Daughterhood the Podcast
Episode #82
Why Your Story Matters with Jason Resendez

- 44:20

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CAREGIVING IN THE US - NAC AND AARP REPORT
GUIDE Program
Older American's Act
Home and community based services
One Big Beautiful Bill HR 1

You can view the testimony, or read the pdf statements of Daughterhood community member Meghan Maher, Jason Resendez and others at the Congressional Hearing from Wednesday, May 13, 2026 - Caught in the Middle: Supporting Families in the Sandwich Generation HERE.

SPEAKERS
Rosanne Corcoran, Jason Resendez

Rosanne Corcoran 00:13
Hello, and welcome to Daughterhood, the Podcast. I'm your host, Rosanne Corcoran, Daughterhood Circle leader and former primary caregiver to my mom, who lived with vascular dementia for 12 years. Through that journey, I experienced every phase of caregiving firsthand: the heartbreak, the joy, and the aftermath. That journey showed me how vital support and connection truly are. And that's why this podcast exists. No matter where you are in your caregiving journey, I'm so glad you found us, because caregiving is far too much to do alone. So, welcome to Daughterhood, the Podcast, part of the Daughterhood community, where we empower caregivers to navigate both the practical and emotional sides of caregiving together. Here, your efforts aren't just good enough, they're heroic, and here you're never alone. Join me in Daughterhood. Before we dive in, I just want to share a quick note. This podcast is part of the Whole Care Network. The conversations you'll hear are here to inform and inspire, but they're not a substitute for professional advice. The views you'll hear are those of the host and guests, and may not always reflect those of the Whole Care network. If you have medical questions, please talk with your doctor, and for legal advice, check in with your attorney. I'm so

glad you're here. Jason Resendez is a nationally recognized family policy expert and advocate dedicated to transforming how America values care. As President and CEO of the National Alliance for Caregiving, he is at the forefront of driving research policy and systems change initiatives that impact the more than 63 million family caregivers across the country. In this conversation, we discuss the call for policy change, the importance of Medicaid, understanding Medicare's role, how sharing your story can be a building block to change, and so much more. I hope you enjoy our conversation. Family caregivers are often doing extraordinary work with very little support. Before we talk about policy, can you share what stands out in your research about the family caregiving experience in the US?

Jason Resendez 02:15
Absolutely. First, thanks for having me. I'm excited to talk about an issue that I know is near and dear to so many people's hearts and experiences, and that really is at the heart of our research at the National Alliance for Caregiving. So, every five years we issue what is a seminal report for the caregiving community, called Caregiving in the US, in partnership with AARP, and what we see in that research is one, the family caregiving community is growing rapidly between 2015 and 2025 We saw a nearly 46% increase in the number of family caregivers across America, that's over 63 million Americans providing ongoing demanding care for a loved one with a serious illness or disability, and what we see in that data is that this is anything but routine care. Over 50% provide support with complex medical and nursing tasks, so think about things like changing feeding tubes, tick lines, and managing complex medication, a lot of this traditionally is taking place in acute care settings, but is more and more moving into home-based care, which puts more responsibilities on the shoulders of family caregivers. So, it's no surprise that, according to our data, nearly 60% of family caregivers are in high intensity care situations, and we measure that by the number of hours of care provided a week and the number of activities that family caregivers support, including those intense medical and nursing tasks, and so the pressures that family caregivers are under has never been more intense, and so, as a result of those pressures, we see in our data that more family caregivers are reporting physical strain. Nearly 50% of family caregivers report financial strain, things like taking on debt, taking on high-yield credit cards, stopping savings, leaving the workforce, and a staggering 60% of family caregivers report moderate to high emotional stress because of their caregiving responsibilities, and I like to say this is not because of caregiving, it's because of the lack of supports in place to make that caregiving sustainable, dignified, and equitable. Right, we're putting family caregivers in these really impossible situations by not having in place the adequate supports, and that's what surprises me the most about the data. So, I'll end here in that, despite all the challenges that we've seen, the increased financial strain, the increased emotional strain, the healthcare impacts of caregiving. One in two family caregivers, over 30 million family caregivers, say that caregiving gives them a deep sense of purpose and meaning, and so, alongside those tough moments, alongside when you know when someone's frantically figuring out how to, you know, YouTube how to change a picc line,

alongside those really stressful moments, there's moments of joy and love and meaning that come with care, and that really is at the heart of the research, and why we do the work we do at the National Alliance for Caregiving.

