

STATE OF MARYLAND

Moderator: Amy Daugherty
October 29, 2014
9:30 a.m. ET

Operator: Good morning. My name is (Kevin) and I'll be your conference operator today. At this time, I would like to welcome everyone to the DDA Waiver Feedback Session.

All lines have been placed on mute to prevent any background noise. After the speakers' remarks, there will be a period for comments. If you would like to make a comment during this time, simply press star then the number one on your telephone keypad. If you would like to withdraw your comment, press the pound key. Thank you.

Amy Daugherty, you may begin your conference.

Amy Daugherty: Thank you, (Kevin). Thank you for participating today. I'd like to welcome everyone to this telephone feedback session. My name is Amy Daugherty and I'm here on behalf of DDA and Deputy Secretary (Bernie Simons).

DDA, as a whole, and (Bernie), specifically, wants to get a candid view of the system through these listening sessions so that policies and practices can be tailored to address real issues and to make sure that DDA has a firm understanding of the many strengths and challenges at Maryland. DDA wants everyone on this call to speak freely and share your opinions about DDA services. In fact, after a brief introduction of our facilitators, I will be leaving the room.

DDA staff has not attended any of the listening sessions, and this is intentional. We feel the best way to collect information and be informed about your perception of how the DDA is doing to conduct the sessions without DDA at the table and use independent facilitators. You do have the opportunity to hear directly from (Bernie) on November 17th.

On November 17th, the Maryland Developmental Disabilities Coalition is sponsoring a town hall meeting where (Bernie) will talk about key initiative and engage in a question-and-answer session. The meeting will be held in Columbia at the Oakland Mills Meeting House. The Oakland Mills Meeting House is located at 5885 Robert Oliver Place in Columbia, Maryland.

The meeting on the 17th of November will last from 7:00 PM until 9:00 PM. So again, that meeting will be November 17th at the Oakland Mills Meeting House located at 5885 Robert Oliver Place in Columbia, Maryland. The meeting will start at 7:00 and conclude at 9:00 PM. While there have also been opportunities related to Maryland's broad transition plan for the home and community-based service setting (rule). This forum will also inform that process.

If you're interested in reviewing those from today's session or other sessions, you can do so by going to the DDA Web site. The DDA Web site is located at www.dda.dhmfh.maryland.gov. Specific questions may come up. For example, in some of the sessions, people had questions about a participant DDA budget. These questions will not be able to be answered on this call, but you can contact regional office staff.

If you could please have a pen handy, I'll quickly go through names and numbers for regional contact so that you can have your specific questions addressed. If you live in the eastern region which includes Caroline, (Seussville), Dorchester, Kent, Queen Anne's, Somerset, Talbot, Wicomico, and (Worchester) County, you can contact Edwina Harris at 410-572-5926. Edwina Harris's telephone number at the Eastern Shore is 410-572-5926.

If you live in the central region which includes Anne Arundel, Baltimore City and County, Harford and Howard Counties, you can contact Phyllis Landry at 410-234-8201. Phyllis Landry can be contacted at 410-234-8201. The western region of DDA includes Allegany, Carroll, Frederick, Garrett, and Washington. Mr. Haywood Evans can be reached at 240-313-3875. Mr. Haywood Evans is at 240-313-3875.

And finally, the southern region includes Calvert, Charles, Montgomery, Prince George's, and St. Mary's. Mr. (Michael Brian) can be reached at 301-362-5118. Mr. (Brian) is at 301-362-5118. In addition, if after today's call, you think of something and wish you'd shared it, please take the time to e-mail your thoughts to me. They can be e-mailed at wfb.dda@maryland.gov. WFB stands for Waiver Feedback. So, it's wfb.dda@maryland.gov.

And if you don't wish to e-mail and prefer to call, my name is Amy Daugherty, and I can be reached at 410-767-5600. If I'm not available, you could leave a message or let the receptionist know you'd like to leave a message with Waiver Feedback. So, at this time, I'd like to introduce our facilitators.

Mary Sowers and (Janine Sloski) are from the National Association of State Directors of Developmental Disability Services, also known as NASDDDS. They facilitated all of the listening sessions and will facilitate today's session. They're also reviewing DDA's waiver to provide recommendations for improvements.

So, I hope you have a great conference call, and thanks again for joining us today.

Mary Sowers: Well, thank you so much, Amy. This is Mary Sowers, and on behalf of myself and (Jeanine Zlockie), we want to thank DDA for the opportunity to talk with you today. But most importantly, to thank you for spending time to share your perspective on the DDA Waiver and your interactions with DDA, overall.

As Amy mentioned, Deputy Secretary (Simons) is interested in getting a very candid view of how DDA services and DDA interactions are going with the people that are most important, the folks that we serve and their family. So, while we don't work for DDA, we are their ears today, and we'll be recording all of the feedback that you have to offer. So, we again, want to thank you for your time this morning, and given that we've got just under an hour to spend together, we'd like to open the floor early to get that conversation going.

