

Peace Dale Library
1057 Kingstown Road
Peace Dale RI
6:00pm – 7:30pm
Meeting Minutes

Introduction and Overview:

RI Health and Human Services Secretary Elizabeth Roberts welcomed the public to the Townhall, focusing the subject on comments, questions and concerns related to the effort to Reinvent Medicaid. Secretary Roberts welcomed Dr. Ira Wilson, one of the Co-Chairs of the Working Group to Reinvent Medicaid, and noted Dr. Wilson will be the moderator this evening. The Secretary expressed her gratitude to the Peace Dale Library for hosting this evening.

Secretary Roberts then gave a brief presentation for context on the Rhode Island Medicaid program, and what this initiative hopes to achieve. That presentation is available for viewing on the website <http://reinventingmedicaid.ri.gov>.

Dr. Wilson then took over the role of moderator, and advised he would begin calling on folks in an orderly fashion to hear comments, questions and concerns. He requested that everyone work to keep their comments under five minutes to ensure all in this large crowd who wish to be heard may have an opportunity to speak. Dr. Wilson also advised that any written recommendations may be submitted through the website or handed to staff at the conclusion of this meeting.

Comments/Questions/Concerns

Tara Townsend came forward as a Medicaid consumer who noted she works for RIPIN. Ms. Townsend told the group that she speaks as a consumer, and a mother of two boys with another on the way. She told the group that her oldest son was born with medical complications, and in the NICU for months after birth, causing Ms. Townsend to leave her job at the time. Today the boy is trached and vented, with muscle tone issues, but non-ambulatory and doing well at age seven. She stated that Medicaid has helped her family provide the care he needs, the supplies he needs. They do have to keep working to ensure that they have enough of what he needs. Medicaid has been instrumental in helping the family to keep him doing well. Ms. Townsend stated she works when she can to provide for her other child and child to come, but to meet all the needs Medicaid has

helped. RItCare helps to provide a continuity of services, reduces burdens and stress on the family. She noted RItCare keeps families keep their heads above water to provide for their families. Ms. Townsend also mentioned the Katie Beckett program, noting that while it is a high cost population it is not the highest cost. These families are already struggling paying out of pocket; still have to pay for some things not covered by Katie Beckett. There are some medications and services that need to be paid out of pocket for and there are some families in her support group that have more than one child in Katie Beckett.

Robin Dedan, the vice chair of the board of directors at Blue River services, a Federally Qualified Health Center in Hope Valley stood to give remarks. Mr. Dedan stated that he has been a patient of Blue River Services as well as a member of the board. Over his years with the facility he has seen the services continue to improve. The health services and the health center itself is an important partner in the Medicaid program improving patient care and reducing patient cost. Mr. Dedan continued that the center has been named recently a Primary Care Medical Home, which he believes allows them to provide better care, coordinated care with other specialists, and as such prevent unnecessary Emergency Room visits. Another important focus, he stated, is case management which improves service and reduces cost. Mr. Dedan noted that a patient with a lot of health issues, respiratory problems and anxiety, may come to the clinic weekly for care, yet in the past they would also go to the ER multiple times a week, 25 times a month. Working with that patient, through case management with their families, the facility now has that ER visit number down to zero, with the patient experiencing a better life quality. This was a 20 year old who aged out of parents' insurance and was unemployed with no coverage and qualified under an extended Medicaid plan. This was a life saver, Medicaid is an excellent program, and Mr. Dedan stated that he views the health centers as partners to improve patient care and reduce costs.

Linda Ujifusa, who identified herself as a representative for Physicians for a National Health Program (PNHP), stood to give remarks, which she noted she would also give to the staff in hard copy. She began by noting that PNHP is very concerned that there may be a cut to services among RI most vulnerable. The organization is also concerned that the selectivity of the data is problematic, as they believe the Group has failed to mention any federal revenues in any materials online. Recently a Robert Wood Johnson Foundation study has shown that Medicaid expansion state show significant savings and revenue gains. Ms. Ujifusa asked if the Working Group could look at more recent data, as opposed to older data, to see that the state isn't doing things that are redundant. She's concerned they may cut what does save money. She continued that PNHP is also concerned that the Group identified high utilization, lack of care coordination, expensive services and yet did not identify the multi-payer system as being a problem. The PNHP has proposed that a single payer system would be a solution, and there is a bill in the General Assembly now which speaks to their proposed solution. She believes that this Group has too narrowly defined the problem. Ms. Ujifusa concluded that she finds it disturbing that in the budget there are six strategies, seems like the Working Group are

being asked to rubber stamp something and she believes that is problematic. She underscored her point that all the work leaves out a single payer suggestion, and thanked the crowd for their time.

