

CLAWS AND WINGS:

AN ORAL HISTORY EXPLORATION OF DISABILITY IN DELAWARE 1917-2017

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Interviewer: Kim Burdick, MA, MPA (Referred to hereafter as KB)

Interviewee: Marie-Anne Aghazadian (Referred to hereafter as M-AA), Parent

Topics included: Autism, Parent Information Center

Run time: 53:56

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M-AA: Well, my name is Marie-Anne Aghazadian. I am, right now I am actually retired. I was the Executive Director for Parent Information Center of Delaware for over 25 years. And at the same time I was also on the board of Autism Delaware. I'm currently the Vice President of Autism Delaware, the advocacy organization for families of individuals with autism. And, that's kind of my most recent history. I do have, I have two children: Stefan, who has autism, who brought me here today, and Megan, who is in education and lives far away in Austin, Texas.

KB: So, tell us a little bit about your own childhood.

M-AA: My own childhood? I grew up in – I was born in Paris. I grew up in France and Germany. I spent a lot of time with my grandparents, who lived in Berlin, vacations and I actually spent a couple of years in Berlin. They insisted that I continue to learn German and keep my German fluent. And then, you know, the rest of my time I went to school in France – I went to boarding school. My parents had a house in Brittany, and we went to Brittany in the summer, along on the seashore. And when I was 19, I came to America to attend college in California. And I have godparents – or, sadly to say, *had* godparents – who sponsored me to come over and who were really, for many years, my “American” parents. So, that's my childhood.

KB: Did you have any experience with autism? [M-AA: No.] No? So...

M-AA: No. Actually, when our son was two and a half, we had noticed – we noticed. He was born in New York City at Lenox Hill Hospital (at the time we lived in Manhattan). And we didn't notice anything at birth. We did notice shortly after birth that he had a lot of difficulties, digestive difficulties. He was very restless, didn't sleep much. So, by the time – but then, he was slow in developing, but nothing terribly, you know, worrisome. Certainly not enough to worry the pediatrician.

But then by the time he was two, we noticed that he wasn't speaking, he wasn't interacting with other children. We really thought something was off. For a while we attributed it to the fact that I was traveling back and forth between New York and, and Paris to visit my family, and that maybe he was confused speaking two – we tried also to teach him French – we thought he was confused having to, to understand and speak two languages, but that really wasn't the reason.

So, he went to a preschool, and the preschool teacher said to me, “You know, Stefan doesn't do well with other children. He also has no eye contact.” And I had no idea what she was talking about. Now you have to remember that was in 1973, so autism wasn't really a diagnosis that was given to anyone at the time. So we really had a hard time

getting a diagnosis for Stefan. And I had read an article in *Ladies' Home Journal* that was written by Lee Salk, the, the brother of Jonas Salk, and Lee Salk was a well-known psychiatrist at the time, about unusual children. And I tracked him down, and was able to get a, an appointment. And so, we took Stefan to his townhouse on the Upper East Side and spent about three hours with him, and he observed Stefan and then he told us that, in as far as he could tell, Stefan had autism. And we had never heard about it.

So, you know, typical reaction of a mother was, "Well, what do we do now?" I mean, we need to help this child, and, and there really wasn't anything available at the time. So, the good thing for us was that he was able to get us into a therapeutic nursery school at the New York University Hospital. And so we went there twice a week. There was counseling for the mothers – you know, 'cause we were those "refrigerator mothers" and didn't know how to raise our children – and then also some kind of counseling and, and, and play therapy for children. So it really (had) nothing to do with what we use now to treat children with autism.

KB: How old was he when you moved down here?

M-AA: He was about eight, nine. He was nine. Yeah. Eight and a half, really.

KB: So from New York to Philadelphia to here?

M-AA: Right. Right.

So, you have to remember: when Stefan was born, there was no right to special education – he was born in 1971. So, by the time he was five and half, there was finally some – and certainly no early intervention. So I, I did quit my job. I, you know, I had to take care of him full-time. I had no help, my parents weren't there to help me, and my mother-in-law lived close by, really, you know, could do very little because he was...he was a handful.

So, he went to four different nursery schools and was always kind of okay in the beginning and then about a month or two later I would get a phone call and say that they just couldn't deal with him. And so when the Education of All Handicapped Children's Act, which is now IDEA, was passed, I could actually – I enrolled him in a pre-K special education program. And so that was the very beginning of special education. It was a little difficult, it was a little helter-skelter, but he did have a very good young teacher who tried her very best to, to work with him. She had relatively little experience working with children with autism but she just had a lot of energy, and a lot of goodwill, and so that's kind of how he started going to school about two and a half hours a day, and then he would spend two and a half hours on the bus.

