

URBAN INSTITUTE

FIRST TUESDAYS

**“WHEN INTERCONNECTED NEEDS CONFRONT
FRAGMENTED SERVICES: ARE THERE BETTER WAYS
TO HELP CHILDREN WITH DISABILITIES?”**

- transcript -

WELCOME:

ROBERT REISCHAUER, URBAN INSTITUTE

OPENING REMARKS:

RICHARD WOLF, *USA TODAY*

PRESENTATIONS:

PAMELA LOPREST, URBAN INSTITUTE

SUE BADEAU,

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SERVICES FOR CHILDREN WITH SPECIAL NEEDS,
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**

12:00 PM–1:30 PM

TUESDAY, FEBRUARY 5, 2008

ROBERT REISCHAUER: Why don't we get under way? My name is Bob Reischauer. I'm the president of the Urban Institute, and I want to welcome you all to this month's First Tuesday forum. First Tuesday forums are an opportunity for us to showcase some research or thinking that's going on at the Urban Institute, and have an interesting discussion with other experts, practitioners, advocates, and policymakers on issues that are of importance to our country.

The topic of today's forum is large, complicated, and oftentimes very distressing. It is the surreal labyrinth of service systems intended to help the 15 million children with disabilities and their families. These unconnected medical, educational, and financial programs usually vary with respect to application processes, eligibility standards, and the breadth of services, and numerous barriers, of course, impede access to these programs. Children with disabilities, as many of you know, are more likely than other children to live in poverty, to live in single-parent homes, to have parents who themselves are in poor health or unemployed or have other problems. Thus, many of these children and their families struggle with problems that are far more complex than the disability alone.

We've been very fortunate today to gather together a panel of true experts with a diversity of perspectives: a physician, an attorney, a welfare professional, an economist, and a journalist. And they will present their unique insights into the problems confronting children with disabilities. They'll also use their expertise and experience to talk about better ways to help these children and these families.

We're going to lead off, after some remarks by the moderator, with Pam Loprest, who is a principal research associate here at the Urban Institute in the Income and Benefits Policy Center. Pam is an economist and she is the coauthor with Laudan Aron of a new book from the Urban Institute Press, *Meeting the Needs of Children with Disabilities*. And I believe, for all of you who don't have it, you can purchase one somewhere in this room. (Laughs.) Maybe we won't let you out unless you do. (Laughter.) No such thing as a free lunch. (Laughter.) Pam's research over the years has focused on policies to promote work for those with significant barriers, including current and former welfare recipients and adults with disabilities.

Sue Badeau is the executive director of the Philadelphia Children's Commission and served as deputy director of the Pew Commission on Children in Foster Care, and she will speak after Pam. Sue served on Philadelphia's Department of Public Health Special Needs Task Force, and is Pennsylvania's representative for Family Voices, a national child health organization. Sue and her husband have been foster parents to more than 50 children and have adopted 20 children from foster care, who they've raised with two of their biological children.

Darcy Gruttadaro directs the Child and Adolescent Action Center at the National Alliance on Mental Illness. She also edits NAMI's *Beginnings*, a publication on issues affecting children and adolescents living with mental illnesses. Darcy is a member of the American Academy of Pediatrics Mental Health Task Force. Before joining NAMI, Darcy was an independent legal advisor and a policy analyst at the American

Management Behavioral Healthcare Association, and practiced law concerning health care– and psychiatric care–related issues.

Following Darcy, we'll hear from **Dr. Merle McPherson**, who is the former director of the Division of Services for Children with Special Health Needs at HHS. She oversaw the implementation of a 10-year plan to achieve community-based service systems for children with special health care needs and their families. Dr. McPherson was instrumental in replacing a deficit-based, categorical medical model of care with a consumer-driven, family-centered, strength-based comprehensive model, and this model has become the standard for care for children and is also being used in adult health care settings.

To guide this very talented group, we're very fortunate to have **Rich Wolf**, who is a domestic policy reporter at *USA Today* where he's worked for 20-odd years. Rich previously was the paper's congressional editor and has covered politics, health care, the budget, almost every issue that I have claimed expertise in. I keep moving and he keeps tracking me down—(laughs)—in new areas; a long-time friend and a wonderful journalist. From 1975 to 1986, Rich was working out of New York for several Gannett newspapers covering local, county, and state government issues, and then he came to Washington and we've been fortunate to have him as part of the national journalist elite.

So let me turn this over to you, Rich, before hearing the various presentations.

RICHARD WOLF: Thank you, Bob. Is this on? Yes. I'll be brief. I work for *USA Today*, so we're trained to be brief. (Laughter.) My main qualification, I think, in being here is that I've been through this. I have a 22-year-old son with autism, so this discussion here is going to be a little bit like "This Is Your Life." I've sort of been past a lot of this. But I'm lucky in the sense that I had to deal with the special-ed system, but I really didn't have to deal too much, while my son was growing up, with Medicaid and SSI because I had private insurance and I wasn't low income. The folks who have to deal with all those systems have much more complications in their lives. And I think what we're going to try to do here today is describe some of the disconnects between the three systems: the educational system, the health care system, and the financial aid system, and then try to explain how some of that can be improved through community-based or family-based services.

The four speakers are going to examine those various challenges. Bob went through their credentials. Quite amazing group of people we have: a doctor, a lawyer, an economist, a child-welfare professional. And my job as journalist is just to serve as timekeeper pretty much, keep everybody on schedule, so we can get to all your questions. I might ask one or two questions, but it's a big crowd here and I want to make sure that everybody gets a chance to turn this into a little bit of conversation before we're all done. So we'll get right to it. We have the better part of 90 minutes, and let me turn it over to Pam to get us started.

PAMELA LOPREST: Thanks, Rich. Is this good? Is this too close? I'm talking about the microphone. Thank you all for coming. I'm really glad to see such a big

audience for this topic. I know that many people in the audience are experts, far more expert than I, and I really hope we do get to have a good conversation after our comments.

We want to talk today about meeting the needs of children with disabilities. We have public programs whose goal are to meet these needs for health care, education, social services, income support, the various needs that children have. In fact, our estimate—myself and my co-author, Laudan’s, estimate—is that government spends over \$60 billion to help children with disabilities, over 15 million children receiving services. So that’s a lot of money, so we are doing a lot. But we want to talk about how we can do it better and how we can make it work better for the families of these children and the children themselves.

I just want to encourage everybody to remember, which you all, I’m sure, know, that we’re talking about a very diverse group of children, and Rich alluded to that, but children in this group called children with disabilities have different needs. We’re talking about children who have physical, functional limitations, children that have special health care needs of other kinds, children with behavioral needs, mental health problems, learning disabilities, a broad range of children with a broad range of needs. Unfortunately, the complexity, the fragmentation of the different systems that exist now and the money that we are spending, make it difficult for families to always know what services exist, how to access services, how to piece together the supports to meet the needs of their children, and that’s what we want to talk about today.

Some of the major programs and funding streams that exist, that we highlight in the book, are the Medicaid program, the public health insurance program that provides for other needs besides just pure medical needs, special education and all the services provided and through special education, and Supplemental Security Income, which is a disability program for low-income families that provides income support for families with children with disabilities. But there are many, many additional programs, some funded through those streams, some funded in other ways and we’re not trying to exclude those. It’s all together as the system that helps these families.

Each service system, each major public program, all of these programs that offer supports, face many challenges within themselves. They’re trying to figure out how to reach out to families, how to meet their mission, how to improve access, how to do so efficiently and keep costs down—the pressure is always on cost—how to juggle competing priorities and goals. We note that all of the major programs also serve other groups of individuals within the program. So there’s a tension between meeting the needs of children and maybe adults or other individuals in the programs. All of these are challenges that these programs face, and we acknowledge that and that those are large.