(Jeanine Zlockie): Hi. I'm (Jeanine Zlockie) and I'm also with the National Association of State Directors of Developmental Disability Services. And Mary Sowers and I would like to open the floor. Anyone who wants to discuss with us what's working with DDA right now or things that you are having some – any issues with regarding anything that needs improvement, we would like you to be as candid with us as possible so that we can collect as much information as possible, and we are delighted to open the line.

Can we have someone with the first comment?

Operator: At this time, I would like to remind everyone that in order to make a comment, please press star then the number one on your telephone keypad. Our first comment comes from the line of (NB). Your line is open.

(NB): I have a daughter who I have been raising since – She was 50 this year, and I'm 84 and I have been sick for quite some time. And what happened, one (one) thing was above company. I broke my arm when I came home and they weren't able to – they say they weren't allowed to come up on (a force) just put her on a bus.

So, that gave me a little bit of trouble but the (inaudible) had settled that, they have employees to come and pick her up and bring her back for a while. But I didn't understand they say they weren't allowed to do that. Anyway, that Thursday, my daughter was put in a nice home I applied for some time. And she's very, very happy there.

I haven't been able to understand some things have been brought out, especially things like her health plan, insurance, (fill) arrangements, things like that. I have – she has insurance that I (take) and nobody has talked to me about those kind of things but I was very surprised that she was very happy at the place that she's in. It's a very nice place.

The last time I've met with you all, I was very upset because I know that at this age, I couldn't take care of her. I had a traumatic accident and I was in (shock trauma) last year and this year. Last year, I broke my arm. So, I'm able to visit her every day at any time I want to and she enjoys herself.

But I would like to know more about the care, the physical – not the physical care but the doctors, the arrangements for his insurance, do I continue to pay that or what?

Female: (Nancy), thank you so much for your comment. We are very happy that your daughter is happy where she's living right now and you brought up two really important points that I want to tell you that we also heard through the other two listening sessions. The first, and you can tell me if I have this right to make sure that I'm capturing your comment correctly, the first issue is transportation.

We have heard a couple of things. There's a lack of transportation options. We've also heard a similar experience to what you have is that some of the transportation providers need to have increased training on assisting those with disability. You also raised another point about getting information and assistance with navigating the many different types of paperwork, and you named insurance paperwork, that you have to deal with and you need a person like a resource coordinator, that would be very helpful to you in those areas.

Did I capture that correctly, (NB)?

(NB): I guess you did. I have insurance that I pay or, you know, since she's not under my care anymore, directly under my care, do I still pay her life insurance, which is \$45 a year. I was wondering if I'd still pay her life

insurance and I want to keep the same benefit, same person who is in charge if something happened to her.

Female: So, thank you for that clarification. I think that we've captured that now. In terms of some additional information on whether one, you should continue your life insurance coverage for your daughter, and it sounded like also perhaps health coverage not particularly clear for you.

(NB): No. I have life insurance on her, and I was wondering if I'm still to pay that.

Female: Right. OK. Thank you. I think we've captured that. And just as a reminder, while we don't work for DDA, Amy Daugherty did provide contact information for the specific regional offices. So, if you want to contact someone directly, you could certainly try your resource coordinator at the DDA regional office contact.

Were you able to copy down that number, (NB), for the region that you live in?

(NB): No, I wasn't. But I'm quite sure I can get it from her.

Female: OK. All right. Thank you so much, (NB), for your comment. Can we have the next caller, please?

Operator: Again, in order to make a comment, please press star and the number one on your telephone keypad. Your next comment comes from the line of (HR). Your line is open.

(HR): Yes. Hello. How are you?

Female: Good morning, (HR).

(HR): Yes. I have a couple of questions. One is my brother (Kenneth) is a resident with the (Catholic Charities) in (Harford) County. And he'll turn 65 in November of this year. And I don't know what that means with respect to his

situation as far as coverage (inaudible). Does he (automatic) covered under Medicare or what have you?

My second question is, I'm not really familiar with this waiver situation. What does it mean, how does it impact my brother's situation or any family situations or et cetera? So, if you could give me explanation if you know what it is, I'd appreciate it.

Female: Well, thank you, (HR), so much for the comment. I think I'll start with your second one first, just to make sure we capture it. And we can give a bit of information on what a waiver program is, but to learn more about sort of what it is specifically in Maryland, we'd encourage you to reach out to your regional office contact. And again, we can make sure that this is located easily, findable on the DDA Web site. But depending on that region, we can hook you up with that name.

But a waiver program is essentially the program that most states use to provide home and community-based services to individuals who meet specific eligibility requirements. In most cases, if an individual receives in-home supports or (with a) provider goes to a day program, oftentimes, that's through a waiver program and it might be not so visible. We're getting a lot of feedback on the line.

(Kevin), can you help with that?