KB: And how did that go? Jeepers. Were there other children on that bus?

M-AA: Yeah, they were these little – you know, just like what we call them, "special education" buses – but the traffic in New York City being what it is. He actually liked the bus. He had no problem with the bus. No, no.

And then we moved to Delaware because my husband – who, at the time worked for Pan American Airways – was offered a position in Philadelphia as a regional manager. So, we first looked for services in Philadelphia, but were told that there's a six-month period during which they're not going to provide services. Which now, if you think of it now, people would say, "What?" But then we heard about a school in Delaware, at the time was

a school for children with intellectual disabilities, the Bush School. And, actually one of the gentlemen who worked for my husband told him about that, because he lived in Delaware.

So we went to look at the school and we liked the school and we liked the teacher, who actually had just come from the Eau Claire School, so she had some experience working with children with autism. And so he started going to the Bush School and there were other children there who also had a similar diagnosis. But then I, I connected with a group of parents who had children with autism of all ages. You know, the oldest at the time, I think, was 14, and the youngest was Stefan, actually. And they had passed legislation, got a legislation passed, that was signed by then-governor Pierre DuPont. And the legislation essentially mandated a program for children with autism within the special education realm in public education system. So these, these parents were really gung-ho and making this work, because they had this really important legislation in hand, and they were, you know, they wanted to get a program started.

So I started kind of meeting with them, and going to their meeting, and got involved. And ultimately, we were able to get a program started in Newark in the wing of an elementary school at Jennie Smith, and I don't – you know, we had Dr. Skinner, who was very good at writing legislation. He wasn't always successful at passing it, getting it passed, but he definitely was very good at writing it and getting information. So we kind of became a team. He would gracefully hand me the legislation and said – and he was a dentist – and he would say, “I, I have to go to a dental convention in London, but when I come back, I expect this to be passed.” [KB: Laughs] Yeah, he was very interesting. But, I... You know, he is the kind of person you'd first think, “Oh, who does he think he is?,” but you know, he meant so well, and he was so resourceful and, and really very good at minute, like technical, legislative stuff that he was so valuable. And you know, I, I had no problem getting legislation passed. I could use charm and all kinds of things. So, you know, I had the tools. I just needed the, the talent. So, I tried to...

KB: So it was a good partnership?

M-AA: Yeah, it was a good partnership. You know, got a little tense at times because you know it's very hard when you try to get a program off the ground, but we did our homework. You know, we went to North Carolina and we looked at the TEACH program, which was the only program at the time in the country that actually, specifically provided services for children with autism. We did a lot of research before the Internet, you know, I always try to point that out, that it was a lot more difficult. So I think we were a very dedicated, methodical and...group of people. You know, we had figured out – and this was one thing I figured out very early on working with the legislature – that we had to do the legwork. They could help us, you know, institutionalize what we want, but we had to do the research and we had to present them with the information, because we couldn't ask them to do that.

So...that was, so we were able to get legislation passed for the program. Wait, no, I'm sorry: that was passed, so we were able to establish the program. It started with about four classrooms and it just started growing. And we...the first director for the program didn't work out very well. The subsequent director, Dr. Andy Bondy, was a really good director. He had started as a psychologist under the previous director and then took over. And, and

the program was really a model program that worked well for many years; and we had parents moving from other states to come to Delaware because of the program. It's also the program that started the picture exchange system for communication for children who are nonverbal. So he really, I think, helped us, you know, make this program into the good program that it was, and to an extent, still is. So, that's kind of...

KB: And what, what years are you talking about?

M-AA: So we're talking about '80s and '90s. My son graduated in '92 from that program. And of course, you know, we had more and more children diagnosed. We had more parents moving to Delaware, because of the program, so the program grew very rapidly. But during that time, I started working on adult services, because one thing I had realized was that there really (we, collectively, realized) there really, the programs for adults were not really equipped to handle our children and their behavioral difficulties.

Also, as part of the education program – the Delaware Autism Program, which it was called – we were able to get funding from the legislature to open two residential programs. So, as the children got older – over 12 and 13 and started showing some very significant behavioral challenges – they would spend part time...some were there full time, some were there part time...for staff to work on behavior. So the program was not just a group home, it was an educationally-based program, and the services were tied in with the IEP. So it was, it worked really well because there was constant teaching going on. And also: data. The, the program was very much based on the use of data, data-collection and using data to improve services and, and address needs, the needs of the students.

