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Mark Masselli: This is Conversations on Health Care. I am Mark Masselli.

Margaret Flinter: And I am Margaret Flinter.

Mark Masselli: Margaret, advocates of health care reform received a setback last week when Secretary Sebelius announced that she would scrap the long-term care program in the law, the Community Living Assistance Services and Supports known as CLASS Act, was officially terminated.

Margaret Flinter: And I thought that was disappointing and really just too bad. It was an original and a good approach to support and care in the community for the elderly, the idea was to insure Americans against the expense of long-term care at home by having people enroll in the program early. And the CLASS Act proposed a basic lifetime benefit of at least \$50 a day to individuals in the event of disability or illness and they could have used it to pay for non-medical needs like hiring a home health care worker to assist with basic everyday activities, but also could have paid a family member to help them stay at home and take care of them, just very sad to see that legislation go.

Mark Masselli: You are absolutely right. It was really a commonsense approach. It was intended first of all to be voluntary open to all working Americans and completely self-financed with premiums from enrollees. One of the concerns which Secretary of Health and Human Services Kathleen Sebelius voiced during last week's announcement was that the premium would be so high, only a few healthy people would sign up.

Margaret Flinter: Right. Although I think that concern was there when they were drafting the legislation. And in addition, the law required the program to be sustainable over 75 years. And I have to wonder Mark, sustainable against what. When we look at the inevitable rising costs associated with our aging population and no matter how you slice it, care at home is far less expensive than care in an institution which Medicaid ends up being the major payer of.

Mark Masselli: You know there were some big advocates for the CLASS Act, the Commonwealth fund was very committed to reform and innovation of the delivery system for the long-term care. And we interviewed Mary Jane Koren from the fund about this issue several months back and I remember she brought up some interesting findings from a poll from the SCAN Foundation where 92% of Americans said they wanted to improve coverage for care, that would keep them out of nursing homes, and that's one of the things that CLASS Act aimed to do.

Margaret Flinter: And I wouldn't be surprised if we see that come back perhaps in some other form, and under some name other than the CLASS Act. Moving

on to today's guest, Stephen Downs, is Chief Technology and Information Officer at the Robert Wood Johnson Foundation. We are happy, he can join us today. He will be talking about a new initiative called Blue Button which has the capability to revolutionize the way patients engage with their own health care.

Mark Masselli: We are happy Stephen Downs will be with us today and no matter what the story, you can always find all of our shows and hear more about us by Googling CHC Radio.

Margaret Flinter: And as always, if you have feedback, email us at www.chcradio.com we love to hear from you. Now before we speak with Stephen Downs, let's check in with our producer Loren Bonner for the Headline News.

Loren Bonner: I am Loren Bonner with this week's Headline News. Democratic Governor Deval Patrick of Massachusetts wants to introduce new legislation aimed at controlling rising health care costs in the state. The bills which are still being written would make Massachusetts the first state to radically revamp the way doctors, hospitals, and other health care providers are paid. The plan would replace the fee-for-service system and would encourage flat global payments to networks of providers for keeping patients well. Back in 2006, Massachusetts mandated that all residents be covered by health insurance but the plan did little to slow the growth of health costs. Legislative leaders hope to hold a vote on the bill early next year. As a result of stimulus spending and increased funding through the 2010 Health Care Law, the number of clinicians participating in a federal program to expand access to care in underserved communities has nearly tripled in the past three years. According to the Obama Administration, about 10,000 doctors, nurses and other providers now participate in the National Health Service Corps, the highest number since the program was established in 1972.

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Mark Masselli: Today, Margaret and I are speaking with Stephen Downs, Chief Technology and Information Officer at the Robert Wood Johnson Foundation. Recently the foundation has been active in supporting a new initiative to make medical information easier to access for patients, it's called Blue Button, welcome Steve.

Steve Downs: Well thank you very much, happy to be here.

Mark Masselli: Yeah. So let's jump right into it. The foundation's pioneer program whose mission is to support innovators whose bold ideas push beyond conventional thinking to explore solutions at the cutting edge of health and health care, I was contemplating that, I was thinking about Star Trek actually, space that

final frontier exploring (overlapping) that's right. So can you tell us exactly what Blue Button is and how does it align with your pioneer program?

