City of Pittsburgh/Allegheny County
Task Force on Disability
Monday March 16th, 2015
Meeting Minutes

Members in Attendance: Dr. Kate Seelman, Jeff Parker, Rich McGann, Karen Warman, Joe Wasserman, Paul O'Hanlon, Milton Henderson, John Tauge, James C. Nochese, Richard Meritzer, Sarah Goldstein, Gabe McMoreland

Task Force Members Absent: Janet Evans, Aurelia Carter-Scott

Also in Attendance*:* Alexis Deriso, Sue Means, Erin Ryan, Carla Falkenstein, Sally Jo Snyder, Pat Raphael, Sarah Kinter, Mary Esther Van Shura, Ali Abdullah, Ryo Nakayama, Joy Dore, Alex Sciuto, Chris Meyers, Mick Keroulac

Welcome

Action Items:

Review and Approval of Treasurer Reports:

No report this month, will be a report in April

Review and Approval of February Minutes:

Have not gotten minutes yet, will review in April

Pittsburgh Medical Costs: Alex Sciuto

Mr. Sciuto: Hello everyone. My name is Alex Sciuto and I am a graduate student at Carnegie Mellon where I do research on how to show Health Pricing to people. We're focusing on how to gather price information from hospitals and how do we get that information back to you. The price you pay for services in hospitals vary widely in Pittsburgh. Some are very cheap and some are expensive for procedures that you think are very similar. A mammogram for instance is very standard – we see some charge up to $575 and some may charge less, around $175. We find a lot of hospitals fall in between and we want to know how to get that information out.

We've created a website, pghmedicalprices.us, where we are putting a lot of info. What we're asking is that people in Pittsburgh take a photo of their medical bills and send them to us anonymously. We don't want your personal information all we want to know is how much you paid for a procedure and from where. We would ask that you visit our website and consider donating your information so we can build a database and help other Pittsburghers.

Ms. Goldstein: Would "Explanation of Benefits" fall under that?

Mr. Sciuto: That would be very helpful! Usually that contains the procedure and how much was charged for it.

Ms. Warman: Gateway sends me an updated list of procedures. It mostly has codes but is that something that can be used.

Mr. Sciuto: Yes that should be enough.

Mr. McGann: Question. The explanation of benefits is that everything included or is that local?

Mr. Sciuto: Right now we're just focusing on Pittsburgh. It's a nationwide problem but right now we're just starting with a local focus.

Ms. Goldstein: Does that include the metropolitan area? So hospitals like Jefferson and Upper St. Clair would be included?

Mr. Sciuto: Yes, We're casting a big net, we're going as far as Penn Highlands hospital way out there.

Mr. Nochese: The problem as I see it on here is people not paying attention to how much the procedure costs. I have insurance and they cover most of it so I simply pay what I need to and don't really look at the bill. How do you plan to get people to send in this information if most of them don't really look at the bill?

Mr. Sciuto: That is a great point. At this moment in time we're asking nicely and really riding on the kindness and observance of others for help.

Ms. Goldstein: Are you seeing that people pay a higher co-pay depending on what insurance they have and what hospital it is?

Mr. Sciuto: The insurance is a whole other layer to it. It may be smarter to go to a provider in your network but that layer does not have a real effect on what hospitals are charging. What we are seeing is that many have high deductible insurance plans or no insurance at all so then price does factor in quite substantially and would be a strong factor in where someone went for care.

SPEAKER: If we get a bill from let's say, we're going way out there. We're not trying to limit it too much we're just saying Pittsburgh so yes.

SPEAKER: Is that yes?

Mr. Sciuto: That's yes, metropolitan area. Again we have the postcards out there so -- oh, yes.

Woman In Audience: I need a microphone. The problem as I see it on here is that for example I have insurance but I often don't pay out of pocket so I just take those bills and put them in my file and pitch them out because my insurance is going to pay for them that's good enough. I don't analyze what's on the bills and so I'm wondering how you are going to convince people to report that information because a lot of times people don't pay attention to that.

Mr.Sciuto: That is a great point. Right now, we're really trying to focus on transparency of this information. We're going to create a series of information visualizations and maps that we hope will give information back to the user but right now it's a lot of sort of timeliness on the part of people getting it. We're asking very nicely.

Man In Audience: How far -- do you see --

Mr.Sciuto: We're looking at individual hospitals or medical clinics like a MedExpress or wall greens but there's no reason that once we have this data we can combine it into the zip codes and start saying hospitals in some zip codes are more expensive than others and one thing we're interested in is most people will go to one hospital. If they have transportation they can potentially make better consumer decisions.

Woman In Audience: Are you finding that people pay higher co-pays when services charge more or does it depend on what insurances they have or does it do --

Mr.Sciuto: Like the gentleman said the insurance is -- a lot of times for individuals it might just be smarter to go to your in network provider. Hospitals are doing a lot of negotiating behind the scenes. What we're finding though is a lot of people have very high deductible insurance plans or they may be under insured. In those cases be more aware of the actual price where your insurance is not so protective is a feasible thing.

Woman In Audience: Right. That's a good answer.

Mr.Sciuto: So I just -- again, help from you guys, there are some postcards over there. If you guys have medical bills, we would greatly appreciate you donating this data. Take a photo of your bill cross out your name and information and we're trying to give away giant eagle gift cards. We're trying to disseminate pricing information. So we're creating a quiz and a series of maps that let you see here are 20 hospitals in Pittsburgh here are how much they're charging. Again, this is not necessarily designed to be price shopping, like, you mentioned, insurance is a huge determiner of that but this is like wouldn't you like to know that one hospital charges 4 or 5 times what another hospital charges for the same procedure.

Mr.Sciuto: It's not across the board so some will be very expensive but cheaper for others. Larger -- I won't mention any names -- but a lot of larger, the very famous hospitals in Pittsburgh are sort of across the board going to be charging more because they have very high levels of service and they're doing a lot of stuff in one hospital. You're smaller hospital might be charging a lot for one type of procedure but not much for another.

Mr. Wasserman: When you get around to disseminating the information on your Web site, however you're going to do this, I hope you take into consideration the blind and visually impaired and DEAF, we're going to have to read that through a screen reader.

