

Bob Kafka and Stephanie Thomas

Disability Rights Advocates

Interview conducted by

Trevor Engel & Sarah Rose

July 10, 2019 in Austin, Texas

Disability Studies Minor

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Biography

(Brief summary of the interviewee's life)

Topics discussed

- ADAPT's interactions with Congressman Gingrich
 - Institutional bias
 - Development of MiCASSA
 - Negotiations in D.C. about MiCASSA and actions against Gingrich
 - Philosophies of other disability activist groups
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-

Rose

This is Sarah Rose.

McKinney

And Courtney McKinney.

Rose

At ADAPT of Texas headquarters in Austin on Wednesday July 10, 2019. With Stephanie Thomas and Bob Kafka.

Thomas

<topic>ADAPT's interactions with Congressman Gingrich</topic>

One thing I kind of want to...because I looked back through the insightments to try to distinguish some of the D.C. actions and I did notice that in the spring of '94 when we went to Washington D.C., that was the visit where congressman Gingrich endorsed the goals of ADAPT related to attendant services.

Rose

Are you serious?

Thomas

I'm serious. He was actually fairly supportive of a lot of what we were talking about. So, I just thought that was kind of...

Rose

How did that happen?

Thomas

He just, I mean he's a weird guy. He supports...okay, he is a bullshit artist of course. But, at the same time, I think he didn't have any problem with people getting government off your back. There's a lot of stuff about what ADAPT was talking about with the attendant services stuff that fits right in with a lot of Republican goals.

Rose

Well, a lot of the ADA in general was fairly conservative.

Thomas

Right.

Kafka

I don't remember all the places, but everywhere he went where we went where we had people, there were protests about him being there, about introducing...

Thomas

Well, this was before the introduction. This is the year before...in '94, that's when we went to his office and forced a meeting with him and with Dingle and they both were supportive of the goals of then CASA, the Community Attendant...

Rose

Okay. So, Dingle and Gingrich.

Thomas

Right.

Rose

You met with them.

Thomas

Right. They were both supportive of the goals of trying to get attendants for people to live in the community and for people to be in charge of their own attendants. Cause in ADAPT history that's kind of a landmark thing. But see, then he didn't do anything about it for a year. So then that's what Bob was talking about where we...in the following year we went back. And we went back to D.C.; it's sometimes called our second Baltimore action because we didn't stay right in D.C. But when we went back that's when we kind of got him to do something.

Kafka

What year did he introduce HR2020? Because that was the first introduction of the Medicaid Community Attendant Services Act, MiCASSA. That came out of the long push to Gingrich.

<topic>Institutional bias</topic>

We actually got a hearing—I'm not real clear on the year, when it was—and we had people testify. Mike Auberger testified for some... they had—I can't remember—the representative from Missouri on the Democratic side testified to Gingrich. It was basically to do away with the institutional bias in terms of that.

Thomas

And what that is is that Medicaid requires that if a states gets Medicaid, they have to provide nursing home services. But, there's no requirement for any community-based services so a lot of states were just doing teeny little community programs and everybody was going to nursing homes.

Kafka

The irony is next year is the 30th anniversary of the ADA and it's the 55th anniversary of the institutional bias. Because in 1965, the Social Security Amendment Titles XVIII and XIX, which is Medicare and Medicaid, which is where the institutional bias—mostly in Medicaid—was there. And still remains even though there was what's called Medicaid waivers. But in essence, your entitled to go into the nursing homes still, but the states has to write what's called a Medicaid waiver to be able to do that.

It still remains, even though things have gotten a lot better, primarily because of the push of ADAPT. But the entitlement still remains just for nursing homes.

Rose

<topic>Development of MiCASSA</topic>

So, can you talk a little bit more about how the fight for MiCASSA developed in ADAPT.

Kafka

We drafted a bill.

Thomas

We wanted to see...

Rose

Where that approach came out of.

Thomas

Right, we started out with the goal of 25% of the Medicaid money going to community services. But people felt like that wasn't really enough because a lot of the community services were...some of them were really focused on specific disabilities—they were done by diagnosis.

And then, another thing was they were real limited in what they would provide. They weren't statewide. They weren't a right. They weren't...