Operator: Mr. (HR), if you could press star six when you're not speaking, that would (leave) your line and maybe eliminate some of the background noise.

(HR): OK. I'll do that now.

Female: Thank you. But a waiver is really an agreement between the state and the federal government on an array of services that can be offered to an individual. With regard to your specific question on your brother's benefit, again, I'd encourage you to speak to the DDA regional office just to make sure that we don't provide any information that might not be applicable in your situation.

But I will say that you raised a couple of really important points that highlight perhaps, an area here communication or information may be really important to have more readily available for family members like yourself. Thank you very much. Next caller, please.

Operator: Your next comment comes from the line of (SG). Your line is open.

(SG): Thank you. Hi. As was noted, my name is (SG), and I was calling basically, I guess, for a comment as well as a suggestion. My daughter works through supported employment in the southern area, and my comment is that it would be great if the provider would work more closely with the transportation provider. My daughter took (Metro Access) back and forth to work, and that's a great – I mean, that's a great service however, oftentimes, they leave the, I guess, the arrangements of getting on and off of the vehicle to the client.

And she has Down Syndrome, and I don't want her to have the responsibility of having to ensure that she gets on the correct vehicle and make her way home. Now, fortunately, the provider that we work with has worked well with me and my daughter in assuring that she has – is (faithly) on the vehicle. But that is not, should I say, policy, and I do believe that that should be a policy of all of the providers who are providing services, support and employment services or whatever, to ensure that since they no longer provide the transportation at one point, the providers were providing the transportation to the work sites themselves, but I guess because of funding concerns, they could no longer do that.

So, I understand that but I still think that if there should be a policy in place where they should work closely with the third party transportation system.

Female: Thank you so much, (SG). You brought up another really important point. Supported employment is to help a person realize their employment goals and increase their independence and although providers do not have a responsibility to provide direct transportation as you stated, it would be – your comment is that it would be very important and helpful if DDA took into

consideration that part of supported employment providers' responsibility would be to ensure that the person they are supporting is safely on whatever mode of transportation that they are using to get back and forth from work. So, thank you so much.

(SG): That's (good) in a nutshell.

Female: It's perfect. Have a good day, (SG). Thank you.

(SG): OK. (Thanks).

Female: Next comment, or do you have another one? I'm so sorry. (SG), I didn't mean to (swap). Do you have another comment?

(SG): Oh, no. That was good.

Female: Good. OK. Thank you.

Operator: Your next comment comes from the line of (ZZ). Your line is open.

(ZZ): Good morning. I basically just have a...

Female: Did we lose you? Is it (ZZ)?

(ZZ): Can you hear me?

Female: Yes. Now, we can.

(ZZ): I'm sorry. My name is (ZZ) and I have a daughter who's in the (New Directions) program. And basically, I just have a comment. She was in the Community (Pathways) waiver and I just wanted to say how valuable I found that the (New Directions) service to be for her. She's greatly benefited from being able to self-direct her in life rather than being places where she had to follow the plan of what everyone else was doing.

So, I just wanted to make the comment that we are very pleased with the (New Directions) services and I'm hoping that as it merges with the Community (Pathways) waiver that nothing will change with it (only) unless it makes it even better.

Female: Thank you so much for that comment. We'll be sure to pass that along. Both the good experience that you've had but also a word of caution to hope that it is only improved and not hindered by the merger with Community (Pathways). So, thank you very much.

(ZZ): Yes. Thank you.

Operator: Just a final reminder, in order to make a comment, please press star then the number one on your telephone keypad. And your next comment comes from the line of (XX). Your line is open.

(XX): Hi. Thank you. I had a standpoint from a provider and I just want to voice in from a provider standpoint how frustrating applications – for not just (Community Pathways) but for (New Directions) and how there's no unity, there's no straight direction. Even requesting information from higher up, there's no one answer. And that can be completely overwhelming not only for the families but those who are helping them apply.

So, it just feels like (this) needs to be streamlined. And when you're requesting documentation, ensuring that it's not (come back when you just) more documentation and (you just want) documentation. If the families don't turn it in with one week turnaround, then they're shut out of the waiver and that has not just repercussions on the services, but their entire life and their health insurance.

Female: Thank you, (XX). You brought up another really important point that we also heard across the state that there really needs to be a consistent streamline way of communicating with all those involved in the system so that one, everybody has the correct information to not only make decisions but as you

stated, correctly follow any DDA policies and procedures so there aren't any consequences to them getting the services and support that they need.

So, thank you, (XX), so much for the comment.

Operator: Your next comment comes from the line of (FL). Your line is open.

(FL): Hi. It's (FL). Could you just tell me what the purpose of this call is? I was calling in to learn what the meaning of this change might be (applied). My daughter's in the Community (Pathways) waiver currently, and what is going to change for her in terms of services, possibly or application procedures and services?