But we want to focus today on coordination across programs, and we feel that that’s important in spite of the challenges, and sometimes because of the challenges that those programs are facing internally. Why should we talk about this uncoordinated, fragmented, siloed system? All of us in the public policy world know that’s not unique to this area. Silos and lack of coordination is kind of a hallmark of many areas of public

policy. But it's particularly important to think about it and this group is particularly important for a couple of reasons.

Children with disabilities often have multiple needs from these different systems. The same child is maybe trying to get their special health care needs met, they have educational needs, they may have income needs or other social services needs, and their families are trying to help them get these services met. But getting one of these services—one of these needs met through services can really impact the effectiveness of the other services offered, and we need to think about that. A child that is unable to get a medical need attended to may have difficulty really making the best use of special educational services. There are real reasons why we need to deal with social services for some of these children, so that they can better be able to use the services, the medical services, that they're getting. So these things come together and they impact each other. A fractured system can lead to poor outcomes for the children.

Also, children are developing and changing. Over time, their needs change and they're moving—all children are moving targets, in a sense. We need to think about the coordination not just across programs, but coordination as children age. There's changes in programs that serve children by age groups. So if a child is before school age, they may have different needs and be eligible for different programs than when they move to school age, and that transition needs coordination. As children age out of child programs and become adults, there's also disconnects and difficulties in making those transitions, and we're going to hear more about that today.

So that's important. But as children change and develop, we know, and the society thinks it's important, that we invest, that we invest in children and in these children, so that they can improve, improve in their functional outcomes, improve in meeting their potentials, improve in their abilities to be independent or move towards independence. And while this is, of course, a good in itself, it also may forestall future spending and future needs and the dependency of these children as they become adults. So that's an important reason to focus on these kids too.

And finally, the coordination is important because the lack of coordination between systems can lead to competition that can hurt outcomes, rather than joint leveraging of the money that we have. I throw in a recent example that we've seen about the Medicaid determination of not paying for special education buses for children. No comment on what's the right answer, just the fact that if systems are fighting about this, and we know children need to get to school, how is this working? Is this leveraging the money in the best way? And it's really important, given the money that we spend, that we need to be able to do that.

So we want to acknowledge that and that coordination is the issue, and we want to talk about that. We also need to acknowledge that families are the main point of advocacy and knowledge for their child. And while we may want to improve case management and all of the coordination issues, it's probably true that families are going to remain this main point, and we need to support those families. We need to help them because they need to know they have the understanding of the different benefits that exist and how to

access them, they need to learn the language of different programs and professionals to be able to make these things work together, how to get payment for different services, knowing who can help and when. And these are all really important for children to access the benefits that they need.

From studies, we know that the knowledge and referral to other programs of certain programs and services within the system is limited. It's not always part of a provider's mission to help you with the service that isn't what they're providing. The medical professional isn't going to necessarily help you access the educational system, but these things connect and there's very significant overlaps. And we need to figure out how to make that work, especially when parents have strong connections to one point in the system.

Finally, families, these families are struggling with additional issues, and Bob said some of this. Children with special health care needs, on average, their families are more likely to live in single-parent households, they're less likely to have working parents, and they're more likely to have parents with health problems and they're more likely to live in poor families. And all these issues compound the difficulty of families navigating the system. We want to bring special attention to the needs of children with disabilities in poor families. Part of that is understanding the impact that poverty has on health and disabilities itself.

Studies show that the relationship between the risk of disability for children and poverty is increasing, meaning that children and families above poverty had about the same risk of disability over a period of time, recent time, but that that relationship is increasing. The risk is increasing for poor children. Many factors are involved in this, including environmental factors, exposure, nutrition, poor-quality health care, a number of things, and including—as mentioned several times here, I'm an economist—including that if you have a child with a disability, it can make it much more difficult to earn and go to work and raise your income.

All of those are issues, but we want to bring attention to the increased difficulty for poor families in navigating the system and how an uncoordinated system makes it difficult. Poor parents have lower levels of education and functional literacy on average, they're more likely to have language barriers that make it difficult. They have, as we said, greater own health problems that can make it difficult, less time perhaps to than—less-poor families, although I'm sure some families here—but I find that hard to believe you've got less time, and just the general stresses of poverty that add to caring for a child with a disability, as well as trying to get—to advocate and wrest the benefits that they need and meet their needs.

This argues for solutions that focus on improving access and coordination, and take into account the needs of these families in particular, and making sure systems, even those that are means tested and serve mainly families that are poor, take into account these extra barriers and difficulties that those families have. I want to say one word about the Supplemental Security Income system because it does stick out sometimes as different. We often are talking about the services that families need, whether it be social

services, medical services, educational services, things happening at the local level that parents are connecting to.

But we really want to bring SSI into the equation because it is a main income support for poor families of children with disabilities and an incredibly important one. It faces a lot of internal challenges and critiques about time to access and difficulty in accessing these benefits, et cetera, and those are important. But it also has a place for coordination. Even though it is not a service provider, it provides a check to these families, it can be a point of access, and can potentially service coordination. And some work is happening now for young people transitioning out of childhood into adulthood in that system, some work about connecting services. And so I think that that's something to think about too.

I've been talking about the need to think about solutions, and there are solutions under way, and our panel is going to talk about some of those and it's important. Service and benefits are accessed and provided locally. We need to think locally, we need to think about the services at that point of delivery. But we also want you to step back and think about the state, local, and federal programs that are funding these services, and the ways that they can either be more coordinated or help improve coordination at the community level. So I'll stop and we can hear from our other experts.

MR. WOLF: Thank you very much. Next we're going to go to Sue Badeau.

SUE BADEAU: Thank you, Pam, for that great overview. I'm really excited to be here as part of this panel and this conversation. I think it's so important. I have—my own educational background is in special education. That's my degree. And then I've worked in my career—although primarily in child welfare, I've also worked in juvenile justice and mental health. And my most significant sort of volunteer work has been, as you heard, with Family Voices, of just primarily focused around physical health and medical needs. So I have spanned all of those areas, both professionally, as well as in our personal life with our family. I was asked to make most of my remarks in this opening part of the panel from the perspective of my experience as a parent. And so that's what I'm going to do for the next several minutes, but I would love to, once we get into the question part of the conversation, share some thoughts on systems as well, and I'll probably sneak a few of those in here as well.

I'm going to divide my time into three basic parts: one, I'm going to talk about the challenges and opportunities for parents who are raising children with special needs. And I'm going to use a couple of stories to illustrate, and I'm going to have a special focus on when those special needs are in the realm of cognitive disabilities or dual diagnoses of other kinds of disabilities and cognitive disabilities. The second thing I'm going to touch on are the unique and specific kinds of challenges and opportunities facing youth that are in the foster care and juvenile justice systems, who also have disabilities and special needs. And finally, the third piece I'll mention has to do with that transition to adulthood, and what that experience is like and particularly, again, from the parent perspective. Obviously, to do all of this in a few minutes, I'm going to just be hitting real

key words and points that I hope will whet your appetite and queue up some of your questions, rather than give you all of the answers.

In terms of—from the a parent’s point of view, what are the unique challenges that parents raising children face when they recognize that their child has special needs? One of the first things we have to realize is that the parents themselves need support. They have feelings about their child’s special needs, about their adequacy as a parent, about their, perhaps, guilt that they feel, whether they should or not. And so they have to have the kinds of support that will help them address and meet those kinds of needs, as well as all the more tangible needs such as poverty-related issues.

Then parents have the challenge of figuring out how to navigate multiple systems in order to get the information that they need in order to make informed decisions about how to best get the care for their children. And in this regard, I often find for parents, it’s whatever door you first enter, often will then really influence the experience both you and your child have.

