

## SAGE CROSSROADS

**KONDRACKE:** Welcome to SAGE Crossroads. Our issue today is developmental disabilities and aging. There are now about half a million individuals who are over sixty years old who have grown up for maybe their whole life with a disability, and they are generally being cared for by parents who are also living much longer lives.

So we have two population streams here: one—the parents are developing disabilities of their own. So we have two streams of people who are older and have disabilities.

The question is how do we treat these people, meet their needs? Are they different? Can they be combined into one system?

Our guests to talk about this are Dr. Edward Ansello, who is director of the Virginia Center on Aging at the Medical College of Virginia Campus of Virginia Commonwealth University in Richmond. Before that he was the co-founder of the Maryland Center on Aging, and was associate director and acting director of that organization

Joining him is Elias Cohen, a lawyer from Pennsylvania, who was originally Pennsylvania's first commissioner on aging, was editor-in-chief of *The Gerontologist*—an academic journal—and is the author of more than a hundred articles and law review articles on gerontology, social services and health care.

I am going to let Ed Ansello sort of explain what the problem is here. You've got these two streams merging together, and I take it that they don't merge well. You'd like them to merge better and have people in both categories treated well. But it may be difficult. So why don't you explain what the problem is and how it could be solved.

**ANSELLO:** In a sentence, the problem is we have a gift of older people with lifelong disabilities whom we are not ready to receive. We are being given a gift. We don't know how to accept it.

The twentieth century added about twenty-six years to the average person's life expectancy, from 1900 to 2000. I've been calling this the gift of time for some while.

We have more or less accepted and incorporated into our lifestyle that we are going to live longer. Women are going to live longer than men. We are probably looking at seven, eight, nine decades of life. We've had time to incorporate that gift.

The aging of people with lifelong disabilities is a very recent phenomenon. Witness that someone with Down's syndrome has nearly doubled average life expectancy in the last twenty years, so that today average life expectancy for someone with Down's syndrome is about fifty. In 1983-84, something in that area, it was half of that. We are not ready for this.

The service systems to help people with lifelong disabilities have been pediatrically oriented in the understandable and correct belief that early intervention would improve the life course.

So you have pediatric physicians, nurses, social workers, direct service providers, etcetera—pediatrically trained people to intervene early in life so that that child with cerebral palsy, or Down’s syndrome, or other intellectual disabilities might have a better chance of surviving longer.

Well, we have succeeded. Now what?

The aging system is oriented toward what I’ve been calling the McDonald’s approach to human services, “Billions and billions served.” You get an appropriation if you are an aging service provider and you spread that as far and as thin as you can, provide as many services as you can.

Well, along comes a population you are not used to serving and a population with what you perceive to have labor-intensive characteristics. So you withdraw.

In a nutshell, just to set the stage, what we have are newcomers to the gift of time, people whose aging has been accelerated very recently, and an aging network, so-called, kind of hierarchical structure, somewhat loose, but more firmed up than the so-called disabilities network. That aging network is much more oriented toward mainstream adults, people who have aged in the community, aged in place, and you kind of know who they are, what they need and that kind of thing, and we can appropriate it.

It’s much more complicated than that simple overview, as Eli will be more than happy to elucidate, but that’s basically the issue. Newcomers—what do we do with them?

**KONDRACKE:** Your proposed solution to this problem is what in—very brief?

**ANSELLO:** Well, very briefly, my solutions are a couple. One is more a merger, in places, of the aging network, which has been on its own track, and the developmental disabilities network, which has been on its own track.

Now, if you’d bring them together too quickly you would have a crash at the intersection. But what we’re trying to do is to have them cooperate, coalesce a bit more in mutual planning and resource sharing and these kinds of things, in ways that respond to or reflect the newness of this phenomenon. So we are not really trying to reinvent the wheel, but we are trying to incorporate people who weren’t on anyone’s radar screen in the past.

**KONDRACKE:** OK. Eli Cohen. Would you explain what the two networks consist of? Who are we talking about here? And then, as I understand it, your position is that the merging is not so easy.

**COHEN:** Well, there's a preliminary consideration, and looking at the view of these two populations—in the popular world of aging there has been long and steady denial about disability in old age. We really don't want to look on old age as anything but the golden years, knowing in the back of our minds that, yes, there are these situations that occur whether it's from Alzheimer's disease or from stroke, or cancer, kidney disease and so on, that bring on disability, and there is some small portion of the elderly that have to go into nursing homes.

But we really want to isolate them. The aging community has not been kind to the disabled. They don't like to talk about disability—or acknowledge that people with disabilities can experience joy, can experience a good life and a full life, albeit with a disability.

In developmental disabilities there has been a different tack. It's been very vigorous advocacy that has really secured from the Supreme Court the dictate that you don't use large institutions to care for people, and that community services are the primary way to deal with this. Those community services have to be of a certain dimension and so on.

In the world of aging, there is almost the view that we like to talk about old age as great, the golden years, and we really don't want people with disabilities around. So we colonize them. It's been a really a very divergent kind of view.

