

## CLAWS AND WINGS:

### AN ORAL HISTORY EXPLORATION OF DISABILITY IN DELAWARE 1917-2017

Transcription of video recorded July 20, 2017

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Topics included: Division of Health and Social Services, Employment

Run time: 50:42

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RL: My name is Rita Landgraf and I'm currently professor of Practice in Health and Social Services at the University of Delaware, and I'm also the director of the UD Partnership for Healthy Communities. Prior to this current work, I served as the cabinet secretary under Governor Markell's administration in the department of Health and Social Services, which is inclusive of disability services. Most of my career has been in service to others, mostly in the not-for-profit world and mostly in disability services.

Also in aging and a lot of that, what drew me to the aging world, and in particular AARP, was when I looked at the aging agenda and I looked at the disability agenda, especially relative to community and access to community services, they both were pretty much identical. And I thought, wow, AARP has very powerful lobby. As a matter of fact, they are the second most powerful lobby in the United States. The NRA is the first most powerful lobby down at, on Capitol Hill. But I felt as though aligning the disability agenda with the aging agenda may accelerate the community services for people with disabilities even faster.

And, so most of my career has been really focused on people with disabilities. When I landed at the Department of Health and Social Services, I was able to expand it relative to individuals who find themselves very challenged and in disenfranchised communities.

But my greatest teacher in – my first and greatest teacher in the world of disability – was Mike Christie is his name. And when I was 12 years old there was Mike on the red bike, who lived in a neighborhood that was next to my neighborhood where I was growing up, as a child and he came down onto our street. We were a very small neighborhood. Children were all about the same age, you know, we were 10-11-12. And in the summertime we would just be out on the street, playing, you know, and just getting to know one another.

And then newcomer Mike comes along, a little bit younger than me, and I could tell he was really interested in joining in and being part of, of our circle of friends. And what was most powerful for me as my first teaching in the world of disability was: we were not very kind to Mike. You know, we would make fun of Mike because he apparently was somewhat different than the rest of us. And I can remember Mike tried – attempted probably two times – to join in with us on different days and always the outcome was mostly the same. And I can remember that feeling in my gut that something was not right about this. And I can remember not really participating in making fun of Mike, but I also remember not stopping the ridicule that was occurring right there in front of me.

And I remember Mike leaving the group and, you know, with, with a profound sadness and it just impacted my soul and Mike never returned. And I didn't blame him for not returning. But the gift that Mike gave me that particular day was the gift that led to the wonderful career that I have had, because I remember saying to myself that I would never, ever, allow that to happen again in my presence and that I would remain silent.

And so, you know, I really think that Mike was given to me for a very good purpose. It still pains me to think that, you know, nothing did occur that day where I could have the courage to stop that from occurring with my peers. But I then had the opportunity later in my life as an adult where I became reunited with Mike and reunited with his family when I served as Executive Director of The Arc of Delaware, which serves individuals with intellectual disabilities, which Mike has.

And his father came through the door. We had created an organization called Delaware Care Plan, which is a special needs trust for individuals with disabilities. And his father came to set up a special needs trust for Michael. And of course I recognized the name and I recognized that he was setting it up for Michael, so I told his father my story. And then Mike again was a part of The Arc in that we supported him in providing employment services, and he was working at the New Castle County Farmer's Market. He was married, he was driving his car, and he was living his American dream.

And for me, it was just such a, a time of celebration that Mike's life went on and went on in a most successful way, and so I did, you know, have an opportunity to, to speak with Mike and to thank him for the tremendous gift that he gave to me that day that did cause him some harm, but indeed accelerated that my purpose then, that summer day at 12 years of age, I had a purpose and I was blessed to know what my purpose was for such a young age and my career path then just continued.

KB: And where did you go to school?

RL: I went to high school at McKean High School, which was also right down the street from our neighborhood, both Mike and my neighborhood. And I went to school at the University of Delaware and how, how history comes full circle: so at the University of Delaware at that time they didn't have a minor in Disability. They do now. And actually I'm now part of creating a Master's program in Disability Leadership at the University of Delaware. But I was able to work with my advisors and specialize in disability as part of my curriculum back in the late '70s and you know really looking – I graduated out of Community and Family Studies, which is now in the College of Human Development and Education.