KB: So, in this time period, he was staying there or coming home every day?

M-AA: He was coming home. He, he started out going two days a week. So, initially, we didn't have a program there, we had, we used some facility at Governor Bacon. Then we were able, so... I personally worked very hard at the, at the vocational program, working with legislatures, because one of the things that had happened in the meantime with the first legislation, we started having friends in the legislature. In fact there was a Senator Berndt, who was – I'm sure you've heard of him. I met him in the supermarket with Stefan. And Stefan had this kind of unusual and unfortunate habit of popping the lids of yogurt containers. And he got a great thrill out of seeing the yogurt pour out. And Senator Berndt was in the same supermarket (I think it was the A&P at the time), and he saw that and he was, he was just a wonderful gentleman, and he came up to me and very quietly said to me, "That's very unusual behavior. What is your child's disability?" And I told him, and then he told me about his grandson – and, you know, that his grandson had Down Syndrome. And we started chatting, and then I was telling him about my involvement with, with the Autism Society – at the time it was called the Autism Society of Delaware. And, so he was very helpful in helping us get legislation to fund the residential programs which are, you know, the 24-hour residential is part of the program...and then subsequently also helped us get, program that specifically addressed the needs of adults with autism.

I also became really – I had a friend, her name was Ginger Galle – and she and I were called "The Autistic Ladies." We would go to the Controller's office, and at the time, Pete Ross was in the Controller's office, and his – John Frazier was also in that same office –

and they would see us coming and they'd say, "Oh, no. There come the Autistic Ladies. They want something!" So, you know, I would bake cookies and bring them cookies and said, "Yes, we want to know, how much does it cost to educate a child in the school system? How much is there available for adult services?" You know, so we tried to get a lot of information from them. We even managed to get them to go to a conference on, a conference on autism in – I think it was also in North Carolina they attended the conference. They came to visit my son at work; several times where he was working. He had actually graduated with a job. One of the things that the Autism Program did very well, they did prepare people for adulthood. And so he started working while he was still in school. So we really have formed, you know, a friendship.

And that was very important, because, you know, at the time, there were very few children with that diagnosis. And I think Delaware at the time, also financially, was in very good shape. And so I think it was for them, it was kind of a drop in the bucket and it made them feel good – and I think they were truly interested. I always felt that the people we worked with... You know, we worked with Senator Holloway, who is very interested in, in, [KB: He's a nice old man.] yeah, yeah, in us and what we wanted to do for our children. You know, Senator Berndt, I just mentioned. You know, the...our friends in the controller's office – I mean, we had a lot of really... We had a lot of support. We also had to work very hard. You know. For instance, the legislation. We also had people in the Department of Education who supported us, I think it was Super... I think it was Mr. Keene at the time. And, so they were supportive – so everybody really wanted to help us. And that was, was really, you know, made a big difference.

KB: And Jane Maroney and Margaret Rose?

M-AA: Jane, Jane Maroney came a little bit later. Jane Maroney helped us with the adult services more, and Margaret Rose also toward the end. So, yeah, Jane Maroney was much more focused on early intervention but she definitely was a great supporter. I mean, she never opposed anything for sure and neither did Margaret Rose. And we're now continue to work with Margaret Rose as well. Yeah, she's a great lady.

So, that's kind of the, the story. But...it was a lot, it's been a long, hard road.

KB: Tell me about this Public Law 94-142 that passed in July '75 – (dealt) with education for all handicapped children. How old was he then?

M-AA: He was five and a half. Four and a half, sorry. Four and a half.

KB: How did it impact his life, at all?

M-AA: As I just mentioned, I mean, he was able to go to school. You know, I didn't have to send him to a private preschool. He had special educators. It was a little shaky in the beginning. You know, people... I mean, it came about very quickly. So, I mean, it was, it was a godsend for, for families with children with disabilities. I mean, before that I, I don't know where I'm going to send him to school other than preschool. But he was young. I met other parents at the time, too, as part of an autism support group in, in Manhattan, and they had older children and their children had never been to school. And they were, you know, six, seven, eight years old, so it was very important. I mean it was really a godsend for, for us.

KB: And 1987, when you started this Parent Information Center. Where was that and how did that work?