Mr. Sciuto: Talking to Richard I met a few weeks ago he was very adamant that a lot of what we do with the university is visually focused and it's something we're going to try to consider as we go forward.

Mr. Wasserman: I certainly appreciate that.

Mr.O'Hanlon: I'm not sure if this is a question or a complaint. But I mean what I think what we all know is that you know, there's this sort of game in terms of the amount of that they charge and then if you have insurance, then of course they'll do that procedure for significantly less and so there always seems to be this two pricing tier scheme involved and it seems that often you don't even know what those two prices

are until after it gets submitted to your insurance because until then, all you're seeing is sort of that Tier 1 price. So what's up with that? And I mean I'm glad that you're doing this but I guess that -- you know, it's sort of like reveals to me how stupid I feel and most of us feel because it's hard to even understand what's going on here.

Mr.Sciuto: That's a lot of the motivation for this project. You're right, the hospitals set a price. The insurance companies will oftentimes negotiate that price down to a much smaller price. If you use Medicare or Medicaid they are also negotiating down prices. So the point of this project is to bring people more aware of this difference. It would be great if we got enough data to say not just here's the price but here's -- let's say Etna health has negotiated down the price. Right now we're trying to get that first baseline number that we can tell people, you should be more aware of this information and not just assume that all hospitals are identical.

Mr.Parker: The Pennsylvania cost containment counsel, are you familiar with them? And I'm wondering about since we have someone from hospital counsel --

Mr.Sciuto: Yes. The Pennsylvania containment counsel does publish this information. We're interested in the outpatient procedures and the Pennsylvania cost containment council the data they collect is more of the bigger procedures. They published an overview of heart transplants we're not interested in that we're more interested in the do you need an MRI do you need a CT do you need an x-ray? These are the things we feel we could give information about.

Pat Raphael: Go ahead I don't want to interrupt you. I will say that my own CFO – my name is Pat and I'm from hospital council of western Pennsylvania. So we represent hospitals in about half the state. Pennsylvania as well as long-term care facilities and I just would -- I don't want to take your you know, time so I won't do that but I just want to comment that hospital charges and what you actually pay are completely different and you are correct that these costs are negotiated with various payers and I will also say that in our hospitals, the primary pairs are Medicare and Medicaid. So these are contracts that are if you're in a managed care program, that are really contracted through both the government and the advantage care company that you are with and I can also tell you that our own CFO has a hard time -- and he worked in hospitals for many years and as have I -- has a hard time explaining this so it is very complicated and I will also say good luck because good luck getting data on especially outpatient payment is very difficult because it is all negotiated frankly. No one pays charges I mean this is an updated system that's a Medicare that's created by CMS that's not something that the hospitals even like getting.

Mr.Sciuto: And I actually – I think those are all really great points one thing I'm worried about is hospitals are moving towards here's the price and they're not discounting it. 'm curious if you think more hospitals will move towards this slightly more transparent here's what our procedures cost here's what you should pay. I don't know if you can answer that or not.

Mr.Sciuto: Thank you. There is a large effort under way in both the insurance communities and the hospital providers to be more transparent but there's a long way to go I mean that's the honest truth. And part of the reason is because consumers, all of us, everybody we know, are confused about you know when you have a plan, what's your co-pay what's your deductible and what are you responsible for as a person versus you know your plan being responsible your employer if you're employed being responsible.

So we've seen these costs going toward the consumer increase quite a bit for all of us and there's a lot of what I would say call financial health literacy that we need to work on together with our employers consumers hospitals insurers so. . .

Mr. O'Hanlon: Yeah now we have a couple of questions. Chris I know had a question. Rob in the back and then Richard, so Chris.

Mr. Nochese: Actually, he was stealing my idea so I'm just going to pass my question. Rob.

Mr. Oliver: My name is Rob Oliver from disability rights network and I'm curious will there be a double price reflection in this to look at the numbers that Paul mentioned so that what the hospital allegedly charges and then -- what you're seeing is what our insurance plans actually paying for the procedures and then I realize that I came in late and so my second question is, what's the -- what is the upshot of all of this? I mean you said it's not designed as a price shopping thing where people are going to go to the cheapest rate is it designed for the end user? What is the goal of having all of this information?

Mr. Sciuto: So first answer, wouldn't it be great if we could say the sticker price and what's being negotiated down? We're trying to just get this first level of information. If as we're getting to become successful and we got more data on individual hospitals it would be great to say to talk about more of the true costs. The main upshot is helping move Pittsburgh forward kind of like you mentioned towards a more transparent city. So this is sort of the center piece but we hope that there will be explanations and information so that people come to the site and start to understand what I'm describing to you because a lot of people you talk about this and they say I get an insurance statement it tells me how much I pay I have good insurance I throw it away or I have no insurance I don't go to the hospital. Those seem to be the two primary sort of responses right now and we want to create sort of more knowledge.

Mr.Nochese: Okay, all the information that you're showing here really is connected with a lot of the hearing community or people who can hear but what about -- what does this do -- what does this have to do with like people with disabilities? I mean how that is connected with this TV and what people with disabilities? I mean are we charged the same as the general public or -- I mean what does this have to do with us specifically?

Mr.Sciuto: That's a great question. I think you guys have – or people here are going to have a unique set of medical bills that the average Pittsburgh population won't have. So coming to you, if we could get sort of the support of you guys here could we start sending information about what you need more often. We're really interested in perform grams MRIs CT scans those are the most common procedures everyone will probably once in their life need. Some more sort of smaller groups that have specific needs will be really interested to learn sort of what you guys are paying and be able to tell information to you.

Mr. O'Hanlon: Thank you. We have to remind everyone that the City County Task Force meeting with UPMC and the legal issues they said that all hospitals get funds for disabilities and they get very little are given out to them. So you know needs -- those costs are probably expanded in the other directions so in other words you know the -- oh like such as ramps you know are kind of cheap because they have to be replaced every 15 years and that's what they do with them so -- or you know different accommodations they need tend to be cheaper or -- they're finding cheaper ways of doing this stuff such as voice recognition or you know some of that they get free but you know the cost of interpreters is -- that's a

whole different ball game. That gets pushed aside or waived and they try to find excuses not to pay for interpreters and yet we pay taxes and we need interpreters or good medical care so it would be great if we could get support for all of those issues you know it's like -- because I depend on interpreters you know and obviously not speech but you know it's really important -- the needs need to be met within the costs of all those things we're talking about.

