with the non-disabled, in essence rejecting a biological basis for their shared cause. While this study did not examine the implications for members, these different claims respectively reflect views of disability as a core element of identity, a strategic focus to be used in political negotiations, or irrelevant to citizen rights. As noted in the critique of the concept of bio-citizenship as reductionist made by Plows and Boddington (2006), “The core issue here is to recognize and the complexity and ambivalence surrounding any construction of identity and related citizenships, because identities are multiple and also fluid.” (123) We would add that this applies to collective, as well as individual, identities. The NGOs represented here should thus be understood as “multiple publics....contesting power relations in multiple arenas” (Boddington 2006.:130), rather than assumed to have bio-citizenship or health consumerism as a core, let alone sole, mobilizing frame.

Conclusion

Contextual elements centrally shape the meaning of models used by health-related NGOs in Croatia. Those pressing for state action using a rights-based discourse may deploy such pressures as part of broader claims on the political arena, legacies of entitlements, and/or a rhetoric of inclusion mandated (but without enforcement) by external standards. In contrast, NGOs promoting a health consumer model act as intermediaries between individuals and state or provider institutions. These organizations seek to enrich formal systems, enabling individuals to be fully involved in their health care. Consumerism thus augments professional medical dominance and the state monopoly of health finance, while also increasingly depending on corporate sponsors. In both cases, NGOs both supplement and challenge the health care system, without directly contesting broader social and structural disparities in health.

In applying models of bio-citizenship and health consumerism, this paper has identified variations that, in the end, force a reconsideration of those frameworks. While any of the approaches discussed – including those termed “consumerist” in this context – could fall under the rubric of bio-citizenship, consideration of this array reveals an inherent lack of conceptual and empirical rigor in the concept. More broadly, social welfare in such transitional settings has long been typified by a mix of actors and objectives. Models of social citizenship in these places are similarly mixed, as actors, including NGOs, have diverse relations with state entities at different levels. The result that is emerging differs significantly from models based on the experience of Western democracies, even if some objectives and actions of collective actors share a surface resemblance.

Understanding the impact of civic associations in mediating the results of transition to democratic market economies is particularly critical when it comes to essential areas such as health care, where state provision has contracted and remains contested parallel to massive growth in private systems. By identifying factors promoting divergent turns within civil society, this analysis has interrogated the consequences for the contribution of NGOs. In turn, this addresses wider concerns about the consequences of both bio-citizenship and health consumerism for representative democracy and distributive social politics in contemporary post-communist states.

¹ An abbreviated form of this paper was presented at the Fourth Health in Transition Conference, Riga, Latvia, August 2015. An earlier version was presented at the 2014 conference of the International Society for Third Sector Research, Münster, Germany, and is included in that conference's Working Papers.

² Research for this paper was supported in part by a Fulbright Scholarship in Zagreb, Croatia, February to July, 2013. The authors express gratitude to colleagues and students at the School of Social Work, Faculty of Law, University of Zagreb, for their kind assistance with this work.

³ The terms used to denote such sectors, organizations and programs vary with the laws of incorporation in particular settings, as well as the analytic purposes of scholars. Key variants include "civil society organizations," "nonprofit organizations," or "non-governmental organizations," along with their respective acronyms. "NGOs" and "CSOs" are the forms we use because they are most commonly applied in analyses of post-socialist developments in health care and social welfare. The OECD defines CSOs as "the multitude of associations around which society voluntarily organizes itself and which represent a wide range of interests and ties" (OECD 2007). In general, we use "NGOs" to designate *udruge*, or "associations," and in particular those dedicated to health and social welfare issues. "CSOs" refers to broader categories of organizations, or is used where source material employs that term without distinguishing among sub-sectors.

⁴ This is likely to have changed. The Croatian government required all NGOs to re-register effective October 1, 2015, and to include identifiable information on their members.