Rosanne Corcoran 05:27
I mean, those numbers are staggering, they're staggering, and to say that 60% experience emotional stress, and we see that at Daughterhood all the time, it is, there's so much that goes with caregiving, aside from the physical, it is that emotional toll, and it's I'm glad that you have the numbers, because people seem to respond to that in a, it's an actual way, instead of, well, you're just taking care of somebody in your house, you know. I thank you for that. Caregivers, thank you for that. What, when it comes to those numbers, and I know you know NAC is an advocacy organization, but what exactly does that mean? Can you share how NAC prioritize, you know, prior what their priority is for advocacy?

Jason Resendez 06:07
Yeah, absolutely. So we are all about turning all that data that I talked about into policy change, like we're all about at NAC. Our north star is to move caregiving from a private struggle into a shared responsibility and public good that we invest public dollars into, because that's how central it is to the economy and to the healthcare system. We need to be investing in supports and services for family caregivers in the same way that we invest in public education and healthcare, right, like family caregivers are an extension of the healthcare system. They are the backbone of our nation's long-term care system, and we need to recognize and value that by making public investments. So, our priorities are one, ensuring that we are investing in the Medicaid program through things like home and community-based services that enable people to provide care in their home and communities, which is one where most people want to receive care, and two is the most cost-effective way of receiving care, two is driving reform within the Medicare program, so that Medicare is doing more to invest in family caregivers through things like training and supports and respite. Three is increasing federal appropriations for the Older Americans Act programs, which fund the aging network in every state across the country to provide direct services to family caregivers and adjacent services like home delivered meals and peer training and respite and educational services. This really is the backbone of the social safety net that the Older Americans Act programs, and one of the only federal line items in place to support family caregivers is through the Older Americans Act, and yet the funding for that program hasn't kept up with the demand that nearly 50% increase in family caregivers totally dwarfs funding increases to support family caregivers through the Older Americans Act. So we leverage our data to champion those kinds of investments, while at the same time promote the importance of culture change, right, policy is necessary, but it's not sufficient. We need a culture of care in this country, so we leverage our data to help employers to help policymakers understand what care really looks like in this country, so that we can move those policies forward, and that really is a heart of advocacy for us.

Rosanne Corcoran 08:41
Yes, and all of those are under attack right now with changes. You brought up the home and community-based services. Can you remind listeners what Medicaid is and its role in funding the home and community-based services?

Jason Resendez 08:55
Absolutely, so Medicaid is the primary payer for long-term care in this country, and that comes in the form of home and community-based services. So, things like having an in-home health aide, direct care assistance, having support with things like training, transportation - all of those services are provided through home and community-based service waivers at the state level, these are things that the Medicare program does not pay for, the things that you know when you have a serious illness or a long-term disability, the things that it takes in order to be able to live in your home and your community versus in an institutional setting like a hospital or a nursing home, Medicaid is the primary payer for those services. It's not perfect, it's hard to access, and you know every state is a different maze, as I'm sure your listeners are familiar with, but it is really the bedrock of ensuring that there is a safety net in place if you were to get a serious a. Illness or a disability that you have options and the ability to live in your home and community.

Rosanne Corcoran 10:07
What's being debated right now with this program?

