



**Intellectual and Developmental Disabilities in the
ACA Era
Alliance for Health Reform
The Centene Corporation
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DEANNA OKRENT: Good afternoon, we are going to get started so please grab your lunch, take your seat and we will be ready for our program.

My name is Deanna Okrent, I am with the Alliance for Health Reform and I want to welcome you to this program on behalf of Senator J. Rockefeller of West Virginia, Senator Roy Blunt of Missouri and our board of directors.

Today's program will look at the world occupied by people with intellectual and developmental disabilities and the programs and providers that serve them. There has been and continues to be much discussion about Medicaid managed care. It's increasing use by states as a way to lower costs and improve access and quality to healthcare for vulnerable populations. The health reform law, the patient protection and Affordable Care Act or ACA as you might hear us refer to it, contains provisions that support those efforts. The question we look at today is to what extent those efforts support the needs of a subset of that population. People with intellectual and developmental disabilities. People born with or who acquire conditions at a young age who need long term services and supports throughout their lives. The types of supports vary and many are increasingly delivered in the community, not in institutions. But do states have the resources to meet the demand? And are consumers sufficiently involved in directing their own care? We are going to hear today from a distinguished panel of experts who will tell us more about the variety of services needed and available, the ACA provisions that support those services and about some of the challenges facing consumers, providers and government agencies to improve access, quality and person directed care, to four and a half million people, particularly with regard to community based services.

But before we turn to our expert panel, there are a couple of housekeeping items that I want to cover. First, I would like you to know you can follow this briefing on Twitter, you can tweet and you can get tweets. The hash tag is #disabilitiesACA. You can see that on the screen in front of you now. And then there is also a lot of information in your packets including a list of background materials, some of which we reprinted for you and some are additional materials that were either very long or were not available at the time we went to print, but are good resources if you need more information. All the materials are also available online at our website. Allhealth.org. And a webcast of this briefing will be available possibly on Friday, but if not Friday, then Monday for sure. Also on the Alliance website at Allhealth.org.

I want to point out, there are green question cards in your packets and you can use those at the appropriate time when we turn the program over to you for questioning our panelists. There is also a blue evaluation sheet. We really learn a great deal from reading your comments and suggestions and we would appreciate your filling it out. In fact today we have a special incentive for filling out those evaluations. If 35% of you submit an evaluation, a \$50 donation will be made to the Arc. If 50% or more evaluations are submitted, a \$100 donation will be made to the Arc, so please fill out those evaluations. And just a word about the Arc, according to their mission statement, they promote and protect the human rights of people with intellectual and developmental disabilities and

actively support their full inclusion and participation in the community throughout their lifetimes. And more about the Arc can be learned at their website, theArc.org.

Now turning back to our program, we are pleased to have as our partner in today's event, the Centene Corporation which contracts to provide Medicaid coverage in 18 states, serving over one and a half million members through locally based health plans. There is a one pager in your kits, you will find it on the left side of your packet, that details where Centene operates. And serving as co moderator for today's program is David Donahue over here on my left. He is senior vice president, Innovative Solutions for Lifeshare. And in this role, he has helped Lifeshare to expand its mission to create empowering home and community based supports and programming for people with developmental disabilities. David has nearly two decades of experience in healthcare, disability rights and advocacy. And he's going to say a few words about the relationship of Lifeshare to Centene's Sunflower State Healthplan in Kansas and particularly about their approach under Medicare managed care. He's going to help us understand the importance of today's topic. David?

DAVID DONAHUE: Thank you. First I would just like to start by thanking the Alliance and the panelists here today and all of you for being here. We think this is such a vitally important conversation and I appreciate you all taking time today. Just to give you a real brief background on Lifeshare, we are a 100% home and community based provider working in eight states around the country. We were founded in New Hampshire, which as many of you likely know was the first state in the nation to close down its institution for people with developmental disabilities. All of our services as a provider are home and community based. We at Lifeshare believe that we are part of the civil rights movement and we very much believe in furthering that mission. Working with Centene, we have partnered with them and have been spending a lot of time in Kansas working with Sunflower State Healthplan, which is the local plan in Kansas. As some of you may know, they may be starting Medicaid managed care for people with developmental disabilities very soon, so we have been working with them from a provider perspective to help develop programming, trainings and other systems so that we as a managed care company can develop what we believe are the appropriate advocacy based delivery methods and support methods for people with developmental disabilities. I would like to point out, we will not be a provider in Kansas, we are partnering with Sunflower but we will not be a provider, we see that as a conflict. So again, I appreciate the opportunity to be here today. We think this is so vitally important and I have heard a few of these speakers present in the past and I think they all bring a unique and interesting perspective.

DEANNA OKRENT: Thank you David. Now it's time to turn to the program I promised. I'm going to say a few words about each panelist before they go into their presentation, but you have more extensive bios in your packets about each of the panelists.

So first we will hear from Barbara Edwards. Barbara serves as director of the Disabled and Elderly Health Programs group in the center for Medicaid and CHP services at CMS. She has been on our panels in the past as a nationally recognized expert in Medicaid

policy on the state and federal levels. She served eight years as the Ohio State Medicaid director, leading significant program reforms there including implementation of Ohio's comprehensive strategy to promote access to home and community based long term services and supports. We are delighted to welcome her back.

BARBARA EDWARDS: Thank you so much. I am happy to be here. The challenge of doing the Alliance panels is always that you only have five to seven minutes and so I am going to cover a few major points and then be happy to take questions from you as we go along.

We have in Medicaid a very strong focus and commitment to supporting home and community based services for people who are living in the community with disabilities and with chronic conditions. We have seen tremendous progress over the years, particularly as states have taken advantage of the 1915 C waiver options in the Medicaid program. And we have seen in the developmental disability IDD world, especially a very strong movement toward community based services and community based spending around long term services and supports. This first slide shows progress over time and you can see that the growth in spending for the IDD world has been toward community based care with the proportion of spending in the institutional settings continuing to decrease over time. What is important to understand about the IDD world is really two things in Medicaid around this issue of community based spending. One is that the IDD world is in fact much further ahead in terms of community based as a proportion of long term care spending than we see for elders and for people with physical disabilities. While the majority of spending for intellectual and developmental disability is in the community, which is not true for elders and for people with physical disabilities. So really, this world has been a leader in this movement toward community based care.

The other thing to understand is in fact, it's a significant expense. There is a lot of dollars that are being spent on community services for people with intellectual and development disabilities. As you can see from this chart, the blue bar is the total spending in community based care for people in the IDD world and the yellow bar represents folks with physical disabilities and you can see what a huge difference there is in the total amount of spending in the community. Part of that is because a larger percentage of spending is in the community for this population, but it also represents the fact that this is in fact a population that is in fact very high cost. So this picture is both the good news of this system, but it also in fact is one of the reasons that there is a lot of attention being paid to spending around this population, around long term services and support, because it does represent a very significant investment of public dollars. One of the major trends that we are seeing, because this is the movement toward long term service – managed long term care – and I will talk a little bit more about that in a minute. Before we go on, I do want to make a mention of the fact that under the Affordable Care Act, Congress gave states significant new options to provide community based services to folks that are living in the community with chronic or disabling conditions and these have been taken up by states across the country. The first new opportunity was the 1915 K community first choice. A new benefit under the state plan that supports community attendant care, for people who have an institutional level of care. We have two states that have currently

have approved 1915 K and we have several other states that are talking to us about that option. It does come with a permanent enhanced federal matching rate of 6% and that certainly has gotten attention from states and we expect to see more states take up that new option. We also saw an enhancement of the 1915 I state plan option to provide waiver-like services through the state plan. Congress gave states the ability to target populations, target benefit packages to specific populations and this has made this more popular among states. We also have seen some opportunities for some grant funds under the balancing incentive program. We are getting ready to approve our 17th state grant under the balancing incentive program where states are committed over the period of the three or four years of the grant period toward moving the spending in their state toward a majority of community based spending versus institutional spending for long term care. There is an enhanced 2% federal matching funds across all community based spending for the period of the grant, which means states get money right away as they move into the balancing incentive program and those dollars are available for reinvestment in changing the infrastructure, supporting more people in waiver programs and so forth. So there is a lot of attention and a lot of opportunity under ACA.