The two—there are so-called networks—that is, organizations that have been built up—

**KONDRACKE:** Who are the principal players in the two networks?

**COHEN:** Well, in aging, so far as the network of organizations that provide service, it's alleged that the Area Agencies on Aging and the State Units on Aging, which supervise them, and which receive certain kinds of funds from the federal and state governments—and all of the agencies that are funded through that—are the aging network.

**KONDRACKE:** Which tend to be senior centers and—

**COHEN:** Well, they may be senior centers. They may be homemaker services, nutrition services, counseling—a variety of community services, which I hasten to add are really beneficial and useful and good.

However, the so-called network does not include Medicaid. It doesn't include Social Security. Now, the beneficiaries are participating. But the aging network has little input into those networks.

In developmental disabilities, I can only speak for Pennsylvania, which I know better than other places. There are, again, public agencies in each county, and sometimes junctures of counties, which have a mission of vindicating the rights—and it's vigorous—vindicating the rights of people with developmental disabilities to assure that they get community services, that they get services in the schools for—if there are

children, that they have access if they are physically disabled and so on. They're quite vigorous, and each person who is developmentally disabled will at least nominally have a formal advocate if they don't have one at home, or family and so on.

These two sets of networks follow—well, I believe—follow different strategies, look for different resources, and I think have different outcomes in mind, particularly when we get to the elderly disabled.

Now, the developmental disability network, as Ed suggests, this is a new phenomenon to them. I might just mention that years and years ago—I would say thirty, forty years ago, when I was commissioner on aging for the State of Pennsylvania, Cerebral Palsy of Pennsylvania was concerned, just as you've indicated, parents were concerned. What was going to happen to their kids when they passed away?

They were making the rounds within state government trying to find out what kinds of resources were available, and they were thinking at that time of developing a special in-patient facility or a group living facility. There was nobody for them to talk to except the commissioner on aging because it had never—it hadn't occurred to anybody.

And I didn't have access to any resources or knowledge about that.

**KONDRACKE:** Let me just ask a specific example. What happens to a person who has cerebral palsy or Down's syndrome when they get to be sixty-something-years-old, if they live to be sixty-years-old, and they need help? What resources do we have for them?

**ANSELLO:** Oh, if I may, and if either of you will allow me, a good analogy, I think, would be that the aging network is broad because it serves as many people as possible, but it's shallow. As far as the money goes, that's what you provide, OK?

**KONDRACKE:** Um-hmm.

**ANSELLO:** OK. The disabilities network, development disabilities network, is narrow and deep, serves a number of people who are placed on a caseload and they get whatever supportive services are for vocational preparation, for job skills, for daily living habilitation. They get as much as they need.

So what happens in the developmental disability systems is that there are massive wait lists to get on to services that you need. What happens in the aging network is that everybody gets something, but it's miniscule. If someone comes along, or a group comes along, that looks like they need something a lot, that's very threatening.

That's a way of conceptualizing the aging network versus developmental disability, plus the developmental disabilities network is funded primarily by Medicaid and that's a federal-state combination or infusion of money. Whereas the Older Americans Act, which is meagerly funded on a national level, funds the—through HHS—funds State Units on Aging and Area Agencies on Aging, and that's spread as thinly as it might be.

**COHEN:** Well, let me just interrupt, because what you said demonstrates how lacking the aging network is.

**ANSELLO:** Oh, yeah.

**COHEN:** We spend—I mean the bulk of money for people with disabilities and aging is spent through Medicaid in nursing homes.

In Pennsylvania, I'm ashamed to say—we are probably one of the worst—93 percent of the funds for elderly people with disabilities are going to people in nursing homes and 7 percent for people in the community. Now, that is very different from New Hampshire and a few other states where there is a lot of money going into community services.

**KONDRACKE:** Well, is there—does there seem to be any awareness on the part of the people who run Medicare and Medicaid, which is after all one federal agency, headed by a fairly imaginative person, Mark McClellan, about this problem?

**ANSELLO:** I cannot speak at the federal level, but there is spotty awareness among the different states in the state administration of these moneys. You asked what happened to someone who turned sixty with cerebral palsy or intellectual disabilities of Down's syndrome's type, or some other.

Upon reaching age sixty, the Older Americans Act kicks in, and whatever services the aging network offers, that individual is eligible to participate in.

The bigger question is not upon reaching age sixty, but that vast wasteland from when habilitation and job preparation skills end in the early twenties for that person and reaching age sixty—this humongous four-decade gap of time when the individual is very oftentimes on his or her own.

Because what has happened is today's cohort of older adults with lifelong disabilities have aged invisibly in the community in the care of their parents.

We have this sense, especially because of the de-institutionalization literature in that whole movement of the sixties and seventies—we have this sense that is erroneous that large numbers of people with disabilities were institutionalized.

In fact, at no point in the twentieth century did that happen. There was never the majority. There was always the minority of individuals and in many states it was less than 10 percent who were institutionalized, and those only with severe disabilities, and they did not survive.

