Bio-citizens or Health Consumers?
How CSOs Negotiate State and Individual Responsibility for Health in Croatia

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Introduction

Now more than twenty years since the transition from socialism, Croatia’s civil society sector encompasses diverse and dynamic actors responding to global as well as national influences. In the sectors of health care and disability, Civil Society Organizations (CSOs) address disparities in health and access to care emerging from the privatization of services, state retrenchment, and growing economic inequality. Different aims, methods, and institutional logics underlie the agendas and actions of these diverse organizations.

This paper examines the two models embodying competing objectives and claims, that of citizenship rights, and that of health consumerism. These models draw on different logics and discourses, center on divergent aims and methods, and promote different agendas and 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, focuses on promoting rational, informed individual decision-making in the context of a global market of biotechnology and health care (Sulik and Eich-Krohm 2008).

Based on public documents, observation of CSO meetings, and interviews with relevant experts and CSO leaders and members, this paper examines the applicability of these models to Croatian CSOs addressing diverse health and disability concerns. CSOs emphasizing bio-citizenship press for extension of state and professional actions using rights-based discourse and claims. The nature of these claims varies, however, reflecting differences in underlying objectives. In contrast, CSOs that bring the health consumer model into play act as intermediaries between individuals and state or provider institutions and provide critical forms of support and information to individual care-seekers. These organizations thus seek to enrich and supplement formal care systems as well as enhance the consumerist abilities of care-seekers.

Neither the age of CSOs (e.g., whether they pre-date the transition from socialism) nor the specific condition addressed differentiates those operating with a bio-citizenship framework from those addressing health consumerist issues. 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 analysis further explores how variation in the models deployed by health- and disability-related CSOs is linked to increasing complexity in the stratification of recipient populations and competing forces shaping health policies.

**Rationale: The Third Sector and social citizenship**

Since the 1990s, shifts in the policies, politics and programs of social welfare have altered relations between individuals and the state, leading to analyses reframing the concept of social citizenship (Evers and Guillemard 2013). The changes center on neoliberal reformulations of the welfare state, but are not reducible either ideologically or programmatically to them. Also implicated are internationally present trends: 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 analysis of these developments, Johansson and Hvinden (2013) identify three underlying models of social citizenship that are not merely co-existent in different ways, but mutually influential with regard to the expected roles and responsibilities of individuals and states. A Socio-liberal model focuses on mutual rights and obligations; the Libertarian approach emphasizes individual responsibility and choice within a market context; and the Republican model emphasizes the participation and self-governance of users (Ibid, pp. 50 ff.). Elements from each of these combine in welfare reform debates, producing hybridization both programmatically and ideologically.

Analyses of health care systems evolving during the same period have documented similar developments. While sharing some conceptual roots (in particular, Foucauldian notions of surveillance and governance) with discussions of social welfare, models here pertain less to transformations at systemic and global levels, and more to the negotiation of state support by particular categories of people. 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; Novas and Rose 2005) extended the term to encompass the shared identity, knowledge and understandings of communities advocating for biologically-based rights. This formulation sees the active undertaking of such knowledge and actions as both individual and collective moral obligations.

While sharing with bio-citizenship the late 20th Century disjuncture with claims made by virtue of membership in a nation state (cf. Novas and Rose Op. cit.), health consumerism has a longer trajectory, tracing to Western consumer and anti-professional social movements of the 1960s and ‘70s (Sulik and Eich-Krohm Op. cit.). These earlier activist movements demanded increased state control of corporate actors, both those which had adverse impacts on health and 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).

Despite the clear linkages between models of social citizenship, on the one hand, and discussions of bio-citizenship and health consumerism, on the other, neither set of literature appears to have incorporated the other. Bio-citizenship resonates most strongly with Socio-liberal and “Republican” (per Johannson and Hvinden) elements based on rights, obligations, and participation; consumerism parallels Libertarian models termed alternately “citizen consumers” or the “consumer citizen” (Johannson and Hvinden 2013, pp. 39 ff.). Moreover, whether the individual (or, for that matter, a collective agent) is more active or passive – an important consideration in understanding the nature of social citizenship – does not distinguish the two sets of approaches, though bio-citizenship implies more active citizen engagement. There is thus considerable room to broaden the concepts of bio-citizenship and health consumerism by seeing them within the context of social welfare reform. In turn, the specific ways in which welfare models are manifest in health care may illumine the openings between and within those models as well as their hybridization in practice.