Jason Resendez 10:10
Yeah, so right now there's a big debate, and a lot of the policy fights that we're in are really focused on the role of home and community-based services and funding for home and community-based services. So, as part of the One Big Beautiful Bill Act, or HR One, whichever you want to call it, that bill is going to result in over a trillion dollars of cuts to the Medicaid program in the form of fewer dollars for states to fund services like home and community-based services, and what we see in research and past history is that when a state has less federal dollars for their Medicaid program, the first programs that get cut at the state level are these home and community-based services, because they're optional services, unlike nursing home care, home and community services are optional. Is one of the biggest tragedies of our the Medicaid program and of American life is that we have a right to receive care in a nursing home setting, but we need a waiver to receive care in our own homes, despite the fact that that is cheaper and what people want most. Now, people should have the option to do both, because not every situation, you know, some folks might need to receive care, and that might be a better setting in a nursing home or a more skilled facility, but most people want to receive that care in their homes, and that's what home acumen a services enable, and so right now, because of those funding decisions that have been made, states are going to be in a

really tough position to what to fund, and we're already seeing states make decisions around scaling back those supports, and that's taken the form of things like capping the number of hours that a family caregiver has access to in terms of in-home support, and many states, all states, basically offer what's called self-directed programs, so the ability for a family member to receive some form of payment in exchange for services. Right, a lot of the services that we're talking about, you know, could be provided by a direct care worker, but we're living in a direct care workforce shortage. We need to add 10 million direct care worker jobs by 2030 just to keep up with the pace for demand, and that's not happening, and so a lot of states have introduced these self-directed pathways, so that me, as an individual with a disability or a serious illness, can say, I want this money to go to, you know, my sister, so that she can provide this care, because I can't find someone, or because she knows she knows me, and I trust her care. States are starting to cap the number of hours that are available through these programs, and so we're seeing a lot of hard choices being made because of these policy decisions that happen at the federal level, and family caregivers, people with disabilities, people who need care are really in the crosshairs of these decisions, and that really is, I think, one of the important reasons for caregivers telling their stories and advocating and engaging in this process, because these are the services that are at stake right now.

Rosanne Corcoran 13:12
So, I mean, it's horrifying to think that that will be no longer, or will be capped, or will be cut down so much when it's so needed. You know, people get confused with the difference between Medicaid and Medicare, and Medicare does not cover long-term care or supports, but they've been - they've started to cover services that can help family caregivers, particularly around training and support and respite. Could you explain what that is and what that looks like?

Jason Resendez 13:38
Yeah, absolutely. So, Medicare is a really critical program to supporting older adults in this country, but you're right, it doesn't cover a lot of the long-term care that Americans need. I mean, let's be real, one of the success stories of American life and of humanity is the longevity boom that we're experiencing over the last five decades, but the reality is that we are living longer, but we're living longer in poor health, and so the Medicare program hasn't kept up with that reality, and now we have families and family caregivers who are really essential to delivering care in this country for folks who are living with a serious illness like Alzheimer's or ALS for what can be years and years, yet there's very little support in that Medicare program for those family caregivers. So Medicare is really created to provide short-term support, in addition to the ongoing, you know, preventative care coverage that it's used to, right? And that is, you know, an important opportunity for modernizing the Medicare program to meet the moment that we're in, in terms of American health, and that support for family caregivers. I think is really at the frontier of what that could look like, and you're right, we've seen some

progress. So, thanks to the advocacy of many organizations, and 1000s, hundreds of 1000s of family caregivers, starting to see. Progress in how Medicare is thinking about supporting family caregivers, thinking about supporting people with disabilities and serious illnesses, and one of those examples is the introduction of what are called caregiver training services. So, for the first time, healthcare providers can be reimbursed for identifying and training a family caregiver for assisting with things like activities of daily living or those complex medical and nursing tasks that I was talking about earlier. Now it's not perfect, right, because only a few types of providers can be reimbursed. The reimbursement rate is pretty low. There's still a copay associated for the caregiver, but it is a move in the right direction, in terms of saying the skills of this family member are really essential to providing better care for the Medicare beneficiary, and that is, I think, an important shift in how the program sees and recognizes family caregivers, and it's also a stepping stone for us to continue to fight for more services and support through the Medicare program, through things like in-home health benefit, through the Medicare program, things like expanded, you know, support for services like hearing and vision, and support for respite, and support for some of the social services that we see within the Medicaid program that we know works and helps to save dollars in the long run, but we don't see in the Medicare program. So, I think it's an exciting opportunity and a stepping stone for more progress ahead.