So the people who have survived to become the topic of this discussion are individuals who have aged in the care of their parents in the community. Nobody knew they were there. Their parents probably were told back in the fifties, "Well, you ought to put that child in an institution, and that child will not live long." And the parents said, "Hell no!

I'm going to do something." Hence, you have the ARC and you have AAMR and you have other kinds of advocacy groups that started because parents said, "No, we are not going to do that. We are going to care for our children in the community. We are going to pull up our own"—you have grassroots political advocacy.

You have a really interesting model here. Now these parents are aging with their children in what we call two-generation geriatric contexts, where in many instances the first awareness either service system has of the existence of this older child with lifelong disabilities is the mother's incapacity or illness.

So when the Area Agency on Aging sends out an intake worker, does an assessment and finds out, "Hey, this mom who is, you know, eighty-two, is caring for a child who is in his upper fifties with Down's syndrome. We didn't know either one of them were out there because they haven't needed anything before. Or if they needed it, they didn't partake of the system."

It's kind of like you are sitting there in Pearl Harbor and suddenly you interpose twenty-first century technology and you look on the radar screen, and there's these gazillion things flying at you. Now all of a sudden we see a half a million people over the age of sixty, most of whom we didn't know were out there in the first place.

**KONDRACKE:** Right.

**ANSELLO:** So that's the import of this aging.

**COHEN:** The response to your question—the people in Medicare and Medicaid are very much aware. They are funding really some very fine research on community-based services.

They are also in a situation of terror about what the costs will be. They can go both ways. I mean, in the world of developmental disability it is generally held that community services are less expensive than institutional services. But I suspect that, as Ed points out, what that doesn't take into account is that there's this big pool of people in the community who have never received institutional services, and where that was never really contemplated, and so what you have is an explosion in the number of cases that come in. Even if they are less expensive—and I'm not sure that that's always the case—less expensive to deal with on a community-based service basis than institutional-based services, the numbers overwhelm you.

I think that there's some genuine fear at the federal level, and at the state level as well, that the numbers are going to overwhelm us and that the costs are going to be enormous. The same thing is true, really, in aging, and while at any given time—what do we have?—4 or 5 percent of people in nursing homes, there are probably twice as many in the community...

**KONDRACKE:** —similar characteristics—

**COHEN:** —with similar characteristics of disability. And some small proportion is receiving services, and the rest is being performed by spouses, children, neighbors, and so on.

So there has to be—I mean it’s almost as though we need that grand idea that came down in 1935, and then again in 1965—Social Security, Medicare, Medicaid—there were huge shifts of responsibility and financial responsibility that moved to federal, state—and states where they have local participation, governmental sources.

**KONDRACKE:** But at the end of the day, isn’t it the same agency that is going to handle—have to handle—a healthy old person who suddenly becomes disabled and a person who has been disabled and is now old. In other words, you’ve got two pools of disabled people, both old. Now why would not the same sort of agencies be handling them both, but perhaps in different ways?

**ANSELLO:** May I rephrase that, because I think that may be the core of my orientation to this discussion?

What’s in common with whether one has aged with a lifelong disability, or has acquired a late-onset disability, is chronic care provided by home—the family. The person who’s not at the table in public policy development, and certainly not in public policy implementation, is the chronic care provider of the family member.

So rather than phrasing the question as, isn’t the same agency going to do it? I would step back and say, “How might we best respond to chronic care needs in terms of public policy formulation?”

Family caregivers have not been recognized. As Eli says, it varies in different states and in our state it is not quite so profound, but he mentioned that a very small percentage of people who are in institutions get an enormous percentage of all the Medicaid dollars. It is not quite as skewed in Virginia as it apparently is in other states.

But still, the most minute amount of money goes to the people providing the overwhelming amount of the care. The difficulty is compounded by the fact that family caregivers providing chronic care, either to a late-onset disability or a lifelong disability, are not articulate. They are involved in the care. They don’t have advocacy. They have lots and lots of duplicated numbers that don’t coalesce. So you have no voice. You have no power. And yet, what happens is you are providing—you are saving billions of dollars for the state and for the federal government by providing this care. Theoretically, if you would just tomorrow say, “I’m not going to do it any more. I’ve had it!”—like the movies—“I’m not going to take care any more!” Open your window. You shout, “I’m not going to do any more care.” We’d go broke in a heartbeat. We have a deficiency of public policy in place and I don’t see any coming along in the pipeline for this reality.

First, we have a half a million older people with lifelong disabilities. But second, those who have been here all along, and have acquired disabilities late in life, we have no

public policy to support the primary caregivers—the spouse, the daughter, the son of those individuals.

That, to me, is the bigger issue than which agency is going to do this or which agency is going to do that.

**KONDRACKE:** Well, it occurs to me that—I mean the one very powerful organization that could be involved in all this is AARP, which theoretically, I mean, it is an aging service provider and policy maker and you'd think that it would be the advocate for both groups. Is that not possible?