And often, this is related to the developmental age your child is at when their disability becomes first apparent. For example, if you have a very young infant or young child that has a disability, who is going to be the one that often recognizes that, along with you as the parent? Probably the pediatrician. So you’re probably going to enter through a medical door and your whole experience from that point on is going to be sort of grounded in medical services and health care, and then how that branches out into the other systems.

If your child’s needs are more in the cognitive level, developmental disabilities, learning disabilities, even some things related to other kinds of medical issues like sight, vision, hearing and so forth, these might not get identified until the child is school age. And it might actually be the school teachers that start identifying these issues for you, and so your door is education and so everything else begins to revolve around that door.

And finally, if your child’s special needs don’t really become fully identified and addressed until they’re an adolescent, it’s often because the needs are more in the mental health and behavioral health category, or some kinds of emerging medical issues that don’t really come forward until that time. And then, your door is most likely going to be child welfare, juvenile justice, or the mental health system. And your experience as being the parent of a child with special needs is going to be determined by which system you first became part of.

So Pam talked about how the systems have to juggle competing priorities. The parents have to juggle amazing competing priorities, and know how to figure out which priorities are the ones that need attention at any given time. We can’t say that we’re going to choose between giving our children housing and food, or meeting their medical needs or their mental health needs or their educational needs. We have to figure out how to do all of that all at the same time.

At the same time, as parents are figuring out how to do this juggling, they have to figure out what are the goals? How do I set goals for myself and for my children? How do I know when I've sort of achieved success, when there's always another mountain to climb ahead of me? How do I help my child experience success when they also are facing the very next hurdle or the very next barrier?

And again, part of that has to do with which priorities we focus on. We have a child who has multiple special needs. He has a terminal illness, he has a genetic condition, he has a mental retardation diagnosis, and he's also deaf. And when we moved from one state to another when he was a young child, and we were first trying to enroll him in school, all the school really focused on was that he was deaf. And they wanted to enroll him in a class that was primarily focused on educating deaf children. And that really wasn't his priority need. He needed a whole range of other things, of which that was a very small piece. So we had to work with the school system around that issue, which brings you to the next piece, that the parent has to really be the educator of these multiple systems, has to help them learn not only about their child, but about the kinds of things that the child needs in order—as you said, how you benefit from one system impacts how you're able to benefit from another system.

We also—one of our children that we adopted, when he was seven and had multiple behavioral health and cognitive disabilities, a psychologist that had been working with him said to us in front of him, one day he might be able to learn to write his name, but don't ever expect high school graduation. And so that's—the professionals that wanted to then track the kinds of services he would get with that as a starting point, whereas we said, well, we're not going to make that our starting point, thank you very much. But we had to become the advocates and the educators for the professionals.

And just to give you the quick update where are they now, Wayne, whose terminal illness has a life expectancy of anywhere between 8 and 13 years is now 21. And the medical professionals are saying, we don't really know what you're doing, but keep doing it. (Laughter.) And our son George, who was probably never going to graduate high school, graduated from college and is now working in a career that he likes very much.

Other challenges for parents are that sometimes in order to get those best kinds of outcomes for our children, we have to help them work through pain and we have to work through pain. And sometimes, that means physical pain, but that's not really all that I'm talking about. Sometimes, the easiest answers, and the ways to avoid pain, are shortcuts that don't help us get to longer-term benefits. And one quick example I would give is that we adopted a child with pretty severe cerebral palsy, and when we were in the phase of deciding that we wanted to adopt her, the professionals were saying to us that they didn't think we were the best-qualified family because at that time, the home we lived in was not wheelchair accessible. She wasn't in a wheelchair yet. She was a toddler.

But their vision was that she was always going to need a wheelchair, and since our home wasn't physically wheelchair accessible, that was the priority that they were focusing on. And probably, it would have come true because our health care that we had

at the time through my employment offered a total of eight physical therapy sessions a year for children and adults, because the view was physical therapy is for rehabilitation. You're in a car accident, you need to get back to full functioning, eight sessions ought to do it. If you have a child with cerebral palsy, who hopes to maybe not end up in a wheelchair, then eight a sessions a year isn't going to do it.

So then we had to become not only the educator, but beyond that, an advocate and a team player with the professionals. And at that time, we couldn't get around eight sessions a year, so we had to figure out how can we use those eight sessions to get the outcomes we want. And we said, we don't want those eight sessions to be therapy for her. We want them to be training for us, so that we can do therapy with her every single day, instead of eight times a year. And so we got that approved, and we had our whole family going for those eight sessions a year to get trained in how to do the various physical therapy exercises that she needed. She now not only walks, but she's a dancer. And she's at a program called the Berkshire Hills Music Academy, which I'm going to mention later as one of sort of promising examples for our children.

So parents have to believe in their own expertise, they have to become their child's primary advocate, but we also have to learn when to be the fighter and when to be the team player. And there are times when it's more effective to be one or the other. There are times that we really have to fight, and just to be the sort of good cop, bad cop; be the bad cop, but there are other times that we won't get the effective outcome we want unless we really are—see ourselves as part of the team, as a full part of the team, as an equal part of the team, perhaps even as the leader of the team, but as a team person. But sometimes we have to break away from that team mentality and actually fight to get whatever it might be that our child needs.

So we need a toolkit of capabilities, and again, if we're also dealing with poverty, if we're also dealing with our own health conditions, if we're also dealing with unsafe housing, then it's hard to say, I'm going to focus on learning anger management and stress management; I'm going to focus on learning problem-solving and creative-thinking strategies, I'm going to focus on learning how to be an advocate and I'm going to focus on developing my own support system, but those are the tools that parents need to successfully raise a child with special needs.

So a couple of examples of good practice, and then moving on to foster care. There's the grassroots family-centered organizations like Family Voices. There's also—in the education models, there's the parent training and information centers, and there's the family-centered approach to health care, such as the medical home initiative that you—and I have web sites and all this for you if you need them. But those are some really good examples of empowering and helping families develop the tools that they need to parent their child.

Now, when we come to children in foster care or juvenile justice, however, who is doing that role? Who is speaking for that child? If they're being moved, as the children we had in foster care, when I did a little quick back-of-the-envelope chart on how many times they had—how many moves they had had in foster care, and how many different

placements they had been in, our children that we had in our home had been in an average of 11 different placements and had been in foster care an average of nine years before coming to us.

So who's speaking for them in the health care system? Who's speaking for them in the education system? What we see then, and what the data definitely shows, is that these children often have health conditions and educational needs that are completely missed, and not met at all. We also see that sometimes they're misdiagnosed, and other times, they'll get a diagnosis, but not a treatment plan that can be implemented because between diagnosis and treatment, they move.

And I have lots of examples—and I know my time is running short, so I won't share them, but—of children who—for example, someone noticed they had a vision problem and then it was months later when they finally got an exam because they moved twice between someone sort of thinking they had the problem to when they could actually get an appointment to be seen. And then they had the appointment and they were seen, and they were identified as having a vision problem and needing glasses, but they were moved again before the glasses came in. And the glasses went in the drawer of the case worker, and a few months later, in the next placement, the child got the glasses.

In one case—example that I wanted to share with you, it was 17 months between someone saying this child has a vision problem and their actually getting glasses that they could put on and use. Obviously, that affects their ability to benefit from school, not to mention many other systems. And there are just dozens and dozens of these kinds of case examples of how children are not getting their educational or health care needs met, particularly when they're in foster care or juvenile justice system.

So I want to jump right to what I see as the opportunities and promising practices in this area. One is by training, supporting, and empowering those foster parents to become the child's advocate in these different arenas, and the handout that I provided addresses that. Here, nearby here, in Maryland, there's an organization called PEATC, that I forget what the letters stand for. The P is parents and that –

MR. WOLF: Parent Educational Advocacy Training Center.