Is there a look to reduce services in some (inaudible) or is she – or just consolidate the programs and make them consistent with each other? I'm confused about what we're supposed to achieve on this call. I thought it was of – tell us what the difference in – what was going to change in terms now because of the merger of the two programs, waivers, and I'd like to hear that.

Female: (FL), thank you so much for the comment and the question. I think that we can clarify what the purpose of the call is a bit, but I'd also encourage you for the specific questions you have to do some follow-up with the DDA regional office. But please note, too, that one of the messages that we've heard as we've gone around the state is a lack of information on just the issues that you raised.

So, we'll certainly convey that. But the purpose of this call is that the new deputy secretary, (Bernie Simons) is new to the state. He wants to get a candid view of how services and support in DDA activities have been serving individuals with disabilities and their families because while there are sort of new aspects to the waiver as a result of the renewal, he wants to take the opportunity to really take a look at whether there are places that improvements can be made both within the waiver and within DDA interactions with people.

And so, the purpose of this call, and we've done four listening sessions on each of the region to try to get from people an unbiased viewpoint of really how things are going on the ground. So, I apologize that this might not have met your expectations in terms of getting information, but please rest assured that one of the message is that we will be conveying to DDA something as we've heard pretty repeatedly throughout our time is the need for clearer, timely, simple to understand, and consistent information to be coming about both changes but also services available and processes.

So, thank you so much for taking the time to make that comment and hope that you get the answers that you seek, too.

Female: And I would just add one thing, that we will providing all the notes from this session to DDA, and any priorities or changes that DDA would make as a result of recommendations based on all of these listening sessions will definitely be communicated to the public at large and out there for comment.

(FL): Yes. I appreciate that. I've read the new waiver and the entire thing. I'm not an expert but I find it incomprehensible to figure out what's different. And I've been really disappointed in the agency for the complicated or lack of information, complete lack of information on this call for the thing that I find most important, and yes, the applications.

There's so many questions that are based on what's, you know, are there new standards, are there new considerations? None of that is evident in the new waiver, and it just feels like it's being forced upon us and yet, we have no idea what it (mean). And I really seriously doubt that (inaudible) is going to be able to explain it over the phone if I'm even able to make contact with these people. It's so complicated. I don't think I'm going to get any real answers.

And so, I just want to communicate back that the process (is very stepped) and secretive to me in spite of just meeting here today and that's basically my point.

(Janine Sloski): Thank you, (FL). We acknowledge your frustration and as Mary stated, we definitely will take back one of the recurring things about the lack of communication, the lack of easily understandable material to know what is in fact changing and how, if any way, that will affect you. And we did get from DDA, though, all of the four regional contacts that were provided to us are definitely people who were noted to be able to help you with any of the questions that you have from this session.

So, I would really definitely urge you to take us up on calling one of those designated people to help answer some of your questions. And thank you...

(FL): OK.

(Janine Sloski): So much for your comment, (FL). Very helpful.

(FL): OK. Thanks.

Operator: Your next comment comes from the line of (VV). Your line is open.

(VV): Hi. I have a young adult just recently graduated from high school and we chose the (New Directions) waiver. I have to tell you thank you so much for giving us options. I have questions, two questions and concerns but I wanted to tell you thank you for helping us put the options (our) team, which includes our broker. I love what you guys have offered.

My first question is or – I don't know if this is a question or a comment. For the transportation, my daughter uses (Metro Access). She also has MTA in Howard County (para-transit). My daughter has to be reimbursed. We have to pay out and then get reimbursed. And I don't understand why there is a middleman.

I don't understand why the money or the funds cannot be put directly into her (Metro Access) account. That's one question. The other question is my daughter has opportunities to volunteer to work and do other things whether it's in Maryland or D. C. Why is it that my daughter's companion cannot

accompany her into D. C. ? Is it (boundary) restrictive for the (New Directions) waiver because if this person (driven), it's supposed to be able to go with the person whether they're in Maryland, Virginia, or D. C.

So, and it's very confusing to me, especially being new, my daughter being (new on) the waiver. So, I'm thinking, if I'm helping her transition and it's confusing to me, what will it mean for her? That's my comment. Thank you.

Female: Thank you, (VV). First of all, we appreciate your positive feedback about the (New Directions) and the options you've been provided, so will definitely take that back to DDA. We will also take back your comment about transportation and the way that it is currently being handled and reimbursed. The fact that you need to put out the funding ahead of time, so will definitely take that back.

And we will also take back your comment about independence and going out into the community and going across state (lines) and the fact that you brought up that, your daughter's companion cannot go along with her to wherever she's going, along those lines. So, we will definitely take back those two comments.

(VV): Right. Because if it's person-centered and person-driven, you and I can go, we don't have boundary restriction, so why should she? If she has opportunities – even a basketball game, even to go to church, volunteering, if it's Maryland, D. C. , or VA, if she has a companion, she has a transportation, why do we have to get permission first for the person (that caused) – that's restrictive. That's not independent.

Female: This comment is well taken.