**COHEN:** The AARP now represents everybody.

**KONDRACKE:** Everybody over fifty.

**COHEN:** Yeah. Everybody over fifty. Everybody here. And AARP, for a very long time—the earliest part of its history was concerned about well older people, and focused on that.

It's only fairly recently that they've gotten into some of the broader issues. But beyond that, one of the great constraints on coming to the logic that you are proposing—after all, hey, Medicare, Medicaid, you know, that's pretty simple. That could take care of everybody.

But we have structured services in categorical groups, and you have to be old enough or disabled enough or young enough to get financial assistance, or old enough to get housing assistance, or disabled—so there are all of these kinds of hoops that you have to go through and hurdles. Then there are different agencies, as Ed described in his example. The mother is eighty-two and the son is fifty and you've got to have two agencies, at least two agencies, going in to deal with that.

If the mother also happens to be medically needy, she's going to have to get directed or help to get direction to Medicaid. The child may already be on disability insurance through Medicare, but not long enough to have become eligible for Medicare services. They've been getting a Social Security disability payment.

So we have gotten this thing very, very complicated and we haven't fashioned at the community and arranged for payment to the services, some of which are really fairly simple to describe. They're not asking to have, you know, a psychiatrist in every home, you know, two hours a day. It isn't something as complex as that.

**KONDRACKE:** So what do you—if you were dictating how this problem should be solved, how would you start down the road? What is your advice to policy makers?

**COHEN:** As an admirer of Don Quixote, I would probably start off with something fairly grand. I think, number one, we need more and better universal health insurance through a single payer agency.

Then, beyond that, when we talk about care for people with long-term disabilities, we've got to change the default system. The default system now is the nursing home. If you are eligible for a nursing home we can give you some service in the community under the waiver program or some other program, depending on how the states have structured their service programs and written their plans.

But we can give you this if you have to go into a nursing home, and if you can justify, you know, community home and community-based service that is going to meet the need. We ought to turn that on its head. We ought to say the default is home and community-based services and you've got to make a special justification to go into a nursing home.

While there has been some drop in nursing home populations in the last few years because of the so-called Medicaid waiver programs, if we could we should cut our nursing home population in half, but recognizing that then we'd better get some good transportation services in place, a whole set of community-based services. We've got to do something about the distribution of physicians and nurses. And what are we going to do in North Dakota, South Dakota, New Mexico, West Virginia, you know, Appalachia, and so on?

This really requires a very, very grand change and—

**KONDRACKE:** —and you don't see it happening?

**COHEN:** I don't see anybody even trying to put it together. I think that, you know, it would do any president proud to say, "We are going to put together a strong, blue ribbon group, and at the end of two years or three years, I want a full-blown plan with estimates and financing and so on."

But, you know, it isn't even being talked about.

**KONDRACKE:** Well, there are the—again, the Medicare and Medicaid systems. At least on the Medicare end of it, the federal government is trying to emphasize prevention and modernization and all of that. In Medicaid they've been trying to put through reforms that do emphasize community-based care, as opposed to nursing home care, I believe. Now, it may not be adequate.

**COHEN:** I don't think it is emphasizing. I think that, yes, they are focusing attention on that. I think that the Office of the Assistant Secretary for Planning and Evaluation—

**KONDRACKE:** There is also CMS, the Centers for Medicare and Medicaid Services.

**COHEN.**—The Centers for Medi—they are interested and they are concerned, but it’s very, very incremental.

**ANSELLO:** I think there are some hopes for some mid-level initiatives that will benefit aging and the issue of chronic care. I don’t see the spark, as I have called it in some of my writings—the sparked individual who really ignites with some passion awareness of an issue. I don’t see that happening.

I think in very large ways aging is a nonstarter politically. There’s also what we call the geriatric imperative—or the gerontological imperative, meaning that as people grow older they grow less and less alike, so that within group variance individuals of a certain age are less and less like their peers in many dimensions—politically, economically, socially, intellectually, sexually, whatever. The variation within a group gets larger and larger as the group gets older.

So the most diffuse group of people is the older population, which is why we had this same response when you asked the question—what AARP is representing by definition is the most diffuse, non-homogeneous group you could ever imagine, so it’s very difficult to coalesce around some core issue that people will relate to.

So that’s one of the other problems with aging being a nonstarter. But at mid level, maybe with creative sparks in CMS or creative sparks at state levels, they may see some of the coalitions that we’ve been building around the country that successfully share resources.

**KONDRACKE:** Well, tell us about some of the coalitions and what success stories there are.

**ANSELLO:** Well, there are a number of them. New York State, Maryland, Virginia, Missouri, Ohio. There have been, by definition, short-lived coalitions that work around a particular deficiency to redress that deficiency. Maybe it’s nothing for the child who is now growing into adulthood to do once the child finishes vocational training—a child having a lifelong disability.

So the formation of support groups for the kids and support groups for the parents, identification of existing resources rather than the creation of new resources—many of these coalitions have been brought together by what we call neutral brokers, which are more often than not people from higher education or some setting where that individual does not represent a potential threat to the aging network and the developmental disabilities network coming together. Because one of the first things that happens when someone calls a meeting is you ask, “Well, why?”