One of things we are seeing in addition to states taking up those opportunities under the Affordable Care Act is a very strong movement toward managed care for long term care. This map shows the number of states that have – in blue that already have some form of managed long term services and supports programming in effect in their state with the pink states, the states that are projecting to move to managed long term care for the first time in 2014. If you will notice in the blue states, several of those states also have a plus mark next to their name and those are states that are currently engaged in expanding managed long term care, sometimes to new geographic areas, sometimes to new populations that might not have yet been into managed long term care. So there is a lot of interest and a lot of activity. There were only about 13 states doing managed long term care in 2010, so we have seen a really dramatic increase in this activity. Now this brings both support and some excitement that states can use managed care to advance the cause of community integration to begin to move dollars around in the system more effectively. To move dollars from institutional to community based care. It also raises some really serious concerns among populations that haven't experienced managed care. One of the biggest that we hear is a great concern that a commercial or a managed care company that has experience with moms and kids around physical healthcare needs are going to medicalize the provision of long term services and supports. Where instead of person centered and person directed, it becomes primary physician centered or primary care physician directed. Which is more of the medical model for acute and primary care. One of the things that we have done is adopted a series of essential elements that we are looking for when we see state – when states come forward and propose to do managed long term services as supports for any population. I have listed them here, what I want to point out about these is that they were developed with a great deal of input from advocates, from providers, from states and other stakeholders and experts around the country in long term services and supports. We are attempting to put a strong focus on bringing the culture of community based long term care into managed care so that it remains very person directed. It remains focused on the goals of our system, which is to promote and support community integration which includes not only housing, but also

employment and other opportunities for individuals and that we are using these guidelines to develop the terms and conditions for 1915 B waivers and the 1115 waivers that states are using to bring managed care to folks in the long term service sector.

I have put here on my last slide some of the resources that are available to states and to others around managed long term services and supports. I encourage people to take a look at these sites; I think you will find a lot of really good information. There is a bit of a tutorial there, worksheets for states to use in the development of long term care and managed care, but also some technical assistance opportunities for states and it's been very popular. So I encourage folks to take a look at that. Thank you.

DEANNA OKRENT: Thank you, Barbara, you finished right on the button within your allotted time. Next we are going to hear from Ari Ne'eman who is president and cofounder of the Autistic Self Advocacy Network. He has served on the National Counsel and Disability since his confirmation by the Senate in 2010 and currently chairs the Counsel's Entitlement's Committee. Previously, Ari served as vice chair of the New Jersey Adults with Autism Task Force and on the New Jersey Special Education Review Commission. He is also the recipient of a number of awards for his advocacy work and we are delighted that he is here. Welcome, Ari.

ARI NE'EMAN: Well, thank you so much for having me. Tragically, I will probably be unable to tweet my presentation while giving it. I have been able to do with the others, but none the less, very pleased to be here and be involved in this discussion. I am going to try and cover a lot of territory relatively quickly. First, I want to touch base on a few of the major opportunities associated with the Affordable Care Act for the IDD community and some of the areas in which further advocacy and policy effort is going to be needed in order to take advantage of those opportunities. As many of you are aware, ACA required that qualified health plans on the marketplaces meet the new essential health benefits standard with ten categories of essential health benefits, specified in statutes. Now the HHS regulations on essential health benefits provides states with a fair amount of discretion to determine what the essential health benefits package requirement is going to be, within their states. Typically, in relation to available commercial insurance plans. The challenge is that many of the services, particularly habilitative services like occupational therapy, speech pathology services and things of that nature, that people with developmental disabilities need, are not significantly present in commercial insurance plans currently and so HHS adopted a – what they termed a transitional policy on habilitative services that has relatively minimal requirements, depending on what level of – what standard a state decides to impose on health plans for covering this. So one of the big areas of advocacy for the IDD community is going to have in relation to the Affordable Care Act, is making sure that habilitative services, which are covered under these ten EHB categories are in fact meaningfully included in the QHPs available in the marketplace. The ACA also prohibits plans from designing their benefits in such a way as to try and discriminate against certain populations, but there is not a lot of clarity as to what that means. And so that is going to be a major area of priority for the IDD community and the disability community at large as well.

There also remains significant questions as to how Medicaid will interact with these new marketplace plans. Many workers with disabilities, who may qualify for exchange or marketplace coverage, are still going to need Medicaid when it comes to accessing long term services and supports and other benefits that may be offered by Medicaid but not by the QHPs on the exchange. So one of the big questions that we have is how will marketplace plans be able to interface with Medicaid? Will individuals who want to access the better provider networks available under the marketplace be able to do so while still getting wraparound coverage from Medicaid? How will people with disabilities that really want to have middle class health insurance be able to do so without losing access to benefits that right now Medicaid is really the only one that offers?

Barb went over I think in substantial detailed issues around the Affordable Care Act's new LTSS options, so I want to talk a little bit about some of the opportunities and challenges associated with the trend – shift to managed care in the disability community. First, managed care has historically been utilized primarily for acute care and where managed long term services in the supports arrangements have been put in place in many states, intellectual and developmental disabilities have been carved out of those arrangements. And so it's relatively new that the IDD community is interacting with managed care. A lot of the existing models of IDD managed care have been run by state run or non-profit plans and so many of the national MCOs are coming to the IDD population really for the first time. There are a couple of significant differences in working with the IDD community. In the typical managed care structure, savings may be realized from preventative care and care coordination and will probably be realized within the life of the average managed care contract. People will – the MCO will be managing primarily medical services and the performance measures will be primarily medically oriented. Has a beneficiary visited an ER in the last 12 months? Things of that nature. Within the context of managed long term services and supports, particularly for the IDD community, savings might take substantially longer to be realized. There are a lot of cost savings to be realized from providing families with the support necessary to keep somebody living at home rather than going into a group home. Having said that, those cost savings might only be realized on a ten or 15 year time frame because families will aim to hold on for as long as possible. Similarly, there are a lot of cost savings associated with helping somebody with a development disability become employed. But many of those cost savings, again, might not be realized on a three to five year time frame and so it becomes very important to really build into the managed care contract an understanding of the scope of services that people with developmental disabilities require. Like employment services and family support in which cost savings and quality improvement can be realized, but the cost savings might not be realized in time for the incentive to be obvious for the managed care plan.

A lot of the same concerns exist in the IDD community around fears of medicalization of services. Its also worth noting that this population has an extraordinarily high and really needs some extraordinary high level of support coordination and so there is a lot of concern as to whether or not that is going to be provided in managed care arrangements. One of the opportunities associated with managed care is that the IDD community, despite the tremendous progress that has been made on closing institutions, still posses a

lot of Legacy infrastructure. Many people with developmental disabilities are still in intermediate care facilities, sheltered workshops and other fairly high cost and low quality service modalities. So if we can look at managed care as an opportunity to move away from that, which might present some opportunities. The concern is, this is really speaks to the importance of well designed managed care contracts. For example, one of the points of contention right now in discussions on Kansas's managed care contract is that the state has decided to exclude public intermediate care facilities from the risk pool that is going into managed care. And so there is concern that that may create perverse incentives for MCO's to shift people into those settings rather than ship people out.

But overall, we look at managed care as an opportunity for the IDD community, but only if the appropriate safe guards are put in place to ensure that the tremendous amount of progress that has been made in developing a really integration focused community oriented system is secured over the long term.

I realize now that I'm out of time and I look forward to a robust question and answer session so that we can go into detail on what can be a somewhat complex and esoteric topic.