->Dennis Keefe, Co-Chair of the Working Group to Reinvent Medicaid joined the meeting, and welcomed the crowd.

Michael Rizzi came forward and thanked the Group for the opportunity to make a comment. Mr. Rizzi stated he would like to respond to the slide that referenced the triple aim, and would like to second the comments made earlier about medical home and health homes. RI recently, with BHDDH and the state Medicaid plan, created a health home for opioid treatment, which will be ending in June of this year. There are some things that are working and happening with the health homes, and he believes it makes RI a leader and innovator. The mental health service association, SAMSA, CMS, and other state regulatory authorities are looking at RI opioid treatment program as a model for the country. Next week a group Mr. Rizzi works with will be with Health and Human Services Secretary Burwell to look further at this program. He believes the current system does not foster inclusion which is why this treatment program and the health home is so crucial, as key staff as case managers interacting with primary care, and specialty care institutions. This helps patients in their organization to get the care they need that is welcoming and accepting. Mr. Rizzi stated that as this health home assists to have multiple prescriptions coordinated and manages patient cases carefully, admissions from hospitals are cut down. He asked the Group to help their patients understand and navigate the system, to get the care they need, to reduce the chance of relapse, to experience the care system in a healthier, efficient way. If this group is not going to emergency rooms, and not going into nursing homes, then Mr. Rizzi believes prices and costs will go down. He wants people to know that this program is working, and it is an excellent way to look at a program that meets all of the objectives mentioned here.

Mark Ryan, a physician practicing in the RI who is also with the RI chapter of Physicians for National Health Program (PNHP), stood to make remarks. Dr. Ryan stated that he has been looking at the data perused by the working group and proposed by the Governor and he believes it is wonderful that there are all these innovations in health care delivery. His main concern is that the focus is on health care delivery when the majority of the waste, in his view, is on health care financing. When one examines the data, he stated, RI spending is not out of line with the rest of the nation. The focus though has been on EOHHS data for RI and to Medicare expenditures nationally under CMS. Dr. Ryan notes that when one reviews Kaiser Family Foundation data, and CMS data to compare RI with the rest of the country, RI is actually in the middle of Medicaid spending for the country. With CMS wage data factored in, he stated that the state actually scores lower on Medicaid spending. Dr. Ryan contends that there is no crisis in Medicaid spending in RI and singling it out as a source of savings hurts the people who need help the most. Rather, he believes that an attempt should be made to seek out cuts elsewhere instead of cutting \$90 million here. House Bill 5387 is now in the General Assembly for a single

payer system. Dr. Ryan implored that the Group realize that in Canada they were piloting this program 40 years ago. Health Care is more expensive now; studies show more and more that there would be significant savings by using a single payer system. His suggestion is for the working group to look at single payer systems. Defunding Medicaid, he believes, is not going to improve health care costs in the states, reducing their funding will not help them, fixing the system will. Avoid fraud and waste by private health insurance companies. Dr. Ryan said the Group should consider looking at the private insurance agencies to avoid interfering with the care needed, along with private mental health providers who do not accept Medicaid. He asked that the Group not make it more difficult, not hurt those seeking care, and concluded by advocating for RI House bill 5387, to fix healthcare for all RI.

Murray Blackadar came forward and identified himself as a member of the RI Organizing Project, and he stated that working with the advocacy group Senior Agenda, the project has conducted fifty three house meetings with about five hundred people. The strongest message they have received is that older people hope to remain in their homes, long for the kind of support systems, family, communities, that can make that possible. Two stories he wanted to share come from senior residences. The first from a woman named Joan in her 70s holding a clerical job in order to stay in her home. She knows the systems will allow for her to continue in her own home independently. Her adult son was brought with her, nearest relative living with her, and she wanted to have him here in order to help her cope. The second story is about Betty, a woman in her 80s who lives with her daughter and grandson, essentially alone all day long, and her concerns focused on issues of transportation, and open hours at the nearest senior center. Betty had been feeling isolated, as her daughter can provide her a home, but not the companionship she needs. Senior Agenda responded to stories like these by working with state legislatures on Meals on Wheels, respite care, etc. They recognize and want to emphasize that keeping seniors in their homes with their own families must be a high priority. Mr. Blackadar stated that these are real life issues that are complicated, involving planning and budget, and there is not a single solution, but rather a number of interrelated solutions.