So if you are on the aging side, the DD people—development and disabilities people—call a meeting, you kind of—your suspicions arise. So what we have found is that neutral brokers offering a place for a first meeting, engendering some kind of contact and cooperation, tend to be the essential ingredients in starting coalitions.

Coalitions then need to set specific purposes, objectives, one-, three-, five-year-plans so that they can see something other than getting together for coffee over some issue.

They are problem solving. When the problem solved—last week in Richmond, for instance, we had a conference on spirituality, loss and aging for persons with lifelong developmental disabilities. We had a national speaker. Rick Moody was our keynote speaker, and we had six breakout sessions on chronic loss. You know, being a caregiver of someone who is never going to get better. Parish nursing. Looking at communities of faith as a potential resource. The aging network and what it may offer to these kinds of issues.

And we had a hundred and—well we joked about it. We had a gross lack of attendance. We had 144 people who came to this conference.

It was one of several that we have run. Others on Down's and dementia. What happens when someone with Down's syndrome ages long enough to acquire dementing illnesses? Well, here's an aging issue. A prime example—an aging issue in an individual who is not older. You know, forty-four, forty-five years of age with Down's syndrome.

So we try to develop awareness in what the responses are and what the resources that exist are that one can use.

I think—as these things—it's the opposite of Eli—and not to contradict his idea, because he is absolutely right. Top down is a wonderful thing.

But what I think is going to happen is a percolation of good ideas, conceptual ideas that are realized and work perking up to get mid-level people where—“Hey, you know, we can, rather than competing for a diminished piece of the pie, because human services are never anyone's top priority, let's cooperate and share resources and make them go farther.”

Further I guess. Make them go further.

So I'm seeing that as a possible way of things happening. But see, it doesn't really redress the fundamental issue which is the problem in the way everything is categorized and how there is low priority for this, that, and the other. But it's an acknowledgement of the real politic, the way things actually are.

**KONDRACKE:** So does any state do this better than the others?

**ANSELLO:** New York State does a wonderful job. They have the New York State Office of Mental Retardation and Developmental Disabilities, and a recently retired director of aging named Matt Janicke, who kind of became the grandfather, if you will—maybe he's the fairy godfather of this movement. He goes around from place to place and more or less helps people to get started. Goes around the world. Kind of like the bee who

goes to Rome or Japan or Australia, he brings back best practices from there, and propagates things around here.

In Maryland and Virginia, and we have had a number of successful cases in North Carolina, Alabama. But they are all time-limited and that's the problem. I don't want to paint a Pollyanna picture of this situation.

The longest-lived coalition was started by an educational gerontologist at Utica College, and that coalition lasted from 1985 to 2002—seventeen years. Did wonderful things, developed new resources and to increase awareness and, in fact, appropriations for this issue. Then it ceased to exist, as well.

You know, people become exhausted or they move on or what have you. But their very success, and then their evaporation, reveal the fundamental dearth of public policy that is meaningful, that's targeted to chronic care.

**KONDRACKE:** So even New York doesn't do this on a systematic basis.

**ANSELLO:** They do, they still do. New York State—the State Office of Mental Retardation and the State Office for the Aging have a very good cooperative arrangement so they are really kind of a paragon of this kind of thing.

But even so, it's driven by these sparks who are within these respective organizations.

**COHEN:** I would just hasten to say that it is mental retardation, which doesn't include the mentally ill—

**ANSELLO:** Right. Exactly.

**COHEN:** It doesn't include the people with spina bifida.

**ANSELLO:** Categories again. Yes.

**COHEN:** It's categorical—you know there are a whole—the spinal cord injury group, the head trauma people, and so on.

**ANSELLO:** But it's inevitable with the geriatric imperative. If we get less and less alike, we kind of find affinity groups.

**COHEN:** Well—

**ANSELLO:** And so some groups (inaudible cross colloquy)

The will all ultimately end up in the aging category of—

**COHEN:** Well—

**ANSELLO:** But with certain sub-characteristics.

**COHEN:** Right, right.

**ANSELLO:** And that's with whom you ally.

**COHEN:** These will work, do work very well, not only time-limited but where it's—I think—in smaller communities it worked better than in larger communities.

There are some places where I am sure it is going on. We don't call it a coalition. I have a hunch that in Elk County, Pennsylvania, a very tiny little county, there's all kinds of cooperation that's going on.

**ANSELLO:** But there aren't resources. That's the problem, see?

**COHEN:** People. But they are using what resources there are and they probably jigger those around, you know, and push them very hard because they are locally driven by good people who understand that there is a commonality of interest.

**KONDRACKE:** So you would both, I take it, both appeal to somebody in Washington, presumably somebody in CMS, the Center for Medicare and Medicaid Services—inaudible—to adopt a New York State kind of model and propagate it, I take it.