But it really enabled me to, to branch forth in the field of disability, and really as an advocate. Most of my career I've been an advocate, I remember when I got appointed by the Senate to serve as the Secretary of Health and Social Services, they all knew me. I lobbied in Legislative Hall since 1986 and they asked me, you know, how I was gonna go from an advocate to a bureaucrat or, you know, how will I transfer being an advocate and now being on the side that I have to respond to advocates? And I told them that I thought we were all advocates, regardless of what hat we wore. But especially if we're in government, we should be advocates for the constituencies that we serve.

KB: Was the right answer. [Laughs] So what was your first job?

RL: So, so my first job... Well, my, my first job was while I was in high school, and actually it was working at a camp for, for children at Archmere. So their summer camp. But when I was in my undergraduate at the University of Delaware, because of Mike, I indeed was interested in disability studies. So I read an ad in the paper about a little girl that was the age of 8 who had cerebral palsy. And her mother was looking for someone to come and support her during the summer months. And so I answered that ad. At that time mom and the family lived in Pike Creek. So I remember going to her home and seeing this beautiful, beautiful young girl of age 8 with the most gorgeous brown eyes, huge brown eyes.

And I remember when I answered the ad and her mother, we were having a conversation, and you know I was asking her what do you want for your – for Chrissy, her name was Chrissy. I said what would you want for Chrissy? And I commented on how beautiful she was, and I remember her mother just looked at me and on the spot she said, “You have the job.” And I said, I said, “Really?” I, I said you know, “Don’t you want, like, references?” And then she said, “Every other person who came to my home would look at my daughter and they would say, ‘I wasn’t expecting to see someone that had such a severe disability. I don’t think I’m prepared to handle this.’” And she said I was the first one that came and looked at her just like a child, just like an 8-year-old little girl.

And so, you know, again being not that well-versed in the field except for what life taught me and now what, what Chrissy was teaching me, that also had a profound impact on me, because we’re all children first, we’re all people first. You know, some of us just might happen to have a disability, but we all have our gifts, and we all have our liabilities, that’s just us as humans. But to see her mother – her mother was actually in tears and she said, “I was becoming so discouraged because everybody would look at Chrissy and couldn’t even see the, the child that Chrissy is.”

And so I actually supported Chrissy in the summer months for, for two years, and, and we just had the time of our life. It really gave – furthered my education, relative to even individuals that might communicate in different ways; Chrissy did not have speech. But Chrissy, you know, I always thought that Chrissy had – in that brain she was a genius, I always thought. Because I would watch her adapt to her environment and how we would communicate – she taught me how to communicate with her – was if you asked her a question, a yes or no question, for “yes” she would smile and for “no” she would stick out her tongue. And I used to know, like, if she really didn’t want something because that tongue would come out so very forceful and she would, like, frown and let you know and I’d be like, “Oh, okay! You really don’t like this, do you, Chrissy?”

And, you know, so it even taught me that for communication, not everybody communicates in the same way, but we all can communicate if we pay attention to each other and we’re very purposeful and deliberate in that moment. So she gave me that gift as well, and you know, again she re-entered into my life when I was at The Arc of Delaware as, as a young adult that she was. She has since passed on, but, you know, I attribute a lot of my foundation relative to, to working with people with disabilities, having friends with disabilities, to my early years and the gift of Mike and the gift of Chrissy. They, they taught me so very, very much.

KB: So what do you think is your defining moment in this field, once you get past Mike

and Chrissy? Then how do you think you personally made the most impact?

RL: Well, you know, I think impact, that's interesting, that how do I think I made the most personal impact, because I think no one on their own makes much of, of an impact. It's more of collectively, how do we make an impact? How do we get from our, like our Chrissys and our Mikes in this world, and how do we utilize that to transform, regardless of what our occupation is? You know, I'm blessed, as I said, to know my purpose, especially from a career track, but regardless, you know, it's inclusive. It's, it's how do we treat each other? How do we promote diversity? We all win when we do that.

And so for me to be able to devote most of my career in this field, again from my lens is a terrific, a gift. Probably the most telling for me on the national stage was the ability to work with Governor Markell when he chaired the National Governor's Association. And at that point he came to me – because he met me through disability, so he knew of my background. Partly why he appointed me as his cabinet secretary was because of my background in aging and disability.