Rosanne Corcoran 16:31
Do you think the advent of The GUIDE program will help boost the other, the other parts of the support through Medicare?

Jason Resendez 16:39
Yeah, absolutely, that's another really exciting example of where there's innovation happening within the Medicare program, and GUIDE is a perfect example of that, right? Sort of this approach that says in order to better deliver care for an individual living with Alzheimer's or another form of dementia, we need to better integrate and support the family caregiver, and so the assessment of the family caregiver is important within the guide model. The referral to social services, the training that comes within the guide model, the respite benefit that's integrated in the guide model, like all these elements of caregiver supports are embedded within guide, and then payment is based off of, you know, those outcomes, and that is a really important move in the right direction, because at the National Alliance for Caregiving, we see if we're successful with Guide, which we're hopeful that we will be, because Guide is based off of a lot of rich evidence and data on the importance of that kind of care coordination and caregiver support, that we can then apply those lessons to other serious illness areas within the Medicare program, so think about things like cancer, right. We talk a lot about Alzheimer's, which is really critical in a very debilitating, you know, progressive disease, but cancer also is a disease that gets, you know, you're progressively at risk for cancer as you get older, right, and so there's a lot of engagement of the family caregiver in cancer as well, being able to apply

what we learn and guide to other serious illness condition areas. I think is something that we're going to see in the coming years as we generate that evidence, but really is an important move in the right direction.

Rosanne Corcoran 18:18
Yup how how much of the advocacy is is offense, meaning trying to improve family caregivers' lives with new policy, and how much is defense trying to prevent the policy changes that would make the lives of caregivers harder.

Jason Resendez 18:31
Yeah, wow, great question. Right now, unfortunately, at least for us at the National Alliance for Caregiving, I'd say it's, you know, 60% defensive. I mean, right now we're really thinking and grappling with the implementation of these Medicaid cuts at the same time that we are pushing back on really dangerous rhetoric around fraud, waste, and abuse within the Medicaid program, and who perpetuates that fraud, waste, and abuse, which right now we're talking about home and community-based services, there's been a coordinated effort to paint those home and community-based services as the most prone to fraud, waste, and abuse, and we've even had some policy makers talk about, you know, that family caregivers are the ones that are perpetuating, you know, that fraud, and what this is an example of is sure there's examples of fraud in every government program, and even in the private sector, see fraud, right? But we're not the importance is the important thing is not to throw the baby out with the bathwater here, right? Where these services are essential to millions of Americans and family caregivers, that we need to root out fraud, waste, and abuse, for sure, but we need to do that intentionally and surgically, and ensure that we, we don't stop and pause with broad stroke policy decisions, access to these services that that families rely on every day, and to be real about the role of the family caregiver, right, that's what. The most dangerous parts of what we're hearing right now is this idea that providing 40 hours of care a week for a family member with a progressive neurological condition is something that families should just do, right? Like, that's the role of the family member, you know, that's not certainly there is, you know, so much love that comes with care, but there's also a level of sacrifice that comes with care, and that sacrifice needs to be honored with home and community-based services, supports, you know, respite, so that we can make sure that that care can be provided sustainably without compromising the physical, financial, and emotional health of the people providing that care, and so, so much of our work right now is on the defense, really making sure that we don't lose ground on all the progress that we made in elevating the role of the family caregiver, as you know, essential segment of the workforce that deserves investment. At the same time, you know, there's still what I liked at that Leonard Cohen song, there's light, the cracks are where the light comes through. There's still some opportunities to be proactive, and we're seeing that within the Medicare program around things like caregiver training service codes, and thinking about how do we expand on that. And CMS has been really receptive to that. The guide model's another great example.

Then we are seeing tremendous progress at the states, within the states, we see what the future of care could look like in this country. 14 states now in the District of Columbia that have established a paid family and medical leave policy, while we still struggle to make that progress at the federal level. Over eight states have caregiver tax credits. New Mexico has universal child care. Washington state established the first long-term care benefit that will start paying out benefits this year, and so what this says to me is that when care is on the ballot, it wins, right? Progress that is possible, and even when we're playing defense at the federal level, there are offensive opportunities at the state level, and we're making inroads there, and I think that's a really exciting reality, and also gives us some lessons that we can apply at the federal level when the moment's right.