Dorothea Lusignan followed and stated that she is also a member of the RI Organizing Project and Senior Agenda and wanted the crowd to know that their primary interest is to try keep people at home, majority of which they know really want to stay out of the nursing homes. A patient Ms. Lusignan knows had to have two ankle surgeries; Medicaid paid for surgeries, but this patient did have to be moved to a nursing home. This person was unhappy there as she was well of mind, and thus she signed herself out, despite having trouble getting around. She cannot afford to pay her copayments and Ms. Lusignan stated she thinks a small amount to increase the Medicaid outreach program can help those who really need it. The aforementioned patient has family members who are

always working, and thus relies on people like Ms. Lusignan to transport her with unexpected medical issues, needs medication etc. The patient needs people to help clean her house but cannot afford the cost. She has a small pension that stops her from receiving assistance, and she does not wish to go into a nursing home. Ms. Lusignan concluded that she strongly believes there should be more dollars for home care.

Ann Maria Folcarelli stood and informed the crowd that she works at Thundermist Health Center as a social services case manager, and in her work helps people with all sorts of issues who need assistance. She told of a family of four with a father who lost his job, spent savings, unemployment benefits, and had lost their insurance, but because of the Affordable Care Act they now have access to insurance. The children have access to services, care. Then she relayed the story of a gentleman who works a low income job, for years he came to Thundermist, where they gave him the best of care, but there were things he lacked; he couldn't afford bloodwork, if he ended up in the emergency room he had no coverage. This individual has coverage now because of Medicaid expansion, he still comes to Thundermist but he can get his medications, he can get bloodwork. It's a great thing. What is important, Ms. Folcarelli stated, is helping people who need it. Individuals who have conditions need care – in the long run it saves them money and saves the state money as well.

Karen Mensel stood and stated that she is neither a healthcare professional nor a recipient, but works with the woman's policy group, and stated she would momentarily defer her time to the Executive Director at Senior Agenda, Bill Flynn, briefly. Ms. Mensel stated that Medicaid is of critical importance for older women, the largest group of elderly in the state, make up 60% of those 70 and older and in her findings, sicker than men while not being as well off as men. She continued that data shows 76% of the nursing home populations are women, and if she recalls correctly two thirds of Medicaid spending in RI goes to nursing homes. She would like to see the Group give some attention to reallocating the resources for seniors, move funding to home care services, community services, as they don't want to be in nursing homes if they do not have to be, and Ms. Mensel stated that nursing homes should not be used as warehouses.

Donna Germani, who chose to identify as a concerned citizen who wanted her story to be heard, told the Group that years ago she had a great job with healthcare benefits. Then one day her daughter was raped by her father. They wound up at WellOne, with Medicaid. Ms. Germani stated that Medicaid and WellOne saved her daughter medically, physically, and financially. They saved her and she is doing well today. Thanks to Medicaid expansion, she now has medical coverage. Thanks to this, now she has the chance to have a mammogram, to have a chance to live.

Bill Flynn with the Senior Agenda Coalition stood and stated that today he wanted to talk about things not covered in Medicaid that should. He noted that he believes there are lessons from other states, one fact that is incontrovertible is that eighty two cents of every Medicaid dollar is spent on residential care, and nursing homes, and hospice. Eighteen cents on the dollar is spent on long term care (LTC). The national average is thirty eight cents on the Medicaid dollar on LTC. Mr. Flynn noted that a managed care system can work if it is done the right way. One of the keys to some of the states who are doing things well in his eyes are those that have case managers who are in the field to see what are the true needs patients. Mr. Flynn spoke of a friend, June, who had surgery for her hip and went to a nursing home said that her care was just enough to sustain her. When she came home from the nursing home, somewhere the ball was dropped. She became bed bound. Eventually Mr. Flynn helped her apply for Medicaid, and she is now in the PACE program. She is now bed bound and in the nursing home because of a lack of care coordination. Better care coordination needs to be looked at. He stated that there is a managed care initiative already underway, but he believes the group needs to look at it further. Mr. Flynn expressed that he believes there are two things this Group can do, one being to expedite the processing of eligibility for Medicaid. He gave the example of Washington state as a good model for this as they have a fast turnaround on presumptive eligibility. For those with the greatest care needs should be able to garner a faster decision on whether they qualify for Medicaid is crucial, or else they may go into a nursing home. Mr. Flynn asked the members to take a hard look at expedited processing. He also requested that they look at the overregulation of home care. He referenced his concerns with RI shared living regulations, noting that if someone moves into someone else's home, provides care, it is for people with high care needs. An agency that runs a similar program in Massachusetts has found it still cheaper than nursing home care, and Mr. Flynn stated that regulations in Massachusetts allow folks to get into the program quickly, whereas in RI participants are required to obtain a TB test, an annual physical, and a whole host of other things, and then face a slow turnaround time on applications. One of the principals of the architect of long term care in Washington is that consumers should be able to trade some degree of risk of home long term care. Mr. Flynn concluded by stating there is a case for trading managed risk for greater choice.