Mr.Sciuto: Are you working? I appreciate your comment and again this is why I'm going to present to you because you have a very different perspective than when I was presenting to the -- you have a specific set of concerns.

Mr. Meritzer: I actually have a question based on what Chris had said. I recently had an experience and I got bills from hospitals and doctors and this one and that one I swear one of the places I got a bill from I never heard from them before but it was a legitimate bill I'm assuming and they're itemized all the way down to the ground and one of them they even charged me for linens but they're very extensive and while hospitals and doctors are not allowed to charge more for the people with disabilities and I would never accuse anyone for breaking the law at the same time if we are looking for transparency and you want to look specifically at some point at people with disabilities and how the bills are different but the bills are coming in anonymously how are you going to identify people with disabilities?

Mr. Sciuto: That is a great, great question and it might be something that we modify on the Web site and we say, jot down do you have a disability. I think if -- and since I've presented here today and you guys are bringing up these points it might be an interesting point to look at.

SPEAKER: Exactly that's my point.

(Interruption.)

Mr. Meritzer: Okay it was too high.

Ms.Warmen: Okay on the card it says something about -- well when they submit their bills like photo wise how are you going to tell that they're disabled if they're not going to -- photo wise?

Mr.Sciuto: Kind of like what Richard was mentioning I think discovering in talking to you we need to add something to have a more specific are you a person with disabilities in Pittsburgh?

Ms.Warmen: Or they could put like a D or something on their paper?

Mr.Sciuto: That would work too but in the long run we're going to add something are you sort of a special group of people.

Ms. Warmen: You do have some people who can't write.

Mr.Sciuto: Exactly, exactly and we have some people who have a hard time accessing the internet. This is a start you know you have to start somewhere and this is where we're beginning.

Ms. Warmen: Thank you.

Mr. McGann: Nursing homes, as far as you were talking about Deaf and hard of hearing need help with communication and there's a lot of barriers between communication in there so historically there's very little help and there's not much in interpreting as well.

Mr. O"Hanlon: We're going to have to get you to wrap up quickly.

Mr. Sciuto: Thank you for listening to me this is about it so I appreciate it. It's better to ask these questions than. . . Thank you.

Mr.O'Hanlon: Appreciate it; very interesting.

Disability Agenda 2000 Retrospective: Healthcare

Mr. O'Hanlon: Okay so how should we do this next panel? What we're going to do next is we have a panel and so the people who are on the panel. Sally Joe, you Pat if you could come on up, have seat at the table that way you'll have a microphone and I think it'll be easier.

Mr.O'Hanlon: Welcome to the panelists maybe if we could start by giving you a moment to introduce yourselves again and then I'll do sort of like some intro but it would be better if everyone knew who you were.

Ms. Raphael: My name is Pat and I work at hospital council of western Pennsylvania we're a nonprofit association of hospitals and long-term care facilities in 30 counties so we cover the small rural areas and even our large systems here in the city.

Mr.O'Hanlon: And you say 30 counties is that spread out pretty much all through Pennsylvania, mostly one side or another or.

Ms. Raphael: So our region is south to West Virginia, west to Ohio east to about the State College area and north up to the New York border although we do have some facilities from West Virginia New York and Ohio that participate with us.

Ms. Snyder: Okay. Hi I'm Sally. I am director of advocacy for the consumer health coalition we're a small but powerful nonprofit on the north side of town and we do a variety of things we are an enrollment agency so how folks get coverage and then we do education programs and then I direct our advocacy, and we potentially work with a lot of groups that are marginalized for whatever the reason and look go really make sure as our name would suggest at the voice of the consumer the voice of the patient is educated informed and involved in every aspect of creating a much more accessible affordable and quality healthcare system.

Ms. Ryan: And my name is Erin Ryan I work for UPMC disability resource center. And disabilities resource center has been around since 2007. So people are probably familiar with that as well.

(Inaudible)

Mr. O'Hanlon: Okay well, in the way of introduction -- so this is the 25th anniversary -- and one of the thing that is we did as a TV was what we could do this year to sort of highlight the progress in a has been made with the ad and so one of the things we've decided to focus on or refocus on, was a process that we

did 15 years ago. So when the ad was just 10 years old, we had this process that we called disability agenda 2000. It was an agenda setting process and we broke things down into sort of sectors like healthcare sector and housing construction and design and communities and culture in the arts and different employment you know different kind of sectors as a society and we hold together people in the area who were active in those sectors and set them upon a mission of coming up with sort of an agenda for the foreseeable future. And so what we're doing this year is revisiting that process, looking what the heck people were talking about 15 years ago what they were identifying as kind of missing or you know something that we should focus on, what we ended up doing you know kind of like whether anything came of it, and so this is one of those sectors then today that is the healthcare sector where we're looking at that. Now unfortunately one of the things that we then did was, in preparation for this try to figure out like who is active in that sector back then? And I can say speaking for myself that it was an interesting process because it was really – that process was the first process that I live in a big city where there was more stuff going on that I could keep track of because there was so many different things going on so unfortunately this was not my primary activity sector.

Although I did participate in it and so one of the things that I saw and the other thing is you know you're kind of left with an interruption of what the heck happened so one of the interruptions I had was that those of us that went to these meetings you know just to give you some sense of kind of context, probably in the last decade before that, there was a whole lot of effort around what was in the Clinton healthcare bill which nothing came of but there was a whole lot of organizing around different ways healthcare for all was one of the groups that was started. So we came to this sector with a whole gigantic assortment of ideas and even raw son who was the co-chair was trying to give us the focus of the nitty-gritty so what they produced was a final report which was very basic very like you know and I kind of remember even saying okay well I hear what you're saying but it sounds like what you're saying is that in the process of setting up appointments, that it's important that complete information is done because they don't know that you're showing up in a wheelchair they don't know that you're definite and you need an interpreter and then you show up and it's a surprise so you know it's very – you can see in this it's a very kind of basic you know this sounds like what you're talking about kind of thing. The other thing that I try to figure out is well what really came out of that process? And some of the things I'm you know we are not sure whether we can claim credit for but it was shortly after this that McGee Women's Hospital had the – the accessible clinic for women that I think started maybe two years after this procedure and it may or may not that we can claim credit but we certainly were part of the voice that I think led to that being created and then I think then after that was the hospital compliance manual that we worked on that primarily got to issues around serving healthcare consumers who had issues around definiteness or hard of hearing or some kind of information reception or conveyance kind of disabilities.