Steve Downs: Sure. So Blue Button is really an idea and an emerging practice. And so what it is, is the notion that you have people in the health care system, organizations in the health care system that have information about you, your medical records or it could be other inside information about your health, and you should be able to get at it. So Blue Button is saying, where that information exists electronically, where you can maybe have a website associated with let's say your physician's office or a hospital that you go to. On that website, they should make it really easy for you and just have a simple button that you can click, we are calling it a Blue Button, that downloads the information to you in a form that you can read and also in a form that is digital so that you have other computer programs maybe turn it into something else and add some value to it as well. So this is something that the Federal Government has been real instigators and actually colleagues of us at the Markle Foundation. And you have seen the veterans in the administration have actually implemented this going on about a year now and has a ton of veterans who have now downloaded their data this way. Medicare beneficiaries can now do this with the data that Medicare holds about them, and we are starting to see some big private sector organizations joining as well. Aetna has said they are going to do this, United Healthcare, another big insurance company and others.

Margaret Flinter: So Stephen, when the foundation rolled out bluebuttondata.org and you wrote about this in a Huffington Post article and I will quote you as having said, "Recognizing the disruptive potential of the Blue Button idea, we at the Robert Wood Johnson Foundation took an interest in it at an early stage and its growth." Tell us what you see as the disruption and the disruptive nature of the Blue Button. It implies that we are breaking up things as they have been and something new will emerge from it and I suspect it's not just about getting access to the data but what you think happens when consumers have that. And so tell us about that and also is that website Bluebuttondata.org helping with this process of disruption and then what comes from there?

Steve Downs: Sure. And actually this will get me back to your question about alignment with Pioneer as well. So I guess the best way to say this is that we believe very much in what's often called the liquidity of data, the data to be able to move freely and of course securely and privately but have data be able to move throughout the system so that people can use it to take care of themselves to make decisions. We sometimes call this a data liberation in other words getting people access to their own data. One of our collaborators Todd Park, who is the Chief Technology Officer of Department of Health and Human Services, the Federal Department of Health and Human Services often calls this data _____ 08:22 to sort of emphasize kind of the revolutionary part of it. But there is I think a moral and a practical reason that we are interested in this. The moral reason is it's your data, it's about you and you should be able to see it.

The practical reason is that the health care system has been very slow in adopting Information Technology to improve care. If you think about so many industries that have been transformed by computers and information systems, you think about travel, you think about banking and how that's changed dramatically in the last decade and a half or so, health care has been quite slow. And so part of this is about saying, rather than wait for the health care system to do something clever and useful with the data that they have about you, why not get it into the hands of the people or get it into the hands of people in the industry or I would say computers programmers in industry who can develop really useful tools for you with access to that data. And I think the other piece of this is that I think fundamentally this notion of sort of giving people access to their own information is a little bit about bringing more balance into a person's relationship with the health care system and their doctors and their care team. And historically, we evolved from a place where sort of the doctor knows best sort of Marcus Welby of medicine where we are now starting to get a little bit more sort of engagement of people in their own care, and I think that information is a good leveler in that and I think that that's a little bit of the power of the disruption.

Mark Masselli: Yeah lot of good thoughts there. You mentioned Todd Park who is a wild and crazy guy, has been on our show but he is also the Chief Technology Officer in the Department of Health and Human Services and he is very excited about this initiative. But is the Federal Government the right group to be also instigating this change in culture? It is a land of steady habits unfortunately in health care, there are all bad habits in terms of innovations and we are always trying to figure out how do you make things efficient, effective and elegant. I don't think in the IT space in health care that it's been made elegant yet, and the design is so important. So, tell me a little bit about your thoughts about who is going to lead this and certainly Todd is a great leader.

Steve Downs: Yeah. Well I think Todd would be the one of the first ones to agree that this is about sort of the irony of the federal government being sort of on the cutting edge and leading the way here. And I think we see this very much as something that is not in terms of Blue Button and it's not a federal government play, it is something that we would like to see happen in a much more widespread way and that's why we are excited to see that there are some major health care providers that are starting to go down that road. I think the broader question of how you are going to see innovation in IT is really interesting and I think that we are seeing a lot of innovation on the consumer side. I was recently at a conference called the Health 2.0 Conference out in San Francisco and there is just company after company that's building, whether they are Smartphone apps or simple kinds of services you get on the web to help people track data about their health. Example of a company is that take the awful explanation of benefit statements you get from your insurance company and actually make them understandable. So there is a lot of innovation going on there. The question is, is that going to filter back into the health care system itself, and that's I think unknown at this point.