Kafka

They could limit the technical scope and everything. So, they could limit the number of hours. They could limit a whole bunch of things.

Thomas

Like the types of tasks that they would do, and that come up even today where they're like, "we don't transfer," which is crazy but, you know. So we came up with a list of things that we wanted to see happen in attendant services programs. What we were trying to do was get the Health and Human Services or Congress or whoever to commit to having those be the rules for attendant services.

And functional need was a really big one because that was where it didn't matter if you needed to transfer because you had MS or because you had a spinal cord injury or because you had a stroke. If you needed to get from your chair to your bed or whatever, that was the thing that mattered.

So, the big push was to try to...and if you needed help with your checkbook who cared if you had an intellectual disability or if you had a brain injury. It was like—again, a stroke—there's a lot of reasons why you need certain kinds of things, but it's not that different what you need, the actual task. So, that was one of the biggest, biggest things that we're still fighting on is trying to get it be based on functional need as opposed to some older category.

Rose

Diagnosis.

Thomas

And age is another one. Because, then people would start to get these programs in their states and they go up to 65 and then you would go turn 66 and you wouldn't be able to have the services you had had up until you were 65.

Kafka

In some states, yeah. Depending on how the waivers were written.

Thomas

So, the point of waivers is—I mean, correct me if you feel differently Bob—but a lot of the point of waivers is to make it limited—the population—so the money is limited so they don't have to spend so much money on it.

Kafka

See, we heard forever—I think we once used it as a theater—that if people were entitled to homecare or community services that people would come out of the woodwork. You had all these visions of cockroaches. That was the argument moneywise.

Thomas

It was a real thing. I remember Georgia was really hot on that. That was a huge thing. And we would joke about this among ourselves, “what is this, a group of quads sitting out in the woods chewing tobacco and sitting in a circle waiting for an attendant to come and liberate them from the woods?” I mean that just isn’t gonna happen, they’d die.

Kafka

And really, even though at the time we didn’t have the visual, it was part of what we had in terms of social change is what the pitchfork approach. We’ve always...everybody knows ADAPT as direct action and they always say we’re like the junkyard dogs, you ring a bell and we’ll just bark. No, that’s seriously! But, we always had a piece of legislation. MiCASSA was the broad outline of what we wanted and then we had various in and out on legal type of things. Then, the education and media stuff we did and administrative and just rulemaking. But, we always try to play in all those arenas or at least know where that was. So, MiCASSA was sort of the legislative thing that we pushed to use as an organizing tool.

Rose

So, were you part of figuring out how to draft MCASA? Or how do you link up with that particular legislation?

Thomas

Well, we started out with this bill called CASA, then we thought, “why aren’t we calling it MiCASA?”

Kafka

Because it’s “my home” in Spanish.

Thomas

It had one S at that time. But then, the DD world was upset that they didn’t have “support”. So, they said it didn’t include them because it didn’t have “support”. Which is not true because we were basing things on functional need and so we used the term “services” for covering a lot of what they were talking about. To make it plainer for everybody and so we wouldn’t have to hear this over and over again and so it would be clear to everyone, we made it with two S’s in the final.

Kafka

<topic>Negotiations in D.C. about MiCASSA and actions against Gingrich</topic>

And that came out of a meeting in D.C., because obviously the legislation...you can't pass it yourself. So we had this big round table and that's where...I mean nothing really changed in the bill except that it said services instead of support and there were some minor changes in definitions.

Thomas

Things that we included in some other ideas we pulled out to emphasize them. But, as for the actual legislation, that actually was written in the fall of '96 at another action...No wait, it would probably be in '97. What happened was we had this paper of what we wanted and Gingrich...we started to dog him like Bob was saying. We went to his offices, we actually—I think it was in '95—we went to his apartment because he wouldn't meet us at his office so we decided to go to his house. Well conveniently, Newt Gingrich had an apartment in this United Methodist building that is next door to the Supreme Court and across from the capitol. So, it was very easy to get there. We went there and we surrounded the front of the building.