**COHEN:** That would be what—that is (inaudible cross colloquy)

**ANSELLO:** That's one approach. But I really fundamentally adhere to Tip O'Neill's axiom that all politics is local.

I would appeal to the county commissioner where this local coalition is operating, and then I would appeal, on a reasonable level, to the state director of mental retardation. I would try to keep things there. Because I think local citizens have more impact there, and you have large numbers of people who represent something substantial on the local that are inconsequential on a national level.

**KONDRACKE:** So when a local coalition forms, as you say this one in Utica did, what does it do, exactly; and why did the Utica coalition fall apart? Is something there to replace it?

**ANSELLO:** Fall apart may be too—backing up for a minute. Fall apart may be too strong a phrase. I think what happened is some of the people have retired, some of the issues got resolved. Some of the problems went away.

First, the people around the table were people from aging services, mental retardation services, parks and recreation, communities of faith, social services, academe, etcetera. So they each brought their own little perspective from—in the prism of what the issue is.

What they found—what we did in Richmond—we have what we call an Area Planning and Services Committee that's now in its second year and has been sponsoring these different trainings and events.

What we did is we each explained to each other who and what we are because the aging system, as Eli has pointed out, and the developmental disabilities system, just to take two, have different philosophies, funding streams, eligibility criteria, etcetera. So someone may know of a given agency, but not know how it operates. Early on in a coalition development, you try to say, "Here's who we are. This is what we can provide," etcetera.

Then what you do is set objectives. What we did in—what they did in Utica, we emulated in Richmond. We set what our priorities were going to be for the next one year, and included public awareness and training of direct-service providers.

Then you go ahead and you do that and you figure, what are the big issues? You do surveys, if you want, among the constituent members and you—then you go and you address those issues.

Up in Utica they did this very effectively—developed resource banks, they developed things that they could share. Cross training is oftentimes less than it used to be, but cross training is oftentimes a line item in an agency's budget. You find you don't need to use your cross training monies around a coalition if you are in a coalition because somebody else is going to provide something because you are going to reciprocate.

Those monies can be used for something else like respite care, or whatever. That's been a very frequent use of it.

So you develop things, and then you proceed with measurable criteria of objectives that you can accomplish. I'm not deluding myself to think this is changing the world. This is changing the world of the people who are concerned, because—

**KONDRACKE:** So we're talking about in these two places specifically (a) the benefit for a person who is developmentally disabled who is old and (b) the person who is old and then becomes disabled—do they merge?

**ANSELLO:** Yes. To give a prime example: there is something called Friendship Café. It's one of the priorities of the Older Americans Act, and there are federal monies to flow down to State Units and Area Agencies on Aging to develop Friendship Cafés, which are more or less supported contexts for meals and social activities to occur, open only to somebody sixty years of age. That is the criterion for the Older Americans Act.

But you have people who present aging early if you have a lifelong developmental disability. So you have people who are fifty, or fifty-six, or even fifty-nine, who cannot go to this Friendship Café, because they don't meet that criterion.

So what we've been able to do in Richmond is to get a Friendship Café first started, and then very much peopled by individuals—fifteen right now—who have lifelong developmental disabilities—to participate in something that is Older American Acts–funded. There are others who are sixty and who meet those criteria and who go to that Friendship Café. But we pooled our resources to provide transportation and payment for the meal that the Older Americans Act requires be paid.

So now in a context that is developed by aging, you have people who are not aging participating. So you have a mix of late-onset disabilities and lifelong disabilities in a context in the neighborhood. Unfortunately, it only happens one day a week; but it's still a success story.

**KONDRACKE:** It seems to be an example of your categorization.

**COHEN:** We're talking about thousands, tens of thousands (inaudible)...

**ANSELLO:** In this particular county.

**COHEN:** In this county.

(Inaudible cross colloquy)

**KONDRACKE:** I was asking for models but—

**COHEN:** There are more than fifteen—there are more than fifteen people.

**KONDRACKE:** Of course, but I was asking for models and he's providing a model. Now you are providing the other half of the argument is that this model has to be duplicated a thousand times...

**COHEN:** It doesn't really address the issue of how you do this ten thousand times.

When I was—there was a time when I had a post in Pennsylvania government where I was—really oversaw social services for all kinds of groups: the poor, the sick, the young, delinquent, blind, handicapped and so on. I used to get calls from the chairman of the Appropriations Committee in the General Assembly, from the governor's office, and so on. They would come in with these horrendous family problems, you know?

“I've got a daughter who's this and a son who's this and grandma is that,” and so on. I never ran into a single problem where I couldn't really resolve that. I did it by calling in chits and I'd call this agency and that agency and so on.

I could do that once. I could do it twice. I could probably do it ten times. I couldn't do it for a thousand people. That's what I object to. I object that we don't by, sometimes, these little examples of success are touted as the answer, and they are not the answer.

I go back to the 1960s with the—when the United States Senate Special Committee on Aging was a powerhouse. It came out—at one time I had a collection of their reports over time. They had 400 reports. That committee, with no legislative power to introduce legislation—they were really like a study committee—they resulted in bringing money for the poor disabled into state hospitals, the so-called Long Amendments that enabled that.