Jean Beahey, stood with her son Brendan who she advised was here to talk about the need for services for people under Medicaid with mental health disabilities. Ms. Beahey Read the following on behalf of her son, "I hear that you are going to make cuts to fund affordable care. It makes no sense to cut programs in existence for people with disabilities. I, Brendan, was born with vision impairment, hearing impairment and some orthopedic issues. I use RIDE, live in a supportive health environment, and have Medicaid as well as federal coverage under [Ms. Beahey's husband]." Ms. Beahey stated that the family Brendan lives with has stated that if the stipend they receive is cut, they

can no longer afford to care for him and Brendan does not want to move back home with his parents. She implored the group to please not make cuts to day programs or disability support programs. It would only hurt those who need it most. Ms. Beahey stated that she works for CrossroadsRI, she teaches job readiness skills, and she sees the needs of her clients. She doesn't know what the state can do, but she stated she knows that cutting existing programs is not a great way to go. Years ago Governor Carcieri looked at the 1115 waiver program. Ms. Beahey stated that while it was supposed to help, she looks and sees that the state is back at this table again.

An unidentified attendee stood to make two quick points, requesting the Group do not look at cutting services for people with disabilities as those are already underfunded. Also, the person stated that cutting reimbursement to psychiatrists would be problematic as would reduce that pop to almost zero for the Medicaid population.

Pat Mackey who identified as a registered nurse stated she has worked in the community, with visiting nurses for most of her career. She stated she speaks from experience and education, and expertise when she talks about what she thinks the state needs. Ms. Mackey remarked that she wouldn't be so glib to say one cannot Reinvent Medicaid, but there are programs that work now, case management, care management, that are working. She told of a recent situation she encountered in her work: a young man Ms. Mackey met through his doctor to see if she could provide assistance. The young man was homeless, left the hospital, and had a follow up appointment with serious medical problems, surgical issues that needed to be address, coupled with psychological problems. While he was in the hospital, all of his care items were thrown out by the shelter he was in according to regulations. Medicaid had already paid for his prescriptions that month and despite their being tossed they would not be paid for again. Homelessness was his greatest challenge, but his medical needs were also significant. The medical health team found him an apartment on Craigslist, funding pulled together from CAP agencies; while she states that this young man is certainly not living happily ever after, he is stable, in his apartment with the things he needs. He is not going to the ER every other week, and his care costs have gone way down. These are the kinds of things that nurses and community health teams do every day. The staff is devoted; she stated that years ago if someone was homeless or needed help, it was a matter of steering them to the right place to get those things. Now services are so tough to get that it takes a whole team working very hard to make an impact. Ms. Mackey noted that she is proud to have a career in this work and thanked the Group their time.

Virginia Burke with the RIHCA stood to speak. Ms. Burke stated she wished to second the concern about the amount that providers are paid. RI may have a high per enrollee cost, but, she contends, that number doesn't tell much. There are a lot of healthy kids compared to others, and a lot of older seniors that Ms. Burke states skews the data. That

same report that has RI 2nd to Alaska has information on how much Rhode Island spends on each category. Ms. Burke does not believe that we are overspending on the elderly rather, the state is underspending. She noted it is painful to hear two ends of the LTC services pitted against each other. The two sides agree that home care is important, but if the service is needed it is key that whatever care provided is the best possible. Nursing homes have to have people to cover the building, the food, the heat, the nurses, the staff. She notes that though this may sound like industry spin, make up the shortfalls on Medicare payment. Nursing home care is underfunded. Ms. Burke stated RI needs to spend more on resident care, and spend more on homecare. Both ends are underfunded for those who work hard, and are compassionate and dedicated in their work. Reinventing Medicaid if it can reduce people at nursing facilities and reducing costs great, but she stated that paying less for the same services would make it worse.