MS. BADEAU: Right, something like that. And they had a whole special project to educate foster parents, in particular, that's very worthwhile. Involving the biologic family and the foster family together in going to appointments, school meetings, other things so that they're sharing information and both on the same page in terms of their child's needs. Co-locating services, like many child welfare offices are starting to have a nurse on site, can make a huge difference. One of my favorite ones really is getting judges involved, and having the judge be that sort of coordinating person who can, at least, ask the questions, because there is no child who ever enters or leaves foster care or juvenile justice without coming before a judge. So if judges can have bench guides that help them recognize how to ask questions about health care and education and these other things, that can make a huge difference. In New York State, they've developed a bench

guide related to health questions, and Casey Family Programs has developed a bench guide related to education questions that are really useful in this regard.

And the last minute that I will add is just in regard to that transition to adulthood. As families prepare to help their child transition from primarily sort of that child world to adulthood, one challenge that parents face is sort of moving from that family-centered approach that I've been talking about to really much more of what—sort of the term of art is that person-centered planning and that person-centered approach that revolves around this emerging adult as an adult. And again, I have some resources if you want to look about person-centered planning and so forth. It's also learning how to engage new systems in helping our young people make that transition and be successful, such as the vocational rehabilitation system. SSI has been mentioned and adult basic education.

Our daughter Trish, who we adopted when she was in eighth grade and had a lot of medical, mental health, and cognitive disabilities, wanted to work in the medical field and everyone throughout high school and special ed said, oh, you can't do that. You've got to plan on maybe being a clerk somewhere at a McDonalds or something. That's probably what you can accomplish. But she wanted to be an X-ray technician; that specifically was her dream. (Laughs.)

But through engaging these other systems, she was able to, little by little, take the necessary prerequisites and classes to become a certified medical assistant. It took her 10 years after finishing high school to get that certification, but at the age of 28, she then got that certification, and she now works in a home health agency, visiting seniors and being their certified medical assistant. It wouldn't have happened without vocational rehabilitation and SSI, and what in Vermont is called the Vermont Work Incentive Initiative, which is one of the promising practices that I would call your attention to in this area.

And then, in regard to that transition to adulthood, I'd just like to share a couple of other examples that I think are promising. One is the Healthy and Ready to Work initiative, which came out of some of the work that Merle may be talking about. Others are services that help youth learn to become their own self-advocates. It's not enough any more to just have the families advocating for them. So there's an organization called Kids as Self Advocates, KASA with a K, that provides training and support to help youth become their own best advocates.

And then we have to think about how are we giving our youth with disabilities—again, particularly those with cognitive disabilities is sort of the focus I'm giving—the opportunity to have that same age-appropriate, developmental stage in life that is college for many of our young people, that next step after high school. And there are some wonderful programs, the Berkshire Hills Music Academy, which I mentioned a few minutes ago, that our daughter is at the threshold program at Lesley College, where one of our other daughters attended.

The biggest problem for facing the ability of young people to benefit from these programs is funding, because these are not degree-granting institutions. They provide the

same college-like experience for youth who have cognitive disabilities, but they're not giving a college degree. Therefore these youth are not eligible for any forms of financial aid that any other student going on to postsecondary education would be eligible for. And the only sort of funding stream that they might be able to get is either through the MR or voc rehab, which doesn't fund that level of a sort of college-like experience.

So that, I think, is one of our biggest challenges, along with the fact that health care and mental health services often end for youth once they reach a certain age and are no longer eligible for it, and sometimes can they still get it as an adult? Yes. But there's often a gap and again, who's the advocate that's standing there helping them make that transition and bridge that gap? That's one of the biggest challenges that our young people, as they have become adults, have faced.

And the last thing I'd add is that there's a particular challenge for those young adults with disabilities, as they themselves become parents, and many of them do. And so we have to look at models that support adults with disabilities, as they become parents themselves, and support not only them as parents, but also support their children. So I think I've used up more than my time. I'm sorry. And I left a lot off stuff out—(laughs)—but I'll be happy to add more during the question time. Thank you.

MR. WOLF: Darcy, next.

DARCY GRUTTADARO: Yes. Thank you very much.

MR. WOLF: Thank you.

MS. GRUTTADARO: I'd like to start by saying thank you for inviting me, and I'm glad that children with mental health treatment needs are part of the agenda, because I think that's a population of children that sometimes get overlooked. I also want to suggest that this book is a wonderful contribution to something that challenges all of us, which is to really, in the work that all of us do, not just talk about fragmentation and interagency collaboration, which we've been talking about for 20 years in mental health, and we don't do very well in most places, but really doing it. So I want to challenge everyone to be really focused on that for children, really to benefit children.

And I'm going to speak in generalities, and I know how incredibly unfair that is because there's some really good work going on. But I come from the perspective of families that have children with serious mental health treatment needs, and I'm going to focus actually on the school system, which many families have not had real positive experiences with that have children with mental illness.

Obviously, there continues to be a tremendous stigma associated with mental illness. We try as best we can to fight that, but it just persists. And we all have a role to play in helping with that, but there also is the nature of these illnesses, which is that children have symptoms that in some cases can be extraordinarily difficult, and they can be extremely difficult in classrooms. They also can be symptoms that come and go. So

there's a perception on the part of some school professionals that this is volitional behavior, that these are just kids being difficult. It's kind of the idea of a hidden illness that you don't always see and that comes and goes and the symptoms come and go.

So I think school professionals legitimately have concerns with how do we differentiate what is just a kid being a jerk versus a child that may have difficult mental health treatment needs or needs some kind of intervention. We also have schools, unfortunately, when it comes to students with serious mental health treatment needs, that set low expectations. And really, I think Sue gave some outstanding examples. Over and over again, children she's had the opportunity to parent, who really—schools have told, you're not going to amount to anything. That's a horrible thing for a child to hear, but unfortunately, when it comes to mental health treatment needs, once that child gets a label, the expectations are extremely low.

Now I think the No Child Left Behind legislation has ironically forced schools to pay a lot more attention to children that have serious disabilities because they're being counted as part of the standardized testing that schools are required to report on. So I want to really—I hope that in the reauthorization process of the No Child Left Behind legislation, we don't disregard the fact that one of these outcomes of these requirements is that there's far more attention paid to the academic performance of students with disabilities, including children with mental illnesses.

The other thing—and Sue alluded to this as well—is there's an expectation within the federal special education law that it won't just help with students' academic achievement, but it will also help with their functional achievement. And this is an area that's been greatly overlooked. We have lots of parents that contact us on a regular basis with concerns related to a lack of transition services, effective transition services, effective transition planning, a lack of life skills, kids coming out of schools who really don't have the independent skills they need to enter employment, to find housing, to understand how to function in our society that really should have those skills coming out, and that actually, the federal law requires to be addressed by the schools and a connection to the voc rehab system. So that's an area that students with mental illnesses have had a very difficult time with.

The other thing is we have the unfortunate distinction of having the highest dropout and failure rates of any disability group. So again, I hope the No Child Left Behind legislation, which is relatively new, when it comes to really understanding the data, will have an impact on that. We shall see, but as schools become accountable for children with mental illnesses and other disabilities, we hope that those numbers improve. And there's a lot more attention being paid to graduation rates, which is clearly extremely important.

The other thing—and this has been alluded to as well—is families often don't understand what their legal rights are. And I'm always amazed when parents call me and say, well, they threw my son out of school again. And the child has an IEP and the parents' rights are just absolutely being railroaded, and there is this real concern about rocking the boat. There is this hierarchical intimidation that often exists with parents not

wanting to rock the boat with schools. Again, I want to be clear that there are exceptions to this, and schools that are doing a really good job with innovation—and I'm going to talk a little bit about that when I get to the solution part—but again, I think we need to find ways to help support parents, better understanding their rights. There are parent information training centers. There are some very good web sites, but we need to make information accessible to families, so that they can really—it can reach them, it's in a language they understand, it's at an educational level they understand. All of those issues are extremely important.