⁵ Experts named support for the poor and marginalized, with particular emphasis on people with disability, as an area of strong CSO impact on society: the first-ranked area of impact according to external stakeholders and second only to that of education and training according to the CSOs themselves. Respondents saw less CSO impact in relation to health; even so, such impact ranked above that on humanitarian relief, employment and housing. Policy experts also commonly named health care as an area where CSOs have an effect on social policy (Bežovan and Matančević 2011).

⁶ For further description of the history and current status of civil society organizations in Croatia, see Bežovan and Zrinščak 2007, Coury and Despot Lučanin 1996, Croatia 2007, Dill 2014, and Stubbs and Zrinščak 2009.

⁷ Government ministries contribute an average 40% share of CSO revenues, and cities and counties, an additional total of over 18% on average (Bežovan and Matančević 2011). According to a recent CIVICUS report (Bežovan and Matančević 2011), in 2009 CSOs received 529,596,954.21 Kuna (roughly 71 million Euro or 67 million US dollars) in national governmental funds, 53% of which came from the state budget and 46.2% from the national lottery.

⁸ We are indebted to Prof. Linda Cook, Brown University, for suggesting this concept.

⁹ For example, the head of the Association of Organisations of Disabled Persons in Croatia (now *Zajednica saveza osoba s invaliditetom Hrvatske*, or "SOIH") was one of twenty members of the

Working Group charged with development of the “National strategy for the creation of an enabling environment for civil society development from 2006 to 2011,” as established by the Decision of the Government of the Republic of Croatia of 12 January 2006 (Government Office for Cooperation with NGOs, 2006.) The only other health-related NGO so represented was the Association of Croatian Patients Association, a patient’s rights organization headed by a physician. The National Coordination of Associations of Homeland War Veterans was also represented. As an umbrella organization, or coalition, SOIH encompasses diverse disability-related associations, only one of which pertains to cognitive, intellectual, or psychiatric conditions, the Croatian Association for Persons with Mental Retardation - HSUMR. SOIH’s members also include the Federation of Civil War Invalids of Croatia; thus, NGOs for these war veterans were doubly represented among the Working Group members, with an additional membership going to the Ministry of the Family, Veterans’ Affairs, and Intergenerational Solidarity. The head of SOIH is now one of twelve civil society organization representatives elected through a poll of associations to the Council for Civil Society Development, an advisory body to the national government; the (veterans) organization of Associations related to the Homeland War also has membership on the Council. (<http://www.uzuvrh.hr/page.aspx?pageID=132>) This is not to say that veterans associations are satisfied with the extent to which their entitlements are provided. In May 2015, such associations organized a rally in the main square in Zagreb, drawing over 50,000 to protest for war veteran rights, capping a protest camp set up over six months previously in front of the War Veterans Ministry. <http://inavukic.com/2015/05/03/croatia-rights-of-people-with-disabilities-need-urgent-attention/>

¹⁰ Financial reports of the Croatian Union of Physically Disabled Persons (HSUTI) show a 36% increase in revenues received from the national budget between 2010 and 2011, during a period when the global financial crisis was significantly affecting Croatia. The following year, as disability-related NGOs were reported to have received an across-the-board cut of over 60% in state funds, HSUTI showed a decrease of 16.4% in revenues from the national budget. (http://www.hsuti.hr/Prihodi_i_rashodi_za_2011.pdf http://www.hsuti.hr/Prihodi_i_rashodi_za_2012.pdf) While these figures are suggestive of a favorable position vis-a-vis the state, they should be interpreted with caution, since lack of centralized data and flows of funding through different ministries make it problematic to compare overall financial support across associations.

¹¹ Examples include EU pre-accession grants enhancing physical accessibility and employment opportunities for people with physical impairment, and a personal assistant program (developed by the Ministry of Family, War Veterans and Inter-Generational Solidarity) exclusively focusing on individuals with physical disabilities, with particular emphasis on veterans and with no intention to expand it to other categories of disability.