We got a meeting—nobody was at his house, or nobody was answering the door— so we got a meeting with the woman who was with the United Methodist Church who was in charge of the building. And she was totally supportive of what we were trying to do and she wanted to get him on board, but he wouldn't stay in the hotel that night. Anyway, we went there.

Like Bob said, when he went places around where we had people they would go and protest there. So, it was a campaign and he was getting harangued about it. Because, he said he supported it but then he didn't really do anything about it so we had this whole campaign about it. In the fall of '96, that was the year where there were the elections.

And it also happened that the **inaudible*** 14.38** convention was in Atlanta. So we went to Atlanta. And it was election so we went to the headquarters of the Democrats and the Republicans there. In the Republicans, we were focused on getting Gingrich to live up to his promise to us. I believe that was the year we had the meeting with him.

Kafka

I don't remember the year. I know we met but I don't remember.

Thomas

But that was in Atlanta.

Kafka

Was it?

Thomas

Yeah.

Kafka

Was that the time we went to the federal building and were dragged out?

Thomas

That was the year before, I believe. But then, we had this meeting in this room with this big table and we were all sitting there. He wrote out on a little piece of paper what he promised to do—which was to introduce the bill and get a hearing for it—and he signed it and Mike Auberger signed it.

Then after that, he was still dragging his feet. So, the way it actually got written was we went back to D.C. the next time around and we went—that's probably '97—and we went into the Rayburn building—which is where his office was—and we rang the driveway. Because, he had agreed to meet with some of our people to draft the legislation. And Bob and Steve Gold, who's an attorney...

Kafka

Cassie. Cassie Johnson.

Thomas

And Zan.

Kafka

Zan Thornton.

Thomas

Thornton, who's from Georgia. Was there anyone else?

Kafka

No, those were the people and one of his staff people. We met in the basement of the building across the way, the Rayburn Building and it must have been the Longworth Building.

Thomas

Or Cannon, one of those two.

Kafka

All I know is I had a 104 temperature; I was wearing a poncho, shivering because I had a UTI.

Thomas

He was so sick.

Rose

Oh no!

Thomas

And it went for hours. But, they actually wrote the legislation there that night. At least, to a degree that would then...I'm sure they do it like here in Texas where they write it up and then you would send it to a legislative council and they tie the bows and ribbons or anything. But, the body of it was written that night.

And all the rest of ADAPT was sitting up on...in the Rayburn Building there's a huge semicircular driveway in front of it and we ringed the whole driveway with our folks and just waited until it was done. Because he kept saying, "I'm gonna do it," but then he would not really do it. So I do believe that he supported the goals, but it was obviously not a big priority.

This was during the time of the Contract on America—as I call it, they call it the Contract for America—and that whole thing was going on so there was a lot of other heavy duty stuff happening and he was very involved in all of that.

But, we wanted him to be the sponsor because he was the Speaker of the House. So, you get someone like that to sponsor a bill and it will probably move. But it moves if they want it to move. People sponsor bills that they don't have any intention of doing anything with.

Kafka

<topic>Philosophies of other disability activist groups</topic>

A little side thing, the quote-unquote Washington D.C. **Intelligence** were only supporting it because they're really not going to do it. I mean, they did everything in their power to shape us as being naïve and not knowing that maybe they were only doing this for a reason that they weren't totally committed to doing it. It just was an ongoing thing about, "you don't understand Washington, we understand better than you direct action folks."

So it still goes on every time we do a protest. The Washington folks think that you don't quite understand how it works. I mean, we very well know how it works and just throwing in that more passion, direct action flavor to policy.

Thomas

And we were planning every time he didn't do something about it we would be back to him. It wasn't like we were thinking that he would suddenly become our super-duper champion.

Kafka

Yup.

Thomas

And it did get a hearing.

Kafka

Right. Again, I don't know exactly when it happened but the AARP and all the other disability groups, they all would be very on one page about, "we need more community services," but they would never say the words "end the institutional bias." Now it's just part of everybody's rhetoric, especially the older community, AARP. They really wanted to keep the entitlement to nursing homes. Not because they loved nursing homes, it's just that they were worried that states would provide stuff.