Rosanne Corcoran 22:11
Yes, and it's, it's interesting because care doesn't happen in a vacuum, it's not like there's nothing else going on in either of the person's lives, and to try to keep up with everything doesn't matter, if you love them, doesn't matter if you love them, doesn't matter if you don't like them, it's still really challenging and hard to keep up with, and the states that are working towards this is, I mean, thank goodness, but do you know of any policy changes that could make the biggest difference in the lives of family caregivers, anything in the pipeline or anything like that.

Jason Resendez 22:43
Yeah, absolutely. I mean, I think when I think about like concrete policy change that even in this environment is possible, you know, I think about these caregiver training service codes. Right, this is - we know from our research that over 60% of family caregivers are assisting with those complex medical and nursing tasks, and yet only 22% have received any form of training to assist with that level of care. But for those who did receive training, 99% say they have a high level of confidence in the care that they're providing. You know, compare that to the family caregiver who doesn't receive that training, who is scrambling, YouTubing how to provide care because she didn't receive directions from her spouses or her parents' healthcare provider. She's kind of out there on a lifeboat, like trying to figure out how to do this work, and so that's changing, right? We see it in the actual claims data as of this year, over 27,000 trainings have taken place across the country, because of those new reimbursement codes. Right, so that's 1000s of family caregivers who have now received support and recognition from the healthcare system about their role in healthcare delivery. Now, that's not the silver bullet, we're talking about 63 million, and I'm talking in 1000s, but it's the beginning of an important shift in support, and I think an important, you know, stepping stone for us to build on, and thinking about, well, what's the next level of support? You know, why not think about how we directly support family caregivers? Over six 50% of family caregivers want some form of direct payment as part of their caregiving responsibilities, and self direction is a great mechanism for making that happen, and recognizing that this is not just, you know, money for a free lunch, right? It's in

exchange for the services that save the Medicaid program and the Medicare program billions of dollars a year, according to AARP, family caregivers contribute a trillion dollars a year and cumulative economic impact. Yet we are doing very little to invest back in the family caregivers. So I think that's the other opportunity for us is that, you know, ways to shore up the financial security of family care. Careers through things like self direction, right.

Rosanne Corcoran 25:02
It's funny because even doctors, professionals, even aging life care managers, or nurse practitioners, when they have to take care of their own people, they say it's the hardest thing, and they are trained in this, for a, you know, I'll say a quote, regular caregiver to step in and take care of whoever they're caring for, their care partner, it's a lot,

Jason Resendez 25:22
Absolutely,

Rosanne Corcoran 25:23
And they're not trained. We're not trained in this, so hopefully this does catch on, Jason. Hopefully this does move forward of all of the policy shifts on the horizon. Which ones concern you the most, and which ones give you hope?

Jason Resendez 25:36
What worries me the most is the backtracking on home and community-based services, because alongside that is this backtracking on the role of the family caregiver and the support that they provide, and government's role in making that as least harmful to the caregiver as possible. Right, we made a lot of progress in at the state and federal level in saying, you know, families are essential to making care work, to making sure people can live in their home and communities, making sure that someone with a serious illness receives quality care, someone with a disability can receive care in their community, and we're now living through an era and a moment in time where we risk that progress in order to pay for tax cuts for the ultra wealthy, I mean, let's be real about what that tax, you know, what that bill was about, right? It wasn't about improving the Medicaid program, right, it wasn't about improving and expanding health care. It wasn't about putting more money in the pockets of low-income and middle-class Americans. It was about continuing tax cuts for the ultra wealthy, and so it's really that trend of prioritizing the people with the most in exchange for the people with the least that worries me. Where I have hope is that there is a growing recognition around how care is something that connects so many of us, right? That 63 million, and when you expand that to include people providing childcare, that number goes up to 130 million, right? So parents, alongside family caregivers, providing care for someone with a serious illness with disability, you know, that's a huge community, you know, that dwarfs the state of California, and in so many other, like, you know, even countries, right. And it's when we can build solidarity across those communities,