Margaret Flinter: Stephen, as you alluded, Blue Button really presents an opportunity to Mobile App and software developers and I know recently the Robert Wood Johnson Foundation and the Markle Foundation ran a Blue Button challenge to encourage developers to build apps, what Todd Parks might call super cool apps, that leverage the Blue Button initiative. Tell us what sort of response in innovations did you get to that and did you see a tie in to some of the foundation's major initiatives over the years, childhood obesity, improving chronic illness care, health disparities, public health, tell us about that.

Steve Downs: Sure. So we got a great response and I have to say this was a really what I would call a really lightweight experiment. We offered \$2500 prize and then coffee with a great author and we literally gave people I think a month to respond to the challenge. So we weren't expecting a whole lot. But we got about 8 or 9 submissions from large companies and small and some were very sort of general and some really targeted and quite interesting. So the winner actually was from Adobe, not a small concern, who had built a prototype of a very nice reader that would sort of take, the Blue Button actually sort of spits out an ugly text file. I shouldn't ugly text file, it's a very simple not elaborately designed text file. And they sort of spiffed it up made it really nice to look at and read and then actually add out a few tools on top of it. And then an example of a very targeted one, there is a small organization called MedCommons that came up with an app that made it easy to take radiology images and sort of ship them off for a second opinion. So you could download your data including your images and then it would kind of walk you through the step of how to package that all together and send it off to a consulting physician. And I think connecting with some of our work overtime and we have had a number of programs around this is we have had this belief that it's helpful for people to be able to see information about themselves that's kept in the health care system but it's even more helpful if they have tools that help them act on that information or use that information. And the way I used to describe this is it's good to know what the list of medications you are taking is but it's better if you have something that reminds you to take them or it's better if you have something that shows you the lowest price to get on each of them. I mean that has real value to you. And so this notion that information is kind of a springboard or a platform for tools that help you to take action has always been really important and I think Blue Button sort of fits into that stream.

Mark Masselli: This is Conversations on Health Care. Today, we are speaking with Stephen Downs from the Robert Wood Johnson Foundation about a new e-health initiative they support called Blue Button and obviously the idea is really about engaging with patients in their health and encouraging them to share health information with other providers through a secure portal. I worry a little bit about some apprehension that might be out there; I certainly had one. I happened to have just download an interesting book on my iPad through my Kindle called Worm: The Story of the First Digital War and your technologists

probably are as well concerned about it. But I learned more about botnets than I ever wanted to know before and I was about ready to disconnect my WiFi but there is some anxiety out there as we see everybody's private information being spilled out over the Internet. How secure these portals are going to be and what's the road to making them more secure?

Mark Masselli: Yeah. So I think it's a great point. I think the one of the key things that I think the Markle Foundation really contributed to this is one, the idea of the Blue Button first came up is they really pulled together some people to say how would you implement that in a way that that makes sense and in particular how would you implement it in a way that's secure, how would you implement it in a way that helps people understand some of the issues associated with this and so they have put together a whole series of documents around how to implement this effectively and how to do this securely. I mean I think what we find with electronic health information is that the way information gets breached sort of more often than not are one just all the stories of carelessness. Somehow a whole bunch of medical records were put on a CD and left in a laptop which was left on the subway. You see a lot of stuff like that and then frankly, I think sometimes the issue is actually people who are technically able because they may work in a health care organization, they are technically able to view their records even though they don't have a legitimate reason to and so sometimes you see breaches in that from. You don't see as much in the way of I think kind of hackers going after sort of individual's personal health information as much unless those people happen to be maybe famous and there is real value in doing that. So I think it is a concern, it is something that when you personally download your health information, you should recognize that you have now essentially taken on some responsibility for what happens to it and there are series of good computer practices around that. But I think that's an important thing for the providers that are offering Blue Button services is to make sure that they do provide that kind of guidance for people to say hey if you are going to download this, and we encourage you to do so, be sure to take care of it, and here are a few things you can do.

