



Mental Health and Disability Services Redesign

Clinton, Iowa Listening Post

Source: Public Comments
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*These public comments were captured during the Clinton, Iowa Listening Post that took place on February 24, 2012. Division Administrator Rick Shults represented DHS. Any case specific materials that were provided publicly were done so by family members. Department responses provided to the consumer and/or family member as a follow-up to a question asked during the meeting are confidential. In addition, the responses are as accurate as the date they were given.

To learn more about the Mental Health and Disabilities Services System Redesign legislation, visit this website: <https://www.legis.iowa.gov/index.aspx>

Comment: Brain injury consumer asked if services for brain injury (BI) victims will include funding for more than one test.

Response: BI services are in its infancy. A Brian Injury Workgroup is currently working on refining recommendations for services and is working on costing out the estimates for services.

Comments: Will services be the same in Clinton as Dubuque?

Response: Yes, the idea is that mental health and disability services system (MHDS) is the same across the state. We are looking for consistent services across the state. There are some areas that go above and beyond what is recommended as the core services, but everyone will have the same basic core services.

Comment: Consumer asked about the \$26.1 million from the state. "What is different from the state sending counties state funds and the state actually having the funding?"

Response The Governor's proposal is to do away with the billing back and forth. In order for the county to send back the state money, the counties are also sending an additional \$26.1M in additional county funds. If the legislature's recommendations are adopted, there would be no county tax

money coming into the state and the counties would be able to keep it all.

Comment: You talk about the \$125 million but you're taking away services away from my son who has a brain injury. Are you taking money away from local services to fund institutional services?

Response: We want to see Medicaid continue to pay for community – based services so that the funds could be moved for more non-Medicaid services. It's a matter of simplifying accounting processes, but individuals who receive county-based services would continue to get county-based services.

Comment: Very impressed with the idea of providing equitable care throughout the state. I have dealt with issues as a teacher, parent and friend and am frustrated. One problem we have is that we have a hard time recruiting qualified people to deliver the services. How are we going to recruit people to fill these positions?

Response There is a serious concern about workforce. Iowa is 48th in the nation with psychiatry and there is no question that we will continue to struggle with that. There are two things that would help. 1) Peer Support: having peers will free up professionals to do more than they were specialty trained to do. We are looking to provide additional training for direct care staff through the College of Direct Supports. 2) Next piece is a little more difficult trying to get adequate staff to come to Iowa. To address this issue, there is a workforce taskforce identified in the bill that would study the issue and make recommendations.

Comment: As a provider, I think lack of sub-acute care is the biggest problem. You said it's down the road. How far down the road?

Response: That's an interesting question and it depends on financing. If the Redesign Bill passes in the form it is in now (both House and Senate) it would help accelerate the delivery of services. We want sub-acute services whether you are in the hospital or not. Assertive Community Treatment (ACT) is a form of sub-acute envisioned to begin in fiscal year 2014. People are very excited and pushing the envelope to move the plan along.

Comment: HCBS (home and community-based services) providers are incapable of policing themselves. DHS doesn't have funding

or power to do so. I have a son and am concerned about his medical treatment. I wanted him to see a specialist instead of a DO. Ran into criticism because they said he was under his parent's influence because I'm concerned about the well-being of my child. In 2008, my son was moved by Community Care from DeWitt to Eldridge and they never turned off the utilities in his apartment and he had to keep paying them. I don't think these people are doing a good job. The system needs a thorough house cleaning, not a pat on the back.

Response:

One of the aspects of MHDS Redesign is the improvement of the effectiveness of the regulatory oversight of the providers. There is an amendment for DIA (Department of Inspections and Appeals) and other oversight agencies to examine all processes and become better at what they do. I understand that substandard services are unacceptable.

Comment from
Rep. Mary Wolfe
Clinton County:

I was there when we did pass House Study Bill 646 out of the Human Resources Committee. I want to thank you for being here. There are some concerns with the bill and it is very much a work in progress, but I did vote yes to move the bill along. The House plan does away with CPC's (county point of coordination) and this leaves the issue with how local people will enter system. Many people don't have access to transportation many times when having problems and they don't know who to. Today the local point of access is very good in Clinton. What will happen?

Response:

The key here is that services will be delivered locally with a local point of access to services. The role that CPC's play will still continue to exist and be a critical component. Only the business functions would be regionalized. Things that have to do with people will occur where people live. Things that have to do with business will occur centrally. The term CPC is taken out but the function is envisioned to remain.