we see that progress is possible. Paid Family and Medical is a great example of that, right. We're talking about 14 states in the District of Columbia, one state literally just this past year in Virginia, Maine starting their paid leave program this year. So that's a great example of a policy that is benefiting both caregivers of people taking care of an aging parent alongside folks welcoming a new baby, that's the reality of care, and that we can move policies that recognize that reality, and even in this environment, it gives me a lot of hope about what's possible for building solidarity across the care movement, and being able to back that up with solid policy gains, right, that is where the magic happens, and paid leave shows us that that is possible, and we just need to keep building, mobilizing, telling our stories, so that when the window window is open and the moment is right, that we can, you know, seize the opportunity,

Rosanne Corcoran 28:35
Right. Right. Well, and you've talked about storytelling as one of the most powerful tools family caregivers have, and it might sound surprising to somebody who feels like they're just trying to get through their day. So, why do you think telling your story actually matters at the policy level?

Jason Resendez 28:50
Yeah, absolutely. Stories, I mean, we're all about data and stories of the National Alliance for Caregiving, because we know that data makes us credible, but stories make us memorable, right? And it really takes both to move the needle, right? You have to move hearts, but you also have to move minds, and it takes both the stories and the data to do that. And you know, stories help to bring to life these policy issues that so often live in a PDF or an Excel sheet in a staffer's inbox or in a brief, in a report, right, but a story around what care looks like every day in a member's congressional district and their backyard, right, that this is where a family member is struggling to make care work. I'll give a great example, you know, we just testified before the Senate Aging Committee, and I talked all about policy, but I guarantee the thing that Senator Rick Scott, the chairman of the committee, remembered wasn't me, but it was Meg, a member of the Daughterhood community from Florida, who talked about the sacrifices that she made providing care for her children alongside care for her father and. And how that impacted her career choices, it impacted her financial health, and in turn impacted in a tax base of Florida, and the in the senators in that room, and so it really is that heart that stories bring to the conversation that is really essential. One of my favorite, you know, I'm always learning about the care movement, and I'm reading a fantastic book by this author, Virginia Eubanks, who's someone that I read a lot about. She writes about technology, and she reached out because she had this book about her experience, because she became overnight a family caregiver for her partner, and she wrote about that experience, and she's coming at it from a totally different perspective than I would think about, and one of the chapters in this book pulls directly from the American Life Saving Association, and she lists out the 10 steps of open water rescue, like what are the things you do when you're engaging in an open water rescue,

step one through 10, and 10 is you document the rescue, because if you don't document the rescue, then it, as if, as if it never happened, and it's with that documentation that you can then fight for more resources, for, you know, that beach, or for that life-saving station, to say, you know, we made 10 rescues here last at last year, and you know, we only have one guard on, you know, so like it's that documentation, right, telling that story, documenting that experience that says this happened, this matters, and this is why we need to invest these public dollars in support, and so stories are essential to that process.

Rosanne Corcoran 31:43
That's great. I've never heard of that. That's fantastic. You know, Meg did a great job, and the one thing that stuck in my mind was what that she said: love is not a policy, and it's not. We need more than that. We need help, we need support, we need resources. You know, there's a. there's really a tension that, that comes with asking caregivers to share these deeply personal experiences, as it can be cathartic, it can also be re-traumatizing. How do you think about getting someone's story in a way that honors all of that?