And so that was, I think – you know so I think what I can sort of say is I can see these practical steps that were taken after that in the area of healthcare while sort of socially we ended up doing whatever we did around healthcare and we are where ever and we're still trying to figure out where the hell we are and what's being done and that kind of thing and I think that healthcare is such a massive field so big and so critical to our lives. So we invited you here really share with us any thoughts you have any insights, any kind of agenda items that you think you know, looking at any of this that seems relevant I think it really -- you know what I would say is kind of this overarching thing what we attempted to do was taking a whole lot of social concern about healthcare and how people with disabilities fit into that and find concrete things that we can do locally that make things better and that's in a nutshell what we ended up

doing was that -- I know that you know you are sort of living it in a way that's more intensive than we were in that process. So I've invited you to come and to speak and give us your thoughts and any sense you have of kind of where we are locally in all of these things. You know whether you think that when you look at what was on this list have we sort of solved all those problems or you know what your perception is of where we are and where we're headed? Who wants to go first? Erin.

Ms.Ryan: No we have not solved any of these things and they go along with solving these issues I don't know if it will ever happen but speaking I guess you know from what's going on at UPMC and I know if I can just preface it by saying I know UPMC has for everything that happens there's probably two different stories. So I know that there's a lot of work to be done and I don't want to come across oh, yeah we did it moving on to the next thing -- but it was interesting for me I've been with UPMC for about two years now and I was not aware of the disability agenda but looking through each of the goals that was listed on here for healthcare and looking to see you know all those things that were -- I was pleasantly surprised to see that almost every single goal is -- we have programs in place to address each of these issues. So I think we're headed in the right direction. Are we there yet? No way. We can talk more about what the things are that we're working on and how we're addressing these things if you want but just in general that was sort of my –

Mr.O'Hanlon: Can we save the questions and let everyone make an opening kind of statement.

Ms.Snyder: Going right down the line. I think part of the deal, looking at this too is I mean the ad is 25 years this year and 25 is a big anniversary and you look at it and even socially we're not where we need to be. I mean the ad was more than ramps and good parking spaces so even within the healthcare field we're not there either but I do think some of the things that were significant is that UPMC has a disability resource center and there's been working done on interpretative services on signage when you go in to ask and you know to ask. I think and swear by for the women's center out at McGee that is absolutely critical and it also highlights an issue that we've yet solved which is I am a sibling of a person with a disability. My sister a person with disabilities and uses a wheelchair so when the center at McGee opened it was glorious and they are incredible how they stagger the patients the sensitivity to the issue but it also highlights a significant problem every time we go there yearly, we'll be there and without a doubt you will see someone there from eerie who drove two and a half hours down for an appointment because there are not clinics like that and that's problematic and that needs to be with not only for that particular care but also exam tables I cannot tell you the number of times this you know if you don't a person who uses a wheelchair, the number of exam rooms are not even close to being accessible and those are few and far between and you have it, it happening with an urban center like Pittsburgh but then there's people in rural areas where you're driving a significant amount of mileage to get to a healthcare provider let alone finding one with accessible exam rooms and that needs to clang and I think it's part of changing the perception that society has with folks with disabilities. And I think that has to play in. I think a lot of times -- and I do a lot of work we'll go out and educate and training and teach folks to be proactive but I do think there's still for lack of a better word – an discomfort with some providers that are almost discounted and you got to teach folks to go in there and be proactive.

Just a quick story was we had one I took my sister to get an MRI and obviously went to a hospital here in the city we go there we're there they take her up and we're sitting there waiting and I'm reading the sports illustrated preview issue and we're there waiting and I'm like man this is taking an awfully long

time and I went and asked the very lovely person the woman I don't know let me call up and so she's just starting to get into the MRI now and I'm like jeez it's been a long time so goes through finishes the

MRI X number of minutes later my sister comes down and I said sue how was it you were up there for a long time what happened and this is the kicker this was 6, 7 years ago and she said well I was up there and apparently they didn't have the hoister lift so there was no way to get me into the MRI and to honor -- and I said okay so what happened were they able to bring one in and she says well no I sat there and I referred to him as Bruno and an orderly came by and they said hey Bruno can you lift her into this machine and I'm like really? I mean the fact of complete disregard for a person's dignity and all of that was problematic. They did and my sister at that point was you know was like that didn't seem like that was right and I'm like that wasn't right and then the neat thing was to celebrate the disability resource center was to have that there and knowing Susan Shaffer who was the

Mary -- being able to call Susan and say hey this happened and wasn't harsh or anything just to report it and to know that it was dealt with and then the training that needs to happen too. About doing that but you wouldn't even -- like seriously? So it also highlights how far we have to go. So I could continue to ramble on but I'm zip for now.

Ms.Falkstein: I also want it's I am proud board member of the consumer help coalition which is an organization I really enjoy. I feel like I'm the at least educated person on this panel and in this room about these issues today and I talked to Richard about that before I came down here so I'm learn. But I was at hospital council when this project was being worked on I did work for even raw son and I see rob so I'm going to ask rob if you want to make a few comments but one of the things that I believe that has happened is awareness has been raised among the hospitals both large and small and one of the things that helped us with that is we had a grant from the fie is a foundation and you know I asked rob to be our consult about on that project and went to the hospitals and tried to do some front line training and I wasn't a part of that project but I was aware of it so I don't know if you want to make any comments.