But what he asked me was – when you're chair of the National Governor's Association, you're chair for a year. And you get to pick any agenda that you want as a sitting governor, that you want to promote across the nation. So he came to me, and he said, "I would like to promote advancing employment of persons with disabilities." And he was like, "What do you think?" And I was like, "Wow! I think that's great!" I said, "I'm so proud of you, Governor, because that really is a tremendous agenda item that would really put more attention on this as a national agenda. Since you have all sitting governors around the table that, you know, will pick this up as their agenda stateside, but also to promote it as, as a national agenda." And he asked me to support him in staffing that agenda.

So I had an opportunity to work with the staff at the NGA and to really take that across the country working with the numerous governors, who absolutely took it on as also a platform for them. What I saw was bipartisanship. Governor Walker from Wisconsin who's a Republican, Governor Markell from Delaware, who's a Democrat. You know, probably in most of their agenda items are at different ends of the spectrum. On this one, they were extremely unified, and I saw that with all the governors there as well.

So the, the fact that you can bring this issue to the table and unify, you know, not only your top CEOs within the state, but then also having the opportunity to work with Senator Harkin. And Senator Harkin was, you know, the author of the Americans with Disabilities Act. To be able to get to know him on a personal level for me, you know, was indeed quite the highlight. And then Congressman Tony Coelho – who now actually lives in Rehoboth, Delaware – you know, from California on the House side of Representatives. He was the promoter of the ADA because he is a man with a disability, with epilepsy. And at the time when he was diagnosed with epilepsy he was shunned by his family. So the stigma and the discrimination that he felt.

Senator Harkin, of course, his brother, who has also passed on, but was deaf. And so Senator Harkin, you know, got his gift – his first education in disability was through his brother. And saw how his brother was constantly...everything was decided for his brother. Even where he wanted to go from an employment perspective, he only had three choices. And those three choices he didn't want. So you know, advocacy was born in the

Harkin family because of Senator Harkin's brother and some of the barriers that he faced just because happened to have a disability. Same with Congressman Coelho, to the point where his family divorced him as, as, as a young man, as a, a high school man.

So, so, you know, my defining moments are always those things that I hear on the ground, at the grass roots. And then I look at, okay, how do we solve that? How do we advance as a society? Because it's discriminatory, it's stigma, but it's even that we're leaving a potential on the table that, or off the table, that we should really be promoting in our society and the advances of that level of diversity.

So that was my most recent defining moment, to be able to do that, to be able to bring it back stateside and really shine the light on it as well. I've placed people with disabilities in employment, I've done employment training with people with disabilities, so to be able to do that during the Markell administration was very exciting for me, to be in a position to, to, you know, call that stronger to light and to, to advance that.

Also, in my work as a policy maker, you know, I want to continue this work because we still have a lot to do. We, we haven't by any means reached where we need to be as a society. And what I see happening now, for me, is quite frightening, because we have the potential of sliding backwards, and very far backwards. When you think about the, the Affordable Care Act and what that provided for people with disabilities through the elimination of pre-existing condition – a disability is a pre-existing condition – so many individuals were never able to obtain, attain health insurance, and that's why they're on the Medicaid program, but there's flaws in Medicaid.

Medicaid was established in the '60s primarily as insurance for individuals in poverty, so now there's an association between poverty and people with disabilities. It's the only class of individuals that by policy we reinforce that they remain in poverty in order to attain benefits that actually enable them to live in the community and to be included. So even when we get individuals employed, many times they're held at a certain income level, so they don't lose that Medicaid that would, you know, then eliminate some of the services that they have to succeed in our community.

So I call that flawed public policy. And the need to really address that as a country, I, you know, I'm a big believer in social determinants of health as the Health Secretary. I saw how poverty devastates all, you know, individuals that are in poverty. They actually don't live the lifespan that people who are not in poverty live to, so they have some, you know, very terrible health outcomes. And that's inclusive of, of people with disabilities.

So from my lens, a lot of work still has to occur in that arena, the fear of sliding backwards because of that. You know, I know I administered Medicaid here in the state, what I'm hearing federally, you know, really taking a lot of that funding away from Medicaid and giving it to the states, when on face value that might look good, but really you need a federal policy relative to health insurance for individuals...Well, actually for all of us. I think our country has to figure out is it, is it a, a right, and you know, I believe health should be a, a right for all of us. It's not a privilege, it's we should all, you know, take care of each other from a health lens.