Thomas

Like they'd do nothing. Because, that was kind of the mode of things at that time. The Contract on-for, on, with, whatever-America, it wanted to block grant all of Medicaid. So, every state would decide what they were going to do. Which previously, states had done very little on community attendant services. They were limiting it and there was this freak out about the costs and everything so...and it is expensive, it's a big part of the budget now, there's no doubt about it. The thing is is that community services are cheaper than nursing homes and they just expected people would do anything to stay out of nursing homes so they'd just leave everybody alone about services. And that is kind of what happened.

<topic>Larry McAfee

There was a guy at the time, Larry McAfee, he sued to have the right to have a switch on his wheelchair where he could turn off his respirator and kill himself. And the reason really he did that is because he was on a vent and Georgia didn't provide vent services. So, he had to live in like Alabama or somewhere far away so he never saw any of his friends or family.

Rose

I think he was living in the ICU for a while too in Georgia.

Thomas

Yeah, but after a while, they shipped him out of state. He just had a horrible...he didn't have a community life. And he won the right to kill himself but they wouldn't give people the right to have services in their own homes. Even today, that's still hanging around in the background. Although, things are so much better than they were.

Kafka

Yeah, and I think a lot of the Georgia advocates finally got to him and...

Thomas

They did, the work made a special effort.

Kafka

I think he changed his mind on that because I don't think ever knew...

Thomas

I think they got him services at home.

Kafka

Yeah, they didn't conceive of the services. But again, I think I've said it before, one of the distinction between the aging and physical ADAPT is that it never really said, "Close all the nursing homes," it was always the original 25%.

But, different from the developmental disability because those were mostly state funded and nursing homes are mostly...it's Medicaid and state money but it's delivered by private pay; different from what it is in the DD world.

Rose

<topic>Government funding for ICFDD and privatization of DD services</topic>

What about we move into the DD world for ICFMRs that are getting government money.

Thomas

Right, that's a...they get state and federal money to run those. But a lot of times the state...they're called state schools or state-supported living centers here—those are run by the state. They also have the group homes that are more private.

Kafka

See—and not to get too policy **womped**—the nursing home is entitlement. The ICFDD now—it changed from ICFMO to now actually ICFIDD but whatever—that is an optional Medicaid program. Everyone thinks it's an entitlement mainly because every state has picked it.

Rose

But, from what I've seen, a lot of those are actually quite large.

Kafka

Oh yeah.

Thomas

They're huge!

Rose

Like California has like 200-person ones.

Thomas

Oh yeah.

Rose

So it's sort of more privatization, not deinstitution.

Kafka

What people haven't looked at is that actual thing. When they talk about the ICFDD and the deinstitutionalization, what they're actually talking about is they almost were all-at the time-state funded. So, when they talk about that they've closed all state institutions, Texas still has 13 state funded. But, what they've done in other states like California is that they did close all the state-run, but then they just did what now happens with nursing homes.

Thomas

What you were saying.

Kafka

Private.

Rose

Private are UCFs

Kafka

Private providers. And the vast majority...

Rose

<topic>Medicaid funding and waivers</topic>

And many of those are Medicaid funded?

Kafka

Oh yeah. They're contracted out to private providers like the same thing that nursing homes are private providers.

Rose

Has there been any pushback from the shift from state-funded State-Supported Living Centers and schools to switch to Medicaid? Or was that basically states...?

Kafka

It's all Medicaid dollars.

Rose

Okay.

Kafka

It's a state decision to do the...

Thomas

Wait, wait. Is what you're saying Bob is that they were run by the state as the State-Supported Living Centers and now they're run privately. But, the money has always been Medicaid and state.

Kafka

Right, always.

Rose

Okay, that's what I was wondering. I thought it was.

Kafka

But they're doing it with the same waiver system that the aged and physical disability.

Rose

Okay, and was the money when people were in institutions...it wasn't Medicaid waivers though?

Kafka

No, they were Medicaid...okay, nursing homes are of Medicaid dollars. The ICFDD—which here in this state was called state schools—all that was Medicaid money.

Thomas

And state money. They match.

Kafka

Well, you have to put up state money to **inaudible*** 26.33**

Thomas

Medicaid works where you match more federal dollars for your state dollars.