Mr.Oliver: Yeah I guess it's fairly for -- I can just make a comment that there was a front line training

that was done at a number of UPMC hospitals. I don't have the numbers in front of me and it was probably 15 years ago now but it was the concept of making sure that the front line individuals, the phone operators, the receptionists those individuals were getting some training on how to deal with people with disabilities when they came in working on person and family center care make sure that the individual was a primary -- was part of the primary understanding of what was going on. So the individual was -- had an empowerment to say this is what I need. This is how they handled me this is what is going on and it wasn't so much the staff working together to figure out how to handle an individual but staff working with the individual how to provide the best possible care for what they needed and also making sure that the individual was being treated for what they were presenting for and not being singled out because they had a and all of a sudden people are coming in and trying to treat them for a disability and they came in and experienced cold -- so that's a broad overview of what we provided and it was done

through hospital council and like I said I think they're doing probably at least a dozen hospitals around the area where that was provided. And at this .one of the things that I think about is how do we take that because the turnover in staff I don't know how many folks that – had that training are still involved – or still employed by UPMC and how do we expand that not to just the front line employees but expand that as well to get it into as much of the hospital staff as we can.

Ms.Falkenstein: Do you want me to finish first? It will only take me a few more minutes if you don't mind. Thank you rob too I appreciate that. I think as rob said you know we raised some awareness through that you know, in person front line hospital training, but -- and again it was limited and as sally Joe said when you get up to a rural hospitals in the northwest or in the east those hospitals did not have even that kind of training and their resources are very much limited especially compared to UPMC or Allegheny health network so they don't even have the ability or resources to you know to have the special technology and it's not that they don't want to because they talked to us about this it's just that their resources are very limited. And so I think if there's some way to somehow reach out to those folks they would appreciate it and I know the people in those communities would appreciate it as well I also want to say there's some work if you are not familiar with it that is being done to the regional health university council in all kinds of literacy including language barriers including physical barriers and that project is housed at hospital council and we also know that the two primary funders have been UPMC and Highmark and they have a Web site if you want to look at that, it is www.ahealthyunderstanding.org and there are some tools and resources for consumers that you can access. And they have a real focus one of their funders is the FISA foundation and there's others as well and they have a focus on people with barriers of all kinds it could be a language barrier so they're developing that and it's a relatively new thing and I wanted to mention that's one of the ways we evolved. There's a lot of room to grow and a lot of room for education.

Mr.O'Hanlon: Thank you. Rich.

Mr.McGann: Yeah this might be a little off topic sorry about that I don't know if this is the right place but maybe you can help me understand better. Is the hospital insurance of UPMC and Highmark, is that how much coverage someone would get like if someone was diagnosed with cancer or something like that, would they give them a scooter or provide that for free? Like if someone is stuck at home then is there something that they can set up like a chair or some sort of thing to take them up the steps even a bathroom can have accessible things. But with that the crisis with UPMC does that affect --

Ms.Falkenstein: To my knowledge the insurance they wouldn't necessarily be providing stuff like that for you know ramp at the home or stair in the home generally. So whatever's going on wouldn't be affected by that to my knowledge it would be more like state waver of programs that might provide those things.

Ms.Synder: With that too you bring up an interesting point is it is that healthcare happens a heck of a lot longer outside of your provider's office and to learn to realize that that it's the whole social reality of how people live and I think rob mentioned patient center care I now, this has dawned on me at a meeting I was

at a couple weeks ago I've now switched to patient driven care and if you're a patient on a gurney and doctors are looking at you it's -- we need to get to that mindset but one of the big things is starting to realize the impact of where you live and connecting that into social environment and hopefully have providers start making that connections. If I had a zillion dollars other than getting the -- I would say make sure that healthcare centers in especially in more economically challenged areas would hire a social worker. That would be absolutely the issue -- that would then connect them to the services they would need.

To have a social worker that would help to make those connections because that's a major deal even without a person with a disability if you have knee replacement surgery it might be helpful to know are you living in a house with steps? Who's going to help you get food once you come out of the hospital? So I think you do touch on that and that is just the face of healthcare which is changing and I think in a good way to be able to realize that health is more than -- it's also social and that whole factor.

Mr.Nochese: Chris, okay I want to go back to Rob's point. About front line. Compared to 15 years ago to today I noticed a big difference. 15 years I had struggled very, very much to get an interpreter, T TY. Every now they might provide an interpreter but it was a huge struggle and today it's fine they would ask hey do you need an interpreter and I'd say yes that's what I've been waiting for this whole time for you to ask me about my need before it was a gigantic struggle back and forth to finally get what I needed and it's such an improvement over 15 years ago. There's a few hospitals that still I do have to struggle with they're here and there but overall I just wanted to let you know that it's a vast improvement but it's not completely fixed yet.

Ms.Falkstein: I would answer that partially because hospitals have to be accredited. There is a major national agency called the joint commission and they have that as a requirement that there be interpreters available and they have several other requirements for hospitals as well and this is a very much respected and sought after accreditation than hops try to get to I would say that's probably part of your answer.

Ms.Snyder: And I would give kudos as well to the TV for what you did along that piece as well and I mean it's still 25 years there's still so much yet to be done what's needed to be done and that's good to hear that it has improved and I would be remised too if, also the whole issue of course is living with mental illness is a major concern and I know when I started consumer help coalition you know our first thing was to do the proactive patient guide and that was to address the issue of people living with serious mental illness and the fact of the matter is that statistic has. Changed and why is that? To do coordination of care is important and the one stop shop is becoming more prevalant that you can go and see your physical doctor. Perfect this then leads to another issue. And a lot of folks that battled this was an accessible transportation system was huge and battling like please don't cut those routes. I mean all those factors we can look at successes we've made and at the same time more work we have to do and the last thing with persons of mental illness is would believe it be wonderful if we could develop a policy. The

fact that we sit and wait and God forbid we don't wait until another incident could we not be proactive enough to put together a mental health policy that works. Are we going to do it as commonwealth? I don't know but that would behoove us to really put together a working involvement with folks to people to put together a policy that works.

Ms.Ryan: If I can just mention sort of Bob what you were saying and then also Chris so I know UPMC a huge focus has been we were talking about the use of interpreters but also folks with visual disabilities all the different reasons where there might be an issue with communication and so as far as training goes this last year --it's not basically 40,000 staff an affected communication piece for disabilities which was huge in terms of what we were able to do before. And then also some training in person but then for the first time we have a system like policy about effective communication and so all of these things we've been able to raise awareness about it which I think is really important and I'm glad to hear people asking this is what you need. But yeah we've realized it's such a huge issue and we've been trying to make a lot of attention to it.