They really foresaw the changes that brought about the Older Americans Act. There were any number of things, but there were giants in there who would articulate this. Today you can't even find out, you know, what that committee is doing. They hold an occasional hearing.

**ANSELLO:** Let's follow that. There aren't the giants and all that's left of the shadows of those giants.

What you have now is a void and what we are seeing in Virginia, I think we are seeing elsewhere, and we are certainly seeing on the federal level, and that is a redefinition of government. Government, if anything, is pulling back from human services. It's no longer a question of, you know, Jeffersonian versus Adamsonian. It is no longer a question of state's rights versus federalism in two different concepts of what government is. Now it's a contrast between some services that are defense related, or highway related, versus no services. I mean it's—the whole question has been redefined.

**KONDRACKE:** As yet—but this at a time when you have an aging population—

**ANSELLO:** Absolutely yes.

**KONDRACKE:** And presumably more power on the part of the aging cohort of the society than ever before.

**ANSELLO:** Presumably. Underline the “presumably.”

**COHEN:** Right.

**ANSELLO:** Again, the gerontologic imperative. We are getting less and less alike, less and less coherent or cohesive, etcetera.

**COHEN:** And the elderly do not vote as a block.

**KONDRACKE:** So you basically—

—but the elderly were powerful enough to force Congress last year to pass the prescription drug benefit.

**COHEN:** No, no...

**KONDRACKE:** Medicare.

**COHEN:** I don't think so.

**ANSELLO:** Well, Congress felt an imperative.

**KONDRACKE:** Congress felt—the perception was—

**COHEN:** The perception was there.

**ANSELLO:** Well, you might celebrate that. I didn't like the result of that. I thought it was a real mistake to go that route and divert so many dollars that could be used elsewhere. But look at the flack that AARP got from that, and they didn't lose that many—just tens of thousands of members out of the millions. It was not big.

But they very much stepped back from that issue. And that more or less makes my point. As you make my point. You don't have the giants; you don't have the sparks; you don't have the clout.

**KONDRACKE:** Is there a kind of discrimination here against the disabled?

**ANSELLO:** You have to do something on the local level.

**KONDRACKE:** In other words, they are at the end, sort of at the end of a stream. They—the aging disabled—how do we describe them? Those who were healthy and have now become disabled because they are old, presumably, you say that they are the sort of—at the—

**ANSELLO:** Adults with late onset disabilities.

**COHEN:** No.

**KONDRACKE:** —low priority end of the aging community.

**COHEN:** You are absolutely on the mark because what we do not like in our culture are those we regard as being biologically inferior: blacks, people of color, women, people with disabilities and the elderly. They are biologically—they are regarded as being biologically inferior and we don't like that, because this is a get-up-and-go society, and it is the land—although it is long gone about a hundred years—it's the land of the frontier. I happen to be a great believer in Frederick Jackson Turner's theory on—it's impact on the American psyche, that if you believe and if you've got the get-up-and-go, you can make it in America. But if you're weak, if you're a woman, if you're black, if you're this or you're that you can't.

I think that it's almost an innate dislike—kind of an “ism”—(inaudible)

**KONDRACKE:** Well, women—I mean the answer to that problem has been organization.

**COHEN:** Right.

**KONDRACKE:** Part of the problem is that the disabled are less able to organize.

**COHEN:** But they have. The physically disabled, the Vietnam veterans—

**KONDRACKE:** (And their parents)—yeah.

**COHEN:** No, the physically disabled, the spinal cord injury groups, they are the ones who have brought the cases before the Supreme Court—some of the mentally retarded—the City of Clayburn case, the Olmsted case, these have not come out of the aging community. Yet these are cases that impinge on trying to shift services from nursing homes to the community.

The aging community doesn't like litigation. They don't like that kind of aggressive advocacy. They have shunned it.

**ANSELLO:** There really is a big cohort difference. First you—the correction for the language, if we talk about not the disabled, but adults with disabilities, person-first language, what you have is a non-embrace, if you will, of aging issues in general.

You add to that disabilities and you've got a further remove, if you will. I opened by talking about the gift of time. You know, we've added 26 years, but we are still not embracing aging. You know, we now have—what we've done is we've added 26 years to mid life. We have a prolonged middle age.

We are not identifying with aging in any significant way so that we could coalesce and advocate and redress the issues that you talk about—the way racism and sexism have been redressed in very substantial ways.

But I think adults with disabilities, or for that matter, adults who grow older—us—we really haven't gotten around that issue in any significant way. Even if we were, we would come back to what you find fault with, which I find inevitable: fragmentation, categorization, because we grow less and less alike. I am going to have something in common with you at one moment and not another moment, or...

**KONDRACKE:** Well, let me ask you about that. You have said that a couple of times, that as you get older you become less and less alike. I mean, to the outside observer, people who get gray and get sicker—one would think that they are more alike than they were when they were young and healthy and some people were playing golf and other people are bowling.

