



















2020 Annual Report

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Our Vision & Mission

The National Consumer Voice for Quality Long-Term Care (Consumer Voice) is the leading national voice representing consumers in issues related to long-term care, helping to ensure that consumers are empowered to advocate for themselves. We are a primary source of information and tools for consumers, families, caregivers, advocates, and Ombudsman program representatives to help ensure quality care for the individual.

To carry out our mission, we:

- Advocate for public policies that support quality care and quality of life responsive to consumers' needs in all long-term care settings.
- Empower and educate consumers and families with the knowledge and tools they need to advocate for themselves.
- Train and support individuals and groups that empower and advocate for consumers of long-term care.
- Promote the critical role of direct-care workers and best practices in quality-care delivery.

The Consumer Voice envisions a world in which all consumers of long-term care, services, and supports are treated with respect and dignity and have a wide range of affordable, quality options across all settings. These options will make it possible for individuals to receive care and services in the location and manner of their choice and to attain a high quality of life.

Consumer Voice Staff

Lori Smetanka, J.D., Executive Director

Robyn Grant, M.S.W., *Director, Public Policy and Advocacy*

Amity Overall-Laib, M.A., *Director*, *National Long-Term Care Ombudsman Resource Center*

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Sam Brooks, J.D., Project Manager

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Director, Sanford Center for Aging Professor, Community Health Sciences, University of Nevada, Reno

Naomi Karp, Secretary Consultant, Aging, Policy and Law

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Officers

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Arlene Germain, Vice Chair Massachusetts Advocates for Nursing Home Reform

Kezia Scales, *Secretary* PHI

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Jane Brink Minnesota Office of the Long-Term Care Ombudsman

Diane Carter Founder, Former President and CEO, American Association on Post-Acute Care Nursing

Marvin Dawkins Consumer Advocate

Chris Doxey Consumer Advocate

Jamie Freschi Fresch Start Consulting

Marion Harrison Consumer Advocate

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Elizabeth Halifax Senior Clinical Research Coordinator, UCSF Volunteer Ombudsman

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Alison Hirschel

Managing Attorney Michigan Elder Justice Initiative

Stephen Johnson

Vice President Emeritus, Government and Community Relations, Cornell University

Tim Johnston

Senior Director of National Projects, SAGE

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Tippy Irwin Consumer Advocate

Dakima Jackson Michigan Elder Justice Initiative/ Michigan Long-Term Care Ombudsman Program

Sumitra Joy Health Over Profit for Everyone

Hillary Kaylor Centralina Area Agency in Aging

Bill Lamb Friends in Residents in Long-Term Care

Jay Leavitt Long-Term Care Resident Consumer Advocate

Steven Levin Levin & Perconti

Laurie Mantz Dementia Training for Life, LLC

John McDermott Hawaii State Long-Term Care Ombudsman Mitzi McFatrich Kansas Advocates for Better Care

Rita Morris Consumer Advocate

Pamela Nadash Department of Gerontology University of Massachusetts Boston

Sean Londergan Vermont State Long-Term Care Ombudsman

Joseph Rodrigues California State Long-Term Care Ombudsman

Alana Russell Lifespan of Greater Rochester, Inc.

Sarah Slocum Center for Eldercare Improvement Altarum

Joy Nathan Stern Family Advocate

Dick Weinman Long-Term Care Resident Consumer Advocate

Jennifer Williams-Woods Nevada State Long-Term Care Ombudsman

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Advocacy in Action

Protecting residents during COVID-19

With the emergence of the COVID-19 pandemic, Consumer Voice advocated for support and protection for residents; raised awareness about the resident experience, including the significant impact of isolation and separation from family caregivers; and kept our network of consumers and advocates informed of the latest policies, resources, tools, and tips.

Consumer Voice advocacy centered around:

- The critical need for adequate **PPE**, **Testing**, and **Vaccines** for residents and staff to help prevent the spread of COVID-19;
- Efforts to Reunite Residents and Families, separated due to the visitation ban imposed by federal and state governments, the resulting **isolation and neglect**; and the importance of essential support and compassionate care for residents;
- Reinstatement of **oversight by surveyors** to address serious care issues and rights violations occurring during the pandemic;
- Support for staff, including hazard pay, benefits (e.g., paid sick leave), and training; and
- Public reporting of COVID data in long-term care facilities, i.e., number of cases, deaths, etc.