Mr.Parker: Well yeah I had something .I guess the concern that I have that I see on the -- take it to the next step are the services that you receive outside of the hospital and outside of the doctor's office. What I'm seeing and this hasn't happened fully in Pennsylvania yet but have colleagues in Ohio that are telling me that those services, the way they're being managed as in managed care are making it much, much harder to live and obtain the services you need in the community that especially in Ohio that managed care has touched the equivalent of what we think of our intended care our independents our com care waivers. So literally I have friends in Ohio that are moving to New York because of the way that the commune services are still administered in New York are less restrictive as they are the bad policy in Ohio is to get these services in the community. But it's not necessarily discriminating us people with disabilities because a lot of people in that situation are not going to pay for it.is going to be a wild words, we the deaf have preferred agencies and services so that services are rendered fairly and correctly, and there's contracts that seem to be getting in the way, or contract issues. Yes is that joy? Yes I'm back here.

Ms.Dore: Financial aid is not always accessible. If you have a certain issue inaudible.)

Mr.O'Hanlon: I mean, one of the things I'm going to follow-up with what Chris had said sometime ago that it does seem that there has been noticeable progress in a lot of these issues and so I think that, you know, you can see that there have been changes, there has been some kind of a cultural shift.

The thing that I guess, I have sort of a twofold one is sort of an observation based -- which is it still makes me sort of mystified why it is that healthcare facilities are often the most sort of dense with respect to accessibility issues. You know like doctors' offices rooms you know hospital facilities with no accessible examination tables and you know and the -- at some level I don't understand who they think are going to

be in these facilities the bathrooms that are connected to the hospital rooms you can't get a wheelchair and it just goes on and on and this is from a legacy that kind of predates us, but that leads to my next question which is that when I've gone into transportation advocacy I've learned that the bus you see on the streets are going to be on the streets for 20 years and then they retire so when you get some change into a system that has a 20-year life cycle you have to be patient.

It takes a while. And so one of the questions I have is, hospital examination tables how long are the life of an exam table? Is there a retirement date that -- for those things? And how do we get it changed that all examination tables have features that are making it accessible for everybody because I can guarantee you that every examination table that isn't accessible will have somebody that's not well served by that table. And so how do we get things to change at that level where you know that eventually you want to get therebut I have this fear that exam tables to be like a 50-year life cycle I mean do you know anything about that?

Ms.Falkenstein: Well I mean in general hospitals around here are very old structures and it's hard to even get changes made to the buildings themselves let alone to what's inside of them but there are -- there has been a lot of movement here in building new rooms, new -- you know surgical suits getting new technology so we had a number of hospitals kind of not that they can't abandon the building they're in but they've created towers or new buildings that have much more of what you are talking about but those go through cycles again as you said I mean Butler hospital they built a whole new towers 5 years ago now but it has all the most current everything in it that you can imagine. So people want to go to that tower. Mon Valley did something very similar. Even up in -- but the buildings themselves are so old. So when they build the new structure that's when they put the new equipment and the new technology and the new exam table everything is brand new. So you have to kind of get into when they're going to be in that cycle it's challenging it is.

Ms.Warman: Okay, yeah, well, I mean, the case that Braddock hospital they had remodeled the inside of it but instead of like keeping the building and remodelling onto it they closed it and they tore it down instead of like turning it into maybe a facility where they could actually you know use it to continue.And yet they just closed it and tore it down instead of using the building for like -- because they went and they built a new hospital across from another hospital in the same community right across the street which really how many people are in that community that's going to use that hospital? You got two hospitals in the same community. They probably have the same insurance, same carrier. I mean if you got a hospital that can be reused or like something different, like maybe manner care or a place where you can have different people, you know, that can -- you know, for different care why not? And if you're
52 going to be tearing down hospitals and like not making -- I mean, they could have built a new wing to it which I think they did, but they just tore a remodelled building down is what they did.

Mr.O'Hanlon: Yes.

Man in Audience: Yeah, I mean, not to get off topic I don't want to get into a lot of what you said but that wasn't a community center or anything like that that was a business decision you know and I'm sure there's probably a number of different reasons that they decided to do so that. And also them deciding to build another hospital in Monroeville was a business decision for competition sake I'm from Braddock

and so I had an I guess if you will, sentimental contact having grown up there and having -- that was my dad used to be the mayor of Braddock and he passed away there. That was in 2007 my dad passed away and shortly thereafter they tore the hospital down so I grew up there seeing my hospital my whole life but that was probably the decision why they made to actually tear the hospital down and build a new one in the Monroeville area so I don't want to get too much into that.

Ms.Warman: I will talk to you after this.

Mr.O'Hanlon: Chris and then -- I mean, rich and then joy and --

Mr.Mcgann: The problem is transportation. For example if an office is closed and moves to another location, for example, downtown if a downtown office closes and then you have to go to North Hills but I'll at this office is access going to take me all the way to North Hills now? It's a waste of time. So that's something that needs to improve. Transportation. So that's also an issue.

Ms.Snyder: Absolutely it is and the fact too with access you have a 2 o'clock doctors appointment so getting there at what you could get there as early as 1230 one o'clock and if the provider's running late you got a real issue because and we've had that too folks say I can't wait any longer the providers half an hour late and you got to catch you know depending on when that is that's a big factor as well and then I just wanted to jump on the transportation piece too is medical assistance transportation program MATP is a huge thing that we should be looking at too. But that was major with the new folks that were added on of a certain class saying you won't have that funding available for you this year so good luck and the majority of people that use MATP funding are people who use dialysis so yeah transportation is significant in a lot of ways.

Mr.O'Hanlon: Joy.

Ms.Dore: Unfortunately also inaudible. I live in that community. I was there at the time that -- they said it was a business decision It was more than emergency medicine it was prevention.

Woman in Audience: I just wanted to say I know a person who uses a wheelchair that was going to appointment that the doctors office wasn't accessible and they transported them by ambulance and they examined her on the ambulance and so she wasn't in a wheelchair and -- so that's what they did for that. And I wondered if that was -- it was creative. It was creative. But that's how she got her examination but she got better. She needed to see specialist and so that was what they did.