¹² Supportive community placements are available for a miniscule number of people with chronic mental illness and less than 3% of those with intellectual disability. Human Rights Watch (2010) identified roughly 250 places in supportive community living programs for persons with intellectual disabilities (only seven of which were for adults with chronic psychiatric difficulties), vs. nearly 12,000 institutional placements. As well, at the end of 2008 approximately 7,300 people with intellectual disabilities and 4,400 people with chronic mental illness lived in social welfare homes, family homes and foster family arrangements; social welfare homes housed the vast majority. Comparable data on residents in long-term psychiatric hospitals were unavailable. Using 2007 official statistics, the World Bank identified 40 social welfare homes (26 of them, state homes) for people with disabilities, serving 5,038 beneficiaries. There were 121 homes for the elderly and infirm (47 under local authority, i.e., county, auspices; 74, non-state), with 14,168 beneficiaries. For people with chronic mental illness, 25 homes (18 of them state homes) served 3,903 beneficiaries. World Bank, [Long Term Care Policies for Older Populations in New EU Member States and Croatia: Challenges and Opportunities; Case Study 2: Croatia.](#)

<http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/ECAEXT/0,,print:Y~isCURL:Y~contentMDK:22785587~menuPK:3970758~pagePK:2865106~piPK:2865128~theSitePK:258599,00.html> The World Bank has continued to fund refurbishment of institutions, while community-based service programs initiated through WB funding were discontinued after three years, reportedly because of lack of government involvement in their continuation. This remains an issue receiving international attention: On April 17, 2015, the UN Committee on the Rights of Persons with Disabilities recommended that the Croatian government should do more to protect the rights of people with disabilities, including legal reform and ensuring that everyone with a disability who is in an institution has the opportunity to move into the community. Involuntary commitments and use of restraints were identified as abuses of human rights, and the Committee also voiced concerns about the extent to which disabled persons in Croatia are denied legal capacity, with over 18,000 individuals placed under guardianship.
<https://www.hrw.org/news/2015/04/27/croatia-un-calls-critical-disability-rights-reforms>

Overall, social inclusion remains poorly developed in Croatia: data presented by the Croatian Cerebral Palsy Association, in a report of a conference in Zagreb held by the European Disability Forum, indicate that less than 6% of people with disabilities who are of working age (19-64) in Croatia are employed, compared to 45% of that population in the rest of the EU.

http://translate.googleusercontent.com/translate_c?depth=1&hl=en&prev=/search%3Fq%3Ddrustvo%2Binvalida%2Bcerebralne%2Bi%2Bdecije%2Bparalize%2BHrvatska%26client%3Dfirefox-a%26hs%3D12g%26rls%3Dorg.mozilla:en-US:official%26channel%3Dsb&rurl=translate.google.com&sl=hr&u=http://www.hsucdp.hr/u-zagreb-odrzana-prva-europska-konferencija-o-polozaju-osoba-s-invaliditetom/&usg=ALkJrhjnz6IYXTQWC1n0LhfNTm6u5ngJoQ Posted 5/20/14.

¹³ Service activities include: provision of six rent-free apartments in Zagreb for families with a child in treatment for a malignant disease; use of email, internet and other facilities at their center; individual information, advice, and support; support groups and counseling; financial support for transportation expenses; publishing educational materials on childhood malignancies; and others. Rights-focused activities include: “legal and other help with achieving rights from the health and social service systems;” and “striving to make the health system recognize and admit the benefits of...therapy dogs;” “inclusion of professionals in creation of the protocols on communication and conduct of medical professionals in extremely sensitive and difficult cases;” and lobbying and advocating for the rights of children inter alia.
<http://www.krijesnica.hr/about/views-21-fireflies-activities>, accessed 6/9/14.

¹⁴ This description is based on long-term acquaintance and interviews with ED members and leadership, as well as participation in ED-sponsored events, beginning in the early 1990s.

¹⁵ In addition to interviews with leaders of these clubs and the Association, this material derives from participation in the Association’s 2012 annual meeting in Opatija, Croatia.

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