Opposing immunity for providers

CONSUMER VOICE FACT SHEET COVID-19 AND NURSING HOMES What Residents and Family Need to Know Coronavirus disease (COVID-19) is an infectious disease caused by a new virus. It can lead to respiratory liness with symptoms such as a cough, fever, and shortness of breath. In a growing number of cases, it can be more servere than the fla, with a higher mortality rate. Certain populations are more at risk of getting this vinus, including individuals age 60 or older and people of any age with serious underlying medical In an effort to reduce the spread of the virus in nursi government has Encused efforts and res COVID-19 Crisis Recommendations for Protecting Residents and Staff of Long-Term Care Facilities (As of 4/28/20)

These recommendations are designed to guide advocates as they work to prevent the spor COVID-19 that is resulting in the liness and deaths of both long-term care facility residents. They should be directed toward state and/or federal government and legislators. The recommendations are drawn from the best and most current thinking and actions of advo including long-term care ombudsmen, and states around the country. ent the spread of widents and staff.

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Require daily reporting by facilities of, at a minimum, the number of COVID-19 cases,
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Immunity for long-term care facilities removes necessary protections for residents and increases the risk of harm to residents and staff. A federal proposal would have barred all lawsuits except those showing gross negligence, a standard that is almost impossible to meet, and even would have prohibited lawsuits in cases involving deliberate short staffing and failure to obtain necessary resources to provide quality care. While Consumer Voice and others were successful in defeating immunity at the federal level, it has been given at the state level through executive order or state legislation in the majority of states. Additional advocacy is needed on this issue.

Fighting for better staffing

Although poor staffing has been a chronic problem in nursing homes, it is among the many issues which COVID-19 brought to light in 2020. Consumer Voice advocacy around staffing included:

- Support for **minimum staffing standards** of at least 4.1 hours per resident per day;
- Increasing support for direct care staff by paying a **living wage and benefits**;
- Requiring registered nurses 24 hours per day;
- Reinstatement of **training requirements** for certified nurse aides that were waived early in the pandemic; and
- Requiring a full time **infection preventionist** in every nursing home.

Chemical Restraints Consumer Education Campaign

Many residents, particularly those living with dementia, are given off-label antipsychotic drugs to control their behavior rather than individualized care to meet their needs. Through a partnership with AARP Foundation, Consumer Voice is educating consumers about the dangers of antipsychotic drugs, best practices for providing person-centered care, and advocacy strategies when concerns arise.

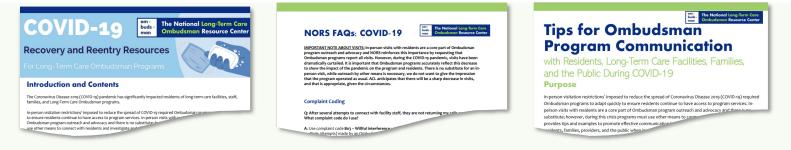


National Long-Term Care Ombudsman Resource Center

Through a grant from the Administration for Community

Living, the Consumer Voice operates the National LTC Ombudsman Resource Center (NORC), providing training, technical assistance, and support to the 53 State Long-Term Care Ombudsman Programs and their regional representatives. NORC activities included:

- Weekly calls with State Ombudsmen to share updates and strategies for programs and management and advocacy for residents during COVID-19;
- Development of COVID-19 resources and training including reentry to facilities, safety considerations, responding to complaints, communication, and the impact of trauma and self-care;
- Training, resources, and support for NORS data reporting, including an on-demand training course and release of COVID-19 NORS FAQs;
- Release of an advocacy toolbox on protecting residents from facility-initiated discharges;
- Multiple webinars and trainings for State Ombudsmen and program representatives, including the State Ombudsman Training Conference.



Preventing Inappropriate Transfer-Discharge

Complaints regarding nursing facility-initiated discharges have been the top complaint made to State Long-Term Care Ombudsman Programs for more than 7 years. The Consumer Voice is working with the states of California and Utah to develop training, resources, and consumer information about discharge requirements and rights. More information will be shared in 2021.

