

CCRC Resident Bill of Rights

During its May 2015 Teleconference the Board of the National Continuing Care Residents Association (NaCCRA) adopted a prototype Bill of Rights which is appended.¹ The intent has been to enact such Rights into law on a state by state basis. Rights for Nursing Home residents were enacted on Federal basis in the Omnibus Budget Reconciliation Act of 1987 and that approach as part of a larger Federal bill has caused problems.

Given the many demands on Congressional resources, it may not have had the full consideration that it deserved; it simply moved through the legislative process as part of a larger whole. The lesson to be drawn from that experience, though, is that it is harder to correct unintended consequences of Federal enactments, as they become evident with experience, than it is to fine tune legislation at the state level.

Now that a year has passed since NaCCRA last considered the Bill of Rights, we can make a few observations based on the reflection that time permits. First, we note that the enactment of Bills of Rights for CCRC residents in several states has not made the lives of residents in those states markedly different from the lives of residents in states without a Bill of Rights. California has one of the most extensive histories of enacting Resident Rights. A California Resident Bill of Rights was enacted some years ago and has been extended since then, most recently in 2015. Despite this extensive history with Resident Rights there is little difference

¹ The NaCCRA prototype Bill of Rights formed the centerpiece of Dan Seeger's Presidency; President Seeger traveled the country extensively to garner interest in rights and input into the document. The result is representative of current resident sentiment and indicates a wide range of matters for the eldercare industry to address.

in the resident experience in California from that in other states without such rights.

Rights without enforcement are easily set aside by reluctant providers through perfunctory conformance with the letter of the law while persisting with the status quo oblivious to the spirit of the law. Since the regulators choose to intervene only when there are complaints, and since residents rightly fear reprisal for complaints, provider compliance with such legislated rights can be in name only with little substance for residents.

It might be expected that the plaintiffs' bar could give substance to such Rights by demanding provider accountability for full compliance, but LeadingAge California, California Association of Housing Authorities, and affiliated provider organizations have been able to block attorneys from having a private right of action to enforce Resident Rights. These circumstances are true in other states as well where Resident Rights have been added to statute.

Hence, the better approach is the one chosen by the residents at Horizon House in Seattle. The Horizon House residents petitioned the Board of Directors (the body which exercises ownership authority alongside the executives) to adopt a resident-centric set of Rights. This has generated a constructive dialogue between the residents and the Board. Horizon House is already more open to residents than are most CCRC provider organizations. Even so, it has been difficult for the Board and the Executives to be willing to concede rights to residents. Most executives and board members are not residents, and they tend to view the residents as wards in their care rather than as people to be respected.

Given that it is thus difficult to persuade provider Boards and Executives that residents should have Rights, it will be much more difficult to persuade them to embrace the need for such Rights under legislative coercion. Unless management accepts the responsibilities and commitments that residents expect in the Rights they seek, it is difficult for those Rights to be realized in practice.

In addition to recognizing the difficulty of gaining Resident Rights through legislation, we can see now with the benefit of time and reflection that the NaCCRA Resident Rights as adopted are lengthy and somewhat verbose. We are more likely to gain credence for rights if we are able to summarize them simply, much as Franklin Roosevelt expounded the Four Freedoms. We remember those Freedoms and how they inspired Americans during World War II. The Roosevelt Freedoms were Freedom of speech; Freedom of worship; Freedom from want; and Freedom from fear. Those were Freedoms worth fighting for.

CCRC Residents, too, want similar Freedoms. The Bill of Rights can be summarized as the following six (self-evident) Freedoms:

- (1) Freedom to understand contracts and to expect them to be fulfilled;
- (2) Freedom to organize and assemble;
- (3) Freedom to have a voice in the decisions that affect residents' lives;
- (4) Freedom to know the financial status of the organization and the bases for management decisions;
- (5) Freedom from unilateral changes by management diminishing the resident experience or increasing costs; and

(6) Freedom for resident self-expression without management disparagement.

The question is how to bring these fundamental Freedoms, which residents have a right to expect, into practice. For the Americans of 1776, it took a Declaration of Independence to give them what they believed to be self-evident truths, “that all [people] are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness.” The struggle of older Americans who trust in CCRC providers to give them the self-evident rights that they expect is no less daunting. We have made a beginning by bringing these matters to the attention of the providers. The providers, assembled in LeadingAge or Argentum² or the American Senior Housing Association, cannot say that residents have been silent. But it will take acceptance to make these Rights a reality.

The clamor for Resident Rights results from a perception by many residents that they don’t have these fundamental rights. No resident should have to feel like a second class person in her or his own home, merely because they have accepted a contract and are paying for services. Yet, that is what many people feel. Our task is to reverse the provider preconceptions that have brought about that mismatch of expectations with experience.