But for people with disabilities, Medicaid plays a critical, critical role in supporting individuals. When the Affordable Care Act was passed, I was very encouraged that that

was an opportunity, especially in the disability arena, to re-imagine Medicaid. And for the health conditions to enable people to be employed at any level of income that they can achieve through their employment. To get the health insurance traditional – that supports people with traditional health care and then to use Medicaid as a wraparound services. And we were starting to have that dialogue, you know, relative to the Obama administration. But now as disability advocates, you know, we're just trying to preserve what is in play now and not lose any of that, 'cause that truly would take our country backwards.

KB: In your position at the University, are you working on public policy?

RL: I am, I am. My position at the University enables me to go across to all the colleges at the University and then I also wanna collaborate with the other institutions of higher learning within our state. So the School of Public Policy and Public Administration, we're working closely with that school. And of course, the Biden Institute. You know, we, we are very blessed here in Delaware by having Vice President Joe Biden return to Delaware and, you know, put his domestic policy work at the University of Delaware. So the Biden Institute, we're engaging them relative to advancing the policy, and especially in the health arena.

You know, the, the other thing I heard a lot as I served as, as Secretary and some of the work that we did under the Markell administration relative to financial empowerment: financial health and wellbeing correlates with overall health and wellbeing. And again, when you think of people with disabilities as a cohort being in poverty, you know, again, how do we advance overall health policy but look at also financial literacy, financial empowerment. We know disparities of health, that certain cohorts have less economic opportunity, less education, and that, you know, rings true also for people with disabilities.

So, from that platform, I know when I started talking to national organizations about where people with disabilities fall from a financial empowerment and a health arena, they started paying attention to it a little differently, 'cause they're used to special interest groups coming as a special interest group, but when you bring it forth as a population health perspective and financial wellbeing correlates with overall health and wellbeing, people kind of see it through a different lens.

So, you know, working with national groups from the financial industry, too, has really leveraged, you know, the, the advocates, if you will, for advancing better policy to address all populations, disenfranchised populations, inclusive of people with disabilities.

KB: Delaware's the right place. So institutions, of course University's an institution.

RL: Oh, yes it is. That's why they call it institutions of higher learning.

KB: So what about institutions like Stockley?

RL: Live-in institutions. Residential institutions. [KB: Yeah.] And, and you know, our society, again, you know, how history sometimes the pendulum swings, right? And, and, you know, in the '20s that was considered best practice. To, and... Actually the intent, the, the mindset around cohabitation of people who were like each other was one that actually did not necessarily come from a bad place. It came from a place where how can we then collaborate and bring the best of the best to, you know, the volume of people that

might have a disability to provide services and supports?

However, in practice it never really was... It, it never went to that level. And still has not gone to that, that level. So what we found, and prior to the ADA and prior to *Olmstead*, the Supreme Court ruling, what we found was we ended up warehousing people. And even the way our language was at that time. You know, I, you know, serve people with mental illness as well, serving at the National Alliance for the Mentally Ill, and we ended up warehousing individuals with serious persistent mental illness, warehousing individuals with developmental disabilities. And in the '20s we thought that we were protecting those individuals from society and society was protected from those individuals.

Even our language... You know, Stockley was called the "Hospital for the Feeble-Minded." Delaware Psychiatric Center was called the "Insane Asylum." So even if you think about the language that we used was very demoralizing, very stigmatizing for the population. And over time, we as a country and even as a state have created laws to address that. People-first language has come about. You know, in order to say it's the person first and the disability second. We even got rid of the "R word" and that the word "mental retardation" – well, in the Webster dictionary really when you looked at what that word was, there was nothing necessarily stigmatizing about those words themselves. But it's how society has used those words over time that demoralizes and stigmatizes a population.

So, you know, when you think about institutions, the movement and actually Wolfensberger [Editor: Dr. Wolf Wolfensberger, 1934-2011] out of Germany back in the '30s called it "normalization." That really what we should be doing as a society is this is just normal and normalizing our systems so that society support people but that we don't isolate people. And if you think about that, that was in the '30s. His work and research came out of the '30s. Well, it took us a long time to get there and we're still not there. So, you know, the pendulum in disability has moved rather slowly, and as I indicated, and is at risk for moving backwards even today, when we're trying to celebrate, to some degree, how far we have come.

There was a time that for people with intellectual disabilities, we didn't even recognize them in our school system, in our public school system. The Arc that I had, you know, that served here in Delaware, was created in the '50s by parents who actually saw a different life for their children and they didn't want to put them in an institution, they wanted to care for them at home. So the original services that The Arc promoted before public education stepped in in the '70s, The Arc promoted the first schools for children with intellectual disabilities.

