

Toppling Goliath: Our Journey from Victim to Victory



Discussion Highlights

- ♥ What compelled Elder Voice Family Advocates to organize
- ♥ Situation 5 years ago
- ♥ Key strategies that drove success
- ♥ Good fortune
- ♥ Challenges
- ♥ Key learning's
- ♥ Questions and Discussion

What Compelled the Creation of Elder Voice Family Advocates?

- ♥ Explosion of complaints of abuse, neglect and exploitation in LTC

562 % Increase in Abuse Complaints from 2010 to 2018

4,000 in 2010

To

22,500 in 2018

- ♥ Outraged families experiencing horrific maltreatment
- ♥ Escalated reporting of maltreatment by aging and academic professionals
- ♥ Minimal accountability for wrong doing of the LTC industry

The Situation Five Years Ago

No Resident Voice

Powerful MN LTC Industry

Assisted Living not licensed

Well funded lobbying program – 2 major industry associations

46 registered lobbyists in 2021 – 10 are full-time lobbyists

\$93,546 PAC money in 2021 – both industry associations

Mismanaged, Underfunded Department of Health

Paper-based investigations

2,000 complaints thrown in trash without reading them

22,500 complaints – only 5% get on-site investigation; 15% or less get any investigation

No Transparency Regarding Sub-par Care at MN LTC

Situation Five Years Ago – No Political Will to Address



“This is why no one knows about these crimes. It’s not because we don’t have a voice. It’s because people in power deliberately choose not to listen.”

MARJORY ALDRICH, 80

★ StarTribune

Key Strategy – Quickly Organized

Recognized that we needed to organize in order to effectively advocate

Critical Skill Sets of the Founders

Elder Law Attorney – Suzy Scheller

Former lobbyist/communications professional – Kris Sundberg

Accounting – Kay Brommelkamp

Elder Abuse Expert/Gerontologist – Dr. Eilon Caspi

Forensic Nurse – Jean Peters

Data Management – Anne Sterner

Elder Voice Family Advocates

Young but Driven Advocacy Organization

- ♥ Established in 2017
- ♥ Focus on public policy advocacy
- ♥ Based on research and telling our stories of neglect, abuse and exploitation in LTC
- ♥ Started with less than a dozen family members, a gerontologist and an elder law attorney
- ♥ Recognized that maintaining credibility was crucial
- ♥ Major accomplishments include:
 - ♥ Investigation and reorganization of MN Department of Health – 2018
 - ♥ Passage of Assisted Living Licensure and other protections – 2019
 - ♥ Threat of delay in rule-making successfully defeated and kept on track for implementation August 1, 2021
 - ♥ Extensive media coverage

Key Strategy – Resident & Family Focused



- ♥ Safe place for families to tell their stories
 - ♥ Support each other
 - ♥ Get advise from founders
- ♥ Gave them opportunities to be a part of the solution
 - ♥ Media interviews
 - ♥ Legislative meetings and hearings

Activate Family Members Willing to Unite

- ♥ Advocacy training
- ♥ Call-to-action: such as Capitol rally
- ♥ Day at the Capitol
- ♥ Member issue update meetings – pandemic stopped in person but shifted to newsletters/webinars
- ♥ Conference participation
- ♥ Speaking events



Family Members Talk Publicly

At the State Capitol

- Committee testimony
- Legislator meetings
- Capitol rally's



At Press Conferences

- Told their stories
- Gathered to support initiatives



Key Strategy – Research Based

Elder Voice Initiated Own Research

Inhumane and Deadly Neglect Revealed in State Assisted Living Facilities – April 22, 2019

- ♥ Investigation of publicly available investigations of abuse, neglect and exploitation – nearly 150 pages
- ♥ Data broken down by legislative district and distributed to each legislator
- ♥ Had a significant impact on the passage of the legislation

State of Elder Care in Central Minnesota – March 2020

- ♥ Alarming abuse, neglect and exploitation – 44% investigated
- ♥ Staffing issues core to poor care
- ♥ Local media attention

Resource for local and national researchers

Key Strategy – Aggressive Media Outreach

- ♥ Find receptive media
- ♥ Help members work with the media
- ♥ Funnel new data and insights to reporters
- ♥ Respond to every inquiry from the media
- ♥ Maintain accuracy of information given

Develop Media Relationships to Drive Coverage

- ♥ Members initiated building relationships with key newspaper and TV reporters
- ♥ Introduced reporters to families who told their shocking stories
- ♥ Became a trusted resource to the media for background information
- ♥ Pursued activities that would appeal to the media
- ♥ Willingness to take strong positions that protect the residents

“Families of elder abuse victims speak out, wield new power” Star Tribune, Dec. 2, 2017

- ♥ In recent weeks this coalition, known as Elder Voice Family Advocates, has emerged from obscurity to play a central role in early efforts by the administration of Gov. Mark Dayton to reform Minnesota's troubled system for responding to violent crimes and other forms of abuse in senior homes.
- ♥ By Chris Serres Star Tribune DECEMBER 2, 2017



KARE 11 Investigates: Family advocates celebrate elder care reforms

May 22, 2019

- ♥ For the first time Minnesota will license assisted living facilities, the last state in the nation to do so. It's the culmination of a two-year battle by families who've experienced abuse and neglect in facilities.
- ♥ For Kris Sundberg and Jean Peters, the new law comes after years of testifying and rallying along with other members of Elder Voice Family Advocates...