More critically for the purposes here, there is good reason to interrogate the elements and institutions that connect individual or collective actors with state and market forces within all of these approaches. This is, for example, 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. Indeed, efforts to promote civil society development in societies transitioning from socialism relied on this mediating function as a way to develop democratic civic norms and practices, and to protect individuals and populations 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 the third sector (and specific CSOs) addresses the “tensions, conflicts and ambiguities” that accompany new hybrid models and expectations at micro and macro-levels (Johannson and Hvinden 2013, p. 52).

To illustrate the forms such mediation is likely to take, consider some fundamental contributions attributed to CSOs: educating and building knowledge about conditions, services, and rights; improving resources and skills for claims-making; providing arenas for social participation and “active citizenship;” articulating claims – material, political, and symbolic – and monitoring accountability; expressing grievances and advocates on individual and collective levels; and acting as providers and co-producers of services (Edwards 2004; Pestoff 2011). Most of these could serve their purpose within any model of social citizenship, e.g., to educate and advocate for rights within the Socio-Liberal approach, or to inform choice within a Libertarian one. Co-production would serve advocacy and access objectives within a Socio-Liberal model, an expansion of privatized options within a Libertarian model, and purposes of participation and self-help in a Republican approach. Seeing how the practices and assumptions of those models are actually expressed in CSO practice would thus shed light both on the experience of social citizenship today and on the significance of the third sector.
Civil Society and health care in Croatia: Background and Current Status

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 reappear 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 Lučanin1996, 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, because of its state-building agenda and late Europeanization, in Croatia democratization proceeded more slowly than elsewhere (Stubbs and Zrinščak 2009).

More favorable state attitudes established dialogue with CSOs in the first years of the millennium, increasing the visibility and legitimacy of civil society. Notwithstanding some fluctuations since then, conditions for civil society development have generally remained favorable, and Croatia is closer to post-communist Central Europe countries with stronger civil societies (like Slovenia, the Czech Republic, or Poland), than to countries which experienced strong 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 CSOs examined here, health care in Croatia has undergone privatization since independence. 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. As well, 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 with the semi-autonomy of Yugoslav republics and self-management (Mastilica and Kušec 2005).

Since these developments, there has been growing inequality in health and health care within Croatia, with adverse effects for access to care, preventative approaches, specialty care delivery, standards of care, and health outcomes, from self-perceived health to mortality (Chen and Mastilica 1998; Kunitz 2004; Mastilica and Kušec 2005; Šućur and Zrinščak 2007). This is particularly the case for socioeconomic disparities and outside major urban areas, as well as for marginalized and vulnerable populations.

CSOs in Croatia have a long history of connection to the health care system. Health-related CSOs have had medical and public health care professionals as leaders, consultants, and participants. 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 CSOs (Dill and Coury 2008). The WHO “Healthy Cities” initiative was likewise initiated by public health physicians in the decade before independence and remains active in multiple sites
throughout the country. Physicians founded currently active CSOs for hospice care, women with breast cancer, alcohol dependency, and bi-polar disorder, among other conditions; even patients’ rights CSOs were founded and remain led by physicians.

It is difficult to verify the numbers, membership, and impact of health- and disability-related CSOs related to health and disability due to issues in the availability and comparability of current data. 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.

To identify health- and disability-related CSOs for this study, we therefore followed an examination of the National Register with analysis of available CSO websites as well as interviews with knowledgeable experts and public officials. This yielded roughly 500 separate health- and disability-related CSOs, excluding trade unions, professional associations and individual members of umbrella, federated, or coalitions of associations. Most 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 like the Roma.

Health-related CSOs, and particularly those concerned with disabilities, are acknowledged as a relatively influential part of civil society in the most recent CIVICUS survey of CSO representatives and external policy experts (Bežovan and Matančević 2011). CSOs have become service providers in nursing home 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 how CSOs address health-related issues come from the green movement, self-help, mutual support, and 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. Yet the impact of these functions – whether positive or negative – for the bigger picture of health care delivery has yet to be assessed.