And then come the '70s and I'm sure Brian [Hartman] has touched upon the law end of this, Public Law 94-142, which was the Education for the Handicapped Children's Act, which for the first time included children with disabilities in the public education system. That law is now IDEA – Individuals with Disabilities Education Act – continues to evolve to ensure that students are actually educated alongside their peers who do not have disabilities. And both sides win in that arena, because we all benefit from diverse thought, from diversity, it helps us problem-solve.

So even if you look at that evolution, in order to do that they need to be included. So

institutions actually prevent that level of inclusion. And what many times you hear is, okay, that's fine for those who are high-functioning, but what about those with the most significant disabilities? Chrissy, the gift of the Chrissy, the eight year old that I had the, the blessing to spend time with. Chrissy gave me an education. Even when her communication was such that was limited, I learned from her and hopefully I gave some teaching to her as well.

So that argument in my mind is flawed. And the onus should be on us, not on the individuals that are born or acquire disability. We need to continue to evolve. We as the United States of America have the ability, have the intellect – we've proven it – as our country, to continue to evolve. And rather than discriminate or isolate populations, we should be at the forefront, actually engaging populations.

KB: Amen.

RL: And as a university, that's where we hope to, to advance. And I'm very pleased when I think about, you know, this fall, we will be offering a Master's in Leadership and Disability. So, because it starts there. You know, and then how do you integrate the work of policy, the work of our teaching as a flagship university? And then how do we give our students the experience on the ground? And, so my work in healthy communities is to actually advance all of that.

KB: So were you involved at all in the beginnings of ADA and IDEA and...?

RL: I was. I started, you know, at the, at The Arc. I, I was just starting in the '80s, really looking at – because the education then, you know, with Public Law 94-142 – had just occurred in the '70s. So I worked with families in helping families actually compose the IEPs – the Individualized Educational Program – for their children. And really kinda being there for, as their advocate. You know, systems sometimes are very difficult to navigate, and usually the system has multiple professionals. And here you are a parent or a student with a disability.

So looking at again through the lens of that student, being – having the honor of being there to learn, what goes on between our systems, whether that's education, whether that's employment, whether that's health, how do you interact with that system and how does that system interact with you? How do we then enhance the skills of the constituents, the families and the individuals, so that they can navigate those barriers? But, also, how do we change the system and transform those systems?

So I had the ability to do that at the school level, I had the ability to do that at, at the adult level. I was at the Client Assistance Program, which is part of Congress, created the Client Assistance Program, which is to advocate for individuals that utilize the vocational rehabilitation program. And so whenever there was discrepancy between what individuals wanted and what the voc rehab system wanted, the Client Assistance Program is there to mediate between the two systems and to serve as a support to the individuals.

So I served as an advisor (then they called it "CAP"), I served as an advisor to that. Had the ability to learn. Again, most of my teachings have come from on the ground, interacting on the ground, interacting with the systems, and then looking at, okay, you know, I might be able to solve this one-on-one for this person, but it's a bigger issue. It's a systemic issue. So how do we use the tools to transform our system? The ADA then

came along, was very involved with advocating for that on the Hill. Then *Olmstead* came along. And then when I landed as the cabinet secretary, our Division of Substance Abuse and Mental Health was under fire. I was able...because of warehousing people with serious persistent mental illness, and not affording them a robust, community-based system.

I then, I think it was – like, I'm blessed to be there at that time, to work with the United States Department of Justice, to create a settlement agreement that would honor the ADA, honor *Olmstead*, but really honor the people themselves that should be afforded the opportunity, with supports, to be in their communities and to do that work for the years that I served as cabinet secretary. We were the first state in the nation that successfully resolved that settlement agreement by the five years that it was intended to be resolved.

And the lives that I saw that were able to leave the Delaware Psychiatric Center that had been there for decades, had never been in community, you know, for like thirty years. And to be able to watch that transformation, to create peer support – peers are individuals that have the same lived experience – to really upgrade that, make the peers part of our system of care, get them certified, so actually then there's a payment stream through insurance that can pay them for those services, and helping others who, you know, are, are coming out of DPC or need that support on the ground through a peer.