The other thing is, one of the things we hear a lot about—and there are some reports that really are documenting this—is that schools really are taking very much a punitive approach to children with disabilities. This is not just for children with mental illnesses, although our children tend to have—some of them, more challenging behaviors, in some cases. These are also internalizing medical conditions and emotional conditions, but certainly, there is a direct pipeline between schools and the juvenile justice system.

And because, unfortunately, the community mental health systems in most communities are not robust, and we have a lot of work to do in developing an effective community mental health system in every community in this country, we don't have crisis intervention systems in a lot of cases. We don't have mobile crisis intervention teams that can go to homes and schools. And families are told if your child is in a crisis to call the police, and schools increasingly are calling the police, so that students with disabilities are being disproportionately fed into the juvenile justice system. And the National Center on Mental Health and Juvenile Justice has released a number of reports that consistently show about 70 percent of youth in the juvenile justice system have one or more psychiatric disorders. This is very, very troubling. Twenty percent have serious mental illness, so these are kids with psychosis. This is really a horrible place for these kids.

So we really need to find a way—and I'm going to suggest some things we can do. I don't want to suggest schools should be doing it all, and I'll tell you why, because the federal government, when they passed IDEA, said that the federal government would spend 40 percent on the cost of special education. And unfortunately, we haven't even gotten close to 20 percent in terms of the federal share of the cost of special ed. So we need to be providing schools with adequate funding. We have No Child Left Behind, which is placing enormous burdens on schools. It's been a huge transition for schools to understand how to collect the data, how to develop the right testing and programs for students, how to stay out of the—how to meet adequate yearly progress and stay out of the danger zone of being a school that's labeled as bad. So we need to find a way to get systems connected, so that the burden doesn't strictly fall on schools. That is critically important.

I think that raises a very—the whole theme of this is the interconnectedness, and really, schools—things are very balkanized, so that schools and the community mental health systems speak different languages, they have different cultures. Schools have really become very insular, and part of the reason is we don't have robust community mental health systems in most communities in the country, so there's not a whole lot to

connect to. Our mental health service system is in complete disarray. So we need to build that, but we also need to build those bridges and connections.

Let me just suggest some things in my limited time here that I think are real promising that are happening around the country and that really give me reason for hope. Did you turn the mike off? (Laughter.) Am I done? (Laughter.) I just got to the good part.

MR. WOLF: Go ahead.

MS. GRUTTADARO: Anyway. There are effective evidence-based interventions that have been developed in terms of behavioral therapy, in terms of positive behavior intervention and supports in schools. And I think it's important that these interventions reach schools. Part of the issue is we have these researchers that develop these wonderful models, they do research on them, they have great outcomes, we see good things coming out of them, and they never reach down to the school level. So we need to find a way for the federal agencies, the Department of Education and others—and I know some of this work is going on. They need to really support efforts to get these interventions down to the school buildings, where they're very much needed.

Now, this is going to take some incentivizing for schools to pick these up. So we're going to need demonstration grants to support the implementation of these programs at the school level. We also have to reform higher ed. We are continuing to teach school professionals that are coming out of these programs the same things they've been taught for a long time, even though they don't work. And then they get out in the field and we have to retrain them. What a waste of resources. We need to find ways to reform higher ed, so that effective interventions are taught at the training level, and not when people get out into school buildings, where there's a tremendous amount of pressure on them.

The systems of care grant programs that SAMHSA and the Center for Mental Health Services run is a great opportunity to develop innovative community-based systems, and it's done a tremendous job around the country. Unfortunately, those community innovative programs have not reached statewide in most states, so they're pockets of hope. And what often happens is, as soon as funding gets tight, as it is now—we're seeing more and more states are in deficit situations—the innovative programs leave. So families say, I remember when we had wraparound teams in our communities. That was under the systems of care grant. After six years, when the funding dried up, they were gone. So we have to find ways to sustain community innovative interconnectedness between child welfare, juvenile justice, education, and the mental health system and we have to take it statewide.

The last thing I'll say is—I think that's it—there's very good work being done at two centers that are funded on school-based mental health. One is at the University of Maryland under the leadership of Dr. Mark Weist. He's doing very innovative work to get interventions to the school level. The other is at UCLA. So we hope that that will translate into changes within school buildings. The other thing is, it takes a village. It is

not going to be schools alone, it is not going to be the community mental health system. It's going to be all of the systems working together. Thanks.

MR. WOLF: Thank you. That was excellent. And we'll go to our last speaker, Merle.

MERLE MCPHERSON: Thanks. And I think we've got enough issues on the table that we can stop and spend the rest of the afternoon talking with you. So I'm going to try to be fairly brief in terms of the comments I make, because I really am hoping to share some of the history and the experiences of the last decade that were directed towards this issue of connecting and integrating, particularly at that family-community level, and just acknowledge some of the macro issues, and then come back down to all these wonderful things and how we fit them together.

I need to say that I am speaking for myself. I in no way represent the federal programs that I was with. I came into the government in the late '70s, and I came into the Social Security Act actually, which had a Title V program, the Maternal and Child Health, that had a crippled children's program as part of it. And it was my understanding when I came in, that the challenge was to redefine that program and move it to a new model.

We all know that the families that we're talking about today are really dealing with 10 to 20 people, individuals in their lives that are working with them to help put together the services and supports that they need in order to support their family and raise their child. And I think that's the focus we need to talk from, because we also know that we have this incredibly complex set of agencies and programs coming from health, education, social services. And we also have—and this is important to acknowledge—it is not just public programs. There's lots of private resources out there, there's voluntary resources out there, and there's a great deal of philanthropy that comes into working with these children, so that you can't solve the issue by successfully coordinating the public programs at the government level.

You have to go down to that community level, understand who those 20 people are that are working with those particular families. And I will tell you that the families obviously have no idea what programs these individuals come from. And in fact, most of the professionals don't know either. They just know they've got a job and they're working in the school system, et cetera. So the families are really faced with putting it all together to taking these people and creating their team to support their child, and we really need to look for ways. The systems issue was an attempt to look for ways to better support the families, so they didn't have to go at it all alone.

I want to tell you about one of the major accomplishments having been our move away from the medical model, which was that model that concerned itself with diagnosing and treating crippling conditions, and it wasn't child-centered and it certainly wasn't family-centered. So that we're now at a model that is family-centered, which really recognizes that children must be served and cared for in the context of the families and the communities in which they live. It takes strong family professional partnerships.

Those are now the standard of practice, whether you're working at the policy level, whether you're working at the program level or you're down—and practice yourself. And it is a model that applies to all of us, whether we're in the educational system, whether we're in the social service system, the mental health system or what, it—we gave up the medical model. We went to a family-centered model and all of our friends have actually gone there too.

So it's the understanding that—and you've said two marvelous examples of what it means to have family partnerships and work with families as you try to change things. I want to make it clear that it is a family professional partnership, and it also requires participating and change from the professionals, so that they really ought to learn how to work differently with families. We are a long way from successfully completing family-centered care for all the programs in this country, but it is the standard of practice, and there's really some strength coming from the families themselves. So that's an important piece in terms of getting the agencies to work together.

I might add that families are a very strong motivator for agencies also to help break down the turf and territory. It's so much easier to sit there and not give up any turf and territory to the other agency, if there aren't families in the room, so that the family-centered care really does help that.