Reversing the imbalance that leads residents to embrace Rights initiatives with such enthusiasm may be achieved through an entrepreneurial disruption that reverses the CCRC power structure to lift to authority those whose funds provide the wherewithal supporting the industry. History, however, shows that colonial authorities yielded power only reluctantly. Closer to home, white elitism has

² Formerly, the Assisted Living Federation of America

been slow to give way to the American Dream of equal opportunity for all. Yet, much as Mahatma Gandhi won self-governance for the people of India, or as Martin Luther King Jr. dramatized the artificiality of societal disadvantaging of African Americans, we are called to secure respect for older Americans and to shatter the bonds of condescending ageism.

We can hope that entrepreneurial insight and understanding will bring humanizing reforms to older Americans. Those who have grown old in service to the nation and the world deserve to be treated with respect and to be allowed to be in charge of their life circumstances for as long as they are able. They may not be as energetic and vibrant as they once were, but that does not mean that they should be coddled like children or treated as doddering nincompoops unable to participate in life choices. Achieving the empowerment for those elderly who responsibly trust in eldercare providers for their wellbeing may take something more than merely hoping for change while enduring the present. It may take a movement of aging Americans demanding more than what is now offered to them.

But we have begun. And we will continue. For as long as it takes.

Active Aging Advocates
July 2, 2016

Bill of Rights for Residents of Continuing Care Retirement Communities

The residents of a Continuing Care Retirement Community continue to enjoy the rights accorded to them under the United States Constitution. In addition, they have the right to:

1. Expect full, prompt and complete fulfillment by the CCRC's management of those services delineated in their contracts.
2. Establish, organize, fund, develop by-laws for, and operate a resident association whose purposes include, but are not limited to, representing the interests of the residents to the administration of and the CCRC's corporate governing board.
3. Freely assemble, with or without the participation of management and staff, as the residents in their judgment deem advisable, to enhance communication and information sharing among the residents, and to promote active learning and discussion of issues facing the CCRC community.
4. Select and appoint, in accordance with the resident association's own by-laws, at least three members of the CCRC's corporate governing board, who, as full-fledged board members, have rights and duties commensurate with the other board members. CCRC residents have the right to receive regularly scheduled reports from the association appointed corporate governing board members about the board's deliberations, actions

and policies. Residents have a right to a corporate governing board every member of which acknowledges their fiduciary responsibility to the residents.

5. Be kept informed by the administration, on an ongoing basis, about all significant issues of management which directly affect residents' well-being or their financial investment, or any issues about which residents are concerned, limited only by necessary and explicitly defined policies of confidentiality and privacy.
6. Full disclosure of the finances of the corporation, presented at least on an annual basis. In cases where a community is a member of a consortium of communities, residents have the right to be fully informed of the finances both of their local community and of the parent corporation. CCRC residents have the right to receive periodic written reports from a duly certified actuary affirming that sufficient funds are being set aside for the future likely needs of the resident population. Residents have the right to be informed in advance if any sale of the community to another operator or provider comes under consideration.
7. A plain English list of those services guaranteed by the contract, as well as a list of those services offered by the CCRC but not guaranteed in the contract (and which therefore may be modified or withdrawn at the discretion of the management or corporate governing board), provided to all prospective residents prior to their being asked to sign the contract.
8. Visit the assisted living and skilled nursing facilities, as well as all the amenities associated with independent living, before signing a contract.

9. Be informed in advance of, and to comment on, changes in the delivery of services, including changes in staffing levels in its administrative and service departments and changes in staff credentialing requirements in areas such as health care, food service, and facilities maintenance.
10. Be informed, at least a month in advance of implementation, about any changes in fees, and have the opportunity to comment on these to management and to the governing board.
11. Participate directly in the governance of the residents association through communication, discussion, and decision-making in open meetings, through membership in association committees, and through the election of officers and members of the resident association's own board of directors.
12. Raise issues concerning their own well-being, their quality of life, and the sufficiency of their involvement in community life and governance, and to advocate openly for issues of concern to them to be discussed and dealt with by the residents' association, the administration, and the governing board, as appropriate.
13. Start up and operate informal activities of any kind, so long as they do not impact negatively on the lives of others, violate the law, interfere with other activities in community space and facilities, or require resident association funds.

14. Organize and seek resident association recognition of a new committee or other resident activity needing community facilities or resident association funds.
15. All the benefits of living in community, including all the services and amenities on offer, and all regulations applying to community life, provided and enforced impartially and without prejudice, regardless of a resident's age, gender, race, economic status, professional background, sexual orientation, past or present advocacy of issues and policies applying to community life and governance, past or present activism in the polity outside of the retirement community, or past or present service on boards or committees.
16. Select, based on availability and the resident's financial qualifications, an independent living apartment of the resident's choice and to appoint and furnish it to the resident's taste, within the provisions of the life-care contract and fire and safety regulations.
17. Participate as fully and meaningfully as possible. when the need to move to an assisted living facility or skilled nursing unit comes under discussion. Family members designated by the resident have the right to be kept informed of the resident's condition and care plan. Residents or their designated medical proxies have the right to refuse medications and treatments.

April 30, 2015