Minnesota assisted living licensing begins | Kare 11.com

Aug, 1 2021

- ♥ Kris Sundberg of Elder Voice Family Advocates calls the licensing decision "monumental" for seniors. KARE 11 has been covering abuse and neglect ...

Numerous headlines, quotes and mentions in leading newspaper

- ♥ Victims denounce a failing state system for responding to reports of elder abuse. February 21, 2018
- ♥ Minnesota elder care reform advocates turn up heat on legislators – Coalition swarms Capitol to push legislators to act. April 9, 2018
- ♥ Minnesota lawmakers, families of abuse victims renew push for elder care reform. Dec. 20, 2018
- ♥ Deal reached for new protections against Minnesota elder abuse, neglect. May 16, 2019
- ♥ Amid deadly virus, Minnesota advocates renew push for senior care protections. July 14, 2020
- ♥ “Lives will be saved’: New protections for Minnesota seniors in assisted living go into effect. July 31, 2021

This 5-Part Series Blew the Dome off the MN State Capitol



StarTribune

Left to suffer

A FIVE-PART SERIES



November 17, 2017

“Each year, hundreds of Minnesotans are beaten, sexually assaulted or robbed in senior care homes. Their cases are seldom investigated, leaving families in the dark.”

Key Strategy: Formed a Coalition with Other Advocacy Groups

- ♥ Governor appointed Elder Voice in 2017 to a task force of advocates
 - ♥ AARP, Alzheimer's Association, Legal Aid and Elder Justice Center
 - ♥ Charged us to develop legislative solutions
 - ♥ Adopted all our recommendations and introduced bill in 2018 legislative session
- ♥ The power of a coalition:
 - ♥ We told our stories to regulators and legislators
 - ♥ Coalition partners leveraged their lobbying resources
- ♥ Reform legislation passed in 2019

“Without Elder Voice Family Advocates' steadfast and tenacious advocacy, we wouldn't have gotten the bill passed.”

Mid- Minnesota Legal Aid of MN

Work Collaboratively with Coalition Partners

- ♥ Leveraged the Governor's task force
- ♥ Numerous planning meetings
- ♥ Worked together to draft bill language
- ♥ Supportive advocacy at Capitol



Key Strategy – Develop Legislator Relationships

- ♥ Encouraged members to talk to their legislators about the problems they are having
- ♥ Created a list members who have legislative leaders and/or key committee members as their legislator
- ♥ Invited legislators to speak at events
- ♥ Go to their district when possible
- ♥ Thanked them for their support



Engaged with Legislators

Invited Legislators and Media to Day at the Capitol



Delivered Investigation Report of LTC Facilities in Their District



Legislator Suggestion Propels Us to Seek Audit of Office of Health Facility Complaints

Office of Health Facility Complaints

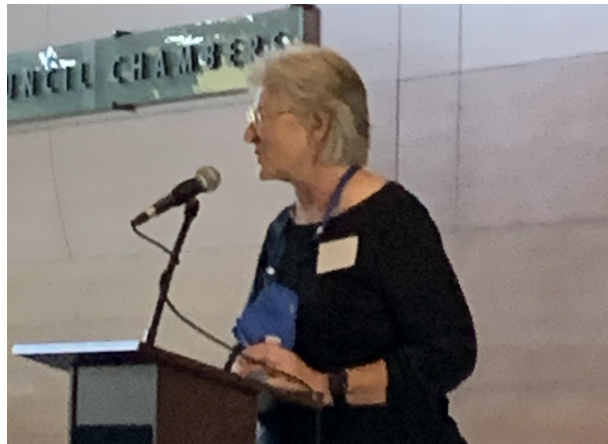
March 6, 2018

The Office of Health Facility Complaints (OHFC) in the Minnesota Department of Health investigates allegations of maltreatment of vulnerable adults in health care facilities. Due to problems with its internal operations and gaps in state regulation, ***OHFC has not met its responsibilities to protect the state's vulnerable adults.*** We make a number of recommendations regarding OHFC's internal operations. We also recommend that the Legislature examine the state's regulatory structure for long-term care providers.