We respond to each other largely through our lived experiences. So we saw so many great things happening by advancing our system of care. But a lot of that has been, you know, has been governed because of these laws that have occurred federally as well as the enforcement of these laws.

So the United States Department of, the United States Department of Justice – and at that time Tom Perez was the Director of the Civil division – was really looking at accelerating both ADA and *Olmstead* by really holding the states accountable for that, and that's when you saw a lot of activity stateside with litigation. You know, against the states for warehousing. If I remember, Tom Perez told me I was the first state, like, that welcomed them in. Because the minute they landed I said, "You are absolutely right and we do have to resolve this issue."

So for me they were more like a partner in helping us really exacate [Editor: execute] a settlement and then really implement that service.

KB: So somebody said Stockley went from like 700 to 100?

RL: Yes. Yeah, now I think it might even be down to 60. Yeah, Stockley actually – that work was done while I was still at The Arc in... And they didn't... That work also was brought on by the state. So that wasn't the United States Department of Justice coming in like we had for people with serious, persistent mental illness. But The Arc actually sued the state for people with intellectual disabilities under *Olmstead*.

The state at that time, that was under Governor Minner's administration, was to produce an *Olmstead* plan, to talk about, you know, how are we gonna advance community-based alternatives, services, programs for people with disabilities. And we actually wanted to support the state in bringing forth that plan, and it was supposed to be rather comprehensive. The state put a plan together. In our mind, that plan was not

comprehensive enough. And it was not just The Arc, it was Delaware People First was involved, Community Legal Aid was involved, where Brian [Hartman] was from, State Council was involved, DD Council was involved. So we all agreed that this was something that we did not think our state had fulfilled what it was intended, to have a comprehensive plan to really promote community and dedicate resources for that.

So we brought litigation in order to promote that at stateside. We ended up settling that litigation. It created a Commission on Community that is still in play today, you know, and the need to continue to evolve and advance in, in that area.

KB: So what more needs to change?

RL: Well I, I think, again, I think a lot is still at stake. And, you know, it's, it's, it's... It's comforting to see the level of engagement in policy from the disability community itself, from individuals, individuals with disabilities. What, what I find a little sad from my perspective, when I think, you know, how far we have come, that, that we still have to advocate at that level just to protect what we have. Because what we have is still not good enough, right? And now we have to spend our energy, not to kind of advance, but to protect, and that's what it remains concerning to me with where we are as a country right now.

There is also, when the pendulum swings, there is also a movement to, to look at, you know, more of an isolation from the perspective of residential and homes and housing. And from my perspective, that takes us backwards. Even if those, those communities are such that they can offer the best of the best, if people aren't included with the rest of us, I think we all lose from that. I've, I've just seen it. I've seen it as an employer of people with disabilities, I've seen it in my neighborhood with people with disabilities. I have a stepson with intellectual disabilities and, you know, my life is richer because he is in my family. And if he, if I never knew him, I would be missing a lot from engaging with him.

So, I think, you know, right now where we are in our point in history, we do have to remain so very vigilant to protect what is there. And then I think we have to advance it. We have to advance it from that, that innovation lens. And again, not blaming the cohort, but looking at, how do we enhance the lives of this cohort in a way that then enhances all of our, our lives?

So, as I said, the onus is on us. And what we do with this moment will be telling. It'll be telling to all those pioneers that came before us. People, you know, like, like, like even, like even President Kennedy and, you know, his family and what they were looking at to advance the civil rights of individuals with disabilities. All of that work didn't happen overnight. It was an evolution. And we were just trying, you know, even today, to fully implement the ADA. And now we have... And then the Affordable Care Act came, and *Olmstead* came, and parity came – we're not at full parity between behavioral addiction and mental health and physical health, but we have a law on the books.

So, we've had these laws on the books now for decades, but yet we're not fully embracing those laws at a time that we have a chance of going backward. And that's why we have to remain vigilant to protect that, but I challenge all of us to go beyond the protection and actually look at how do we advance?

Because at the end of the day, and you know, as what we all think about, here in

Delaware, we're thinking about it, across the country we're thinking about it, as a nation we think about it: economics. And, you know, the fiscal stability of our country and of our state. At the end of the day, though, when people are included, when individuals with disabilities get the same opportunity as people without disabilities, we indeed fiscally have more to gain in that type of system than the current system we have in play.

KB: Talking about fiscal responsibility, tell me. Some people think it's cheaper to have the people in the community with support staff. How does that play out with what you know?