M-AA: Well, Parent Information Center actually...the organization itself existed. It was in – so as part of the public law – which now, I mean it's with the IDEA, it's really a part of IDEA – there is a provision for parent information and education centers, and the parent information centers are in part funded by the U.S. Department of Education, and the premise is that there is at least one in every state. And the, the reason behind those centers was that for parents to be equal partners in their children's education as it is, you know, written in the law, they had to, they had to know the law. They had to know how to apply it. And they had to also learn how to interact with professionals. And so that's not something that you learn either very quickly or very well on your own. So those centers are designed to provide problem-solving, information, training, and support to families of children with disabilities who attend public schools – so from birth to (because in the meantime, we also have Part C which is the Early Education legislation that was passed in '81), so we had, you know, all of that, I think it was '81, it was the early '80s. So we had, you know, parents of children of all ages up to age 22. So that's what Parent Information Center provided in Delaware.

KB: And was it in Dover?

M-AA: No, it was actually, up in Newark. You know, and, as I said, I, I took over the organization, it was at the end of a, I think, three-year grant. And the first thing I did was to write a grant for another five years so just to keep the organization going. The first grant I think was kind of a foot in the door grant, it wasn't very...well-funded. So I also changed some of the things from the original grant. I had people who were then housed in, in Lewes, in, in southern Delaware, and in Dover, so that we were spread across the state. Yeah.

KB: And how many employees did it have?

M-AA: I started out actually with about five employees, all of them part time. And then we had many grants over the years. We took on a, a very large federal grant to provide that same kind of service to families of children who didn't have disabilities – so really just promoting parental engagement. And at that time we had about twelve employees. So, it, it varied depending on the funding.

KB: And does it still exist?

M-AA: Oh, yeah. Yeah.

KB: And what happened in this recent budget thing, just that twenty percent down?

M-AA: Are you talking about the federal budget? I, I think they weren't touched. So the Parent Centers actually, from what I understand, are, are unscathed. Now, their funding isn't very much to begin with. So it is a nonprofit organization, you know, they, we always had to look for additional funding. I think really was fortunate, I was, always had good partnership with our Department of Education – so, you know, Delaware Department of Education always generously supported us – and we would have contracts to provide certain services and training. We've worked with the Center for Disabilities

Studies. So, it's, it's a lot, but also, you know, partnerships, and, and kind of maximizing existing services or, in collaboration with other entities, create new services.

KB: So it's a nice network. [M-AA: Yeah.] Yeah. That's good. What about these, the increase in the number of autistic kids? Is that just because they changed the way they're diagnosed? Are there really a greater number of them?

M-AA: Well, so, you know, we looked at autism as a single disability; now we're looking at autism as a spectrum disability. So it could go from someone who has very mild manifestation of autism to somebody who has a very severe – such as my son, you know, who's 46, but really functions at a 3½-year-old level. So that is one reason. The other is that the diagnostic tools have become a lot better. So, for instance, you know as I said earlier, it was very difficult for us to get a diagnosis because there really weren't any tools to diagnose autism accurately. So I think that has changed a lot. I think parents are more aware, teachers are more aware – children like that being diagnosed in school, which, you know, initially, they probably weren't. So I think it's a combination of, of all of those, and the fact that we are, you know, diagnosing autism of the Asperger type that was not diagnosed in the past. So that really, you know, did swell the numbers.

KB: So it's not that there's actually more kids, it's just –

M-AA: There probably... There also probably are more kids. It's just hard to, kind of, you know, decide which really is the determining factor. I think it's a combination and most people would say it's a combination of all of the...

KB: It's, it's so tricky because, when I was a kid they had “special education” in the schools, but they were Down Syndrome and other things, now we have –

M-AA: Right, they were the “visible” disabilities. Now we have many children with invisible disabilities. [KB: And this is ...] Learning disabilities. Children with, you know, who are on the spectrum, whether it's Asperger or, you know, so, children who have behavioral health issues. And we, we can't tell by looking at them. Which is good, I think.

KB: Yes, it is. Some of the autistic kids are really beautiful to look at, too.

M-AA: Yeah, they are. But many children, other children are, too.

KB: Tell me about the, the group home effort.

M-AA: The adult? Or for...? Well, so, there always...when my son graduated or was ready to graduate – actually, I have to say that I became really involved in looking at adult services by the time my son was about 12. I started thinking about it, and the, one reason I started thinking about it, I had learned that it takes about five to six years to get anything off the ground. The other thing I had, in the meantime, I'd become guardian to a young man with autism who was a foster child, and he was quite a bit older than Stefan, and I was very concerned about him.