DEANNA OKRENT: Thank you Ari, thank you for keeping to your allotted time frame, I know you had a lot of good information in your presentation and I suspect that there will be lots of questions for you.

Let me now turn to James Bart, our next speaker. Besides his broad experience in business advocacy and non-profit work, James is celebrating his first anniversary as Kansas's only KanCare Ombudsman where he focuses on home and community based service waiver programs and other long term care services in managed care. He has a law degree from Creighton University and he also brings to his job the personal experience of being a parent of a 20 year old son, Jacob, with significant development disabilities. Thank you for coming all the way from Kansas. He's actually bringing us a good weather report, saying it's a little warmer there now than here and it's on the way. So thank you for joining us today, James.

JAMES BART: Well, thank you very much, Deanna. Good afternoon everybody. Once again, my name is James Bart and I have the dubious title of KanCare Ombudsman so if any of you didn't Google Ombudsman prior to the presentation, I will have you say that Ombudsman can mean a lot of different things in a lot of different settings. In my personal experience it has given me the opportunity to address some of the same issues and concerns that the fellow panelists here have discussed. On a personal level, more in the public sector, I have been able to work and reach and work with folks on the IDD waiver directly.

Just to give you a little bit of a snapshot of the Managed Care experiment as it's been called in Kansas, it is a relatively small rural state. If you look at the map that we provided recently, we are kind of right, stuck there in the middle of the state. I will give you a little bit of a picture of the current Medicaid program. There is about 380,000

participants, about three billion a year in costs. In the Medicaid system there are apparently six home and community based waivers, about 20,000 people. 10,000 of those are in the nursing facility and the intermediate care facilities, both public and private that we already discussed previously – there are about 400-500. Currently there is about 8,000 people on the IDD waiver and there is an extensive waiting list for services. The IDD waiver population has proposed being included in KanCare January 1st of 2014. As you all may be aware, my anniversary coincides with the existence of KanCare in Kansas, which was initially implemented for the other waiver populations, January first in 2013.

Some of the changes in Kansas regarding the IDD care that has come into discussion recently with the proposed inclusion, there is kind of some statements here that were taken from Secretary Sullivan and I won't to attribute those to myself. I do want to attribute those to the source that I believe he's in a better position to give you kind of an overview of some of those changes and I am here in his stead; he is very occupied in Kansas and working with the CMS and the proposed amendment in Kansas. KanCare essentially is managed care light for IDD. It's not necessarily the massive cede change that it's been painted to be. In Kansas there has been some various state protections that are available to consumers through [unintelligible] through the legislature, through the state DD act and through some system – I guess recognizing system strengths and integrating those in the contracts in KanCare. In Kansas, the local community development disability organizations continuing their role of eligibility and finding determination. The role of the targeted case manager is recognized and perpetuated in KanCare as the local point of contact and expertise regarding DD services. As I mentioned, those protections have all been built in by the contract, the legislative proviso, which initially had carved out the I/DD services for one year in Kansas and perpetuating the services and the TCM through the continuity of care provisions in KanCare. The benefits under KanCare would be that there would be more flexibility in addition to the HCBS waiver services; the managed care organizations can bring non-waiver services to the table. So for my personal perspective, instead of 242 hours of supportive homecare being dropped on my household, it allows us to focus on Jake and build the services up from Jacob. Not only including those waiver services, but possibly supplementing those non-waiver services to better meet Jacob's needs. There is also the advantage of a tandem team of a targeted case manager and the managed care organization's care coordinator. This allows from a personal perspective, mom and dad who are really the experts regarding Jacob's services, could really use help regarding coordinating their Medicaid benefits and services the way I describe it on a practical basis. We still want to be coached, but we need a quarterback to help us implement both services. And although the target of case manager has been a good quarterback, the care coordinators allow additional perspective and additional resources towards that same team approach.

Finally, there are some assurances in KanCare through the contract where those benchmarks for quality are – and the services that Ari mentioned, the employment behavioral health, physical health, those are all measured in Kansas through the contract, through pay for performance measures. Through that contract, the managed care organizations, the state and the stakeholders all work together to accomplish those goals. In Kansas, the preferred vision for the IDD community is that there is a continuum of

services available including employment, state funded family support services, the waiver servers, the HCBS waiver and the intermediate care facility where my son currently resides.

Some of the concerns that have been on the table regarding KanCare that have been received by my office, if you can imagine a KanCare Ombudsman, I hope to bring to the table, being able to speak the language and have compassion and understanding and clarity and offer the resource of somebody that will listen and be responsive to consumer needs. I really believe that is an opportunity that Kansas has been in the forefront; they haven't resorted to Legacy support systems. They were – had the insight to get somebody involved that has lived in the system for 15 years and utilizes those services and knows not only the challenges but the opportunities. Through this effort, I have received numerous contacts. The interface ACA has that big E word involved, the eligibility continues to be a huge concern in Kansas. More so than other states and continues to resonate in my office. Folks really cannot be poor enough in Kansas to be eligible for Medicaid. A lot of folks are accessing services only through their disability or other categories other than income. There are issues that I have been working with or prior authorizations and denials, helping consumers understand and providers understand how these processes work. That they have an independent right for an informal dispute resolution through my office and also through the grievance and appeal process, through the managed care organizations and the state fair hearing process. Some of the issues that kind of percolated to the top are kind of familiar in the healthcare environment. The pharmacy and durable medical equipment issues. The possibility of reductions of plans and cares and the status of provider networks. Once again, I believe that Kansas is unique in that they – consumers do have an Ombudsman available that can work in tandem with them. Not take care of it for them, but work in tandem with them so consumers can solve issues regarding these accesses to service.

I'm going to kind of gloss over the case data. I guess I will just paint a quick picture for you. I am sitting with my telephone that rings quite frequently, my computer which responds to a lot of emails and a sign behind my desk that says, "complaints". So really, a lot of people ask why I do this, but really as a parent, I didn't have that resource and I did not have somebody that would join hands with me and resolve these issues and that is the essence of the Ombudsman position in Kansas. Again, the case data and resolutions, there are some objective measures, contacts that are recorded through my office, are incorporated in the Ombudsman log and there is a random survey that is going to be reported.

In conclusion, I have received positive feedback from the HCBS consumers, the folks that really need the help, that are on the ground working with folks with intellectual and developmental disabilities and that is my primary customer, is those HCBS consumers. But I have also had great success working with the managed care organization and concerned resolution staff. A great partnership with the state HCBS program staff and a great partnership with the stakeholders group in Kansas. I thank you for the opportunity to visit with you today and I will be open to any questions during the panel – thank you.

DEANNA OKRENT: Thank you very much, James. This was a terrific panel, you have all heard what they have had to say. Not only their pearls of wisdom, but how they kept their presentations within the time allotted. So that gives you a turn now to join this conversation. There are two microphones in the room, just kind of in the center on either side of the center tables. You can go to those mics and ask your question or you can submit one on a green card and just hold it up and a member of the Alliance staff will come around and collect it from you. So I was actually going to start with one of my own as the moderator's prerogative, but I see someone already standing at the mic and so I will give him a turn.

CHUCK GOLDMAN: Thank you, my name is Chuck Goldman and I am an attorney and I was there when the ADA was signed. It was actually a nice day, no humidity. It was 1990 and we amended the law in 2008. So there is never a question now when we go into court whether or not a person with intellectual disabilities is covered by the law. It comes along in the ACA and I see 25 years later, after the ADA, the ACA, the ADA amendment, I don't see an increase in employment of persons with disability. I especially don't see it in the IDD community. I'm not getting clients who are fired with IDD, my clients are not that clients. But I have enough of them. I think the challenge to you all is to harness the ACA so that it can bring the promise of the ADA into fruition for your target population. I'm wondering, what specifically, if you are Santa Claus, if you could have your wish, what would be your wish list to create a synergistic relationship that is designed by these laws?