Ms.Snyder: And those are stories you hear and you're like that's amazing that need to be much more public as well. The fact that we said earlier of the incredible lack of accessible exam tables is horrific to me. And.

Woman in Audience: And the doctor was in network for her.

Ms.Snyder: That's ridiculous.

Mr.Oliver: Can I say something? Now I'm fix sated on the exam tables too because it's an index of how -- so I'm thinking 15 years ago experience having someone in a hospital say well literally say it's not my job to get you on the exam table and then two years ago, me going to an appointment taking two people with we so I made sure I was going to get on the exam table and having a nurse say I'm glad they're here

because I'm sure as hell not going to get you on the exam table so index wise I'm not sure it's just the exam table it's what's going to happen with the patient too.

Mr.O'Hanlon: Well okay I have to move the agenda so I want to thank you all for your contributions helping us with this discussion and hopefully we'll see what can come of it. So thank you very much. On our next agenda item is the new ADA icon and Christopher Myers is going to lead this section.

Mr.Myers: Hi everybody my name is Chris Myers I'm an intern under Richard and one of the projects we've been working on is the accessible icon project based out of Massachusetts. What I want to do is change the old international symbol of accessible which is currently just a person in a wheelchair and switch it to a person who is moving in a wheelchair and the project started to pick up some -- project started to pick up some support across the country and more specifically in the northeast some municipalities some schools, even the Social Security administration the federal agency has supported the project and I think it's crowning achievement so far is it's been enacted as law in the state of New York and when they did that pretty recently in 2014 one of the things that governor said is that the purpose of this law for the New York legislature is one to improve people's understanding of disabilities and as it being just an important step not the whole way there but an important step and another thing he said is that's a really important way to start moving stigmas that are attached to the project. So one of the things we looked into is that it's not Pennsylvania's law. There is a New Jersey bill that's out that the same language as the New York bill that would also make it a requirement of the New Jersey so it's around Pennsylvania but there's still some concern that is this something that's more federally regulated is this something that the federal government is supposed to be making the law on not the states. To some of the research we did got people questioning to department of justice and the department of justice essentially did not confirm nor deny the legally of this new symbol as opposed to the old symbol and this is exactly what they said. They said it's not the same symbol as the one that's in the ADA accessibility guidelines what they did say is it's definitely grounds for -- although it might be the same it's something that's promoting the rights of people with disabilities more or it's same kind of access but also provide for innovation. What the department of justice does not do is get any certification process to allow this to happen so one of the things we started looking at is the department of transportation does have an equivalent waiver program and this is brought up in Albertson's case, which is a very important case and I got it from my disability law class and it describes this as an environmental waiver it's supposed to give then department of transportation data so you can confirm that there's some unforeseeable problems that's not strictly within the confines of the department of justice or so this – so this certified regulations section 37 they do outline this process for strictly for -- the process is based on notice advertisement to the community and most importantly it's based on support of individuals with disabilities. So I do think there is a possibility that the department of transportation be very open to maybe an isolated almost experiment if you will to make sure people are recognizing that it is a symbol of accessibility and also that's something that's helping the community start to like governor from New York said -- and it's not just people in wheelchairs it's much more than that and it's just a step and how you know dynamic the ADA and its laws can be. So next step would be it's a little bit -- I really think the next step would be to contact the department of transportation and to see if they would be open to like pretty much making an isolated experiment find transportation facility or a small group of them and say we want to these a new symbol up and just the community's interest see if they recognize it as the same symbol as accessible that they're going to recognize that it is you know what that means and that in generally speaking that the whole

process the advertisement would one you know advocate for disability rights and hopefully bring this icon into a community and to make the statement what the icon project is trying to say and that's –

Mr.Mertitzer: Can I add something? If I may one of the main reasons that we're doing this is because the biggest activity we use the accessible icon for is parking, which is definitely a transportation issue. So this is a case where just changing all the parking signs in the city over time would make a real statement. I believe Christopher there's also a community request component?

Mr.Myer: Oh yeah, one of the things that makes this very interesting is that often something that you people are looking to get the approval of with the disability community because it's not strictly adhering to the guidelines set forth by the department of justice department of transportation for the ADA however what makes this different is something that might also support not just give the okay for. So it makes it a big case to the department of transportation. I did look up there's one city in Kansas that just it was called Marion it just legalized the new icon and I looked up and I found that one of their council agendas and there's one guy who had went through it had interviewed somebody from the department of justice and other agencies and we talked about to them and they said as long as you approach this with caution and slowly it has a very, very likelihood of passing that test and being legal -- from any state laws and something of that nature.

Mr.Meritzer: So on our -- the next thing is to pass a resolution at some point asking the city to change to a new icon so we can take that to the department of transportation.

Mr.Myer: Thank you. I can take any questions.

Man in Audience: I think there's two points on here one we can't guarantee it's going to change of one perspective. Secondly, in your perspective at this level, this icon here what makes this one different than the one we got now?

Mr.Myer: Oh sure I think those are great questions. Just to start I think even with the new icon you can clearly find that still, the new icon it's not a perfect depiction of people with disabilities in general. What I think is new icon is trying to say to a dynamic icon is they're trying to say pretty much you know the perception of disability rights is changing .The old icon is from 1965, 25 years before the first version of ADA. It's very old. I think just the change is somewhat of the symbol and in part the idea that the person in the symbol is moving is any type of stigma these are people in the community that help the community that are assets to the community that's the stigma that when you talk to the accessible icon project governor will address it.

Mr.Myer: Anymore questions or comment?

Man in Audience: So I mean I guess obviously I mean I think it's a great idea. I'm sure many others do as well. From what I've seen around in the community I've driven around and I've seen a donation box that they have for veterans and they seem to already have this symbol and they seem to have gotten it quite quickly because maybe in the last year or two just saw the boxes started popping up with the symbol on the veteran's donation box in the community just like you would donate clothes or I don't know if it accepts other goods but just donation boxes and they have the symbol on it. I'm just wondering in the same capacity why it might be taking so long or why is it that you have to go through these different measures to have that implemented?

Man in Audience: I just want to respond. It wasn't that easy.