(VV): Thank you so much. Thank you.

Female: Thank you very much for raising it.

Operator: Your next comment comes from the line of (RM). Your line is open.

(RM): Thank you very much. Number one, thank you for giving us this opportunity, but I would love to see if you can give us an opportunity for, at least, for me to explain how (long) the program is going. Number one, I have a disabled child which has graduated this year from (inaudible) (Center School). And for many years, I've been trying to be part of the (New Direction) waiver and they didn't allow me to, I don't know for what reasons. They always force me to go with a provider.

Number two, finally, they told me that when she graduated then I will have that option. No one in the school educated to me what are the options of how good the (New Direction) waiver would be or how bad it will be. They only just encourage me to be part of that waiver, of the (New Directions) waiver.

They gave me a hard time and to the present day, while she's going to start having the services November the 1st, but thanks to (book assist) to Mr. (Willard). He is going to be able to have these services. In the school, nobody has helped. The service coordination doesn't know anything about the (New Direction) waiver, and I think it's a big problem that you need to fix.

There is no instructions and only (just) encouragement. They invite you to think that DDA or the whatever is working for that, has something or a partnership with their providers. If you get a little bit more information what the providers, you know, how they make money, they make you think that it's just a business, that they make business with your children. And that is not right.

There are (other) things that they need to be fixed. Number two, the providers that are (offer), my son not only has Down Syndrome but he also has autism. And he needs really a one-to-one assistant. So, they give you a hard time for all those necessities. They made your life impossible, and the only thing they want us to do is be part of a provider.

I can go on and on (and let) you know what the providers can provide for you and is really a catastrophe. Number two, the most important, I have been visiting those places for my son to (home) and it's been so (inaudible) today.

And they really don't have a program for them. I don't know how DDA, you know, I have called and (filed) complaint to DDA and there is nothing successful about it.

I don't know how they give the money to these people to provide those kind of services. I have (inaudible) on these things like after they graduate, there is nothing (equal) to that. Their services go really down to zero. Ad that's (two). When you go on visit, the only thing they have is a setup, like beautiful woman present the program they have. But nothing of it is true.

The only thing the have is 50 people, 100 people in one room. And they are taken care by one or two or three people for 100 and 50 people, and they provide money and pay for those services. They need – everything has to be changed about that. It's not right. They wait these children are treated after they graduate. So, please, take that into consideration and you have to force these providers to provide better services for them to at least, to have somebody like a classroom or a teacher that keeps give them – who's going to give them more instruction on health and in the development of the (light).

But it's not right that they graduate and they are going to be treated like a potato, like – because when I go in a room, my son is not part of the group (of able) children that is going to be working. But if you are not (lucky know) that to be working or to be going out to a provider or something like that, they are going to be treated like put in a room with 50 people and they tell you they're going to be doing wonderful things and they do nothing.

So, please, if you want to hear more about it, you can get in touch with me, but for now, it's my intention that you take into consideration my complaint and do something for these children because they really need assistance for you. Thank you.

Female: Thank you, (RM). I think you've very eloquently stated some challenges that you've experienced both in terms of learning and having access to all the options that might be available for your son, but also maybe highlighting

some challenges with some of the more traditional services that you were exploring for your son. So, thank you very much.

(RM): That's all right. Let me tell you something. It's not right that an 80-year-old person, because I'm not 25, that is what I'm saying. I'm old. It's not right that with all my illness, get together with a 21-year-old who just graduate from the services, from the school. So, they (keep) thinking about that and you need to request the provider that at least put them by ages and not like 50 by 50 but see classrooms from five and that they are being taken care of or that they are able to take care of them.

And think about it that when a so-called regular child graduates from high school, they have the opportunity to go to college. How about these children? They have their opportunity to go and mix with the 80-year-old who is in, you know, with a drainage bag or something like that. That's the opportunity my son has right now.

But he doesn't have any of the opportunity to be in a group of at least 21- to 40-year-old group and then receiving some (extra) instruction. No. You know, you are (just dumping) money to the providers but you are not requesting anything about it from them. That's my concern, my big concern.

Female: Thank you, (RM).

(RM): OK. Thank you.

Female: Thank you again.

(RM): OK. Thank you. OK. Bye-bye.

Female: Bye.

Operator: Your next comment comes from the line of (GG). Your line is open.

(GG): Yes. Good morning.

Female: Good morning, (GG).

(GG): I have a concern. I have a son who just transitioned last year from high school. He's 22 and he's in an agency, (he's) with a provider. And the services are fine with my particular provider. My concern is he receives a one-on-one. And when we were going to the transition process, it was essential that he keep that one-on-one. He had a one-on-one since he was about six years old. So, when they transitioned him, everybody told me, "Well, there's no guarantee that you'll get a one-on-one so you really got to justify it. "

So, even though I went from service coordination and they were very helpful, no one could say to me, "Well, (given his chase). " Everyone said, "Well, (given his chase), he'll probably get one. " But no one could say to me, "Oh. He's going to get one. Don't worry about it. " No one could guarantee that DDA would approve that.