ARI NE'EMAN: So what I would say is I think you are absolutely right. We have not seen anywhere near the kind of progress we would like to employment, particularly integrated employment, which is the kind of employment we should be focusing on for people with intellectual and developmental disabilities. The percentage of people with IDD in integrated employment rose in the '90s and then sort of began to stagnate in the late '90s and early '00's at around 20%, which is really unacceptable. I think what we need to be doing and we are starting to see this occur, is placing a really heavy focus on moving people out of sheltered workshops and out of facility based day habilitation centers, in real integrated employment opportunities and build the infrastructure to do that in a process that is very similar to what we have done around the institutionalization and building the capacity on integrated residential supports. There are, I would say, a number of discussions as to how to do that. In September of 2011 – hopefully Barb can speak to this, CMS took I would say a very big step with an information bulletin outlining new requirements on states for employment and day services. The National Counsel on Disability, last year, issued a report with a number of recommendations on changes to the Medicaid statute on expending integrated employment opportunities. But to me, we really need to bring a moral imperative to the discussion on integrated employment and getting people out of wasting their lives in sheltered workshops and segregated dayhab centers in order to make progress and it needs to come with the relentless focus on the numbers and coordination across service provision infrastructure we have seen in states like Vermont and Washington, that have made progress on this issue.

BARBARA EDWARDS: It's a very important issue and thank you for raising it. A very high priority and I think in addition to a commitment to promoting competitive employment, there is a lot of interest on states – is it time to make a commitment at least to the new generation of young folks coming out of school, that they actually have employment as a goal for their lives and what do we have to do to support that? We are trying to point out how Medicaid can be used – we don't pay for employment, but Medicaid services particularly in community based long terms services and supports can be used to promote success in competitive employment and we are very committed to that and working with states toward that goal. And in fact, committed to discouraging inappropriate use of Medicaid to promote long term sheltered workshop as though that were in fact employment. So I think it's an important goal and encourage everybody to be focused on it.

JAMES BART: I appreciate those perspectives and would like to provide a little bit of detail about Kansas. Kansas is currently at about 10% on their competitive integrated employment. There are the strong pressures of Legacy systems that Ari mentioned that are kind of cross wind that the IDD community is facing. I also would reflect back to Mr. Donahue's comment about it really being a civil rights movement and along with the employment goal, just community integration on a real basis is a huge challenge and you really need to look at it on an individual basis. My son is in an institutional care facility. Had previously been a member of an institution. He belongs at home. He belongs with his family. He belongs in his community and he deserves a job and those are all opportunities that are good to talk about, but need to happen through the Affordable Care Act and through our collaboration to increase outcomes. To be metric based. To provide actual results along with the talk.

DEANNA OKRENT: Thank you. I wanted to piggy back something, being you raised the employment issue. Ari, you mentioned something about wrap around services and I wonder if you could explain that and how that is different than – one time people were making a choice to either be employed or not be employed so that they could qualify for Medicaid services and not be in an income category where they couldn't get Medicaid services. So could you say a little something more about how it works that now they can get insurance in the marketplace but also have Medicaid?

ARI NE'EMAN: So that is actually one the questions – can and to what degree can people do that? As you said, at one point people with disabilities had to choose between seeking employment and gaining income and having access to Medicaid for the vital long term services and supports they needed. Now, because of programs like the Medicaid buy in, which is present in almost every state now and 1619 B, that choice is no long put before people with disabilities. People can, up to a relatively significant level of income, I think it's about 400% of the poverty level, depending on what state, buy in to Medicaid and maintain access to LTSS. The challenge that I think we are facing is two-fold. Number one, there still remains a tremendous amount of misconceptions. Many people still do avoid moving into the world of work or discourage family members who require LTSS from moving into the world of work because of misperceptions that these programs do not exist. And second, relating to the ACA, its not yet clear whether or not or if so,

how individuals who need to maintain eligibility for Medicaid, to get long term services and supports and under benefits that won't be covered by plans on the marketplace, can also purchase a marketplace plan. The likelihood is that because they have Medicaid coverage, they won't qualify for the tax credits that subsidize QHPs. We're interested in exploring various possibilities with states for states to utilize Medicaid or CHP funds to provide premium assistance for such individuals to access marketplace plans, while getting wrap around coverage from Medicaid for everything the marketplace does not cover. We haven't yet seen states adopt that model in part because the ACA is so new, but we are very intrigued by it and I think the next step, now that people don't have to choose between employment and losing access to their LTSS coverage is not asking people to choose between the better provider networks that will be offered by marketplace plans and losing access to their LTSS coverage.

DEANNA OKRENT: We have a question on a green card. David, do you want to take that?

DAVID DONAHUE: Sure this is a question from the audience. It says, given KanCare is a capitated program and that HCBS services are usually paid on a case rate, what concerns do providers and beneficiaries have regarding adequacy of providers and service and furthermore, how did Kansas accommodate this population and its development of its rates?

JAMES BART: I will have to profess my ignorance; I can't answer that question directly. I will try to get to the - is the person that asked this question available to perhaps focus this more from an Ombudsman perspective? Somebody that could come to the mic.

SPEAKER FROM AUDIENCE: I'm sorry about that. I wanted you – I was asking in the context of historically since Kansas is one of the one states that has moved forward to a model where managed care plans are driving the care delivery as opposed to a bifurcation of the IDD population would stay out and perhaps managed care would have long term care or duals what have you. So I can't really focus more on the Ombudsman but I know that there was a great deal of concern about the movement to managed care by the beneficiaries, hence why it was kind of staggered. Contract to managed care plan started, the delivery started for the regular population and the IDD is slowly moving into it, if I recall the way the sequence went. So I just was curious, since it's not fully, if you will, implemented yet, vis-à-vis the managed care delivery, what the beneficiaries are saying and what roles Kansas is taking to assuage their fears and also to monitor if you will the fact that managed care plans are getting a capitation for a population and its not just kind of rolling into the mix. This will actually need money that flows to special services in the delivery.

JAMES BART: I appreciate that clarification and again, I know it's not a popular stance in the city, but I'm going to profess that I don't know the answer to that question. So I would open it up to the other panelists to provide their insight. I could get you some specific answers and I would be happy to reach back with you and get some clarification on these issues for you.

BARBARA EDWARDS: I can't answer for Kansas specifically, I wouldn't want to do that, but I can say that the issue of moving long term services and supports into a capitated managed care environment is not new. It is sometimes new for some populations. They have not experienced it yet, but the basic premise really isn't different for – based on diagnosis of the individual who is receiving services from the long term care plan. So the way – the requirement for managed care capitation payment is that it must be an actually sound rate. That means that the rate paid to the plan by the state has to have been certified to appropriately reflect a reasonable amount of dollars in the aggregate to be paid on that per capita basis. The idea behind any insurance product really is that the risk is shared across the pool and some people are going to be higher users of services than other people, but in the case of the managed care plan, they are paid a per capita rate. It may be risk adjusted based on certain factors, demographic, geographic, maybe even diagnostic, depending on how the state puts the rates all together and the actuary certifies it. But the point is that within that contract, the managed care plan then negotiates with providers on how those individual providers are going to be paid. So the obligation of the plan contractually is that they must meet the service needs of the individual. The provider is then paid by the health plan and that maybe you paid using state – the state's Medicaid reimbursement model or the plan may negotiate a different reimbursement model. It is very common that health plans pay on more of a fee for service or if it's a case rate, they may use a case rate, even if the plan is being capitated, the way they do business with the providers in that system, more often looks like the same way the state has been doing business with those providers, though it is subject to negotiation and the health plan might propose alternative approaches. And maybe even different fees and different financial arrangements. So it can vary by plan, states can sometimes require that the plan has to at least pay the Medicaid rate, but again that varies again as to whether the state takes that stance or not and I don't know what the – I just don't know as I sit here what the requirement is in Kansas. I hope that helps but it's -