And I knew other parents of older children and they were worried. And so I think collectively, you know, we said we have to see how our children – you know, by then adults – will fit into an existing model of group homes where there isn't much happening. You know, people, or people are verbal and they can express their wishes or people have, you know, higher skills. But what we had seen, just in looking at group homes and

visiting different agencies, was that there wasn't much going on. And we had children who graduated from the Delaware Autism knowing how to swim – you know, my son learned, he can swim, he can ride a bike independently, he...you know, had certainly enough independent skills, he could dress himself. He does still need help with some self-care skills, such as showering and tooth brushing – but they had, at least they had some really solid leisure skills. And we didn't want them to lose that. And so we wanted to have agencies that were able to deal, give, provide them with that support. But the most important part for us were the behaviors. The existing, at the time, the agencies that had group homes didn't have individuals, didn't serve individuals, who had severe and challenging behaviors.

You know, I mean, people with autism – including my own son – can be aggressive. They can, you know, be self-injurious, dangerously self-injurious. You know, they can be destructive. So these are things that no one really... You know, they just didn't know how to do that. So that was our focus. We wanted to have a program that would be able to address all of those things that were important to us, but we also were very interested in having a program that would continue their employment. So, a number of students at the time were graduating from the Autism Program with a job. So my son [pause]. My son had a job at a local supermarket – he still works there actually, at a Shop Rite – and I wanted to make sure he kept that job. Other students were working for a time at Rickel's. I don't know if you remember that, it's like a, was before Home Depot, right? And we wanted to make sure they kept those jobs.

Well, typically, the agencies at the time, people weren't graduating with jobs. So, you know, actually my son was the first individual who graduated with a supported employment job, with a job coach. So, you know, we wanted to make sure we had kept all those things we had worked for so hard. So that's why we worked with the legislators, and they created something called a "Post-21 Program" for adults with behavioral challenges – and I think it was "behavioral challenges and exceptional needs." So that included people with autism. We also became good friends with families who had children with Prader-Willi Syndrome – you know, some of these more exceptional and challenging disabilities – and were funded for this Post-21 Program, so, which (in the meantime) has been kind of absorbed in the overall DDDS service delivery.

KB: So it's kind of there but –

M-AA: Yeah, I was a little annoyed that they just kind of, you know, very quietly did away with it. So...

KB: How long did it last?

M-AA: I'd say about... You know, we had a director – had several directors. I would say about 15 years or so. But I mean the services are still there, they're just not concentrated. And you have to fight for them again. You know, it's not... you have to kind of, we know that, their needs that, that they have to pay attention to.

KB: And he lives in a group home now? [M-AA: Yes.] Where is it?

M-AA: The group home is... So we, in the mean... We also one of the things we have done, we have bought a house for him. Because one of the issues we had with the early – you know, like any early new services – people... There were these agencies that were

hired to provide the services were, at first, not very good. So we had to continue, you know, working with the state. One of the agencies, Growth Horizons, we basically were able to have their contract terminated. Actually, Pat Maichle was very instrumental in helping us with that. And then we had other – you know, a myriad of other agencies – come in and try and, you know, none of them were ever a hundred percent of what we really wanted. But at least we could work with them. So... I'm sorry, what did you ask? Cut! Cut!

KB: How is a group home staffed? I mean, how many kids are there – I mean adults?

M-AA: Right. So we bought the home because they were putting people in these apartments, and one of the apartment complexes was at Lancaster Court. And Lancaster Court was at the time like “Drug Trading Capital” of Delaware. And our son's apartment was broken into several times, and so we, we were just beside ourselves. And so we decided we'd talk with the director of DDDS at the time and said, “If we buy a home, will you give us the services?” “Yes, we will do that.” So we bought a home, in Devon, Firethorn Court – it's a little neighborhood of Newark. It's in a cul-de-sac, it's a very nice home. But then, unfortunately the state did not give us any money to maintain the home, so that was difficult for us to do. And so ultimately we, you know, had to pay for some of the repairs ourselves.

But then at the time, then I did talk with the director and said, “Look, you know, something has to give here.” And what the state recognized was that, while they wanted to have homes that were independent of the agencies, one of the things we had learned was that when you let an agency go – like we did with Growth Horizons – if they own the homes, the people were not, they were literally on the street, because they took that with them. So, or they sold it, whatever. So that's one thing that the state didn't want to ever happen again, and so they decided to create this program with The Arc. And where The Arc manages, buys and manages homes which are tied in with McKee's Homes for Life, you know, but, except these are HUD homes, versus some of the other homes that The Arc manages.