So, I went through that whole anxiety for a year and a half, two years it took me to find an agency (quality business) when it all happened and he's been at this agency over a year now. But we got a surprise last spring when we were doing his yearly review for his IP, my service coordinator called and said, "You have to justify his one-on-one again. " And I said, "What do you mean I have to justify it again? We just did this last year. "

And she says, "No. DDA is requiring that we do it every year now for everyone that gets on one-on-one. " When I called the agency, and this agency has been doing autism since the '50s, so they've very experienced. And they said, "Mr. (GG), that's a new thing. We didn't even know about it. " So, they found out about it.

Now, it was (key) that the agency did the proper documentation and the service coordinator did their proper documentation. By pointing all this is that I had to go back through his daily logs and thank God they kept the daily log, and find evidence that he still needed a one-on-one. And the reason I had to do it was I'm his guardian. And my concern was that the agency or service

coordination wouldn't do an adequate job for DDA, and it caused a lot of anxiety and a lot of work.

And at the end of the day, I was told, "You're approved till next year. " And we're supposed to go through this again next year. And I don't understand why DDA is requiring anybody with a one-on-one to do this every year. It seems like an excessive amount of paperwork and a big waste of time. And that's my comment.

Female: Thank you, (GG). You brought up two points that we definitely will take back. The first being that there isn't a seamless transition from school to adult life, meaning the supports that you're receiving through the school system allowing for a seamless transition as a person graduate from high school. And then secondly, the amount of paperwork and justification that is required for someone to continue one-on-one supports that were designated as needed and then have to be re-designated every year.

(GG): I'm sorry to interrupt. I apologize.

Female: That's OK. Go ahead, (GG).

(GG): I just want to add this point. My son went to Kennedy Krieger School through high school. So, they were fantastic in having everything documented and helped with every way in the transition that you could imagine. They were all over it.

The problem was they couldn't even tell me – they kept saying DDA will probably approve this, DDA will probably... But no one could say DDA will approve this. It's like it goes into this vapor land from my perspective as a parent and a guardian. It goes to vapor land and I'm hoping for an approval.

And it just seems to me there could be a better way DDA could handle that. If you have a kid that's had a one-on-one since he was five or six, and he's transitioning to adult, it just seems to me it should be a no-brainer, especially if you have adequate documentation.

- Female: Thank you again, (GG). The third point being that no one is aware of any criteria that set forth from DDA that allows you to know what criteria a one-to-one would be approved.
- (GG): Right. And a lot of the agencies, many that I – I mean, I did this process like you look for your kid’s college. And I went to all these different agencies and interviewed and then all this, and the bottom line was they said, “Well, we’ll take him if he gets the one-on-one. ” And I was like, “Well, I don’t know if he’s going to get a one-on-one. ” And they said, “Well, we can’t take him if he doesn’t get a one-on-one. ”
- So, it’s like it’s a catch (point), too. They won’t take him without a one-on-one but DDA won’t tell you if you’re coming into them with a one-on-one.
- Female: So, that affects a lot of different things. His choice...
- (GG): Yes, it does.
- Female: Of provider, as well as so many other things in his life. So, thank you so much, (G), for sharing that.
- (GG): Thank you for your time.
- Female: You’re welcome.
- Operator: Your next comment comes from the line of (LT). Your line is open.
- (LT): Good morning. Can you hear me?
- Female: Yes. Good morning.
- (LT): OK. I’m sorry. I have you on speaker, I forgot about that. I did attend a meeting last night, and this morning, I’m glad that I tapped into the phone call to echo some of (RM’s) comment. And I know she’s probably in shock and

awe after having her job transitioning and then looking at a provider and what the reality of services are for adult, and especially an adult that has autism.

Yes. The service providers don't really have anything. My sister's service provider is (--). The happen to be the only one with autism services on the shore and they take care of children. But that does not translate to adult. And clearly, they're going to be future needs because there are so many more people seemingly on that spectrum. But right now, they all get (lumped) together.

But just to echo that, I know it's difficult and only through pushing and getting a temporary one-to-one where my sisters need better fill. And still, the services are only as good as the direct caregiver, but the direct caregivers don't have training with autism. So, they're not going – there's a total disjoint and a total gap from what a child might get while they're in school, say at Kennedy Krieger like (GG's) son versus, you know, once they get to a service provider. It's just – it's a sad reality and difficult.

In fact, for my sister, her only opportunities were to be in a sheltered workshop which she did for many, many years of her life and it no longer works well for her. Or staying in a room like they said with 20 people. It's my – I know at least at (--), and I'm assuming this is a model for many agencies. It is four individuals or five to one care provider to look after all of their needs for the day.