Health-related CSOs: The Importance of the State

While legally separate from the state, Croatian CSOs are not, strictly speaking, independent of it. The state retains its dominance in social welfare and the health care system, for example, being the sole source of primary health insurance. Many health- and disability-related CSOs are privatized forms of state-controlled initiatives from the Yugoslav era, meaning that state-organized entities transferred to auspices formally under private direction, but still largely dependent on public resources. The state, in these cases, was less hollowed-out than repositioned. These CSOs range from advocacy groups for people with different disabilities, to
“clubs” and “self-help groups” for patients with diverse conditions (e.g., diverse cancers, hypertension, and diabetes), generally formed by or in association with professional providers and institutions (Dill and Coury 2008).

Those CSOs arising since Croatian independence have largely originated among urban, relatively educated populations with connections to professional organizations and institutions, including those of the state such as particular bureaucracies or ministries. So, although formed as categorical membership associations, they did not, and do not, have boundaries totally distinct from those of state institutions. Moreover, all NGOs depend on precarious programmatic and project funding from the national governmental level. Government ministries contributing an average 40% share of CSO revenues, and cities and counties, an additional total of over 18% on average (Bežovan and Matančević 2011). 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 CSOs rather than increasing their organizational autonomy (Dill 2014).

Policy, legal, and financial frameworks established by the state have created different opportunity structures that affect CSO resources, missions, and livelihoods. Divisions between CSOs that deal with physical as opposed to mental or intellectual disabilities particularly reflect how some CSOs benefit more than others from legacies of prior organization and connection to the state, although relations between the state and civil society are complex, and CSO longevity per se does not necessarily translate into a more favorable position.

Differences between CSOs dealing with physical versus mental or intellectual disabilities illustrate how some CSOs benefit more than others from legacies of prior connection to the state. Associations of people with physical disability pre-date Croatian independence: associations for disabled veterans formed following the Second World War, and other leagues and associations 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 CSOs for people with physical disability and, among those, particularly associations of veterans -- operate with “legacy missions” that are reliably represented in policy discussions and government-sponsored committees relevant to sector development. While it is beyond the scope of this research to assess the extent of their funding from the state, they are considered relatively unassailable in terms of state support. Social policy and program development have favored their constituents. 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.

In contrast, CSOs 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 programmatic development by such associations, social policy has stalled around the development of a public plan for community-based care for affected individuals. Supportive community placements are available for a miniscule number of people with chronic mental illness and less than 3% of those with intellectual disability. The government has committed
itself to deinstitutionalization, but development of a strategic plan for community-based care has been slow in forthcoming, delayed by current economic conditions and related concerns. 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.\textsuperscript{ix}

As demonstrated next, the position of CSOs vis-à-vis the state is an important contextual element defining the nature of both rights-based claims and health consumerism.

CSOs, “Rights” and “Health Consumers”

It is important first to acknowledge that to define CSOs in terms of missions and activities related to rights versus those with a consumerist orientation, would greatly over-simplify the orientation and practices of most CSOs in the health arena. In prior analysis, we have 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), psychosocial 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, including purely recreational ones such as summer camps. CSOs 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, CSOs provide information, education, advice, and referrals for care to both members and the public at large. As well, they offer concrete personal support, e.g., 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 CSO 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.

Rather than investigating empirical illustrations of ideal types, it might therefore be more accurate to typify CSOs 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. As an example, K\textsubscript{ri}j\textsubscript{es}nica (“Firefly,” “an association for helping children and families facing malignant diseases,”) lists many service activities on its webpages alongside lobbying and advocacy \textless http://www.krjesnica.hr/\textgreater . Most health- and disability-related NGOs would include some such combination, though the exact activities as well as the extent to which each type of approach receives emphasis would, of course, vary. Further research would be needed to find and apply indicators for assessing the balance between these approaches. Still, it
is possible through case examples to illustrate some particular and distinctive forms each assumes in the current Croatian context.