The other model that's been mentioned here—and I just want to mention it from the medical side—is the medical home, and I hope you all have heard that word and adjusted to it. We had a lot of trouble with the words, but it is a model to assure access to quality health care for every child. The Academy of Pediatrics was very involved in the leadership role with all of us in defining and developing that medical home. It is based on family-professional partnership, so it is very family-centered. Families helped develop it, and in addition to the usual immunizations and acute-care kinds of stuff, it has really moved back to strengthen the prevention, early identification, early intervention for the kids, so drawing the pediatricians and the family practitioners into working with the other community programs.

And then on the other end, it obviously has expanded and trained the physicians as primary-care physicians in the chronic-care management and the long-term working with families who have special health care needs. It involves follow-up of referrals and shared management with a specialist, sub-specialists that are working with the family. It involves better integration with the community programs, has been particularly important in the early childhood programs and the transition programs. And it allows for coordination, some help, people helping, not just asking families to put it all together, but paid-for-care coordination from the medicals and from the schools, so that they are helping bringing that team together.

The medical home has been endorsed by other physician groups, by the health care payers, by employers, and it is actually being moved as a model into the adult health care, so you're going to hear a great deal about the medical home as a way to change the practice of medicine to be more supportive to families. I understand there was a *Wall Street Journal* article last week that talked about the medical homes.

Closely tied to these changes that we were involved with from the health side, but our friends were also involved with from the education side, the mental health side, the social service side, is this support for systems change at that national-state level. Originally, this really began as a consensus process, not just with the public programs, but with the professional providers and the families, et cetera. And it was led by Surgeon General Dr. Koop, who was a very real mentor of mine. And now there is statutory language, the president's Freedom Initiative, which is based on a Supreme Court decision for community options, and the health goals for the nation all call for the states to have and create these comprehensive, family-centered, culturally competent community systems of care. It's a real focus of trying to bring us down to that family-provider community level, and look at the services and supports that are there and build processes.

And there are actually very, very many exciting models or communities. Ultimately, it is—ultimately, the communities that come together to better integrate the services, so families can use them easily. And in some ways, it has to be at the community level because there is such diversity at a state level, but certainly, at a community level in terms of what's there, what is the health care program, where are the educational services, who are the philanthropy organizations that are in that particular community? So it's really been a focus down at the community level.

I want to point out that the accomplishments, and I keep making this point, but it's an important point for the discussion of how do you get to collaboration, is that the things that I have spoken about involve all of the agencies that we are discussing here today. It's not my program, it's not somebody else's program. It is a universal solution to try to come together at that family-provider community level with support from the various programs and some effort and infrastructure to support that. There's different degrees of involvement, there's different pieces at different times. In fact, much of this work actually began—the innovation and the development of it began outside of the three major programs at the federal level. It was not those programs, except for the education, particularly in the early intervention part. They were big players in getting this going, so that it is all the agencies involved.

And I think we need to think about that in terms of what's already going on there. There is partial implementation in every state of these efforts to support communities, to build medical homes, to have family-centered care, and continued effort should bring the convergence of those agencies at the federal level together. It is so much easier at a federal level to agree to work with 6 other agencies or 12 other agencies, if you're really solving a joint problem. It's not being invited to sit down and try to do something for another program. It's saying, hey, we've all got to put this program in place, so we really do need to set up some processes. And I think that's important just to think about how the agencies can continue to develop that infrastructure and support, so all of these good things can go on.

And my last comment—so that we can move on—is that I suspect that—my sense is that strong leadership processes at the state and federal level could support the community development, and be a better strategy than efforts to achieve full integration

at the federal and state level. It's too complex up there. You just can't untangle it all at the federal level, or even at the state level. But if you have a leadership process at your state—if you have a governor's council that is saying, we will come together and we will support all of the communities who have agreed to put this together, these are the programs you have to have in your community, we want you to do that.

So I think that, yes, we need to continue to work at the federal and state levels, but I think trying to fix it all, the hundreds of programs there, is just too overwhelming, and putting people in place, leadership ways in place, that help the communities, which is what we're after, as I understand it. It is ultimately to help that family out there with the 10 to 20 people that they're trying to put together for their child. And I think I'll leave it at that.

MR. WOLF: Thank you. I think that was very hopeful, all of those discussions, rather than depressing. I heard a lot of—I was expecting a little more on the depressing side and less good community-based, family-based programs. I'm going to ask one question, and then I want you all to get your questions ready and there will be people with microphones. So when I call on you, just wait one second and we'll get a microphone to you. I'm just going to ask one quickly and try to get a quick answer from any of the folks here.

If we're interested in best practices at the community level, a lot of you had suggestions—I know, Sue, you have a handout—where can folks go to learn what the best programs and practices are that are being implemented around the country, often just in counties or in cities? Is there any kind of one-stop shopping, so that people could come away from here today or know where to go on the Internet to find some of the best programs around the country?

MS. BADEAU: There's not a one-stop shop for all of these things we've talked about, but there are some different clearinghouses and gateways. For example, in child welfare, we talked about using evidence and bringing—Darcy talked about bringing evidence-based practices to the schools. At UCLA, there's a clearinghouse for bringing evidence-based practice to child welfare, and so that's one web site that you can look at for a number of these things. When it comes to some of the education models, there's a web site that's called Pacer.org that is kind of an umbrella that has a lot of these. So some of them are listed in the materials that we'll be posting, I believe, on the web site from this seminar, as well as in the handouts. So there might be 10 or 12 of those places that you could begin to get that, but there's not one.

MR. WOLF: Let me just ask one more follow-up to that. Is there a role for state or federal governments to play in becoming that gatherer of material, so that everyone out there at the community level has that kind of information? I know, through my 22 years of raising a child with a disability, it was always—you fear that you're going to go through the 22 years and then find out, oh, there was this great program in Iowa—(laughter)—but I never knew it existed. Is there a role that governments at any level can play to get that information out?

MS. GRUTTADARO: Yes, and they do play that role now. They fund centers. The University of Maryland, their school-based Mental Health Center for Action and Analysis, for example, that's funded through federal grants. They have very good information about evidence-based practices. There's a positive behavioral support and intervention site, www.pbis.org that's funded by the Department of Education if you want to learn about PBIS, which is actually included in IDEA, as an evidence-based intervention that's schoolwide. So there are—the federal government does fund academic centers that provide this kind of information. Again, it's always a challenge to get it down to the school level, but certainly, families can carry that message, family advocates. And they are, they are doing that.

MS. MCPHERSON: I think it's an excellent question, and I think the answer is that all of the fields have those centers, and it's been a challenge to try to figure out how you could put it together in such a way. And with the new IT—the other thing that hasn't been talked about is IT and the effect that that could have in bringing some of these things together and translating it down. So yes, it's there. It's not incredibly well put together at this point.

MR. WOLF: Let's get some questions from the audience. I saw a hand way back here first, so let's go to you. And not everybody can see you, so maybe you want to walk over—okay.

Q: (Off mike)—it's called Family Support 360 and it's a series of 21 shops across the country that provide a one-stop resource center for parents with children with disabilities, especially healthcare needs, to access the systems. And we actually are from the one in Washington, D.C., and there's one in Maryland and even Hawaii, but that is what the federal government is trying to do and it is a five-year pilot project.

MR. WOLF: If we want to go to the one in Hawaii, rather than the one in—(inaudible). (Laughter.) Yes, right here. Hang on one second—(off mike).

Q: My name is Margaret Junkel. I'm sorry. My name is Margaret Junkel. I'm a recovering Washingtonian who now spends a lot of my time in Los Angeles County, which, they will tell you, has more children in one health care program than D.C. has people, about 500,000, so it's pretty big. First, on the comment of what communities can do, and this is not about best practices, but this is about what you get funding and services for, whether or not they're good practice. The Los Angeles County is using a model based on the OregonHelps.org model called LACountyHelps.org, which is a pre-screener, web-based pre-screener, as you were mentioning, which you can go into. It's user-friendly and you can determine what kinds of services you might qualify for or your kid might qualify for. So it's a way to give you an idea of what's a dead end and what might work, and it's an excellent system. It's LACountyHelps.org, OregonHelps.org.