SPEAKER FROM AUDIENCE: If I may ask a follow-up question directly to you as a representative from CMS. With the IDD population and so on and so forth, just using Medicare advantage as an apples to oranges comparison. So Medicare advantage has the HCC risk adjustment, so you have co morbidities, lets say if you are diabetic with a 1.0 score with diabetics from CHF, 1.2. So plans are paid for the acute care that is delivered to these beneficiaries. Medicaid on a national level doesn't necessarily have that kind of risk adjustment. The CMS contemplate – obviously risk adjustment you assume will eventually migrate over to other public programs like Medicaid to adjust for the acuity of care for these beneficiaries and more to the point, the beneficiaries that are the IDD folks have non-quantitative acuity issues that – outside their somatic health. So they have IDL, ADL problems in terms of bathing and so on and so forth. And so one of the things, talking to various states and talking to their Medicaid directors, trying to figure out how they account for that. Because at the end of the day when it comes to managed care plans delivering care, they are based on a capitation and then within their first year after experiencing the first round of MLRs, they might come back to the States for additional relief, bump up our rates because we are suffering and we don't want to exit out until we

are all committed and have infrastructure and so on and so forth. And so as you kind of titrate now these different populations and duals IDD long term care, you have to kind of feed the capitation to make sure that the plans are made whole, if you will, for the care they are delivering. So my point and question is, do you anticipate risk adjustment for this population or in Medicare at large over time when it comes to managed care?

BARBARA EDWARDS: I guess what I would say is, states are already using risk adjustment. States have been doing managed care for 20-30 years in Medicaid and all populations vary in terms of their medical need. It's not just within the IDD population, so not everybody has the same heart disease, not everybody has the same risk of cancer, not everybody has the same expenditures on physical health. Within in the aging population where there is experience in long term care, there is also the need for risk adjustment within the mental health population, within the population of people with physical disabilities, this is again – risk adjustment is a part of how states pay long term care facilities today. There is risk adjustment in the way states actually do plans of care in effect, that is where we are doing some risk adjustment in that assessment. I think risk adjustment is a very important part of how states pay managed care plans and how states approach that is not in fact dictated at a federal level. States have some flexibility in how they approach that. Sometimes states do that through the development of rate cells, so that they subdivide the population even as people go in, buy some things that reflect different aggregate risk or different average risks. Some states might build a risk corridor with their health plans so that based on actual experience as to who goes in, they might have to come back and make some adjustment at the end of the year. Other states may have other approaches, but again that is why every state comes and they make their proposals and they work with their actuaries to develop what is in fact a reasonable approach and then frankly, the managed care plan has some obligation to also assess whether or not the state's approach to that risk adjustment is appropriate. So the health plans in fact have to accept that rate or not. Or in some cases they are actually making a bid. So risk adjustment is very important, there are different ways of doing it and I think that certainly as more and more people who had long term care needs move into this kind of environment, we would expect to see increase sophistication around those risk adjustment models.

ARINE'EMAN: Let me speak to this because in my role at the National Counsel on Disability, we were in Kansas last week and spoke to many of these – learned a lot about many of these exact issues. First, I think the reality that does need to be kept in mind is that there is not significant experience with assessing appropriate capitated rates for this population. And that presents unique challenges and if the accountability is not going to come primarily through capitation, because again it's an area in which everyone from the states to the MCOs to really all the stakeholders involved, have relatively little experience doing for the IDD population. I mean, ten years from now we will be in a different status quo around that. Then procedural protections become much more important and it is our perception and the National Counsel on Disability recently sent a letter to CMS suggesting that, well we are not opposed to KanCare incorporating the developmental disability population. We do believe that a further delay will be necessary to evaluate the model and to ensure that the appropriate safeguards are put in place. Some of the issues

that we highlighted included the fact that there are widespread issues with providers getting paid on time and this does constitute a fairly significant transition for many providers to move from a status quo where you bill the state to a status quo where you bill three different MCOs with three different processes and for small providers who may have cash flow issues, there may be significant challenges associated with that. We raised the concern that currently the state has carved out its public intermediate care facilities which create some perverse incentives with respect to high cost individuals potentially being off-loaded into those settings in order to improve the risk pools for the MCO. Third, I do think that there is a need for much stronger infrastructure around where consumers and families go. Where they have problems with the MCO. Most of the state oversight of MCO decisions to cut care plans, I think there have been about 1200 cases to date, have resulted in the care plans – care plan cuts being upheld. 1100 or so have resulted in care cut plans being upheld. That is a source of concern for us.

Now the flip side to that is, you have to ask why this is occurring and I do think you could make an argument that part of the reason why the DD population isn't yet going into managed care is that it has only been relatively recently that there has been serious engagement on the part of the DD community and the state as to what safeguards are necessary and what program design is appropriate. An argument could be made that that is the fault of the states and equally valid argument could be made that that is the fault of the people in the DD community who thought they could just get a carve out and be done with it. So I really want to reinforce here, I don't believe Kansas is ready to move its DD population into managed care yet. That doesn't mean that I think the IDD population can't be served with an effective and well designed managed care infrastructure.

DAVID DONAHUE: I would just like to add and it may not speak specifically to your question, but I do think having spent a lot of time in Kansas, there are some opportunities that we face from a managed care environment. As we all know, under traditional fee for service, it is very fragmented care. Often we don't know what is happening on the long term side versus the acute side, so we are seeing the opportunity to look at that whole life, to look at that person and to look at everything that is impacting their life. Often with our population, folks who are experiencing behavioral problems, which is sometimes a label, that may be because they are unhappy with their current living situation and that can really impact everything along their continuum of care. Things like they have an issue with their roommate in their group home and then they are going to wind up having what is often labeled as a behavior, but we see often its just a form of communication. But that behavior may lead to them having an ER visit or some form of inpatient visit. That impacts cost, but that also frankly impacts their quality of life. So if we are able to look at them as a whole person, look at everything that is impacting their life, I do think it may – I understand what Ari is saying, particularly in terms of the long term impacts, but we can hopefully make short term improvements that will have long term impacts. I also think that involving the person is very important and I think everyone would agree. They have a right to be a part of their care and their supports. And that is something that we have been doing in Kansas. I hope it's not unique to us. But making sure that those folks have a voice in determining how they live their life.

JAMES BART: I would also like to have a brief conclusion to that question. I know that was a quite lengthy answer to your question. To circle back and to provide just a little bit of Kansas specific information, I wasn't involved in the contracting component of KanCare, but I do know that the risk have been assessed and the Kansas system traditionally, through the Community Developmental Disability organizations, through a tier rating that kind of adjusts that the funding by the assessment of the individual. I would also make the observation that there are a lot of Legacy provisions implemented as part of the contract including that tier determination as a risk corridor. That is specific to your answer. But also the Legacy in the inclusion and the risk benefit of managed care for IDD services. Kansas has had a year in which they implemented the previous – the other ACBS waiver services in Kansas and a lot of bumps in the road have been worked out. The funding concerns that Ari discussed, I have worked individually with consumers, with providers, and have been able to reach resolution on those issues. Again, just coming in and meeting with the Legacy folks at the State House is a little different than meeting with the folks at the kitchen table or talking to folks about individual concerns. And I do believe that if you look at it from a Kansas perspective, that consumers have had a positive experience having their resolutions to the issues that have come up. I do believe as Ari has suggested through the National Counsel of Developmental Disabilities that additional resources are available. That is a challenge to all of us in all our jobs, but you know, quite personally I believe that the recommendations that are being made here in Washington DC need to also reflect the reality of what is in the ground in Kansas and are consumers getting effective relief. Are Legacy issues being perpetuated in the consideration of whether or not to transition to managed care? Those are all questions that are being faced for the first time in Kansas and maybe answered loud and clear by providers or by Legacy groups, but I really think that if you get on the street and on the ground and in the homes with consumers, some of these opportunities are real and are areas that can be improved through the utilization of managed care.