So that, I think, was a good idea. It was, you know, we didn't have to worry about paying, you know, for the repairs for a home, where many other, you know, three other individuals lived as well. And so we sold the home to The Arc. And so, but for us it was great because it was... This was a really great experience. We could get him to live where we wanted him to live and you also had a little more autonomy, you know. As long as we had the home we could decide what we wanted it to look like and so, it did help. And I think it was good because in the end it helped that, helped to create The Arc Home Program.

KB: And talk about The Arc: what is it? What's it mean?

M-AA: It used to be the Association for Retarded Citizens in the Dark Ages. It is now called something totally different, but the acronym remains. So we talk about The Arc, and it's essentially a very large, well-known organization that provides, you know, supports individuals with intellectual disabilities.

KB: And in these group homes, did you have staff people living in there?

M-AA: They don't live there. We started out with live-in staff and we found out that that didn't work very well.

KB: So what happens in the night?

M-AA: They have people there overnight. So we had, we wrote, we had legislation passed with this program – Post-21 Program – that mandated how many staff there would be, but it all changed over time, because, you know, the DDDS (Developmental, Division of Developmental, Developmental Disabilities Services), you know, they had started assessing people differently by using ICAP, you know, a new test, a new assessment, so things evolved. I mean, Stefan has been in adult services way over twenty years, and so things have changed.

KB: And how does he get up in the morning and get to work?

M-AA: He gets up in the morning! He gets help getting a shower, and, you know, and get, dresses himself, some one comes. I mean, they're, he's in a home with three other individuals, and they all – three other individuals – also have autism. The staff, he's kind of, you know, staff ratio is maybe 2 to 1, sometimes 1 on 1, depending on the activity. So it's, it's okay, as long as the agency is responsible. We continue to have issues with staff training, you know, but then it's very difficult to get really good staff and to train staff when you have a lot of turnover, and the turnover is mainly because they're so poorly paid. And if we don't as a state – or even as a nation – value people who take care of people who need, *need* support, then we're always going to have dismal services, you know? I think that's kind of a foregone conclusion. So until we can pay people better – and I know there's a bill right now in, in committee to increase the salaries for direct support staff, so...

KB: That's good.

M-AA: Well, I don't know if it'll pass.

KB: Well, maybe not this year, we don't know. What committee is handling it?

M-AA: It's possible one of four. I don't know, probably Human Resources or something. Yeah, I have to look it up.

KB: House Bill 104, so I'll keep track of it. And so what is your defining moment? You've had a long career with this issue. What, what stands out most in your mind about the things you've accomplished or seen?

M-AA: I think the parents. The parents and people who were... Who respected our concerns, who understood our, the difficulty we had, and who, you know, would put politics aside and support us. That to me, is probably what I will always remember. But parents, yeah. I mean, you know, it's kind of nice to be able to talk to people who walk in the same kind of pair of shoes, literally, so yeah.

KB: Tell me about your Governor's Volunteer Award. That was a nice thing you got. You deserved it.

M-AA: It was an award. I actually have gotten several. It's a very nice one. I have, I had no idea I had been nominated, I mean, I hadn't... Obviously I had to submit some information, but I was very honored. It was a little awkward standing on the stage when

Governor Markell said to me, “See, can you think of all the people you’ve helped?” and I’m like, “Hm.” [KB: Laugh] So anyway, yeah. It was very nice. Very nice.

KB: Sometime you had said you were always thinking five years ahead of Stefan’s needs. [M-AA: I am.] So what are you thinking now?

M-AA: Well, now I’m thinking of what’s going to happen when I die? That’s not a very pleasant subject, so we, you know, we’ve tried several things to, planning – and again, I think at this point I hope I’m planning at least ten, you know, [KB: Maybe 20?] maybe 15 years ahead. But things do move, move a little slower nowadays. So I don’t really know. I’m, I’m, you know, we for a while thought that maybe we can move to Texas and we kind of crossed that off, because Texas is... Austin is wonderful for many things, but Texas is not a state where people with disabilities or people with any kind of special needs are particularly important. So I think we, to my daughter’s great despair – she really wanted us to be closer – we might not do that.