First, there are several variations in the manifestations of what might be deemed rights-based claims. Some older CSOs, particularly those noted as having “legacy missions,” are intent on maintaining the entitlements already accorded their constituents. Associations for disabled veterans have the maintenance of members’ rights as a central part of their mission and are generally successful in achieving it, as noted. Groups representing individuals with particular disabilities, descendants of associations from the 1950s-70s, 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. Since the Association provides assistive and adaptive technology as well as certifying which individuals can receive free transportation tickets, membership in it provides, in essence, an enhancement of citizenship rights. A rights-based emphasis is further evidenced in activities such as a workshop held this April for representatives of leaders from country-wide associations for the deaf as well as blind, entitled “Advocating for change in public policy in the local community” [http://www.udruga-slijepih-zagreb.hr/index-s.html](http://www.udruga-slijepih-zagreb.hr/index-s.html). One of five workshops in the association’s NGO Open Days program this June was “And the blind and deaf people have a right to watch television” (advocating for enhanced audio descriptors). Even a demonstration of sensory gardening 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 projects of this association are focused on transforming care from its current institutional base to community settings. In one, it is currently partnered with the Ministry of Social Policy and Youth and the Centre for Adult Education “Validus” in a three-year, Open Society Institute-funded project; another involves EU initiatives, and others center on creating subsidiary centers throughout Croatia [http://inkluzija.hr/eng/about-api/](http://inkluzija.hr/eng/about-api/). *Udruga za Samozastupanje* (“The Association for Self-Advocacy,” [http://www.samozastupanje.hr/](http://www.samozastupanje.hr/)), which often allies itself with *Inkluzija*, focuses on an even broader set of claims in its Winter 2013 newsletter description of 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 cannot (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

Claims for rights and forms of social inclusion are found as well among non-disability-related CSOs. RODA (Roditelji u akciji, “Parents in Action,”) was begun in 2001 by parents objecting to cuts in maternity leave benefits. Focused on the rights of pregnant women, parents and children, the organization advocates for parental leave commitments and other health care rights, including that to medically-assisted conception (Evers and Ewert 2012). Recent postings 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](http://www.roda.hr/article/category/u-akciji). A further example of claims-making 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 funding expensive biologic drugs from hospital coffers rather than a fund for expensive drugs within the national health insurance program [http://www.index.hr/vijesti/clanak/pacijenti-oboljeli-od-cijevnih-bolesti-omogucite-svima-jednaku-dostupnost-bioloskih-lijekova/748066.aspx](http://www.index.hr/vijesti/clanak/pacijenti-oboljeli-od-cijevnih-bolesti-omogucite-svima-jednaku-dostupnost-bioloskih-lijekova/748066.aspx), posted 5/18/14.

What unites these examples are claims to recognition of the specific rights of the represented group, to 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 and individual inclusion in the process of care rather than an extension of state-provided support.

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; for the association’s draft of the legislation, see [http://www.pravapacijenata.hr/eng/pdf/stradovi/Law.pdf](http://www.pravapacijenata.hr/eng/pdf/stradovi/Law.pdf)). Beyond detailing rights to health care, respect for dignity, informed consent, refusal of care, and so forth, the act specifies obligations and responsibilities of users as well as providers of care, defining the provision of services as contractual in nature. While this legislation has yet fully to impact health care provision, informed consent procedures are gaining force in institutional settings, and requesting a second opinion (another of the provisions of the legislation) has reportedly 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. Such actions fall generally within a Libertarian paradigm, as discussed by Johansson Hvinden (Op. cit.), with emphasis on the rights of individuals and their exercise of choice to promote their own well-being.

To develop even more sense of consumer choice, moving further in the direction of “consumer-citizenship” (Ibid., p. 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 CSOs 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-‘80s, self-help groups for people with hypertension, diabetes, alcoholism, and other conditions formed around objectives of promoting 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 direct 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 became registered as NGOs, and their numbers were augmented by many newer groups serving individuals with a wide variety of conditions.

A Croatian branch of the European breast cancer advocacy organization “Europa Donna” (ED), which emerged from the cancer club structure, remains active today and provides an instructive example of the evolution of consumerist approaches. This NGO was founded and is still led by a physician, although its club meetings are organized and run by patient members. Initially it subsumed the “cancer clubs” for women who had breast cancer surgery, framing this as an offer of 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 its international connections, which the nationalist state viewed, in general, with suspicion and which required membership dues rather than providing material resources. In the mid- to late ‘90’s, ED used fundraising campaigns to provide mobile mammography units to underserved areas, extending the formal care system. As mammography became more widely available through private as well as public means, the organization shifted focus and began to focus on establishing and ensuring quality standards for oncology in treatment of breast cancer. This mission is in line with that of the international umbrella organization of ED. In the context of Croatia’s becoming an EU member, that international connection is now an advantage, but the new mission is uniquely feasible for ED because of its long history of ties with the medical system and professional leadership.