Steve Roth, local physician at a community health center stood to relay a patient story to enlighten the group. An 11 year old patient hurt her ankle on a Sunday. Her mom took her to the emergency room since the mother works on Mondays, and she knew the child could get the necessary x-ray at the hospital. What she did not know was that if three questions had been answered by a provider, that child may not have needed that x-ray. Access to a primary care doctor or extension of a practice would ensure the child would get the care she needs, rather than the care people think they need.

Tara Mconaghey stood and noted she works with South County CAP, and FCCP. She stated that she believes it is not that there needs to be spending more, or working harder, just smarter, and implored the group to avoid waste. Ms. Mconaghey stated that they should not waste all the training and the informal infrastructure building that the FCCPs have built over the years which are strong networks that reach across doctors, private therapists etc. She believes her work can help make services more effective, reduce no show rates etc. There is staff out there working with the families, helping the providers be more effective with the individuals they serve. While she noted that she did not have the numbers on investment in training of wrap around supports, she did want to make a pitch for not wasting the good work being done. If there was a small program for the top 9%, the super utilizers, a super team for the super utilizers, then she believes it would run it faster. Ms. Mconaghey suggested a single facility perhaps to work with someone like a patient, a 14 year old girl out of a residential program. If that girl is placed in kinship custody, and the mom is working on a recovery plan to get her stable to bring the daughter home. That said there will be a period where mom will be on public assistance – their organization will push for job training track; work with the criminal justice system to keep her stable, but that now 15 year old could end up pregnant, and that results in truancy issues, health issues, etc. The point she wished to make is that their organization work with everyone, with many of these issues, across different providers and it is clear to Ms. Mconaghey that community based services are key. She concluded by asking that the Group keep all the investment in mind, don't let the work done go to waste.

Patrick Quinn, a member of the Working Group to Reinvent Medicaid, stood to say he would like the crowd to know he would say spend more for all direct care staff. Mr. Quinn noted that many working in home care should be paid a living wage, for home care is cheaper because the people working do not get vacation, or higher wages. He supports home care, but he knows that one cannot not dodge this bullet and think that suddenly oodles of money will be saved. The state is buying direct care services in multiple different areas, whether a home, a DD facility, a nursing home. These people working there, Mr. Quinn continued, should be paid a living wage to support themselves and their families. In hospitals it's challenging as well. Mr. Quinn noted that he thinks people have executive talent, and to recruit and retain them at a top level they do need to be paid a decent wage; but he stated that perhaps that should be capped at a per client or per consumer number. Mr. Quinn advocated to not over pay executives, and that more money spent should go to providers, not offices.

An individual came forward who chose not to identify herself, and stated that this state has lost a lot of its behavioral health services. Whatever funding that has been allotted to this part of the state has been cut, and as such she finds that as much as behavioral providers are not participating in Medicaid that result in a double whammy of cuts. The woman noted that Vermont received a waiver to do more community living for its seniors and asked that the group look into the result of that waiver.

Kristen Clark stood to speak and advised the crowd that she has a young adult son with Asperger's and some other issues. Through the time of the diagnosis, when he was ten, and going through school the family had to become involved with Bradley Hospital and work to get a psychiatrist. Clark stated she wished to reiterate some things she heard tonight. She stated that her son's friend had the same psychiatrist for years, and this man who was a positive role model in their life, had to leave the state because he couldn't keep his office open as the reimbursement rate was too low. She noted that her family will not put her son in a group home – for while there are always good people – they believe there are a lot of others who are transient and looking just to make some money and are gone. It's an environment she feels is not safe for her son. She stated that she wants the lowest functioning people to develop and contribute to society and to achieve that everyone has to work with them. Work with a service agency, with the state, because everyone feels better when they take care of him or herself, contribute. Ms. Clark concluded by stating that cuts terrify her, and it angers her when she reads that the state can give seventy five million to one person for one business which fails. She encouraged the crowd to think what could be done if seventy five million was given to help the needy in the state.

Conclusion:

Dr. Wilson, Mr. Keefe and Secretary Roberts thanked everyone for coming out tonight, and thanked the library for providing the space for this important meeting to take place.