ARI NE'EMAN: I will say one last thing. It is definitely a complex issue and I think it's important that we move the conversation from the binary of do we or don't we to when is the most appropriate time and is a particular state system ready at this time? I want to say and I think it's important to really reinforce the difference between policy and people because I have a tremendous amount of confidence in James, in you as an individual, but I do think that we need to think about what level of resources are being allocated to your office and whether or not that is going to be sufficient to reflect the scope of beneficiaries and the scope of responsibilities that you will need to take on. So it's going to require a lot of additional work and a lot of additional oversight. We are moving into new territory but as James said, there are opportunities to be had if we do it in the right way.

DEANNA OKRENT: Thank you, the next questioner?

TOMMY HOUSNER: Tommy Housner, formally with CMS. So one of the essential things it to have good quality of care measures, outcome measures as best as possible so my speculation is that its still an evolving process in terms of development of those measures, but I would be interested in your comments about – I'm directing this to

several of the panel members to comment on where you think things stand as far as the quality of care measures, outcome measures, things like that.

BARBARA EDWARDS: I will say generally the issue of appropriate quality measures around long term services and supports lags what we see in primary and acute care. That is an issue that certainly HHS is interested in. CMS and – I could give you an alphabet of [unintelligible] and other folks that are interested or involved in the development of quality measures. Affordable Care Act provided some funding at the federal level to focus on developing core quality measures for adults in addition to the core quality measures that were developed for children under CHPRA. There have been a set of core quality measures developed and issued, but again, long term care really wasn't a part of that original – and that really comes from the fact that there has not been a lot of work in the field with regard to standardizing and testing and validating measures. We have been doing some work at CMS and with our partners across the federal government around the development of some – beginning measures around long term care and particularly community care. We are actually in the process right now, we have a [TEFT] grant opportunity out there with I think five or six states interested in participating, to begin to test some measures in the field, including a consumer experience of care – a tool that we hope will end up with a CAPS brand name. So there is work being done to have better measures. In the meantime, I think its states and programs on their own are sort of creating their own sets of measures. Some of those may be processed, some of those may be outcomes and I think that is very important. We certainly encourage states, as they build their contracts, to think about what their goals are. Are there particular medical issues they want to see dealt with? Are there issues of community opportunity and integration that they would like to see advanced? That they ought to articulate those and call those out in their health plans. I don't think that is a substitute for their being some tested and validated measures in that system so it feels like it's a both and kind of a conversation that states need to be pushing measures forward that reflect their goals and their priorities and we need to be continuing to do work to really develop rigorous measures that have been tested and that could be used to compare across programs, across plans, across states. Both in fee for service and in managed care. Let's be clear because this is not just an issue where we are lacking good measures in managed care.

The other thing I will mention is that states that are bringing their C Waiver programs for example into a managed care environment, those C Wavier expectations and obligations largely are coming into those managed care environments and another thing that we are working out is how that translates into managed care. That is an ongoing piece of work.

JAMES BART: Ari is deferring to me. I promised we wouldn't be engaged in point, counter point; we both share a lot of similar perspectives and a lot of the same values, so I appreciate the opportunity to be on the panel with these folks. As far as Kansas, I would be willing to discuss the quality management strategy, having a personal stake in the game; I wanted to make sure that there were adequate protections for consumers available in the managed care environment. There has been a lot of work in pioneering in Kansas and coming up with effective quality measures during the first year. The issue that Ari had brought up regarding payment was the first pay for performance that

providers needed to have confidence in the system that they could get paid correctly and promptly. During the second year of KanCare, the focus in the pay for performance measures are more quality related from a common sense perspective. We look at such things as morbidity in the IDD population when you realize that folks in the IDD population have a significantly lower life expectancy and setting that as an expectation to move that bar is really kind of the base and the most basic level. And it does evolve to a more system sensitive issues regarding the community integration, the employment outcomes. All those topics that we discussed on an ancillary basis here. It's important that the states do get involved and do include that information in their contracts. They do have objective mechanisms to verify the quality moving into the new environment.

ARI NE'EMAN: I want to add just a few things very briefly. First, James it is my impression, correct me if I'm wrong on this, that the state is withholding a small percentage of the capitated payments to the MCOs in subsequent years in order to evaluate whether or not they meet those performance measures. I would say that is a relatively good practice. Let me confirm that -

JAMES BART: Yeah, it's not a small percentage, we are talking 5% of a contract and anyone who has been in business knows that that cuts your profit margin to the bone if you don't meet those measures.

ARI NE'EMAN: And that is an example of where performance measures can be utilized to ensure quality. I do think, just a couple of things very quickly. We are going to need to utilize performance measures that are very new in the IDD space. It is not going to be, have you been to the ER in the last 12 months or are you obese or do you have diabetes? It's going to be, are you employed? What are your weekly earnings? Also a number of things that can't be reflected quantitatively. I think the best performance measures in IDD right now are the national core indicators project, which are utilized over 30 states and run by the Human Services Research Institute and the National Association of State Directors of DD Services and in addition to quantitative questions like the percentage of people and integrated employment or in supported living versus group home versus institutional settings, they also have qualitative questions. Like for example, asking people with development disabilities, "Does someone open your mail before you are allowed to see it?" "Did you choose where you live?" "Did you choose with whom you live?" Those required data collection efforts that are very different from what there may have been previous familiarity with and so as we look to quality improvement not just in managed care, but also in fee for service, a heavy emphasis on those types of metrics will be very important.

JULIE WARD: Hi, I'm Julie Ward, I'm with the Arc and I want to first of all thank you for recognizing our organization and urge my colleagues to complete their evaluation forms. I wanted to come back to the question of whether plans had sold in the exchange are going to be better for people with IDD than Medicaid? And I think that is a very open question right now, given the essential health benefits and given - I recognize that provider networks is a concern in Medicaid, but we are seeing some pretty limited, in some states, provider networks in the plans being sold in the exchange as well as

problems with the drug formularies and I think there is a lot of issues around essential health benefits that in the next two years we are going to have to look at very closely. The biggest concern to our organization is the habilitation benefit, which Ari mentioned, but I think if we can get some support from NCD or CMS in terms of really doing some analysis of what is happening in the States so that in 2016 when they revisit some of these questions, we will have a better base of data to work from. I would really urge our colleagues at the – on this panel to really look at those issues and help us address them.

DEANNA OKRENT: I'm going to add to that a very specific question with regard to essential health benefits that actually came to us through the internet with someone's registration. So I want to say that for future briefings, you can submit questions ahead of time and we will get to them as appropriate. But speaking to essential health benefits, this questioner asks, what is the likelihood that applied behavior analysis "ABA" services will be deemed an essential benefit for members with ASD, which I think is autism spectrum disorder and DD in managed Medicaid programs. So very specific but also talking about essential health benefits.

ARI NE'EMAN: So I would just start very quickly by saying, I think you are right, Julie. If it's a question of Medicaid or the QHP plans, 99 times out of 100 the Medicaid will be better for people with developmental disabilities. The question that we have is, does it have to be "or"? Can we look to a possibility where we can use Medicaid to wrap around the QHPs and give people the opportunity for the best of both worlds? And I think that hasn't yet been answered and we are going to need some policy innovation by states to get us there. The question of whether or not ABA will be a benefit in Medicaid managed care plans, that is really up to the state and whether or not the state decides to cover that benefit. I would say that it is the position of my organization, the Autistic Self Advocacy Network, that applied behavioral analysis is one of many forms of habilitative services associated with autism and if applied behavioral analysis is covered, then things like DIR floor time, CERTS and other more developmentally oriented autism methodologies should also be covered rather than only applied behavior analysis because many individuals and families prefer methodologies that have more of a history of being utilized in natural settings. But certainly I think the question of covering habilitative services is very important. Remembering that ABA is not the only habilitative service.

AUDIENCE MEMBER: I just wanted to follow up about the habilitative services and the transitional policy. If you could share sort of the process and timeline to get to a more developed, less transitional policy.