Comment:

I didn't notice anything about funding for staff training. Money isn't there to properly train staff on how to deal with people with a mental illness or brain injury. I also notice that when a new case manager comes on board it is difficult to access the consumer option choice with that person. It has been a confused mess for a lot of them. Medicaid Enterprise (IME) is starting quarterly training and the first training just happened. But I heard the state cut funding for this training? Without training problems will just persist. Also when it

comes to funding for transportation at the federal level, I heard this was in jeopardy. Has there been any progress on keep transportation funding in place?

Response: I will take the concern about training aback with us. One of the significant items identified was the expanded use of College of Direct Supports. This is a national training forum. The Redesign Bill in the Senate would establish standards for direct support staff. In terms of transportation at the national level, my limited understanding is that the transportation bill, often thought of as the roads and bridges bill, is currently being held up by one section that allows funding for local transportation services and there is controversy on whether this section should be removed. To my knowledge, nothing has been decided yet.

Comment: The infoNET newsletter states the Governor hasn't recommended enough money to pay for Redesign, and there is not enough in the budget to sustain current services (<http://www.infonetiowa.com/>). Could you address this issue again?

Response: The Department (DHS) issued a [Final Report](#) where we identified where the MHDS funding could be spent. 1) DHS identified possible sources for the \$125M needed for non-Medicaid services. There was no consensus on where the money should come from but there is a consensus that it is needed. The observation that the Governor did not put enough in the budget is the difference between what DHS priced out to buy-out Medicaid. We identified that amount was \$42M. The Governor concluded to buy-out Medicaid was \$26.1M. People are looking at buying out Medicaid all at once versus over two-years. The numbers are pretty close to what the legislatures put in last year. Now the issue is how much do we need and how quickly do we need it. No one is saying that the system is overfunded. We definitely need more.

Comment: I am an advocate and mother of a mentally ill child and am raising two mentally ill grand children. It is difficult to get into the system, and once we are in the system, will we stay in? Also, I echo that we need training. We also need peer support services ranging from young children to adulthood. We need to develop support systems from very young throughout a person's whole life.

Response: That is a good observation. The College of Direct Supports is currently focused on the intellectual disabilities population

but they are looking to expand to train direct care professionals on dealing with consumers suffering from mental illnesses. Life-long supports are critical for children and we have a challenge to create one children's support system. The Children's Workgroup will continue for another year and has been given the charge to address the very issues you are talking about. Today we don't have all the answers but we are making progress.

Comment: Today there are an estimated 2.7 million grandparents raising grandchildren. We (grandparents) need support; we need help with these kids; and we need funding with their care programs. Long-term this will bankrupt you but we need across the board support. We would like to see something addressed for when kinship or grandparents' adoption would qualify for MHDS support. Big enough battle already and having to wait for services makes it 100 times harder.

*Note: There is a support network in Clinton for grandparents raising children that meets on the 1st Sunday of every month from 2:00 pm – 4:00 pm at First United Methodist located at 236 7th Avenue South, Clinton, Iowa. For more information, contact Shirley at 563-243-5978, Marge at 563-242-8566 or Anna at 309-292-7790.
(<http://www.dhs.state.ia.us/docs/GrandparentsUnitedForPositiveChanges.pdf>)

Response: Thank you for your advocacy.

Comment: With people with disabilities, how much can they work? Is it between 15-25 hours per week? If you work, you risk losing medical but otherwise I couldn't pay for the meds.

Response: Yes, most certainly. One of the things you've hit on is benefits counseling and finding out what you qualify for such as ticket to work programs. You bring up a good point that ties back to needing adequate training for case managers. How do you bridge that employment while you're getting the support services you need? We need to make sure that consumers know what programs are available for you to get employment. This is something we need to work on.

Comment: I work in residential care and am also an advocate. I have been working in the field over 30 years and have seen a lot of changes. I am concerned we're making plans for changes without having the money to implement them. We're already losing funds. I heard residential care is not part of the

Redesign. Scott County has great services. What services are being cut?

Response: The point of Redesign is to maintain the existing array of core services. You won't see a specific name of a service in code but that doesn't mean it is done-away with. We are interested in continuing progress in transitioning for more and more people to live in their own homes and for more people to live with jobs. In terms of adequate money, as we move forward it is becoming clear that any change is affecting different counties in different ways. Some counties outside of Redesign have serious money challenges; structural challenges in system that we need to address.

Comment: When does Redesign take effect? Scott County is facing program cuts around \$375,000 due to money shortages. Any thought to supplement us through last quarter of this fiscal year so we have money for next fiscal year?