Margaret Flinter: Stephen, in the press conference that we saw a few weeks back about Blue Button it was interesting to see the line up of players HRSA, the VA, folks from CMS and Medicare, Aetna, United, Walgreens, kind of non sequiturs in some ways between the federal worlds', the not-for-profit world certainly and then the big for-profit health companies. And the VA for years had a well-deserved reputation for having developed an electronic health record Vista that they made public source, I am not sure how many groups were able to use it outside the VA but nonetheless it was put out there as public service. And Blue Button is a repeat of that, right. It's developed primarily by the VA, licensed by the VA but there are no fees for anybody to use it as I understand it. And that's a real shift when you see, and I think Todd Park is playing off Aetna against United, you have got 20 million but you have got 22 million and that was kind of a great thing.

Steve Downs: I hear a bit.

Margaret Flinter: Right. It was kind of a great thing to see this in the domain of making something public source that's for the public good especially during this very partisan debate around health care reformers. Can you share your thoughts on that? Do you think that that's going to be part of the success of Blue Button that it's out there as a non-profit driven, non-commoditized benefit?

Steve Downs: Well, it's interesting and I think there is actually a distinction here which is that Blue Button is not a product or a service or a tangible piece of code either. It is actually really an idea in the practice and so in other words when we say to somebody like whether it's Aetna or pick a hospital in your region, we want to encourage you to Blue Button your data. They are not really picking up on an existing system so much as saying, okay so in order to do this, what it simply means is we go to the system that we have and then we essentially create an export of that data for an individual and then it's really up to them to design the format. The guidelines that folks like the VA have put around this, if you want to call it Blue Button, you should make sure that (a) it's readable by humans so that at a minimum someone can read what they download, and (b) it's in machine-readable form as well so that if somebody wanted to write computer programs that could read it and then add value to it in a pretty it up format that that's possible as well.

So at this point, it is really just an idea and some basic very minimal guidelines about how to do that idea. I mentioned sort of the Markle documents on how to implement it effectively and so it's different than something like Vista which actually literally was a lot of code, the whole system that you could implement.

Margaret Flinter: Steve, we like to ask all of our guests this final question. When you look around the country, and the world, what do you see in terms of innovation and who should our listeners at Conversations be keeping an eye on?

Steve Downs: I am thinking about some of the things I have seen in the marketplace. There is an app called Fooducate where you literally point your iPhone at the food label or actually the barcode on any kind of food in the grocery store and it's going to give you a letter grade along with a quick analysis of why this is good or not good for you. I think Nike putting sensors in shoes increasingly integrating with things like iPods and iPhone so that you are automatically getting any kind of fitness data uploaded to websites. There is a company in Boston called RunKeeper that does something similar that's getting a ton of data about people's health whether it's their weight or their sleep data. There is another Boston company called 23:06 _____ which at this conference I was at recently showed a wrist watch that is collecting constant heart rate data as well as a number of other factors including your activity load. So you are going to get ton and ton of data potentially being collected and I think once we

start to understand how to analyze it all, we are going to get new understandings about what makes us healthy I think or again, much more sophisticated understanding of the relationship of our day-to-day environments, our day-to-day activities and what they have to do with health.

Margaret Flinter: Today, Margaret and I have been speaking with Stephen Downs, Chief Technology and Information Officer at Robert Wood Johnson Foundation. Stephen, thank you for joining us today.

Steve Downs: It was my pleasure.

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Mark Masselli: Each week Conversations highlights a bright idea about how to make wellness a part of our communities and everyday lives. This week's bright idea inspires health in the workplace.

Our feeling is if adults can lead by example, we can really work to combat the childhood obesity issue that is a huge health problem for this country.

Mark Masselli: Run@WorkDay is a national event created by the Road Runners Club of America to mobilize organizations across the country to promote physical activity amongst staff. Every September, employees from communities far and wide participate in the annual Run@WorkDay. The event is intended to be fun with just one rule in mind, participants must walk or run at least 30 minutes at a time that doesn't interfere with their work. At our Community Health Care, right here in Connecticut, a group of our employees gathered before work to run and walk in the nearby park. In addition to getting some exercise, they shared inspirational stories about getting fit and even tossed around ideas about ways they could all get together for some fitness fun. Spreading the message of physical activity, with a national event that motivates employees to exercise and encourages companies to accommodate this, now that's a bright idea.