BARBARA EDWARDS: I don't think we have anybody from [unintelligible] here and that is really their responsibility, not CMCS, so I really can't speak to the details of that. Medicaid is required by the statute to use the essential health benefit that is identified by the state as the starting place for the state's development of their benefit designed for newly eligible populations in states that are choosing to expand. So essential health benefit design is important to Medicaid, but is not being driven by Medicaid nor CMCS policy at this point. So I think we are watching the development of the commercial product with a great deal of interest. We are watching state selections around which plan

they choose to be their essential health benefit mark or benchmark with a great deal of interest. States can choose from among about ten different plans that function within their state or nationally. And we think that – we are hoping to learn as states make those choices – and keep in mind that states can make a different choice for their Medicaid DHB actually, but is still a state choice. And so the definition of HAB within that benefit is of great interest to us and we – it is really a little early for us to know for sure what that is going to look like in the early days but it feels like, for the most part, we are seeing EHBs that seem to treat HAB as a variant of rehab and so it's looking sort of at the same kinds of services and providers but for an habilitative purpose, not just a rehabilitative purpose. So I'm not sure if that is what folks expected when they worked on the original legislation, but I think that is what we are observing early days and we expect that that will continue to evolve.

The other thing I'm going to mention just as an FYI for folks is that at least among the folks that are early Medicaid expanders and that is about half the states, we are seeing a majority of those states very interested in aligning their Medicaid – traditional Medicaid benefit packages and their new Medicaid offerings under the alternative benefit plan. I think we didn't know what we would see in terms of whether states were preferring to offer a different benefit or preferring to offer a benefit that looks like their regular program. We are seeing most states, not all, but most states coming in and saying that they very much want to get those benefits to be the same and interestingly, that means in some cases, states offering more of a benefit to the newly eligible population than the technically would have to offer if they were just using their EHB as the standard. But it also in some cases means that states are contemplating modifying their traditional Medicaid program to add benefits that don't otherwise exist in their traditional Medicaid program that might be a part of EHB and HAB is one of those services. Now again, maybe defined by the commercial market. So it's going to be a very interesting development that we may see states – some states at least, making a choice of the best of both worlds in terms of how they are thinking about benefit design going forward. So I think this next year, next couple of years, we are going to see a lot of learning and we may see some different choices on the parts of states even within their traditional Medicaid program as a result of what is going on in the marketplace.

MARY TIERNEY: I'm Mary Tierney, I'm a pediatrician and I worked in Medicaid for a long time also. At one point during the Clinton Administration, I was the Medical Director of a group called Health Services for Children with Special Needs, a managed care program in the District of Columbia. We had children and youth on SSI, which is a huge, large number of different kinds of healthcare issues. One of the things that we found, we didn't have data as to what these children and youth had as diagnosis. We found that there were a large number with developmental disabilities, we also found that there were a large number of children and youth with serious emotional disturbances and we also found that of course there was a big cross hatch with children and youth with what we in the biz call "co occurring" issues which are mental health and development disabilities. I think it is a huge issue. One of the things we did was of course reach out to everybody in the DC community, but we also integrated our care management teams with both physical health, if you will and mental health and developmental disabilities, so that

every team was talking to each other about these issues. But I think mental health is something I would ask then, is mental health an issue that you are concerned about as maybe co occurring and does anybody have some thoughts about what is going on? But just keep your eye out for that as we move along.

BARBARA EDWARDS: I would like to say that we think behavioral health issues are absolutely critical to improving quality of healthcare and the quality of life for individuals across the board. But I think maybe especially for folks that have chronic and disabling conditions because the co morbidity is so high at all ages, including among our elder population. And I think that it's one of the reasons we are very – we feel very strongly in my shop that regardless of the delivery system, we have got to become more holistic in how we think about the individuals who are relying on Medicaid for services. We are very excited about health home model that is available under the Affordable Care Act. We have about 18 health home models approved at the moment in 14 states and there is a lot of ongoing interest. Health homes is an opportunity for states to get – to be able to purchase services like family support, individual support, transition services, care management, care coordination including with social supports, not just across medical and healthcare services, but across community based services as well, for people that have multiple chronic conditions and for people that have serious mental illness. There is an opportunity here to look holistically – primary, acute, long term care and behavioral healthcare services are a required component of that health home model in terms of the kinds of coordination going on. And we have seen tremendous interest from states around this. A lot of the interest has started from the behavioral health point of view, but we are seeing states offering a broad array of models and for the first 24 months there is a 90% federal matching fund available around those health home services, those care coordination family supports, individual support transition services for every model. So there is a lot of interest. Some states are doing in a fee for service environment; some states are introducing health home models through their formal managed care delivery systems. There is a lot of potential there and whether its that model or a different model, we think it's really critical that we stop siloing people either neck and up and neck and down or we are only going to look at your one diagnosis and we are not going to look for your other issues. We have really – we are not doing people justice and our systems are failing them if we are not attempting to deal from the individual's perspective outward – dealing with all of the – making sure that we are being appropriate with all their issues. So I'm glad Mary, for raising that issue, because we think it's a very high concern for children especially. It's a very key concern among the children in the child welfare system and there is a lot of work going on there as well.

AL MILIKIN: Al Milikin, AM Media. The last report I saw actually on television about what happens to those diagnosed with autism after the age of 21 was really scary to me and I actually have more than one niece that they are approaching that age and they both have different types of autism. What is the current outlook on someone in that category? I guess an adult over 21? It seems like under 21, those with autism in the past have been pretty well taken care of.

ARINE'EMAN: I would say I think we still have a long way to go under 21 too, but I think you are right. Just speaking as an autistic person and I was diagnosed on the autism spectrum when I was 12 years old, so this topic of transition is really important to me on a personal level as well as on a policy level. We know that the vast majority of autistic people aren't as lucky as I was. Most people on the spectrum aren't getting the chance to transition into a job that they like or any job at all. To have the opportunity to have access to post secondary education, have the opportunity to get the support they need to live independently. It's a very real obstacle. We know that currently over a third of autistic young adults transitioning out of high school have no access to employment or higher education opportunities in the six years after they leave high school. We know that number becomes significantly higher if you are in the bottom income cortile or if you are African-American or Hispanic. What I would say here is two fold. First, at least to some degree, these issues are continuations of broader problems and our developmental disability and special education service provision system. We put a lot of money and time and effort into IDA services and then when kids turn 21 and leave the special education system, we say to them, in a lot of ways, either you are on your own or good luck maneuvering with the VOC rehab system or if you do qualify for Medicaid waiver services, I hope you live in a state that doesn't have a long waiting list. So I think you are absolutely right in saying that this is a real problem. The one thing that I would reinforce is that it's a problem of politics. It's not a problem of biology. Autistic people at every level of disability, not just people like me who can talk, but also autistic people who require significant ongoing support across the entirety of their lifespan, can succeed and can live happy fulfilled lives, its just a question of whether or not we are going to see the political will on the part of state governments and also on the part of the federal government to ensure that that happens.

KIM : Hi, Kim [name] from the Association of University Centers on Disabilities (AUCD). I was just wondering how you are going about making sure that people with IDD are getting the right Medicaid as they go to get services. I didn't realize until after the Affordable Care Act was passed that the alternative benefit package was going to be different than that original Medicaid and it worries me that people will be moved into the wrong services.

