# Public Comments Received on Person-Centered Planning Practices

April 10 – April 30, 2017

# Contents

## Comments received by email

1. **From state or local government staff on 4/10/2017**
   While I agree that Person Centered thinking is admirable, as a Tax Payer--Have you seriously given this a thought as to HOW this could possibly be paid? I live on a budget and what I cannot afford, I must go without!! Please reconsider your planning for everyone's individual living, this is just NOT SUSTAINABLE. Thank you for listening.

2. **From family member of a person with a disability on 4/11/2017**
   Why are you asking about Person Centered Planning, when too many professionals are not at the level of using Person Centered Thinking? You will get an answer but are you asking the right questions? Person Centered [thinking] Planning has been around since 1987. When anyone uses the Person Centered Thinking and Planning for all process' it has incredible outcomes. Why you ask? Because the services are individually tailored and not just put in a wasteful lump of "things" that can be wasted and I say wasted because it is not helping the individual to gain "Independence, Productivity, Self-Determination, Integration and Inclusion". Will everyone reach this goal maybe not but everyone is at individual levels and need individual supports in individual ways. One shoe does not fit all.

3. **From a family member of a person with a disability on 4/12/2017**
   Hello, I am commenting on person centered planning in MN. The person centered planning I have seen is useful but nowhere near what it should have been. As I see it, person centered planning is a civil rights issue. Used correctly, it gives the person power to design a life of their own. The person invites who they want, they bring up subjects important to them, and they know they can call his group together again if needed. These are people who help the person work out how to build a life of their choosing, not people who put someone into a program or help them fit into a program, although sometimes that's exactly what a person needs and wants.

   The PCP meetings I observed, it was obvious these were not just friends chosen by the person. They were all the service providers and one or two friends and family. If you say that the fiance' and prospective mother-in-law were family, then no friends attended at all. There were no graphic artists. The person did not lead their meeting although the person was completely able to do that with just a little support. It was a nice meeting, a little tear-provoking, but so far hasn't inspired a lot of action on anyone's part. In fact in a couple of situations the providers were more deeply entrenched than ever, blocks to helping the person even larger.

   The social worker scolded me for being off-subject when I thought I was right on the subject the person wanted to talk about – housing options. But a big provider was there and that provider was already providing services – services that the person did not like for a several reasons – and the family was worried about changing to any other. There were three or four people representing that big provider and one of me. I was effectively shut down. No other options were discussed. That's OK, the person will make it happen some other way. But social workers should not be scolding participants – the facilitator should take care of any of that.

   Also it was run very much like a typical "meeting". No snacks, no social opportunity. Worst thing of all – it was expected to be a one-time event. This one and done. PCP was designed to be the way the person manages their life day to day, and within their control to be able to call people together as they wish or need.

I think, as well as these so-called “trained” (I don’t know what kind of training they could have had) facilitators did, any person could replicate this. They didn’t seem to display any special talent. I don’t see evidence of PATH training or ESL training or anything – just someone who went from one subject to another leading the group’s discussion. A bunch of papers stuck on the wall, but not a butcher paper with graphics. Writing that I couldn’t read on it. She tried to get the person’s input, but he clearly was not leading the group. He didn’t think he was in charge and he didn’t think this vehicle, structure would be available to him in the future any way.

It was such a disappointment. Person Centered Planning can be a real revolution if it is done correctly. I’ve seen teams totally turn around from fractious groups to teams following the person’s lead united in their direction, or from teams that aren’t going anywhere to teams that are churning out natural supports of all kinds (because lots of friends and neighbors were invited), or teams that don’t know what to do, to teams that are really united in how to support a person because everyone tries to see things from the person’s point of view all together in one group – not providers, but regular people, neighbors, church members, etc.

It could have been an example of how to tap friends and family for more support, for how to get the person up in front and leading everyone, or how to unite behind the will of the person who the meeting is about. It could have been all that and more. MN spends lots of dollars but forgets to spend time stimulating, generating community resources. But what it really was, an intractable large group home company, a couple of meek parents, a person, while very verbal but uncertain, with a facilitator who did most of the work. Me, I wasn’t going to open my mouth anymore, not after the criticism. Other people weren’t talking much.

I’m so sorry to be so negative. On the other hand, in the past I have some wonderful person centered planning – [redacted]

What I saw was highly expensive service ($800 – much more than it was worth – I haven’t even received any notes yet and they promised them – [redacted] the same-old Minnesota top down system.

PCP should be a required method of agencies serving people with disabilities not a service so rare and expensive and poorly done that it is useless. I predict Minnesotans will lose interest in a year or so and move on to some other thing. No one is building it into the system.