Response: The Senate's version of the Redesign Bill establishes July 1, 2013 as the start. But some pieces of the plan are already beginning. There are some funds left in the risk pool. There are talks about what we can do with the money to help people out. It is difficult to distribute funds to where they need to be in a fair way. In the current system, it is hard to line money up with where the problems are. The Senate is working on this now.

Comment: I think the MHDS Redesign is really great, especially because it will provide services at the local level. How will you do that? How can you make sure there are core services where they live and make that affordable?

Response: You've raised a very valid point. Just as we don't have access to every service in Iowa, there has to be a reasonable access to basic services in Iowa. Disparity won't be totally eliminated but there must be a balance between effectiveness and efficiency. One advantage of regions is that there will be more access to services; regions will be able to share access with other regions. However, we don't want to overpromise; you won't have everything in your backyard.

Comment: How is MHDS Redesign going to help eliminate slipping back and forth from community back to residential? People get lost in the cracks and when they slip back and forth.

Response: Excellent point. This goes back to the oversight we talked about earlier. But if we join forces and come together in groups we can take advantage of joint competency training. The College of Direct Supports is a nationally recognized training program that trains care workers working with persons with intellectual disabilities. This requires investment with time and money, but doesn't require every provider to do the same training over and over. Joining together we can start sharing and building upon. This is something that we need to work on. I only gave one example and we need more programs.

Comment: I am a provider with well-trained employees. I need incentives to retain employees; yet reimbursement rates have not increased so it makes it hard to provide a living wage. So while I see dedicated staff, and I understand the concept of more training, I'm also really concerned about retaining those who have dedicated their lives to helping people.

Response: You have hit one of the areas that is a soft spot for me. It is very important that we have a way to support current health care staff and that should be an important aspect to workforce development.

Comment: What I'm hearing is a pipe dream right now. When rubber meets the road, money gets cut and programs get cut daily in today's society. I don't know what to believe. When you Redesign the system somebody loses in the end.

Response: I'm not here to dissuade you from your concerns; you need to keep them. I can tell you the way the system is currently operating is not nearly as efficient as it could be if we allow for saving from improved efficiency to get reinvested in the system. But yes, it depends on the level of funding. Funding is based on what the state is able to spend. A wise man said you should under promise and over perform. We should try to do that. Right now we have a plan laid before us that hundreds of lowans have committed to and the legislature is dedicated to making it happen and what you're saying is show me the results.

Comment: What is the vision of case managers?

Response: Regions would designate case management agencies that serve their region.

Comment: When you're talking about children and children's services one of the most frustrating things is that kids are aging out and falling through the cracks. How are you defining children?

Response: Below age 18.

Comment: When funding for Redesign will entities such as Magellan be the managed care company overseeing and managing those funds?

Response: What Magellan does today they will do the same job in the future, but they will be responsible for psych in-patient for children. The Medicaid program for HCBS waivers will be operated by the Department, while non-Medicaid services will be covered by the Region.

Comment: For folks that don't qualify for Medicaid are having difficulty getting medications. Many people can afford them. In our county we are helping people pay for those medications. What will happen?

Response: While this issue is current not addressed by the current Redesign Bill, NAMI (<http://namiowa.com/>) is raising this up as an issue.

Comment: I am a consumer who currently likes my services. Please don't mess it up.

Response: So what I'm hearing you say is...don't mess it up right?

Comment: I am a consumer of services. I received services through community care and my experience was wonderful. I'm on SSI disability and am working not even 20 hours each week. It depends on how many units you are receiving each month. I would have the guy who has questions call his case manager.

Response: Once again, we need to make sure case managers have right training including how to help consumers get employment in their community.

Comment: What happens to durational legal settlement?

Response: With Redesign, there will be no more need for durational legal settlement. Where the person resides will be where the services are paid. If the state takes over Medicaid, legal settlement is off the table. You simply need to be a resident of Iowa and eligible for Medicaid. For folks getting non-Medicaid or not Medicaid eligible folks would move to residency and the area where you reside will be responsible for funding services.

Comment from Rep.
Mary Wolfe

There is a big concern for border counties if people move from out of state they must live in the county for a year before paying for non-Medicaid services or they become a state case. Under the House version, even if a person is here for a day the county has to pay for it. The problem is with the transitory population. It is hard to budget for this group. There is also a concern that Clinton has a reputation for having good mental health services and concerns that people will come here because they don't like the services they currently get so they will move into Clinton for services. On one hand Clinton is concerned with the ability to provide great services. We need to fix this. I will not vote for a plan that has this kind of residency definition. The Chair is working with it. The Attorney General has a lot of concerns about the current definition as well. I think we'll see some changes on how Redesign defines residency.