And on the other question, I really think the issue that it kind of came through to me here was—we have people like Sue, and if every kid had a parent like her, we might not need some of the service integration stuff because she's figured it out and it's just incredible, and I think we should give her a round of applause. (Applause.)

But the bad news is every kid doesn't have a parent like her, and I think that one of the things that we often do is focus on community training and parent training, and that's really passing the buck to where it shouldn't be. We should not put that kind of extra burden on parents or communities when we can prevent it. And we need to, while also training parents and communities, push the responsibilities upward to the systems. And we're in the middle of a presidential election right now—Super Tuesday, we've noticed this—and the president and the governors and mayors have control over multiple programs and multiple agencies and multiple systems. And they have responsibilities at each of their respective levels of government for coming up with draft bills that can, in their individuality and entirety, either increase or decrease the level of fragmentation.

So one question I have for you—and I think we should think about this with our presidential election—is all these programs come up for reauthorization and get re-upped by Congress periodically, just as state and local programs do. But on the Individuals with Disabilities Education Act, in the Public Law 94-142, which started in—what, it was '74, '76—5. Okay, on average, yes—(laughter)—and then a couple of years later, because they said, oh, my God, that's just schools-age kids. We're not getting the—soon enough, they added the 3- to 5-year-olds, Part B, section 619, as it's snappily called. And then in 1986, they said, oh, my gosh, we really have to go younger and get to the 0- to 36 months old. So now, we have—and I hear a lot about this because I run an early identification intervention collaborative in Los Angeles County—is we have to teach parents how to navigate the system between different service providers, different eligibility rules, different therapists for 0 to 3 and 3 to 5. And this is coming up for reauthorization in 2010 again through the Health Committee and Educational Workforce.

So my question to the panel is—we know that the 0 to 3 and 3 to 5 programs were set up at different times because that's when Congress thought of them. They also have different eligibility rules, different funding streams and kids' preschool get half as much per kid as school-age kids, even though school-age kids need the help, all the help they can get as well.

But my question to the members of the panel is: is there any sensible programmatic reason why we shouldn't have a 0 to 5 program with multiple service providers and one set of eligibility for IDEA, for kids 0 to 5 years old? Is there any reason that we shouldn't have one program for those kids, which would immediately reduce the fragmentation and the problems that parents have navigating those systems, because they wouldn't have to switch at age 3, which also happens to be the age at which a lot of kids with autism and very serious disabilities are first identified?

MR. WOLF: Let me ask Merle, not speaking for the federal government, whether you have a view on that right off the bat. (Laughter.)

MS. MCPHERSON: I don't think I'll get into that. (Laughter.) It's a very complex issue and I would not—(inaudible)—that.

MR. WOLF: Anybody on 0 to 5?

MS. MCPHERSON: I don't think anybody in education—(off mike).

MS. GRUTTADARO (?): I think more than just having a—whether we call it one program or not, I think that's across programs and that's two examples, but we could—between us, we could come up with 20 more. We should push legislation at the federal and state level and regulation, the regulatory process, in particular, to try to streamline and unify things like eligibility and make it—whenever there's a transition, whether it's from two-and-a-half-to-three or whether it's starting school or whether it's when you're going from elementary school to middle school, or whether you're transitioning to adulthood, all the transition periods are the most problematic for children and for their parents. And whatever we can do to streamline that and to make it possible to keep some of our same providers, whether it's our same doctor, our same therapist, our same teacher, I think that's a good strategy as a general approach, and there might be multiple ways to accomplish it.

Q: But that puts it back on the parents. What about the system, that there are now two separate systems invoking the same law? Why shouldn't there be one system?

MS. LOPREST (?): I can't speak to that. I'm no expert on that, but I can say that putting things in the same system isn't always the solution to make everything go away, all the problems. There's plenty of same-system funding that is just very problematic. So I think the goal is the same, and the goal is to get it to be more streamlined.

MR. WOLF: The woman right here. We're going to try to—(inaudible). Sorry. There's a lot of questions—(inaudible)—get to.

Q: Hi. I'm Lois Tett. I'm an independent writer. I see a wonderful conference here, every one of you women, with people-plus to solve this. I want to thank you for bringing this together. A question that I have, though, attending these conferences with the colleges and schools and whatever, I have a discussion of crazy checks. Do you know what I'm talking about?

MS. BADEAU (?): Of what? I'm sorry?

Q: Of crazy checks. My daughter is an instructor, or was in Ohio. A parent approached her and says, will you write this report, so that my child can be deemed—she was in special ed, by the way, at that time—whatever? And my daughter looked at her and says, I don't know you nor your child; I can't take this responsibility. After those checks are given, is there monitoring on this money to make sure that the money is going to enhance the educational experience of the child, or is it just let go, give them a check and they keep on coming back with checks and we've got a poverty pimp mentality here with this. It's got to be erased because we can deal with this.

I had a child myself, twins, rather; one that they said, oh, he's bad ADD, and all this kind of thing, Ritalin, blah, blah, blah. And I looked, and I wasn't familiar with the system at all. I said—I rejected it. I got one report that a doctor at Children's Hospital had

written on my son, who is now 34, graduated from Carnegie Mellon, engineer, EE, and he said he's a little skinny, poor kid. He's got a hole in his pants, so he must need Ritalin. I rejected it. I laugh at that note all the time because it's so foolish. They don't have credentials to judge these children and they mess up people's lives. We ought to look at that.

MS. GRUTTADARO: Let me respond to that because I think you raised a number of important issues. One is making sure that, first of all, schools should never attempt to suggest a diagnosis for a child. It's not the role of a school professional; they're not qualified to do that. We have heard some anecdotal reference to that happening and it's very concerning. On the other hand, school professionals—on average, it's 8 to 10 years from the onset of symptoms until a child with a mental illness is diagnosed. In the life of a child, that's a lifetime. So you can't learn with undiagnosed and untreated mental illness. These are real illnesses and they impact children's lives dramatically.

What's critically important is that a child be evaluated. Unfortunately, in this country, we have about 7,500 child psychiatrists with a need close to 20,000, so we don't have enough child psychiatrists. We have a lot of workforce issues in this country that really need to be addressed. So I guess in response to your question, I would say we are always very concerned when we hear school professionals suggesting a diagnosis or a medication. That's not their role and it shouldn't be their role. On the other hand, we want them to openly communicate with families about mental health-related concerns, so we can close that 8- to 10-year gap, but we also want to have enough qualified mental health professionals to be able to evaluate and work with families to get an accurate diagnosis and treatment.

MR. WOLF: Let me—right here.

Q: Hi. I'm Gretchen Martens with Fair Chance, and one of the things we do is to basically do organizational development with community-based nonprofits. And one of the partners that I'm really privileged to work with actually does exactly what you talk about, Darcy. She's about the only clinical therapist living east of the river. She works directly with two schools. One of the most extraordinary things about what she does, she has a 24-hour turnaround for mental health services and nobody is turned away from her door because they can't pay. And I've been encouraging her, saying, why don't you try to get money for the city? You're poised to open a second center, and her reaction is, absolutely not, because it will slow me down and I won't be able to do 24-hour turnaround and I may have to turn people away.

And with all due respect to philanthropy, it's just not very sexy to fund mental health in Anacostia, and I know that's kind of ugly, but that's the reality. Funders want to fund cute little kids learning how to read and doing dance projects. And so I'm looking at how does the system respond to that? Like her statistics, compared to what's considered successful in the mental health field, are extraordinary, and yet she can't find the funding to do what she does best. And she knows the people, she lives in the community, she does culturally competent mental health. And yet she can't find the funding to meet the needs

of the 45,000 children that live in wards 7 and 8. So how do we change the system to respond to someone who wants to do good work and the money gets in the way and the government rules and regulations get in the way?