And it's true. They say they're going to do wonderful activities, the activities are arts and craft maybe or watching a movie, maybe there's an outing. You know, there's only so much that they can do because they'll have people with various types of disabilities all (lumped) together. And I knew some get wonderful care while others may fall through the class.

My further comment on, I mean, to echo (GG's) comment, with getting one-to-one services. It was wonderful when we were able to secure some one-to-one services because that was the only way the provider could continue to take care of my sister and offer her what she needed. But, yes. Every six

months or every year, it's the minute that you finish, you start all over again and it's horrible, and it is absolutely taking control of my complete life.

I'm not her guardian but I have her power of attorney for financial and medical and I'd do everything possible to facilitate anything that I can do to help her life be on the best level that it can be. But it is absolutely taking over my life and getting documentation is – and good documentation is very difficult (school) might have (been) one thing with Kennedy Krieger but as an adult in the system already, it's such a (crap shoot) and I'm actually enlisted to help our state senator's office because we're definitely scared she's going to lose her one-to-one because of a lack of good documentation or (enough) it.

And there are – to the best of my knowledge, I haven't seen a list of here's what you need. All I've been told is letters from doctors and notes from the agency. So, you're praying the whole time. And every few months, you just go do the process.

Female: (LT), thank you so much. I think you've raised or reinforced some of the comments we heard earlier but also raised some important additional aspects to that. So, thank you so much. We'll be sure to include that for DDA's review.

(LT): Yes. Thank you for listening. I really appreciate it.

Female: Wonderful. Thank you.

Operator: Your next comment comes from the line of (SS). Your line is open.

(SS): I'm calling because at one time, we were under Community Pathway which we still are now, but we had thought about going to New Direction because Community Pathway didn't allow us to do some of the things that we wanted to do. And we were in the process of changing and now you've merged them. But you're not saying whether everything stays the same with Community Pathway or everything stays way the same with New (Directions), or they're going to have to all be under the rules or just (New Pathway) able to keep

what they have and Community – I'm sorry. Community Pathway keep what they want and New Direction keep what they had been able to do.

None of that's been directed. I have loads of questions on everything else that's happening with our son. We have a 50-year-old son and we're getting older, too. And that's some of my concerns. What's actually happening, now that they've merged, what's happening with the merging? I mean, are they still considered separate? Do they have (to stay so) separately or is it all one ruling for both of them?

(Jeanine Zlockie): (SS), hi. Your questions echo what we've heard also from another person on this call on the desire and need to have information on how (New Direction) will change if any way with the new one-waiver Community Pathway. We will take back your comment. I urge you once again to call your regional contact that we've offered from today because we can't answer specific questions on the Community Pathway waiver since we do not work for DDA.

But I think more importantly, that your theme on not having adequate information that impacts you directly or the person that you love and support is really an important thing to take back to DDA.

(SS): This was a good question-and-answer session but not really any explanation on what's happening (inaudible) should change.

(Jeanine Zlockie): I know. And we're sorry about that, (SS). This session is really, as Mary stated, to really gather and be the ears for DDA and gather all the information.

(SS): That has (inaudible) work, too, because we didn't get to go to any of those meetings. If that's the same thing that was done there or was there more explanation done there?

Female: Yes. The same thing was completed and all of the other four sessions that we had and all of the information that we've obtained will be posted on DDA's Web site.

Female: And then, I don't know if you were on the line at the beginning of the call, but there will be a town hall meeting where Deputy Secretary (Simons) will participate on November 17th. It's in Columbia, the Oakland Mills Meeting House. And that may be an additional time for you to get some direct interaction with DDA staff for additional information and feedback.

We hope that this information in the area that are bubbling up in our conversations (would still) will help DDA make some priorities on areas that need addressing very soon. So, the issues you raised are really relevant and important and certainly echo a lot of the issues that we've heard around the state with regard to a shortage of clear, consistent and understandable information about what's happening.

(SS): Thank you.

Female: Thank you.

Female: Thank you, (SS).

Operator: Your next comment comes from the line of (AA). Your line is open.

(AA): Hi, there. (AA). I am the legal guardian of my 50-year-old autistic and deaf brother. I am taking over the responsibility that my 82-year-old mother has had her whole life (on). And I am now presently walking in her shoes.

And this is my very first experience in this world of the handicap and dealing with agencies and DDA and service coordinators. So, this is my very first, I'd say, nine months down the trail and the journey. And I have frankly found it to be a nightmare. I'm glad I have participated in this thing today because I have heard other people bringing up issues that I have found like the (herd) mentality of the dayroom that everyone is just herded into the dayroom and there's no structure, there's no activities.

There could be music, there could be movies, structured activity to make it a pleasant environment, and instead, my brother is taken to a room and lays on a

mat and rocks or spends the day in the bathroom. And the other thing is he has one-to-one. And believe me, you can have one-to-one and my outcry is the same as everybody else.

DDA gives these agencies the money but they're not providing the services. And that's the battle I see I'm going through is pulling (teeth) just fighting with the agency constantly to get them to provide the services that they're getting paid for. He has one-to-one. He is to go out in the community. He is very disruptive in the dayroom environment.