Over the last four years, while ED has still supported clubs, 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 in 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 to do a monthly breast self-exam along with instructions for doing it http://www.svezanju.hr/projekti/266-promocija-kampanje-breast-test.html.
Like the self-help groups and cancer clubs, Clubs for Treated Alcoholics evolved under professional sponsorship but with lay management (Marušić and Maravić 2008). 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**


In short, consumerism among Croatian health-related CSOs has not developed as a challenge to professionalism so much as a supplement to it. While it includes efforts to promote accountability of providers, the greater focus is on the contractual obligations of the patients. The groups discussed here arguably exhibit a fairly high degree of professional involvement, even if their formal leadership is non-professional, and none have been found completely to reject professional control or the biomedical model. While NGO members might voice private dissatisfaction with treatment by particular providers, or with the intransigency of public medical institutions, the stance of NGOs towards health professionals has been predominantly one of partnership and non-adversarial relations.

**Discussion and Conclusion**

Neither the age or life stage of CSOs (e.g., whether they pre-date the transition from socialism) nor the specific condition addressed appears to differentiate those operating with a bi-citizenship framework from those addressing health consumerist issues. 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. As well, variation in the models deployed by health- and disability-related CSOs is linked to increasing complexity in the stratification of recipient populations and competing institutional logics (e.g., professional, administrative and economic) shaping health policies. In particular, those with more middle class members and professional connections are more likely to push for rights-based advancement. Others are not necessarily consumer-oriented, but rather, more likely to promote activities enhancing the quality of life (e.g., arts and crafts activities, recreational outings, camps).
The division between those CSOs adopting a focus centered on entitlements and those advocating goals of inclusion of participation does, to some extent, fall along the lines of those that are older, with “legacy missions,” versus those founded more recently; but this has less to do with chronology (not all older CSOs take any given approach) than with the extent to which institutionalized entitlements can still be politically protected. A focus on “inclusion” has been promoted by externally sponsored projects as well as EU standards, but without any ability to enforce or mandate inclusion, as the barriers to community-based care demonstrate. Professional and institutional dominance lie behind the expansion of “managed participation” and consumerist approaches, as far as they go. Given the state monopoly as the primary insurer, in addition to professional dominance, consumerism still supplements professional medical agendas, e.g., 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.

Last, inequalities in access to care are increasing the importance of CSO activities, even as the organizations themselves remain subsidiary actors in the health care system. Despite the retention of universal health care entitlement 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. Thus health-related NGOs 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 (such as rare illnesses of children) that might otherwise elude state attention. This is the case whether they evolved out of parts of state systems reconfigured into non-state structures, or arose in response to state transformation. In either event, the role of health-related NGOs remains largely residual: they can amend and 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. Arguably, to set a more proactive advocacy agenda would require a change of organizational structure and mission for NGOs individually and collectively.

Understanding the impact of CSOs 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 of
providers and institutions. By identifying factors promoting divergent turns within civil society, this analysis has interrogated the consequences for the contribution of CSOs. 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.

Works Cited:


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\(^1\) Presented at the 2014 conference of the International Society for Third Sector Research, Muenster, Germany.

\(^{ii}\) The empirical material presented here and in subsequent sections was derived from systematic analysis of the National Register of CSOs in Croatia, examination of public documents and websites, observation of CSO meetings and conferences, and interviews with CSO leaders and members as well as policy experts.

\(^{iii}\) 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).

\(^{iv}\) According to the latest 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.

\(^{v}\) I am indebted to Prof. Linda Cook, Brown University, for suggesting this concept.

\(^{vi}\) 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)

\(^{vii}\) 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.
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/WEBSITE/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.

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http://translate.googleusercontent.com/translate_c?depth=1&hl=en&prev=/search%3Fq%3Ddrustvo%2Binvalida%2Bcerebralne%2Bdece%2Bparalize%2BHrvatska%2B%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-zagrebu-odrzana-prva-europska-konferencija-o-polozaju-osoba-s-invaliditetom/&usg=ALkJrhjnz6fYXTQWC1n0LhfNTm6u5ngJoQ Posted 5/20/14.

x 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-fireflys-activities, accessed 6/9/14.