Response: The way we priced out the plan in the Dec. 9 [Final Report](#) is to take \$12.5M spent on state cases and give this money to local administering agencies. We did ask ISAC to start making a list of questions that we can start working on. These are very important questions with potential issues that need to be resolved.

Comment: I had problem when I moved from Illinois. I had to wait a year before I could receive services, but when I moved to Scott County this was different.

Response: That is one of the issues we are trying to address. We need more immediate access to services along with more funding.

Comment: How will legislatures inject funds to start to develop new core services? When would funds be available?

Response: The conversations in the legislation mirror the plan the Department laid out. There is a basic set of core services that are pretty much what is delivered now. Expansion would only occur when funds were available. We laid out a

schedule that is built out on when we believe funds will become available.

Comment: DHS case manager in Davenport said that one thing they are dealing with being right on Illinois border is they have many families with kids in Illinois with disabilities. Illinois currently has 20,000 people on waiting list for waivers. People are planning on moving over to the Iowa side. We are getting more and more referrals from ID (intellectual disability) waiver kids from Illinois. These kids become adults and then they the county has to pay a certain share of services. My concern for Iowa is that there is only so much money. At what point do you end the waiting list?

Response: We have waiting lists now but not as large as other states. The Legislature is going to provide additional funds to buy down that list. Next year we will continue to work on that. Your observation is just a fact of life. We will always be challenged with this.

Comment: How does substance abuse treatment fit into Redesign?

Response: There is not a lot done with the exception that one key element we need to develop the capability to serve and provide services for those with co-occurring disorders. The next phase is to collaborate to make sure that happens. We can go further and should go further.

Comment: We're getting 5-10 calls a day looking for an inpatient bed. What will change the need for beds?

Response: It's going to be extremely hard work on everyone's part but we're going to get there. We need to make sure people are where they need to be and only there as long as they need to be. That includes all the service levels including sub-acute, crisis, peer support, etc. It also includes pre-commitment screenings, which has decreased the need for beds by 40 percent. Today, we get calls that a person is ready for discharge but they don't have anywhere for them to go. This needs work.

Comment: This is a multi-generational, long-term problem. This is a long journey and they fall through the cracks in between. Are we looking at this as long-term? Not just the next five years but next century?

Response: There is a group of people whose needs can be met with isolated episodic treatment. There are other individuals with

chronic conditions that that will need life-long support. What we need to do is provide better support for this effort to provide long-term services and supports for both where we live and where we work.

Comments: I want to emphasize the situation of workforce shortage at the psychiatric level. When a hospital closed its unit for a while, they came up with innovative and inexpensive ways to address needs such as tele-psychiatry. Not sure we have the people to provide needed services such as pre-commitment services. There is a shortage of professionals critical to making this Redesign successful.

Comment: I am a county supervisor. Thank you for coming here. There is un-uniformity in level rates from county to county. Will there be uniformity in Regions? One question is that as individuals move across the border into an Iowa county, would the state recognize the person moving into Iowa and could the state become responsible for the individual immediately?

Response: We have money for state cases and we want to give it to local administrators. How do we know what is the right amount? We need to continue working with people such as you to answer this question. We also need to continue working out how equitable distribution of funds happens. This could come from the state. This is not our call but someone else's call.

Comment: I've had experience over past year where there are times I'm in crisis and go to ER. You get interviewed and they ask you if you're a danger to yourself or others and if you say no they send you back home. It encourages people to lie to get help. We really need some support in between the home and the hospital. This is an observation I have that needs to be fixed.

Response: I really appreciate this observation and it helps me to hear you say it. It is really important to ensure people get the support they need, where they need it and when they need it. We happen to be calling this crisis services or subacute. It doesn't matter what the name is, you've identified an area where we need more support and services.

Response from
Office of Consumer
Affairs:

This is an area that peer support training and peer support services can become critical. We need to have them in the

hospital when they need it as well as have peer support to help them before they need to go to the hospital.

If you have additional input that you feel is critical to consider in the redesign process, please email your comments to: DHS-MHSRedesign@dhs.state.ia.us.

If you would like to learn more about the Redesign process and follow the progress of the workgroups, visit: <http://www.dhs.state.ia.us/Partners/MHDSRedesign.html>.