Kafka

Medicaid is all state and federal match. But, the big change is that they move—both in the nursing facility and in the ICFDD—into Medicaid waivers.

Thomas

As opposed to?

Kafka

To the institution. They're called 1915-C waivers. Those are aged and disabled waivers that you can write for specific populations.

Rose

So, Denton's State-supported Living Center...

Kafka

Right.

Rose

Which is state funded...

Kafka

No, state and federal.

Rose

State and federal funded...I guess state run, as opposed to an ICFDD.

Kafka

Right.

Thomas

It is an ICFDD. Isn't it?

Kafka

Yeah.

Rose

It is also, okay.

Thomas

But they have different...

Rose

Because some states have moved to shoving people from institutions to ICFDDs that are still very large and private. So that's what I was...so, Texas is combining?

Thomas

It uses the money for both.

Rose

Okay.

Thomas

<topic>Characteristics of ICFDD</topic>

And the other thing about ICFDDs is that even the small ones, a lot of them are pretty institutional.

Kafka

Four to six beds, yeah.

Thomas

I mean there's so many rules on them.

Rose

Isn't there like sixteen beds and larger

Kafka

<topic>Current effect of age of onset on received funds</topic>

Up to. There's four...and each state sets their own. Here, they have like up to eight and then eight to 16 in terms of that. Again, I don't know all the designation but most of those now are done through waivers. It gets complicated now with managed care...it gets too policy womped.

But the bottom line is—and this has always been—the waivers that we're talking about because you have the nursing home which—I'll just make these numbers up just for illustration—\$60,000 a year for a nursing home resident. The ICFDD is \$160,000 a year. So when the state writes the waiver to live in the community, they

have what they call course neutrality. So, you have to provide those services less than you would in the institutions.

So, the aged and physical, you have \$60,000 to play with. To the ICFDD, you have 160,000, even though there may be people in the aged and physical with stroke, brain injury that have...

Thomas

An event. People with very significant, heavy duty disabilities.

Kafka

But they are still limited to the 60, even though you'll have someone walking around with an IQ of 68 getting up to \$160,000. That's why ADAPT's position has always been you should get what you need regardless of age of onset.

Rose

Okay.

Thomas

Bob and I are big, big pushers of that. Some people just say, "Hey, that's the way it is."

Kafka

Technically, if Stephanie was on services, she's eligible for developmental disability services. Because, she broke her back at age...

Thomas

Seventeen.

Kafka

Seventeen, before 22. I broke my neck at age 27. So even though we might need the exact same set of services, because she technically by government definition is a person with a developmental disability.

Rose

Okay.

Kafka

See, and that's...there's not a way to really...there is a way to blend them, but it's not really relevant to the history. See that is the distinction, this identity politics that we were talking about.

Rose

Yeah.

Thomas

Remember when we were talking about the S's in MiCASSA? It's the same...

Rose

Yeah, it pits groups against each other.

Thomas

Exactly.

Rose

In really odd ways.

Thomas

Very odd, very odd.

Kafka

Well, it's really unfair because literally if you had a brain injury when you were 20, and then the same person was in the car but they were 23, the person who's 20 gets this whole package of services. While the person—because they were 23 when they got the brain injury—same car wreck, same exact brain injury—gets literally one-third of the potential services. Yeah, it's totally inequitable.

Rose

What was the logic originally?

Kafka

<topic>Philosophy of the Independent Living community</topic>

The arc and the...the DD community is so much smarter and more organized than the aging and physical disability. Just leaps and bounds. The IL—again, this is my pet peeve—the IL were taught, “Don’t play in the Medicaid arena.”

So, they were very holier than thou, “Hey, we’re gonna just get some peer counseling, get some education, you’re gonna get a job and live happily ever after,” when all our population was on SSI/SSDI.

But because they had their disabilities post-22, they end up getting butkis while the DD world—who went over to HHS because IL was over at the department of education. So, they basically had no interaction with Medicaid and it was only until Olmstead.

Thomas

Well, that was by design. That’s what they wanted.

Kafka

No, it wasn’t against them. That’s Justin and Lex and all of them wanted.

Thomas

Nickle.