So I’m thinking of a project to – I’m actually working with, with Autism Delaware – a project where we would hire and train specific advocates to basically become the parent per se. They would replace the parent and would do the things that parents would do to make sure that their adult child has a good life. So that’s in a nutshell what, what I’m working on. And people would be paid, they would not be volunteers. So many of us obviously are thinking about the future and putting money aside for services. It could also be that maybe some state agencies would pay for part of it – maybe DDDS when things get better, I think that’s a valuable service. But that’s kind of the idea I have that I’m working on right now.

KB: And where would you draw these people from?

M-AA: Well, the way we... It could be retired teachers. I, I took the idea from a program that exists in the schools which (is) called an “educational surrogate program” that is administered by Parent Information Center, and I, I have been an educational surrogate parent – still am – for, for a child. And I really replace the parent for the education piece. I go to IEP meetings. I visit his classroom. I do all of the things that parents do.

And so that gave me the idea that we could do something similar for adults. Now the difference is that the educational surrogate parent program is a volunteer program. I find that it’s very difficult to have consistency with volunteers. If you make it a job – and that’s why I’m working with Autism Delaware – because they would be, be administering the program. And, and so. It could be many people, you know. It could be teachers, it could be other parents, you know. I think if, if we really – you have to have people who have a, who really have an interest in, in doing this. So it’s kind of a... I think of it as a volunteer job with a little perk. You know, you still get a little bit of money, but you, you also do something really valuable.

KB: So. What other kind of partners are out there? [M-AA: What other partners are there where?] For, for the world of autism in general?

M-AA: Well, there are a lot of things going on in autism, you know, larger association, Autism Speaks is – I’m sure everybody’s heard of Autism Speaks – Autism Delaware is a very, pretty large organization by now. They have very good, we have a very good employment program called POWER, very innovative program. So we’re looking at

probably expanding into some residential options, but we're thinking more in terms of people sharing apartments, or families, or homes where families would purchase the home and then contract the services with the support of, you know, Medicaid funding or waiver funding.

So really looking at, we'd like to get away from the "typical" group home, big agencies, multistate, you know, providers with very high overhead. We really want to kind of start doing something that, like POWER, that is home-grown, that is in Delaware, that is very little overhead, and more, more of the funding will actually go to the individuals. And the one thing that bothers, bothered me from the very beginning with these agencies that come in, they have, they're housed in Baltimore or Harrisburg and they have, you know, a hundred groups all in one state, fifty in another...and it's just... And, and... By the time that the, the funding that they have to provide services, by the time it gets to the level of the individual and the personnel, and the direct support staff, there's no money left, really. It, it's all basically supporting this huge bureaucracy. And that to me is...not, not necessary anymore. We, we, we're pretty great. We can do better than that.

And, you know, parents, if they want to participate, should be able to. And right now the system doesn't really allow you to do that. It's kind of one size fits all – and it's very difficult for families who are not able to get a slot to get a group home, and then they have nothing, or very little, you know, and that's not... We can do better. We can give everyone a little bit more, and we can participate if you're able to.

KB: Tell me about your Parent Leadership Academy.

M-AA: The Parent Leadership Academy is really based on my own experience because I had... I really didn't have very good skills to begin with, but I did hone them over the years and learned a lot. And, and one of the grants – you know, we used to apply for grants every three to five years – I wrote in that we wanted to provide that kind of leadership experience for families so that they didn't have to start from scratch and kind of fall flat on their face, and they would know exactly what to do when and what circumstance and how to deal with professionals and the information that they needed to know, understanding systems. You know, you can't work with a system if you don't know how it operates and, and, so, and if you don't know the players. And so that's really what that's based on.

KB: So it's sort of like an "apprenticeship" for parents?

M-AA: Yeah, that's right! And then it actually did have an apprenticeship piece, had an intern piece. So, after the second session – so there were Leadership 1 and 2 – after the second, so they, they, we typically have like three days. It's a little bit like the DD Council has that program... I can't think of it right now. Where families and, and consumers go and have this advocacy training, very concentrated advocacy training. This is a little bit the same model but it's focused on schools, so it's really focused on dealing with schools, with service, you know, related service agencies and providers and other families and how to start a support group. It's kind of a toolkit for parent of a child with a disability.

KB: So sort of the who-you-gonna-call thing?

M-AA: Who, who, who are you going to call and what are you going to say? What are you *not* going to say – you know, like, don't threaten people, right off the bat. Things like

that, yeah. [KB: That's good.] Better to, you know, smear a little honey on things before you start blasting people.

KB: And what about institutions? Don't get her started. He's never been in one, right? [M-AA: No.] What is the, the kind of majors of people that are trained to work with the autistic children? Are they sociology, psychology, doctors...