**ANSELLO:** Yeah.

**KONDRACKE:** So why do you say that they become less alike?

**ANSELLO:** Well, if one were to compare cross-sectionally groups of people who are twenty, forty, sixty, eighty on whatever the measure happened to be, political orientation, economic wherewithal, problem-solving ability, intellectual acumen, whatever it happened to be, you would get a scatter of scores among the twenty-year-olds, the forty-year-olds, the sixty-year-olds, and the eighty-year-olds within their respective groups.

What you would find among the younger people is whatever you were looking at—good, bad or indifferent—the scatter of scores around the mean would be pretty small. As you get older, the scatter of scores around the means get larger and larger.

You can always compute a mean as simply, you know, that average of the scores. But the mean means less the older you are because you've got more dispersion. You've got more dispersal around that score. It's kind of like saying, "Well, I have a team of—the average age of my little league team is fourteen, and you've got a bunch of kids who are ten and a bunch of people who are forty-five, you know. You can still come up with a mean, but it doesn't necessarily mean anything.

As one gets older, then, you have this gerontological imperative to become more yourself, and you may have chronological age and some outward characteristics in common with your age mates, but you have had a life history that has differentiated you from the person sitting next to you. You are the same—you know—

Then you add to that some differentiated life events, historical life events. We were talking before we went on air about World War II and the Depression—a very homogenizing experience for a cohort. So as that cohort gets older and less and less alike, it still has many bonds that knit it together.

But what are the events that post-war baby boomers have in common, that bond them in the way the Depression or World War II bonded early generations? What counteracts or at least qualifies this diffusion? Well—

**KONDRACKE:** OK. We've only got five minutes left.

**ANSELLO:** Oh, sure.

**KONDRACKE:** Let's give advice here to policy makers. This is your chance to address governors, Congress, the federal government and also the various participants in these groups, you know, the networks. What's your advice?

**ANSELLO:** Thank you. What I would advise is to recognize and reinforce family caregivers. In Virginia we worked for a number of years to get the Virginia Caregivers Grant Program funded, a very modest effort to pay a \$500 stipend to family caregivers who provide care to relatives of any age with two or more activities of daily living

impairments. OK. So individuals who met a certain financial and certain physical characteristics—qualifications. Individuals who, by any other measure would be in a nursing home, but are in the care of their families. We developed this bill to provide the caregiver \$500 that might be used for durable medical equipment, prescriptions, anything the caregiver wanted. We discovered that if only 10 percent of the recipients postponed entry to a nursing home by four months—sixteen weeks—the entire bill paid for itself, OK?

**KONDRACKE:** This is \$500 a year?

**ABSELLO:** Five-hundred dollars a year, yet, that bill—which on the face of it reinforces family values, is economically prudent, saves money—wasn't re-funded. It's been authorized for ten years but funded for one. Go figure.

So what I would advise is, start thinking long-term about chronic care, and about who is providing the care. It's the family. Whether we are talking about lifelong disabilities, as we have been in this conversation, or late-onset disabilities, who is going to provide the care? It's the family caregiver. That caregiver needs training, reinforcement, supports, diversion of money from institutional care. But the difficulty, as we have been saying all along is, those caregivers have no voice, have no impact.

What I would say at the federal level for the Family Medical Leave Act, strengthening that, Family Caregiver Act, strengthening that, at the local level developing initiatives to reinforce families—that's where I would put my emphasis. I think these local coalitions and regional coalitions can be players in that.

**KONDRACKE:** Eli? I take it that you would have a grander—

**COHEN:** Yeah. I would not only have a grander vision, but I would say that looking and trying to tinker with this bill and that bill and this piece of legislation and this set of services and provide \$500, you are just putting it off and not doing really is called for.

I think that I would try to advise governors, the president, key legislators to step back and say, "What is it—let's try to find out what is it that people with disabilities want and expect out of their lives, and what can be."

The same for elderly with disabilities. And their caregivers. Then let's take a look and say, "What have we got now? And does what we have contribute to that? Or does it really get in the way?"

I think much of our expenditures, you know, if we've got a 1,800,000 people in nursing homes and there ought to be 900,000 or a million, that's a big reconfiguration and a big change in dollars and shifts. We are going to need more dollars given the demographics and so on.

I think we've got to get—step back. I would love to see in the Senate and in the House those committees reinvigorated with a grander sense of mission and not trying to get something passed in the usual two- or four-year political time period. But let's say, you know, we've really got to do something for the next decade.

**ANSELLO:** May I add one thing to that?

**KONDRACKE:** Very quickly. We're almost out of time.

**ANSELLO:** I agree 100 percent. He's absolutely right. But I think it's almost oxymoronic to expect an elected leader to think big about human service issues. I just don't think that's going to happen. But if it were, I would embrace that wholeheartedly.

**KONDRACKE:** Well, it's happened before.

**COHEN:** Well, I'm glad you said oxymoronic!

**KONDRACKE:** It's happened before. Thank you so much Dr. Ansello and Mr. Cohen. Thank you all for joining us. We look forward to the next SAGE Crossroads broadcast.

END