Kafka

They didn’t want to be in the welfare, medical model. Again, I say it...I understand the philosophy, except it was based on Judy Newman, the best and the brightest. Judy Newman did her little training and everything else. She would go and get a job at the Royal Bank.

Thomas

Where she can pay for own attendant out of her salary.

Kafka

Right.

Rose

Yeah.

Thomas

There are so many things that really are barriers to people that they can't just...if you get an entry-level job, if you need any level of attendant services, you're not going to be able to afford that-plus housing-and have a life. It's just not gonna happen. There have been some sort of little fixes.

The other side of it too is that the Independent Living Movement, a lot of the leadership of it, they were trying to embrace all of disability and make it one big basket. They wanted to be inclusive so they didn't want to say, "Well, we're going to fight against your benefit or your benefit."

Because, blind people get more Social Security money than everyone else does. These little infighting inequities, most people felt like, "we'll do better if we got for the big basket and we don't pick fights with other members of our thing." And those two communities: what was then MR and the blind communities, they organized earlier in history than a lot of other people did.

Veterans were early organized and they actually get some additional stuff too. But as the population got larger, then it was harder to look like more money so everybody kind of freaked out.

Kafka

<topic>Medical versus functional models of disability in terms of foundation of activist groups</topic>

The other thing, if you look at developmental disability, cognitive, mental are functional. Deafness is functional. They don't care what medically brought it to there. Blind the same way, it's a functional definition.

In the physical world-just put IL aside because that's functionally-based in Independent Living-but, the MS society, muscular dystrophy, polio, were very much in the medical disability model. And those people-even though they don't interact much with the IL-are very powerful. And those lobbies are for cure and pharmacy, but it's not a functional.

It was always so frustrating to us that when we used to go in to D.C., usually it was around May. And this wasn't purposeful, the week we were there-either a day or two crossover or right behind us-the MS society. And all these people are in scooters and wheelchairs, all coming into D.C.

Thomas

They have their MS lobby days.

Kafka

But they weren't lobbying for attendant services-even though they used attendant-they were doing it for cure and a whole bunch of other things.

The whole DDIL split has been...and the DD, because of the providers of them and the family members...if you look at the DD movement, if you look at it and they're getting Medicaid money, it's awfully white and it's awfully middle-class. Because they were brilliant in the sense of, if Michael Dell had a disabled child and his child got on a waiting list for services and got services-they call it the Medicaid waiver-if his child got even \$1 of Medicaid money, his child would get every Medicaid service and Michael Dell would have to contribute zero. That's why it's such a white, middle-class and that's why when you go to every legislature here, you wonder why all the advocates/parents bringing their kids are mostly-not all-are mostly white, middle-class and their educated, able to play the system...

Thomas

And they have the time and money to do it too.

Kafka

Right, and the providers make a lot of money so they're there. So it all is layered. And I must admit, the DD community they have the DD councils which give money for research and stuff. They get statistics. The protection and advocacy started mostly with DD and mental health. Then you have the arc and all that. In the IL world, you don't have quite the funding—SILCs do not have research money. But again, it is what it is. But that was always layered in the years when we were fighting for stuff. That's where, like Steph said, the second S was because we needed to bring them along in terms of that.

Rose

<topic>HCS waiver and the CLASS waiver</topic>
This is Bob talking about the HCS waivers.

Kafka

The waivers that serve people with developmental disabilities. Okay, the DD definition—the federal definition of DD—if people have acquired their disability before the age of 22 and have a need for ongoing type of thing. It doesn't say you have to have a cognitive. The DD definition has always included people with cognitive and physical acquirements. Spina Bifida...

Rose

Sensory.

Kafka

Any other disability.

Rose

Chronic illnesses.

Thomas

Deafness?

Rose

Yeah.

Kafka

So, the HCS waiver—which at the time was the only waiver—did not serve people with what at the time was called “related conditions” which is basically those...

Thomas

Everything that isn't IQ.

Kafka

Everything that isn't IQ related. All the related conditions. So, at the time, the United Cerebral Palsy of Texas was run by a woman named Patty Anderson, who now works at Disability Rights Texas. Patty Anderson hooked up with Advocacy Inc.—which is now the Disability Rights Texas. Jim Comstock Allen was the executive director.