Elder Abuse Prevention and Response

As a partner with the National Center on Elder Abuse, the Consumer Voice develops resources and information for consumers and others about the prevention of elder abuse and neglect. Fact sheets, webinars, and podcast recordings are available on the Consumer Voice website.

Taking Care of You	Should I Take My Loved One Home During the COVID-19 Crisis?	Taking Care of You
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Consumer Voice in the News

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Quoted or mentioned in more than **90** articles or news reports.

- We really do as a society need to relook at how we are providing long-term care in this country...Looking at how we can better ensure quality care in a way that meets the residents' needs and protects them from things like we're experiencing today.
 - Lori Smetanka, KUNR

66 [W]e need a much stronger oversight and enforcement system, because you have a system that's basically permitting problems to continue year after year, and we are paying the consequences right now.

- Robyn Grant, Loudoun Times

Consumer Voice Annual Conference



- 643 registrants5 plenary sessions
- 24 workshops
- 14 discussion lounges
- 6 networking sessions
- 16 sponsors
- 17 exhibitors

Technical Assistance Requests

Responded to **2,138** requests for technical assistance and information.

Webinars



Top 5 request categories:

- COVID-19
- Quality Care Issues
- Ombudsman Program Management
- Issues with Long-Term Care Provider
- Quality of Life Issues

Pursing Quality Long-Term Care Podcast



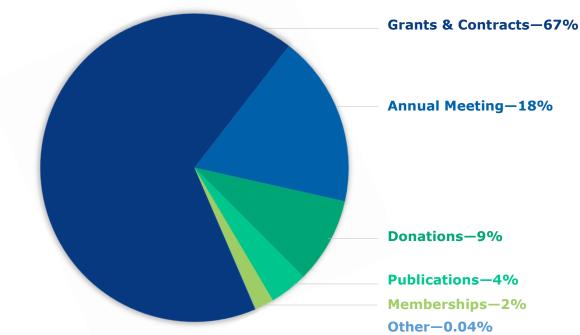
Residents' Rights Month



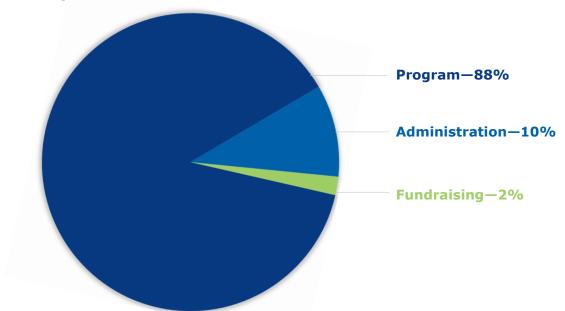
Website and Social Media



Total Revenue—\$1,293,771



Total Expenses-\$1,131,914





By Oscar Nieves Sanchez, Resident's Voice Challenge submission



Sailing in the Cove at Dusk By Gwendee Lichvar, Resident's Voice Challenge Submission

Thank you to all our donors and funders. Your support makes a difference!

Grants/Contracts funded by:

AARP	Frances Lane Memorial Family Council	NORC at the University of Chicago
AARP Foundation	Fund of the Edward H Lane Foundation	Nursing Home Litigation Group of the
Administration for Community Living	NAELA Foundation	American Association for Justice
California Department of Public Health	NCEA	Utah Department of Health

Conference Sponsors

AARP	Barbara Frank	NAAP	PeerPlace
AARP Foundation	Justice in Aging	NALLTCO	Patricia Powers
California State Long-Term Care Program	Levin & Perconti	NASW	Elma Holder Stallings
	MANHR	NCEA	WISER

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President's Circle members are individuals who have donated \$1,000 or more in a calendar year.

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Hanna Fink	Sara Hunt	Andrew and Ruth Newman	David Zimmerman
Barbara Frank	Cathy Hurwit	Judith Peres	
Iris Freeman	Mary Ellen Jacobs	Patricia Powers	

If you would like to support Consumer Voice's advocacy for long-term care residents, visit our <u>donation page</u>.



By Betsy Greene, Resident's Voice Challenge submission



Pathways, created using wheelchair wheels By clients at Kula Hospital, Resident's Voice Challenge Submission