Obesity Bill of Rights

Applications from the GSA KAER Toolkit on the Management of Obesity in Older Adults

Momentum Discussions Podcast from the Gerontological Society of America

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Announcer: The Gerontological Society of America, meaningful lives as we age.

Jen Pettis:

Welcome to this GSA Momentum Discussion podcast, addressing the nation's first Obesity Bill of Rights, introduced on January 31st, 2024, by the <u>National Consumers League</u> and the <u>National Council on Aging</u>. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We're grateful to Novo Nordisk for their support of the <u>GSA Toolkit for the Management of Obesity in</u> <u>Older Adults</u> and today's podcast episode. My name is Jen Pettis, and I'm the Director of Strategic Alliances at the Gerontological Society of America (GSA).







Jen Pettis:

I'm delighted to serve as a host for today's Momentum Discussion. Joining me for this podcast are Nancy Glick, Director of Food and Nutrition Policy for the <u>National Consumers League (NCL)</u>, and Dorothea Vafiadis, Senior Director of <u>National Council on Aging's (NOCA's) Center for Healthy Aging</u>. Dorothea and Nancy, welcome. Thank you for taking the time out of your day to discuss the new Obesity Bill of Rights with me.

Nancy Glick:

We're delighted. Thank you for having us.

Dorothea Vafiadis:

Jen, thanks for having me. It's an honor to be here.

Jen Pettis:

Nancy, I'd like to start with you and ask why and why now. That is, why do we need an Obesity Bill of Rights, and why is now the right time for one?

Nancy Glick:

I'm so glad you asked that question because this was the question that the NCL asked in 2021. The reason we did it was because, first of all, we represent everybody in this country because everyone is a consumer, and we are aware of the striking statistics that have come out of the CDC. In fact, in 2021, the CDC announced that we had reached a new milestone as a nation with 42% of adult Americans now are considered to have obesity and 73% of adult Americans have either overweight or obesity. We said to ourselves, how could we have gotten to this point when the science of obesity is just exploding? We've learned so many new things about the brain and satiety. There are new treatments that we know work, and we have guidelines from numerous societies that tell doctors exactly what to do and when.

However, the problem is that only 10% of adult Americans have ever seen a doctor and had a conversation about obesity, which is a staggering statistic. We did an expert panel with leading obesity experts, and what we learned is that the problem is ourselves. It's the human obstacles: misinformation; bad, outdated thinking; terrible stigma, and then these awful problems with insurance barriers and even regulatory decisions that are keeping people from getting care. That's why we did it. What we thought we would do with a Bill of Rights is empower Americans to say, I deserve to get the same kind of care because I have a disease of obesity. If I have arthritis or if I have diabetes, I can go to a doctor, I can get the best care, and I can reduce my symptoms and maybe even go into remission or cure a problem. That doesn't exist right now. That's the reason for the Obesity Bill of Rights.

Jen Pettis:

I think it's important to note that the NCOA and the NCL developed the Obesity Bill of Rights with a great deal of input. You mentioned a panel, Nancy, but you had a variety of communities of interest including GSA. We certainly appreciate that you've taken the opportunity to be involved in the work do. Dorothea, would you share with our listeners the process that you used to develop the Bill of Rights?

Dorothea Vafiadis:

This important document is years in the making. We know many people with obesity, especially people of color, feel stuck because they don't get the care they need.

Dorothea Vafiadis:

We wanted to dig deeper into the situation and hear directly from older adults in their communities to learn what was going on. We held a series of town hall meetings across the country in senior centers and at faith-based organizations in Los Angeles, California;, Oklahoma City, Oklahoma; Jackson, Mississippi; and Wilmington, Delaware to bring people together to share information about what's important to them, and to hear feedback on what's working and what could be better. Each event included adults with lived experience as well as healthcare providers, local healthcare professionals, doctors, and clinicians. We heard from hundreds of people and what we heard were incredible stories from older adults with obesity who face both ageism and weight stigma.

Those who are Black or Latino are also facing racial bias from healthcare providers. What's more, we heard that access is a big barrier for those seeking treatment, and these were powerful stories. One participant in Delaware said, "I feel invisible. Living with obesity makes me feel invisible." Another man at our town hall in Jackson said, "We live sick, and we die quick." He had lost his grandmother, his mother, his aunt, and several other relatives to obesity-related diseases, and they were all in their 50s. It was incredible. We took this information and began to create the Bill of Rights. In addition to capturing the lived experience from these communities and these town halls, we engaged the broader public health community and reached out to partners such as GSA and others who are working to serve those living with obesity every day. We also met with scientists and medical doctors at <u>The Obesity Society</u> meeting to hear their thoughts on this work. We are proud that this Bill of Rights incorporates the very best thinking of leading obesity experts, aging and public health leaders, and, most importantly, people with lived experiences, including older adults.

Jen Pettis:

What you shared certainly paints a picture of the present and perhaps the past for some of these folks that live with obesity or overweight. But what is the future, Dorothea, that is envisioned with this Bill of Rights?