Jason Resendez 32:15
Yeah, absolutely. I think that's such an important consideration, and for us, I think we want to make it clear that your story is going to be put to good use, right? So, like, everything that we, you know, premise our storytelling work around is that we are going to leverage this story for changing and shifting and informing policy change, right? So I think that's part of it, sort of knowing that, you know, my come from a research background, and one of the big no-nos in research is, you know, to extract data, and then not tell the person that you're working with, and providing that data, how it's being used, and what was the outcome, right? They know that's highly exploitative, right? That's so, I think one, have to make sure that it's very clear in how these stories will be used, and then to make sure that you know folks are making that decision that they're in a good place to tell that story right that could be the case and it's still a traumatic story but making sure that you're not you we're not going in to capitalize on that traumatic experience I think is important and so really thinking about what is that context for the storytelling I think, is really essential, and then knowing that not everyone is going to be able to share that story, right? That that story, I mean, this is the reality of stories, at least from our perspective, is they have extreme value and power, and so, because of that, we can't just expect someone to be able to do that, right? Yeah, at any point in their life, right? So it's like when you're ready, you should, you should feel confident and tell your story, but know when you're ready, I think is the important part of the storytelling experience, and but I hope that when people do feel that they're ready, that they choose to tell that story. I was just on a panel with a gentleman who had a brother with severe schizophrenia, and he talked about, you know, he wasn't able to tell that story for a long time, and when he decided to do it, he talked about how, yeah, it was traumatic, but it was also restorative to be able to share that experience, and to then give permission to others to share their experience, and it creates

connection, right. So I think that's the other part, that's how we build empathy and connection around these really tough issues, even if they're traumatic, is knowing that you're not alone, rather people share these stories, and through that storytelling we can build and bring that bond into the light and out of the shadows.

Rosanne Corcoran 34:41
Yes, and we hear that all the time in our circles, where people think I thought it was just me, and it's not just you, you know. You feel alone because you're in your house, and you're, or wherever, and you're not talking to other people, but you're not alone in this. It's, you know, I love that, that you gather that. At that, you gather the stories, and because it's very frustrating for somebody to share their story, and then nothing happens. So, at NAC, what do you do to make sure the stories reach the right people who need to hear them and who can drive real change?

Jason Resendez 35:14
Yeah, absolutely. So, one of the things we do is we have built a story platform, so on our website, if you go to caregiving.org you'll see a platform called Portraits of Care, and that is a story bank that enables people to share their story, and then we organize it by state and by things like condition, so that we then have the ability for one folks just to come and see how care is impacting every community across the country and every state, but then also that we have the ability to strategically target a story to a policymaker to an issue, so whether that's in championing an issue like the ASAP Act, which is a piece of legislation that would expand Medicare coverage for blood-based Alzheimer's testing, because that would enable us to have a diagnosis as early as possible in Alzheimer's disease, which gives family caregivers more time to plan, more time to access a potential disease-modifying treatment, access to clinical trial opportunities, and then that can bend the curve of the hardship that family caregivers face, being able to see who has this Alzheimer's experience, and I can think about, is this something they'd be willing to share, so we ensure that we're identifying timely issues and also the right targets, so that all comes down to like how we are collecting those stories, and then also working with those families. I mean, I think that's the most amazing part of the advocacy that we do, is we're not just relying on policy analysis, we're not just relying on research, we're not just relying on stories, we're combining them all, so we're making sure that when we're talking about caregiver training services, we are talking about our data that shows the importance of training, and then we're able to highlight, you know, a family member who can tell her story to Kaiser Health News about how hard it was to navigate her husband's cancer diagnosis and treatment because she didn't receive the training and support she needed, and so it's really being able to combine those different elements is how we make sure that we are being intentional for the impact that we need.

Rosanne Corcoran 37:31

It feels like there's just something new every day, of you know what to pay attention to. There's so much noise, there's so much, you know, how do you rank these these things that are happening, crises and whatever, but for a caregiver who's listening right now, who feels invisible to policy makers, what would you want them to know about the difference that their voice actually can make, and can it make that difference?