Key Strategy – Engage with State Agencies

- ♥ Develop relationships within the agencies
- ♥ Work constructively with them, offering solutions not just complaints
- ♥ Thank them by recognizing their important role in the new legislation

Commissioner Jan Malcolm



Worked with The Department Of Health

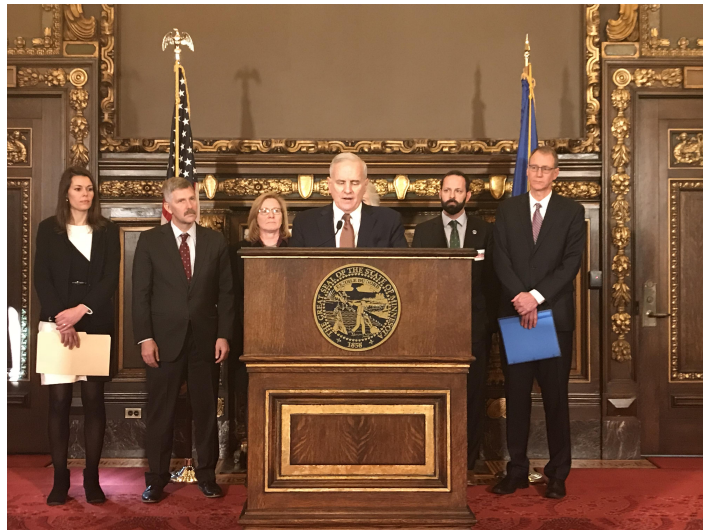
Commissioner Jan Malcolm

- ♥ She spearheaded the negotiations by bringing the advocates, industry, and regulators together
- ♥ Welcomed significant contributions to the Elder Care Reform Legislation of 2019
- ♥ Adoption of many of our recommendations during the 2-year rule making process



Result – Brought to the Table for Negotiating Legislation & Writing Rules

- ♥ Governor appointment to task force to develop reform legislation
- ♥ Invited to months long drafting and negotiating sessions by MDH
- ♥ Several appointments to MDH task forces and work groups
- ♥ Appointed to the 2–year rule making work group



Key Strategy – Public Education

- ♥ Website provides informational resources
- ♥ Webinars given on range of topics
 - ♥ Ageism, Racism
 - ♥ Legislator Forums
- ♥ Speaking Engagements with various organizations – pre-pandemic
 - ♥ Senior Centers
 - ♥ Union/Retiree
 - ♥ Civic Organizations
 - ♥ Professionals

Leverage Social Media

- ♥ Cost-effective means of educating and promoting webinars
- ♥ Professional website gives enormous credibility
- ♥ Social media effectively grows the supporter base
- ♥ Webinars are highly effective in growing recognition and furthering the educational efforts
- ♥ Can connect directly with families who have questions, needs
- ♥ Builds relationships with academic, advocacy and other organizations
- ♥ Easy to share our work – research, newsletters, fundraisers, events, etc.
- ♥ Grant money available



Ceremonial Signing of Elder Abuse Protection Legislation 2019

Governor Walz and Lt. Governor Flanagan



Where did good fortune help?

- ♥ Valuable skill sets of the founders and commitment to work hard
- ♥ Minnesota was only state to not license assisted living
- ♥ Skyrocketing abuse, neglect and exploitation complaints
- ♥ Dysfunctional MN Department of Health
- ♥ Political control changed to a split party legislature
- ♥ Other advocacy organizations ready to advocate for reform
- ♥ Pandemic kept the media heat on

Challenges – Advocacy

Working with other advocacy organizations

- ♥ Staying true to our mission
- ♥ Leveraging each others strengths
- ♥ Breaking into a well established coalition

Keeping the media interested

- ♥ Fresh stories/news
- ♥ Competing issues

Navigating relationship with MN Department of Health

- ♥ Staying true to our mission
- ♥ Being a constructive contributor
- ♥ Building trust

Working with the industry

- ♥ Family anger and frustration
- ♥ Finding compromise
- ♥ Shaky trust on both sides

Challenges – Organizational

- ♥ Advocacy funding is limited
- ♥ Pandemic shifted foundation interest away from elder care
- ♥ Volunteer driven organization leaves gaps in dependable help
- ♥ Keeping tabs on the ever changing political landscape
- ♥ Keeping media engaged
- ♥ Competing with industry PAC money and lobbying clout
- ♥ Managing Board burn-out

Key Learning's

- ♥ Attract and leverage critical expertise
- ♥ Lone-wolf approach does not work
- ♥ Guard credibility – limit rogues
- ♥ Stories of abuse/neglect and government mismanagement attract media attention
- ♥ Volunteer base appeals to media, legislators and regulators
- ♥ Be politically aware but not politically driven
- ♥ Take the message to the legislative districts – what is happening in their district?
- ♥ Stay strong to the mission – don't back down easily



Want Help Establishing a Similar Organization?

Technical Assistance – Contact:
kris@ElderVoiceFamilyAdvocates.org.

Questions and Discussion

elder voice
FAMILY ADVOCATES



Thank You

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