BARBARA EDWARDS: That is a – it is potentially a challenge. There are some people who don't qualify under the new eligibility group because they qualify for other things. So for example people that have SSI determination cannot come in through the new door. They will continue to come through the regular Medicaid - so some of this is built into just the original – the design of those eligibility groups. But its also try that the way the new adult group works, that there are going to be some people, who just based on income, would qualify to come through that door. That is the good news. That today they might be turned away, but in an expansion state, they are going to be eligible for Medicaid. And maybe they haven't been through the SSI determination, but they do have some sort of a medical condition or a healthcare need that might make them vulnerable. So there is a provision in the alternative benefit plan section that says that people that are medically frail – that is the word that is used, Congress invented that some years ago. We aren't quite sure what that means and not everybody likes that word. But it is what the

statute says. But the people who are medically frail cannot be mandated into an alternative benefit plan, must have basically a choice of traditional Medicaid or the – whatever the alternative benefit plan is that the state is offering. So that means that states are going to have an obligation – do have an obligation beginning in January. Actually, even today, because states can today use alternative benefit plans, but beginning in January, states that are expanding and offering a new door into Medicaid are going to have to have a way to identify people – either the state identifying them, allowing people to self-identify, some combination of maybe watching people’s utilization of healthcare. There could be a variety of ways that states are going to have to do this. To identify individuals who might fall into that medically frail category and offer them a choice. Now it’s important, the state can’t just mandate that they go into the traditional Medicaid program because it might not be a better benefit package for them. It’s really going to depend on what the person’s individual needs are and what the state’s traditional benefit plan looks like. One of the things that has been most interesting as we have watched states come forward with their alternative benefit plan designs based on the essential health benefits that Ari was referencing, is that some states have come in and assumed that their regular Medicaid program is better for people who are medically frail, but when you have the state break down the comparison of those benefits, you find out that – hmmm, there are more – maybe there is more utilization limits in the Medicaid program than what is being offered in that commercial model. There may be services like substance use disorder treatment services that are available in that commercial marketplace that at least a third of the states in the country still don’t offer through their Medicaid programs. So there is not an automatic answer as to which benefit design is better. So for us, it’s really important that that individual is given a choice that suggests they are going to need some counseling or some navigator help. So there are some challenges there as states are building those systems. We actually think that is one of the reasons that is driving the majority of states to date to say, I don’t want to have to do that. I want to align those benefit packages from the get-go so that there isn’t a need to identify people who are medically frail. There is not a need to counsel people about which benefit plan, because it’s the same benefit either way. And I think that is not a bad outcome. Because there is always going to be gaps in any kind of a system of trying to identify. So I think most states are trying to avoid having to do that, by aligning, and that means people are going to get the best of both benefit packages. States who prefer in fact to have a different benefit package are having to develop mechanisms and describe those mechanisms to us about how they are going to run that identification and offer and we are going to have to work with states I think, on going with that half a dozen states or so, at least to start to make sure that those things are working. We are also talking to people on the ground in those states and trying to have kind of a way to not to just do a little bit of check and balance as the systems begin to go into operation. To hear from groups on the ground about how that is going.

DEANNA OKRENT: Well, I didn’t take the prerogative of having the first question, so I am going to take the prerogative of having the last question and while I am doing that, it means that we are winding down, so if you would take out those blue evaluation forms that you have been reminded about a couple of times and take this moment to fill those out so that we can – you can submit them as you leave today. But as the last question, I’m

going to turn back to – Ari, you said something about waiting lists and we really didn't touch on that much today with regard to states and their waiting lists. So I would like to kind of – with a nod to the Olmstead Decision of 1999, as long as we started out the questions with a little historical nod to the ADA, now I will do a little historical nod to the Olmstead Decision in '99 which kind of spurred the demand for community based services. Would you say that some of these initiatives that are being supported by the ACA, like the balancing incentive payments, the 17 programs that you mentioned, are those mitigating the waiting list somewhat? Is that how states are using those incentives?

BARBARA EDWARDS: States have a lot of design options with balancing incentive program, but we are working very closely with them, because the statute says, the goal is to move that bar where their current spending proportion is, so that its more than 50% of their spending, is going to be in the community if it isn't already. We are in fact seeing states make some really dramatic starts and in some cases it is absolutely beginning to take people off waiting lists that are several thousand people that have already been served in BIP states, because the state has said, that is where we are starting. We are starting to move people off those waiting lists. In other cases, states are building infrastructure, other kinds of things; to help make community options the first choice for individuals in terms of a diversion from institutional care. Lots of different strategies. Some states are focusing more in some population areas, though they are required - the measurement is across all populations, as we have said before, not every population group is in the same place, even inside the same state in terms of their current access to community care. So sometimes states are going after their weakest link in their current systems. But waiting lists are certainly one of the ways states are measuring their progress. It's also – in some cases what we are seeing in states that are looking at managed care as another measure that they are looking at, can they bring those waiting lists down as they go forward? So I think that is an important measure. I think that there is a complexity around waiting lists and we always caution people that you have seen one waiting list, you have seen one waiting list, because they vary in terms of how states use them. They vary in terms of how families and individuals use the idea of a waiting list. And so but it does, I think, always reflect the level of pent up demand for community based care.

ARINE'EMAN: I think there are very few issues in the IDD community that do not in some way connect with the waiting list problem. There are hundreds of thousands of people with developmental disabilities who are waiting for access to home and community based services and I think certainly as Barb mentioned, the Affordable Care Acts provisions around long term services and supports offer an opportunity to help address that problem and its important to remember that the ACA reauthorized one of the most successful efforts of addressing that problem. The money follows the person demonstration. Barb spoke to the state balancing incentive. Many states are using the community first choice state option in order to gain new federal funds, which requires states to not run a waiting list for those services that are covered by the CFC, which isn't the full scope of home and community based waiver services, but it's significant. I do think the waiver issue also connects to the managed care issue in that the degree of progress a state has or has not made on addressing its waiting list, may be either an

indicator of its degree of readiness to move into managed care or conceivably could also be an argument for ensuring that any cost savings brought about by a shift to managed care are reinvested in the system with an eye towards ending or significantly reducing that waiting list. The final thing I would say is we are seeing a lot of excellent work by the Justice Department, bringing Olmstead litigation to bear on states that are not making progress on their waiting list or not making progress on institutional closure or are backsliding in ways that could send more people back into institutions. So the Olmstead Decision has really changed the nature of the game and we are hoping to see more of that litigation and greater state compliance.

BARBARA EDWARDS: I would also just point out that we are working to finalize some new regulations around our home and community based programs. The 1915 C waivers, the 1915 I state plan option and finishing some of the regulations around the 1915 K community first choice. And we also hope that those – it is certainly our intention that those final regulations will help advance the value of community based services, the area of biggest challenge in those regulations has been proposing some definitions of what the characteristics of a home and community based setting are, how does an individual experience a home and community based service and that has been very controversial. But it has also been very enlightening conversation as we have worked for five, six, seven years around these standards and we do believe that finalizing those standards will be another advance in the effort to make Olmstead a reality and we have had a lot of input from our federal partners as well as lots of advocates – probably many people in this room, but also the Department of Justice has been very involved in that conversation as well. So it has been an interesting experience and we do think – we are looking forward to finalizing those regs, we think they will help.

DEANNA OKRENT: Before we close, I just want to ask if our panelists have a final closing statement and including our co moderator, David Donahue?

DAVID DONAHUE: Thank you. Again, I just want to thank everyone for coming out today, this is obviously – I think you can see for everyone here in the panel, I'm sure for a lot of people here in the room this is a vitally important issue for all of us. Just to dovetail on the Olmstead discussion, I would encourage anyone here who hasn't looked at the health report that was put out in, I think it was July, to look through that. I think it is a great resource to just see where states are or where they aren't in terms of their Olmstead implementation. And a few things I think moving forward that will be important for all of us to look at, we heard about competitive employment, which continues to be a very important goal. I had a very interesting discussion this past Friday with a dentist, talking about the need for dental care for adults with developmental disabilities. That is something I think we will all be looking at in the future. And then also the issue of aging care givers. It is something that we are going to continue to see – it is going to become more and more of an issue, particularly if we want to maintain our focus on home and community based services. So thank you.

DEANNA OKRENT: Okay, well this is the time for all of you to also join in our thanks to the panel for this excellent program. But let me thank you first for your time and

attention and then ask you to join me in thanking our panel today and the Centene Corporation for bringing you this program.