MS. GRUTTADARO: Wow, that is a really big question. (Laughter.) I think it's a great question. I think you're absolutely right about kids with mental health treatment needs not being the cute little kids. I think the media, with all due respect to Rich, is not always our friend. And we get lots of calls at NAMI that say, we want a story about a family whose child was on medication and went on a violent rampage. That's—and we don't get success stories. I think the media has not always—always—and sometimes they've been okay about this, but we need to be sharing the success stories. I think we need to be making sure that people understand that effective interventions work well. I think when there's an incident like Virginia Tech and that level of tragedy, then we pay attention. Governor Kaine has said \$42 million in mental health services in the state of Virginia, and that's—we're very reactionary. And I think we just need to continue to work, as the family advocacy groups and others have done—provider groups as well—in making sure that funders and government agencies understand that services can be effective and we can achieve real success. I just think we have to keep working at that. I think it's an uphill battle.

MS. BADEAU: And if I could just add one comment to that, is that I don't know how many people remember sort of the deserving poor and undeserving poor kind of language, but we have a similar mentality often when it comes to children and that sort of the good kids and the bad kids. So when it comes to funding, when it comes to politicians, when it comes to media stories, wherever it is, there's sort of this broad—certain kinds of issues are the good kid issues. And certain kinds of issues—and particularly when it happens in mental health, it happens in child welfare, foster care, juvenile justice, it happens for some children with mental retardation diagnosis—we have sort of the bad kids and good kids mentality that affects funding decisions and policy decisions. So we have to build that sense of public will that all kids are good kids, all kids are deserving kids, and that therefore, we need to look at the resource—the needs assessment and the allocation of resources accordingly. But first, we have to name it, and we have to acknowledge that sort of elephant in the room. We have to name the fact that we do have this sort of good kids/bad kids thing out there that we have to address.

MS. LOPREST: I would just add that the idea of government and bureaucracy getting in the way of people doing services goes beyond the good kids/bad kids, and that it happens in all systems and it's part of why community solutions need to rise up. So we need to see an up-down conversation, not just a down. It needs to go both ways, so that those kind of solutions can talk to the programs.

MR. WOLF: A question over here.

Q: Thank you. I'm Sharman Ward Dennis. I have some information I'd like to share and then a question. There's an excellent web site that's put out by the federal government. It's called DisabilityInfo.gov and it links to every city in the United States in every area. I have a question. We all love the web. Here's a link, I just gave you a link,

and we're going to find all this information. If you're talking about low-income families, there are a large number of low-income families that do not have access to the web. They may all have a cell phone, but they're still not getting access to the web with that because it costs money. So how are we going to get the information about services for your child if all we have are web links all over the place and people do not have access to the web?

MS. GRUTTADARO: I think we need to keep struggling with how are we going to make information accessible? Now, public libraries is one. The web is not going away. It's where we're—and I think it's just accelerating. In community health centers, having resource centers for families that are right there in community health centers, and we have to really locate information where families are. The faith-based community, if there are ways to partner with faith-based communities, so that families can use during the time there, at services and after, information and technology there. We just have to continually work toward because I agree with you, this technology gap is very concerning. We have accelerated the way information is transferred, as far as focusing really on technology, and it's leaving too many families behind. I think we have to be very careful to locate information where families are across the socioeconomic world.

MR. WOLF: A question right here in the back, black vest, then we're going to go over here.

Q: Hi. My name is Mira Krivoshey. I'm from the National Center for Victims of Crime. And we know that there's sort of a dearth of information and research on people with disabilities who are victims, but we do know that it is disproportionately high. Can you speak a little bit to victim services and your experiences with them and any promising practices in that area?

MS. BADEAU: I've had lots of—way more experience with that than I have time to say—(laughs)—but it's a huge issue that people with disabilities are disproportionately represented as accused perpetrators of crime, as well as victims of crime, and are also not treated well, even when they're witnesses to crime, and have something—so the whole spectrum. There is some work at Temple University there that, I think, is a promising practice in terms of some training of crime professionals, the DAs, the police officers and others, in how to interact with a person with a disability when they're involved in any aspect of a criminal investigation, whether as the victim, as the alleged perpetrator or as a witnesses.

And so I think that's one model people can look at, but I think we really have to look at it again broadly, as whenever there's this intersection of someone showing up as part of the picture when a crime is committed that has a disability, we have to be able to ensure that they have access to information in a language they can understand, that they have access to the kinds of advocacy and support, so that they'll know what their rights are and that they're treated well in the process. So that's the really quick answer.

MS. GRUTTADARO: And I would just like to mention there's—on the mental health side, there's crisis intervention teams in training. It's CIT. You could do a search on that. It's a Memphis model that was developed in Tennessee as a result of a person

who was seriously mentally ill shooting and killing a police officer. And it's all on training law enforcement on how to address psychiatric calls and how to deescalate, and it's really just caught fire across the country. And lots and lots—Maryland has it. Lots of police officers have been trained and they get the calls and they really like doing this. They get to know the people in the community that have mental illnesses. They help support them, even just dropping in occasionally. It's a really great model. It's been very effective.

MR. WOLF: I think we have time for about one more. There's a question over here on the wall.

Q: My name is Ruby Neville and I work with the Substance Abuse Mental Health Services Administration. I'm a clinical social worker by training. I'm concerned with kids not being identified at an early age, and I know you all had spoken about this, but I look at the disproportionate number of African-Americans who are in the penal system. And if you've seen some of the research recently, they're showing that many of them, and many of the people in general, who are in the system, in the criminal justice system, have mental health issues. So obviously, if we can identify these people early on, particularly in the school setting, perhaps they won't take that path. It does affect us as regular citizens because we have to deal with these kids who are angry, because no one—people didn't identify them at an early age in school, while they were in school, to help them to get accommodations under the IDEA legislation.

So what can we do to turn this around? And one of the things I have in mind is when we have meetings like this, couldn't we also have people from those communities who are experts, some of the grassroots folks, and have them be a part of discussions like this, because if you don't see people like this, somehow or another, they get left in the shadows. So my challenge, or my question to you, is how do we start to reverse this trend of having this disproportionate number of African-Americans in the penal system who have mental issues?

MS. GRUTTADARO: I actually have a couple thoughts. There's some good work actually going on. The president—as you know, President Bush's New Freedom Commission report had six goals, and goal four was school should play—part of goal four was on early identification and said school should play a much bigger role, and so should primary care. And as a member of the American Academy of Pediatrics Mental Health Task Force, there's a big focus within AAP on doing a better job in the pediatric office, which is a perfect place for it. We should not be examining children from the neck down. Through well-child visits and beyond, we should be looking at children in terms of how they're doing in their mental health.

The AAP is really focusing on this, looking at screening tools, looking at assessment tools, developing very nice co-location models, good connections with the child psychiatry system, even though its capacity issues persist. Schools also need to play a bigger role. There was a bit of a political pushback when there was a suggestion that kids should be screened in school. There are some groups that politically think that is not the right thing to do. I happen to think schools are where children are, and if there's an

opportunity to—certainly, school professionals should be trained on early warning signs. Some kids have clear signs and nothing’s really being done. So schools can play a big role.

There are screening programs. The Columbia University TeenScreen Program was actually featured in the president’s New Freedom Commission report as a model program. So I think we need to continue to think about the role that schools can play because you’re absolutely right. We are putting too many kids with mental health treatment needs in juvenile justice, and it really dictates the rest of their lives and it’s just—we have to stop this.

MR. WOLF: I think that’s about all the time we have. So thank you, everybody, for coming. It was an excellent panel. I think I learned a lot. (Applause.)

(END)