RL: Well, the, the highest cost of care is at a facility-based level cost of care. And in Delaware for a, a long time, I said that we have a bias in facility-based care. Being Secretary of, of Health, I was actually responsible for five facilities that largely supported people with disabilities and other chronic health, health issues. And for being a population of less than a million, like, that is kinda unheard of. So that's why I said, we seem to have a facility-based bias in our services to people with disabilities. But just like anything, acute care, hospital care, is your highest cost of care.

So fiscally, you can leverage your funding to serve more people in a community-based framework. AARP would estimate for every one person that's served in a nursing home, you can serve three in the community. And you need to provide a robust menu of supports that will help individuals. Sometimes how we fund for this level of care, we don't fund necessarily a menu or that menu's restricted, so you may have, you know, certain support needs or service needs and you might not be able to get all of them. What we did in Delaware, if they're under what we call a "waiver," but what we did in Delaware was looking at, how do we offer the ability to individualize services rather than categorize services in a menu?

And when you individualize services, then whatever you need, you're able to get through the Medicaid program. In order for us to do that, we had to kind of pull ourselves out of some of the waivers that we had with the Center for Medicaid/Medicare Services, and what we did was, we put it under our managed care organizations. And that was the best place to afford, that we could offer individualized services. What I said to the ground when that happened, some states do that actually to curb cost. That wasn't our intent. Our intent was to be able to have a more robust offering and support for individuals based on their individualized needs.

But what, what, what... Where we needed to gain competency, was our managed care organizations needed to gain those competencies to support the population of individuals with disabilities. So, you know, that I hope, you know, continues, those competencies continue to go up, and people with disabilities are getting what they need based on their individualized needs.

KB: So, what more needs to change? If you had a magic wand, what would you do?

RL: Well, and, and I think there's still stigma. I think there's still stigma. I think also, you know, what I see happening, you know, I also think that we, we need to, to focus on individuals with disabilities who are aging. You know, I think we kinda created our system as individuals were growing up, so you know, The Arc was created in the '50s because they wanted to keep their children at home. So they focused on the education

system; how do I keep my children at home and get them education?

Well then their children grew up and now most of those children that were born in the '50s are older adults and, you know, I don't believe in that arena we have advanced to the degree that we do. So many of our older adults, many times the system doesn't allow for them to even retire, like it does for people that don't have disabilities, because of how their care is supported. So they need...like they may still need to be working or, and, or going to vocational programs. I mean, I remember a gentleman said to me – who, he's a friend of mine – and he said, "Rita," and I think he's 68 years old, he's like, 'cause, you know, I was like, "How you doing, Fred?" And he goes, "Well, I would really like to retire," and he's still working. But that's not his wish, right?

So, I think in advancing, again let's go back to the grass roots. Let's listen, let's understand what the people want, then the onus is on us to create those systems of care that will afford people what their desires are, what their dreams are. So if he wants to retire, let's come up with a retirement plan that meets what he wants to do at this stage in his life. So I think from that perspective is just one example. I also think the quality of our services – we need to continue to challenge ourselves at all levels. For what people desire, what their dreams are, how do we support them in achieving their dreams, even if they're diverse across all the spectrum? But then how do we also ensure that what we're providing is of a quality and something of what that population really wants?

KB: So the field is evolving with the baby boomers as we get older, huh?

RL: It is, but remember, there's still a lot at, at risk, and you do see people almost going backwards, wanting what was the traditional delivery of service, where you congregate people. In, in of like, you know, you congregate people, and then you bring in the service delivery to them, where we had been evolving under ADA and *Olmstead*, to get the people amongst all people walking in, you know, all walks of life, but providing the supports and services that they need in order to be successful.

KB: So what, if we were going to write a biography of you, and I hope someday they do, right? What would you like people to know about you in the future? What would be your few words that would be self-descriptive?

RL: Well, I, I, I think, I think, you know, my core value is promoting a diverse society and community. And that we need to value the gifts of all that are brought to the table. And we really need to promote equity and equality. And from my lens, that should be the core value of our country. And then how we allocate our funding and how we develop our policy should be wrapped around that core value. And so what I see, in allocation of funding and what I see in policy, whether that be looking at people with disabilities, whether that be looking at people in poverty, whether that be looking at childcare, I see that that is not our core value as a country.

So what I would hope for our future, is that we advance and make that our core value.