M-AA: Well, in the school they're teachers, obviously special education teachers. Unfortunately in adult services they're none, none of that.

KB: So are, are kids trained in college how to deal with autistic children? Or is it so generic they don't...

M-AA: It depends. Usually special education teachers, back in Delaware, they have to take a course, which is kind of a supplemental autism certification. Unfortunately, you know, they, I think they have up to three or four years to, to get that certification. So that gives us a little bit more, you know, assurance that they, they're going to be able to teach children with autism. But overall it really has to do with school districts' ability to provide, you know, personnel development. It has to do with the state making sure that people are equipped to, to teach kids with autism.

So, you know, it's like with everything else. We have some really, really great teachers, and we have some teachers who need help. And teachers want help. We, we know that. You know, one of the things that we developed as part of the original Autism Program were several safeguards. One is a state monitoring review board that actually allows the director of the Autism Program to go and observe classrooms and work with different sites. And as a part of that there is a group of professionals and one parent advocate, and so I was on that for many years. And I learned that teachers really want help – they, they really want that. You know, it's... These are very challenging kids, and they really deserve everything there is to help them do the job that they want to do.

KB: And are there... I can't imagine having disruptive kids in a classroom of, of twenty or thirty other kids that have to focus.

M-AA: No, no. They're much smaller groups. So again, as a part of that initial autism legislation for program is a ratio, you know, which kind of now fell by the wayside because now we have this non-categorical funding. But typically the classrooms are, you know, one teacher, four students, one para, two para, yeah.

KB: So they're not mainstreamed then?

M-AA: No. Some, I mean if they are higher functioning then they can actually participate, fully participate in the, in the general education curriculum, absolutely. But not, certainly my son has never been in a classroom with more than six kids.

KB: Yeah, that's about as much as...

M-AA: 'Cause about as much as he handle – and they can handle.

KB: Yeah, I would think so. What about ADA? Did that come before or after he was born and what difference has that...?

M-AA: No, that came way after. And the ADA I think is really, I think it was passed when he was still a teenager or late teens. I think the ADA, in my view, may not have had

– certainly didn't help him directly – but I think the ADA opened our eyes to people with disabilities and their rightful place in society, I think that's what the ADA did. It forced employers to hire people with disabilities and, and I think many do that very willingly, unfortunately not enough. It also, you know, forced us to make life a little more pleasant for people with disabilities. You know, we have curb cuts. We have all kinds of things. I think my development finally put in curb cuts two years ago. So, which is great when you have a baby stroller or roller skates! So I think that's what it did. I think it just opened everybody's eyes to people with disabilities as being, you know, equals. That's what people with disabilities are, equals, not before where, you know, we looked at them and said, "Oh, those poor people have a disability." You know, they, they're not, they're part of the society and they are right there with us. And so they need, they need some accommodations? Big deal. We can do that.

KB: So, if somebody was going to write a biography about you or something, what do you want the future to know about you? What would you say about you?

M-AA: Well, I would say that I have... I have one thing is I just don't quit. Don't quit. That's about all.

KB: And that's a good philosophy, right? [Laughs]

M-AA: And to keep at it. Yeah, keep at it. And, and try to be positive about things, even things get... Sometimes you can really get down on things, you know, get, get very depressed, and, but you have to pick up. And, and I always think of – I never really, I really never enjoy my victories very much, because I'm already planning for the next thing, which one of my staff always said, "Can't you just relax and enjoy, you know, what you've accomplished?" I said, "Oh, I can't, because now I have this I need to work on."

KB: It never ends, huh? Wow, that's great. Can you think of anything else you'd like to say for the good of the cause?

M-AA: I think parents have to get involved. This is one thing that I noticed toward the end when I was working at Parent Information Center, toward the end, before I retired. I was getting very discouraged because I found that parents wanted everything done for them. They wanted something – immediate solution. They were always, see, looking, being unhappy about everything. And that, to me, is very counterproductive. So, you don't always get everything you want. If you get something you want, it's good.

You know, always go to the table with a Plan B. That was a philosophy we used at Parent Information Center when we attended meetings with parents, we would brief them. Go with your Plan A, but we have to have a Plan B. So I think I want parents to really understand how much power they have if they really work at it and they inform themselves. They can't ask other people to do the thinking for them, and they can't ask the other people to do the learning for them. They have to do that.

KB: I always like "People Power," so I'm all about it. So thank you very much. This is great!

M-AA: Thank you! Thank you for the opportunity!