He has now been in the program says they don't have a vehicle, to be patient. So, for three months he has spent in the dayroom (have that) behave yourself, injury, you know, instant reports taken to the ER because of behaviors he's been having being contained in the dayroom when it doesn't work for him. And so, that is one of the issues.

The other biggest issue I'm finding is he's not only autism, is he's deaf. And because of the problems and that we've been fighting with the program the whole year and it's been an unpleasant experience, I'm sure, for them and for me, is that we're trying to find him the program that provides not only for his autism but for his deafness. And we had (him) he has been in numerous, numerous program and when staff doesn't have training to deal with his deaf issues, his behaviors have increased because he's not able to communicate, he's angry and frustrated, and the caregiver is frustrated because she doesn't know what he wants or needs.

So, that has been a big, big problem in finding – we're trying to find a program that will handle not only his autism but the deaf. And it seems like I know my brother can't be the only autistic-deaf person out there that were experiencing this problem. And so, finding a program to fit that have staff and the program after a year being in the program of fighting, fighting, fighting.

And it was until we had a communication evaluation in August and the whole time I kept saying his main way of communicating is signs and they kept

trying to push communication board and pictures that he didn't want nothing to do with the communication evaluation confirmed. This is his major way of communicating. They brought (Deafnet) in for six weeks of training. After a year of battling with them, after years of grief, after now, where's the (end of) where I've been looking for another program, they brought (Deafnet) in.

And I'm like when you have all these problems, why do you have to go through all this unnecessary grief and battling with agency that provides the services that your loved one needs. And so, they are my questions.

Female: Thank you, (AA). You brought up some truly very important points. I think one that's resounding has been across many of the different sessions is whether you're new to the system or you've been part of the system for a long time or a short time, there is definitely been a lack of support and information for you. And also, you brought up some strong concerns about provider capacity to provide certain services, especially a provider's capacity to support someone with hearing challenges.

So, we definitely will take your concerns back to DDA and thank you, (AA), for your comments this morning.

(AA): Thank you for listening.

Female: I think we have...

Female: We have time for I think one more comment. So, (thank you).

Operator: Your final comment comes from the line of (MB). Your line is open.

(MB): Good morning, everyone.

Female: Good morning.

(MB): My daughter has Down Syndrome and she's in a group home, supposedly, but she's been the only client there for about a year. So, of course, she's very

lonely and her caregiver is very bossy and critical of her. And when I call her and say, please (don't) because my daughter also has health problems of two ulcers in her stomach and irritable bowel syndrome there, and I say, "I'd like to speak with you about fussing at my daughter so much especially when she's eating. "

She tells her, "Hurry up, hurry up, hurry up. " And she said, "Thank you, MB," and hangs up on me. So, I think I wonder whether or not you do check on these caregivers, are they trained in how to care for these people who really need their help but not so much their criticism. And also, I'm wondering is it possible for me to transfer my daughter to another group home where she might be happier in the place, you know, if there's a place where the caregivers are more caring.

Female: Well, thank you for sharing that experience and I am truly sorry that your daughter's experiencing that on a (hostile) level. I think you raised an important point around the opportunities for choice if your daughter wants to move and isn't happy where she's currently living and getting information so that you and your daughter can make decisions about that is very important.

(MB): Yes.

Female: And really, also you raised a great point about the DDA's oversight of providers to make sure that individuals supporting your daughter and other folks receiving services are qualified and supportive and hopefully helping individuals reach their goals and full potential. So, thank you for sharing that. I do encourage you to reach out to your resource coordinator and again, the regional office folks to see about other options that might be available if you do indeed want to switch. So...

(MB): Well, I did talk with a resource coordinator because she used to be her caregiver. So, she's aware of the situation and she said she would try to help us, however, everything is, you know, DDA's so slow. DDA's so slow in response. And I think maybe in time, she will help but (inaudible) my daughter is I think ill because of all this harassment all the time.

I had her to the doctor and the doctor said too, it's not good for her to be criticized or whatever when she's trying to eat a meal. That's just her problem health-wise.

Female: Right. And that's just – you had another good point, (MB), in terms of DDA's ability to be responsive when an individual needs change. So, we'll definitely include that in our comments and encourage folks to check on the Web site over the next week as the comments from this session as well as each of the sessions that we've held around the state will be posted for folks to review.

(MB): Wonderful.

Female: OK.

(MB): That's wonderful. Thank you.

Female: Thank you very much for sharing your morning with us and for sharing your perspective.

(MB): Thank you. Thanks.

(Jeanine Zlockie): And thank you to all of you on the call today for sharing the information that you did with us. Mary and I truly appreciate it. We've learned a lot this morning on this call and we hope you have a wonderful rest of the day today.

Operator: This concludes today – this concludes today's conference call. You may now disconnect.

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