Mr.Nochese: Yeah, I just -- can I pick this up? Oh cool. I'm really excited that you're bringing this into the task force and I would like to encourage everyone else on the task force to support this and I hope we can do everything we can to get this changed. You know, obviously it's symbolic change. It's quite literally a symbolic change. But already the accessible icon project itself has generated a lot of media attention around how we view people with disabilities in our society and the actual -- like you said the actual process of changing the signs getting the regulation changed, doing that kind of pushes a conversation about how we view people with disabilities and the message of the icon is you know it's a simple change because if you decided to change all the stop signs you couldn't change them all that much So I think that it's a small change but I would really like this happen and I'm also curious about think it's smart to take the path with the department of transportation but because we want to make sure that this is something that can happen broadly and it's legal. But is there -- could we also move this forward at the city council level? Like could they pass a resolution saying this is policy in our city and see if it holds up?

Mr.Oliver: Absolutely. I think that's certainly a way to do it and I think really I think that's the way New York did it. New York City is a municipality did that beforehand. Some of the cities -- Kansas did that and they corresponded with the department of justice before happened. My impression of it is they're trying to be careful. They don't want to take any consequences but the department of transportation is, these agencies are regulating the ADA at a federal level really think and this is something that's going to help people with disabilities advocate their message and that the change is like you said small enough that it's not going to cause that much problems. Going back to what he said too it does seem almost -- a broader way to get that message and without some of the hoops that you might have to go through so I think that's certainly another way you can pursue it.

Mr.Meritzer: And this is just between us as friends, right? Very often the law department is very resistant to change and most of what we do is putting up parking signs and signs on buildings. If we go to transportation and they say yeah go ahead and do it we're much likely to get it passed through city council. I think having the piece of paper from the transportation department saying oh go ahead try it will really make it a lot easier to get it through without the law department throwing up roadblocks like well what authority do we have?

Mr.O'Hanlnon: Okay, I think that we need to probably move to the next agenda item. So I should kind of close out questions. Thank you. Now do we need to take action.

SPEAKER: Someone can make a motion to move this forward right now speak spook I make a motion for that.

SPEAKER: I second.

Mr.O'Hanlon: Well I think that we should -- let's hold that. I mean, my only concern is that I'm not sure that we've had enough time to have a conversation about what our next step is. So I mean would you be opposed to that GABE? I mean my inclination would be that we look at what do we want to do next and what motion should we do to do that because at this point there seems to be a couple of ideas one of which is to move forward with something at the city level the other is that the department of transportation level and those are mutually –

Mr. McMoreland: Can we bring a motion to the next meeting?

Mr.O'Hanlon: Yeah.

Mr.McMoreland: It's kind of an open motion. It's open for discussion now. So can we continue the discussion at the next meeting?

Mr.O'Hanlon: Yeah I would ask for somebody -- and GABE if this is you feel free -- but somebody to be willing at the next meeting they kind of run that part of the meeting where we'll have some discussion maybe come up with a proposal for us to work off of, and we can take action. So anybody want to take that on to the --

Ms.Warmen: I will.

Mr.McMoreland: I will.

Mr.O'Hanlon: Okay. Good. Okay thank you. Okay so -- okay thank you. So we should move onto the next thing on the agenda which is the report on the ADA celebration. Who's doing that?

Mr.Meritzer: That was brought up at the last meeting. I assume that those on the committee can talk about what's going on.

Mr.O'Hanlon: Are you ready to do that?

Mr.Meritzer: I can certainly do some of it since I am on the committee. The committee is putting together a big program to be kicked off with the national council meeting here in May. That's sort of the kick off of what they're doing although we already do have on the task force web page the calendar of events and this meeting including the agenda was on the calendar of events so anyone who has anything regarding disability celebration of any sort is welcomed to put stuff on. There are now 4 committees, I believe. There is communication which is what I'm serving on obviously. There is a bus committee because Port Authority is very engaged in this and they're going to be doing a lot of stuff. We're talking about having a bus that's wrapped with information it's called wrapped which will be going out so people can see that the celebration is going on. We're also talking about putting information in the icon on all of the schedules and also possibly putting some bus signs on the inside or outside of buses. There's also going to be an events committee which is going to work specifically on events around the celebration. There's a fourth committee and -- oh, fund raising because this is always going to cost us money and while the F ISA foundation really put a lot of money into it it's turning up that things are a lot more expensive than we thought and getting people to donate is a lot harder than we thought.

Man in Audience: Yes we're trying to do something in May June and July actually around the ADA. Also we looked at the arts festival. We're going to try to actually get a booth set up for the ADA. But the first thing was if we can get a booth -- are we -- we're trying to get it and hopefully it doesn't cost anything and we're going to reach out to other organizations to see if we can have someone behind this booth the whole 3 weeks of the arts festival to represent the ADA persons with disabilities that's just two of the things we're trying to do. Any questions?

Mr.Tauge: Yeah, just additional comment about the transportation. We're actually -- tarry from access is chairperson that committee and we have a meeting on Friday to have some further discussion about it and the Port Authority is as Richard said is very active in this and is very helpful in moving transportation forward so I just wanted to comment on that. So what we can do is just, I guess, update the task force on what's going on. One of the things is the way Richard maybe providing information to the task force but on an ongoing basis

Man in Audience: We can certainly set up briefings by the e-mail so that if everyone on the committee gets me briefings I can get them out.

Mr.O'Hanlon: Joy.

Ms.Dore: Inaudible.

Mr.O'Hanlon: I know that Kate Seelman hit him up to do something with the national council when they're in town so honestly I'm not sure yet if something's going to kind of firmed up on that but I do know that we met with him.

Man in Audience: I'm sure though once the he will be invited. And our office will do what we can to apprise him of what's going on.

Mr.O'Hanlon: Are there any other questions or comments? Because we're running over and I want to call the meeting to a conclusion that joy -- yes.

Ms.Dore: Inaudible.

Mr.O'Hanlon: All right, anything else? Do I have a motion to adjourn?

Man in Audience: Second.

Man in Audience: All in favor say eye. Okay everyone enjoy your spring.

(Meeting ended at 3:06 p.m.)

New ADA Icon: Christopher Meyers

Report on ADA Celebration

Vox Pop

Adjournment

Next Meeting: March 16th, 2015