Jason Resendez 37:56
Absolutely, I want every caregiver listening today to know that your lived experience is expertise, right? I mean, just think about that in terms of your day-to-day life. When you're providing care, one of the terms I hate is informal caregiver, right? Informal about balancing six medical appointments a week, alongside grocery shopping, alongside, you know, managing medications, alongside changing feeding tubes, alongside, you know, all the other realities of care, that's skilled, right, that's expertise, and that's has value. So, recognizing that your lived experience is expertise, and so that your story has the power to help people understand what caregiving really looks like, the sacrifices that come with caregiving, and that when those stories are shared, we start to build a sense of what the community of care looks like, right. We talked about 63 million Americans, 63 million is a big number, but when it's just a number on, you know, a spreadsheet, it doesn't mean much, but when you pair those 63 million points to 63 million stories that help us understand the sacrifices that are taking place every day in every community, in every zip code, in every congressional district across the country, you can start to shift perspectives to build empathy with policymakers and to inspire action, and we've seen that a great example of that is Senator Andy Kim. Last year at our Caregiver Nation Summit in Washington, DC, he took the stage and made a pledge that he was going to make caregiving one of his top priorities, because of his experience as a sandwich caregiver for his father living with Alzheimer's disease, and his two young boys, and he has stuck to that pledge and has just introduced new legislation last week around better data collection on sandwich caregivers. Has been a strong advocate for home and community-based services, for funding for the Older Americans Act program for Alzheimer's research. You know, and it is in part his story that has helped to create connections across the aisle, including in that hearing, alongside Chairman Scott, who is from another party, has another different perspective on the role of the Medicaid program in supporting family caregivers, but through that connection with Senator Kim, he created this hearing on sandwich caregiving specifically to recognize and in partnership with Senator Kim. So storytelling helps to build connection and connection helps to build a movement, and that's how change happens.

Rosanne Corcoran 40:40
Okay and if somebody wants to, is ready to share their story, and wants to try to influence policy. What should they do, and where should they go?

Jason Resendez 40:48

Absolutely, so we'd welcome them to come to caregiving.org and engage with our Portraits of Care platform, and tell their story there. They can also sign up for our action alerts there as well? I think that would be a great landing place to start that advocacy journey, and then continue to follow Daughterhood. We're cooking up some exciting ways to partner on advocacy with Meg, as a great example, right? We were able to partner with Daughterhood and put out a call, hey, we were looking for someone who'd be willing to share their story from Florida, and really excited about replicating and building on that opportunity for advocacy throughout the Daughterhood Network.

Rosanne Corcoran 41:29
Wonderful. And what you know, what's the most important thing that you would want a family caregiver who's listening today to walk away from this conversation in either knowing or feeling, or both.

Jason Resendez 41:41
Yeah, I think both is to know that you know you're not alone. I think one of the things we see in our research is how isolating the caregiving experience is. We've seen an increase in the number of family caregivers who feel isolated, particularly amongst women. But what we know from that data is there's 63 million Americans who are providing care alongside you, and so know that you're not alone. Know that when those stories are shared, that's how connection is made. And in community, there's power, and so I really encourage you to embrace that power, and that power can help us make progress, even in the face of these challenges that family caregivers experience, you know, every day, and so I really just want folks to understand that there is a larger community out there of support and recognition, like we seen you, and it might not feel like it, and I know, like you said, caregiving is hour to hour, but just know that that sacrifice is seen, and there are people out there, this in this network, and the Daughterhood Network, and beyond, at the National Alliance for Caregiving, and our partner organizations, and on the Hill, and folks like Senator Andy Kim, who are working to make sure that those sacrifices are honored and valued.

Rosanne Corcoran 42:56
A big thank you to Jason Resendez for being my guest today. For more information about the National Alliance for Caregiving, and if you are willing to share your voice and your story, visit caregiving.org and click on the Caregiving Portraits tab. I hope you enjoyed today's episode and found something helpful, whether it was information, inspiration, or even just a little company. You'll find the full transcript and links to resources mentioned today@daughterhood.org in the podcast section. While you're there, explore more of what Daughterhood offers. We're more than a podcast, we're a nonprofit community providing free services and support for caregivers, including nationwide virtual support groups we call circles. On our website, you can register for a circle, sign up for our newsletter, and read our founders

blog. Don't forget to subscribe and review us on Apple Podcasts, or wherever you listen. Your reviews help other caregivers discover the support they need. Follow us on Facebook and Instagram at Daughterhood to stay connected, and if you know someone else who may benefit from Daughterhood, share it with them. Also, a very special thank you to Susan Rowe for our theme music, Mama's Eyes. This is Rosanne Corcoran. I'm so grateful you spent your time with me, and I look forward to being with you again next time here in Daughterhood.