They threatened to sue the state because they weren't serving people with a DD definition—related condition. So the state, rather than get sued, then wrote what is now called the CLASS waiver. So now we have instead of one DD waiver...because HCC didn't want to have and the advocates didn't want—the arc included—didn't want to include because that would take money away, they thought, from there people. So they wrote two waivers.

Even today, the CLASS waiver is only like one-fifth the number of people that are in the HCS waiver/ Even though there may be a long...

Rose

And what does HCS stand for?

Kafka

It's like Home and Community Services.

Rose

And CLASS stands for?

Kafka

Community Living and Support services I think.

Rose

Okay, and are they the same amount of money?

Kafka

No, no. It's much more in the HCS than it is in the CLASS waiver.

Thomas

And isn't a more institutional?

Kafka

Well, the HCS has a residential component. The CLASS waiver has no residential component. But that's what I mean, because the HCS providers and the arc—which was primarily people with cognitive disabilities—didn't want basically to have it shared with other...their brothers and sisters DD.

So that is why we had...in some, there's HCS, CLASS, and then there's another waiver that's called Texas Home Living. But, that is provided by both cognitive and physical. That is that whole identity politics. And like I said, that's all separate from the aged and disabled waivers.

Like I said, some of that is caused by the federal government categories and some state politics that go on.

Again, like I said, Texas is—I believe—the leader in terms of still having state-supported living centers who are thirteen...

Rose

That's also...I know it's in the number of people.

Thomas

That are in those thirteen places.

Rose

Yeah, it was over 3,000 in 2016.

Kafka

Yeah, yeah.

Thomas

There's a group called...Oh god.

Kafka

Arc.

Thomas

No. Community...

Kafka

Community Now?

Thomas

Community Now! They're fighting...they kind of took over the...we used to really do a lot more fighting on the state schools and stuff like that, but then they kind of took over that side of things.

Kafka

<topic>Perception of ADAPT as anti-DD and anti-paratransit</topic>

We're seen as being anti-DD and the reason why we're anti-DD is because we want services based on functional need.

Rose

Not on diagnosis.

Thomas

Right.

Kafka

Again, that's what...we're not seeing as a developmental disability advocacy group, 90% of the people who are part of our group had their disability before age 22. So they feel by talking about functional, you're anti-DD. So, it is what it is.

Rose

Interesting.

Kafka

Oh! We were going back historically, when we started ADAPT, the local advocates thought we were against paratransit.

Rose

Oh yeah!

Kafka

Yeah, because we were for...

Rose

Mainline.

Kafka

Mainline.

Thomas

And we didn't talk about paratransit. We weren't against it but...there's plenty of support for that!

Kafka

So it's almost like the same thing. But the philosophy of ADAPT has always been the same. It's the community integration based on your need, not based on your medical label or your age of onset. But that seems to be a toxic.

Rose

It's a subtlety.

Kafka

Yeah, yes. It's about money, it's all about money and providers.

Thomas

<topic>Developmental Disabilities councils</topic>

One thing I did want to also mention about the developmental disabilities council is that when I came to Austin and I was working at the Austin Research Center of Independent Living, we were pushing to get them to...they used to only fund giant organizations like universities and like the arc and really big institutional kind of places. We wanted them to provide more grassroots organizational support so that smaller organizations could get the money to do things.

It took a really long time but we did get them to turn that around and agree to support a lot more smaller things. And they did that for a long time. But now, they're reversing themselves again. But, their grants have always been very, very nitpicky. It's just disturbing.

Kafka

Well, and in 1977 I believe when the Developmental Disabilities Act was first passed, it included creating the DD councils funding a developmental disabilities P and A—protection and advocacy—and, they weren't called centers on excellence at the time...

Rose

Inaudible***46.05–46.07

Kafka

Those were the three prongs of the DD Act. Then over the years, they've added to—the P and A has added—mental health and some physical disability that...something called **pair**. The DD council's language has gotten a little bit easier to do similar functions but that's a state-by-state type of thing. And the centers on excellence, they are all over the place. You'll have one here and then one in A&M.