Dorothea Vafiadis:

There are three points I want to make. First, we want to support self-advocacy for older adults and for all people living with obesity. The Obesity Bill of Rights will empower people to seek the care they deserve without stigma or judgment. It is a tool that can enable them to ask for treatment with respect and professionalism, which too often are missing from their healthcare experience right now. Secondly, we hope the Obesity Bill of Rights will change the national dialogue about these issues towards empathy and understanding that obesity is a disease, and that we want to continue to educate the public about the Bill of Rights. We want to get these into the hands of older adults, into the hands of caregivers, families, community leaders, so they know the issues are real and there's a feeling of empowerment. When individuals go to see their doctors, they have the Bill of Rights and they can feel empowered. Thirdly, we hope the Obesity Bill of Rights will change the national dialogue about these issues and understand that they're not invisible. We don't want them to feel invisible, and we don't want them to feel lost. That's simply unacceptable.

Jen Pettis:

I understand that there are eight rights in the Bill of Rights. Would you share? I know this is going to be tough to summarize in a podcast, but if you could share with our listeners some high-level key points about them. Nancy, would you go ahead and start us off with the first four?

Nancy Glick:

Some of these seem so simple that we shouldn't even have to have them, and yet we need them. The first is the right to accurate, clear, trusted information about obesity. This was something that we learned through the town halls. People don't know where to go. Their doctors don't have the information, and they don't know the accuracy of what they find on the web. This is something that can be done quickly, and we need to empower people by letting them have access to the real facts about obesity as a treatable disease.

The second is one of the most important things that's necessary to change obesity care, which is the right of respect. Right now, people are so disheartened by the attitudes and weight bias of health professionals. It's terrible that throughout the country people are fat-shamed by doctors, social workers, and nurses. They wag their fingers at them. They don't listen to them. We need to demand that people with obesity be treated with respect in clinical practice by health professionals. This is something that we are going to do in numerous ways.

The third is the right to make treatment decisions. With every other chronic disease, people with a disease are an equal partner with their healthcare provider in making decisions. We need to be able to talk about obesity, but once we have empowered people wanting to talk about obesity, they need to be able to ask questions, get them answered, and decide with their health professional about what to do.

The fourth, which is basically a little aspirational, is the right to be treated by qualified health professionals. Right now, most physicians who have gone to medical school have never had a course in obesity. Think about that. A lot of doctors and other clinicians are just doing the best they can because they don't have the training. By having a right, we are in effect saying to the medical community, you must stand up now and train doctors and credential them. People with obesity should be treated by a qualified provider or a specialist in obesity just as they would for arthritis or diabetes. There are people qualified to give you the best care. Those are the first four.

Dorothea Vafiadis:

The fifth Bill of Right is the person's right to person-centered obesity care. We strongly feel that all people with overweight and obesity have the right to receive obesity care that's personalized, which reflects their cultural beliefs, meets specific health goals that they have, and considers their whole health, not just their weight status. That would include things like receiving considerate, respectful, and compassionate care in a safe setting. Obesity is a chronic disease that's very complex. Individuals with obesity are entitled to the same best standards of care as those with other chronic conditions. It really requires their expertise and services of a range of health providers working to provide coordinated care. Access to insurance as well, and coverage for a health educator trained in obesity management as a key part of the management team.

The next one is the right to accessible obesity care and services from health systems. All people living with obesity have the right to receive obesity care in systems that are equipped and accessible for larger body size. We know that oftentimes people of large body size may go into an exam room or a waiting room where they're not made to feel welcome. That's because health spaces and equipment are not always appropriate for their size. Within the clinical environment, they need to have size and weight accessible equipment, such as larger hospital beds, lifts, stretchers, examination tables, and wheelchairs. That's critically important for those who are living with obesity.

Dorothea Vafiadis:

When it comes to number seven, it's the right for older adults with obesity to receive quality obesity care. People aged 60 and over who are living with obesity face different health challenges when seeking care, and they deserve respect. They should have a comprehensive care approach consistent with their personalized medical needs. The simple truth is that older adults not only face weight bias when they live with obesity, but they also face ageism when seeking obesity care. That presents a unique challenge in the healthcare system because older adults have different physiology. They need experts who can understand and treat the special needs that they have. It's a key issue. Looking at the combination of obesity and the naturally occurring decline in skeletal muscle called sarcopenia, which increases the risk for disease and requires tailored treatment. It's critical that older adults receive quality obesity care.

Then finally, Jen, is the right to coverage for obesity treatment. All people living with obesity have the right to the full contingent of treatment options for their disease as prescribed by their physician through health insurance that's widely available, comprehensive, and affordable. We know many employers, both public and commercial, exclude obesity management services as part of their reimbursement. It's a barrier for all adults that are living with obesity who cannot receive that treatment. This situation needs to change, and it should be covered. It should be a covered benefit in health insurance so that those with the disease are afforded the same rights and access as they are for other chronic diseases.

Jen Pettis:

Nancy, where can folks go to read the full Obesity Bill of Rights? I know you ladies have given us a highlevel overview, but where can they read the full Obesity Bill of Rights and learn more?

Nancy Glick:

We have a website called <u>right2obesitycare.org</u>. We have described the purpose of the Bill of Rights. We have a list of the Bill of Rights, and we have a lot of background on why this matters. We go into great detail about the treatment of obesity. Since 2013, the American Medical Association has classified obesity as a disease requiring treatment. We want people to understand the cost, the prevalence, the fact that obesity is directly related to over 200 chronic diseases. All that information is on there. In addition, we have an area where we allow people to act. Right now, since we're such a new organization, we are spearheading a movement, and everybody who is listening to this podcast, we invite you to be part of this movement, because what we are talking about here is changing healthcare.

It's not just about awareness. It's not just about bringing a Bill of Rights to a doctor. It's saying that the medical system needs to treat obesity correctly, and that means a lot of change. We want people to be advocates. We want people to say we deserve the best care. The <u>right2obesitycare.org</u> is a rallying cry. You can learn about the Obesity Bill of Rights, but you can also do something to make sure we have those Bill of Rights in place. Please, if you have any ideas and you want to join us, there's a place on the website where you can sign up and we will get back to you.

Jen Pettis:

Dorothea, I'm going to ask you this quick follow up question to what Nancy shared about this site. I understand there are quite a few organizations who have contacted you all in support of this the Bill of Rights. Can you tell us just about how folks are supporting the effort?

Dorothea Vafiadis:

We have more than 40 organizations that have signed on to support the Obesity Bill of Rights, and we are getting more contacts day by day. It's really phenomenal.

Dorothea Vafiadis:

People are excited and enthusiastic to get the word out. Nancy and I will be working with these organizations to place the Obesity Bill of Rights into the hands of their constituents and to continue to beat the drum. Secondly, NCOA will be launching an educational campaign around the Obesity Bill of Rights that's going to be even beyond what we've currently done. We're planning to continue that town hall model to meet the people where they are and reach out to the communities and help them get the Bill of Rights in their hands to advocate for themselves. Nancy's correct; it's beyond individuals, but individuals have a part to play, and they want to act because it's a real issue. Getting out, spreading the word, blowing out the campaign and really spreading the information about this and the right2obesitycare.org is very important. We'll have more information about how additional organizations can get involved on that site.

Jen Pettis:

Is there anything else, Dorothea, that you want to share that NCOA is doing? You mentioned the town hall. Can you give us a little glimpse of what that might be?

Dorothea Vafiadis:

We're still in the early stages of planning. We're definitely going to be doing more. We have an annual meeting where lots of older adults and those in the aging network come to town. We'll be helping those advocates go out and spread the word to key thought leaders about the Obesity Bill of Rights.

Jen Pettis:

Nancy, how about you and your colleagues at NCL? What are you all doing with the Obesity Bill of Rights and who is involved?

Nancy Glick:

We at NCL see ourselves as a catalyst. Of course, that's one of the reasons that we've joined forces with NCOA, and we are excited to be working with GSA, but we have big thoughts. We consider this the beginning of a long process. Some of the things that we have in our Bill of Rights are not possible today. For example, having a large workforce of physicians and clinicians who are well trained. What we're going to start doing is working on creating goals for the nation on how to implement all these Bill of Rights by the end of 2029. In other words, by 2030, everything will be in place. We are going to be inviting stakeholders to come together and think through what is going to be necessary to make real change happen, throughout the health system.

We are going to chart these goals, and then we're going to hold people accountable. That is sort of exciting. The other thing that we're doing, and I know that Dorothea is doing as well, is the Bill of Rights provides a new framework for advocacy. Right now, in Congress there is a bill called TROA the Treat and Reduce Obesity Act. The Bill of Rights provides a new framework for going back and trying to get Congress to pass legislation that will solve two big problems. One is that there's something called IBT intensive behavioral therapy, which is very important for people with obesity. Medicare Part B limits access to very specific healthcare settings. We think it should be available in all health settings.

The second is the fact, and we are all aligned on this, is that Medicare still refuses to cover these new anti-obesity medicines under a rule that they developed 20 years ago. TROA would stop that and give people who are now Medicare beneficiaries the help with the access that they cannot now have.

These are the older Americans that Dorothea and GSA are working for. We think we've got something, as Dorothea has said, that's a tool, and we need to get it to advocate who are also fighting at state levels, where some of these retirement systems run by states don't want to pay for obesity treatments. We need to also use it in terms of state bills that will deal with discrimination where we can get rid of this whole idea of weight bias. We have a new tool, and we should all use it. We think it's just a new framework for saying some of the things we've been saying for a long time. But now maybe with a little more oomph.

Jen Pettis:

I think a little more oomph is a good way to wrap up our discussion. This was a terrific discussion, ladies, thanks so much for taking the time out of your busy schedules to join me. Thanks to your organizations for really leading the way in demanding person-centered appropriate care for older adults and others with obesity. GSA is delighted to be among the many organizations supporting the Bill. I also want to thank our listeners. We hope that you all found this an informative and enjoyable discussion.

Announcer: The Gerontological Society of America was founded in 1945 to cultivate excellence in interdisciplinary aging research and education to advance innovations in practice and policy. For more information about GSA, visit <u>geron.org</u>.