4. **From a STAR Advisory Council member on 4/12/2017**
Person centered planning is depend person’s situation. For example, I don’t have hands, I need to survive, be a human and find opportunity as normal person who is not disabled. Therefore, I must plan and change my condition and find a path which can lead me to good outcome. In order to change my situation, I need following sample

I must identify my need to develop and adjust, educational environment for better care to suit my preferences vision for my future life.
I have vision for my future and find supporting environment and move it in that direction what I want to accomplishes.

I have to discover effectively aspirations, capacities and by exploring resources that I can gain power to survive and overcome barriers.
I have to Identify and explore what is available for me and network and resources that is useful for me.
I have to put my plan into action to achieve through development making my future real changed.
Education with supporting environment is one of the factors that can change person's center planning without discrimination or looking down.

5. **From a county worker from Douglas County on 4/17/2017**
After working at the county for 22+ years it has been invigorating to be a part of PCT. PCT skills/tools are very efficient/helpful in getting below the surface of people's needs. I recently completed a Person Centered Description with someone I have worked with for many years. She was SO much more engaged in that process than I had ever experienced when completing the necessary/required six month ICSP paperwork with her. The challenge I find is pulling these tools into the current paperwork requirements we have to do, such as the ICSP required by AMH TCM services. In my conversations with coworkers, with other county AMH TCM workers, It is easier for them to keep doing what they have always done because that is what they know how to do. It is hard for people to add to the paperwork they have, even if that change will result in them working faster or get to better information. People are swamped. Until the system encourages counties to move to PCT, incorporating these practices will continue to move at a snail's pace. Private providers are doing a much better job of changing their paperwork requirements to support PCT practices.

6. **From a service provider from Ramsey County on 4/17/2017**
I appreciate the attestation document as the administration of my organization had done no prompting or organization to document the work we do on person centered practices. The administration has done no updating of the entire staff and those of us who are aware found out by doing independent research or signing up for DHS updates on our own. Although I understand the switch in practices for providers across the country will be difficult, it should not be and any provider who is not able to show proper documentation should have significant consequences for the provider as the Olmstead plan is critical in getting each individual with disabilities the quality of life they deserve rather than the lowest common denominator.

7. **From a service provider in St. Louis County on 4/17/2017**
I have always tried to be person centered and included my residents in their plans and I'm happy that things are turning this way. The only concern that I have is residents that choose to move when they aren't really ready and explaining that to them isn't working because they know they have that choice and we can't stand in their way. I never liked having to put hands on a resident because I have always told my staff to treat them as if they were family and how they would want to be treated so I am happy with the change to that but that does overload the assistance given by the local law enforcement, not by us so much but I'm sure by others. My residents are pretty mellow and respond well to verbal direction.

8. **From a family member of a person with a disability on 4/17/2017**
I worry about the limitations placed on providers and the lack of ability to set healthy boundaries on the individuals with disabilities. They have a disability and need boundaries and guidance. I don't see it helpful to say we cannot place limits on how many hours they play video games, or how many calories the take in or how many people they sleep with and hope that natural consequences will take care of the situation.

9. **From a foster care provider in Dakota County on 4/17/2017**

   I am a foster care provider in Dakota County. I have been a provider for the past 13 years and have seen many changes over those years. For the most part I agree with most of the changes and movement toward person-centered planning and participation and have worked within my program to be as person-centered as possible; including getting all the training I could work into my schedule. My issue is with settings such as mine and the issue of privacy and allowing residents to basically do whatever whenever they want. I don't look at adult foster care homes as an apartment setting, but rather a boarding situation since all residents, the provider and the provider's family have to share the same common areas. If one resident decides they want to have visitors at midnight then it affects all the other people living in the home. How do we assure ALL residents privacy and rights when each one can do what they want? I have had some residents over the years that wanted to be up all night playing loud music and having friends over through the night while my teenage son was trying to sleep in the next room so he could get up and go to school. I have had some residents who worked. What do we say to those people who want to share space and live in this less restrictive (but with the needed supports) setting but need to be able to sleep during the night? It seems suddenly like I am not allowed to ask anyone to quiet down to protect the others in my home. I am unable to tell a resident who has a drug problem that her drug dealer cannot come onto the property (even though my county licensor has required that). Thankfully this particular issue is no longer a problem in my home. However, it will affect who I will agree to provide services for in the future.

   The discussions I have had with other providers mainly centers around safety and the well-being of ALL residents in the home. Our concern is that there will be incidents where someone gets hurt due to a resident not being able to make good safety decisions about who to allow into the home. What will have to happen before we realize we have moved too far in the direction of allowances and rights? Residents should have to comply with some basic rules for living in a situation in which they share space with other individuals. Even in that scenario each resident would still have the choice to move into that setting or some other setting that might suit their needs and wants better.

10. **From a service provider on 4/18/2017**

    Very hard to provide person centered services when wages are so low that we can't hire enough staff to implement person centered plans with single staff and 4 clients!!!!!

11. **From a parent of an adult with a disability on 4/18/2017**

    My daughter is developmentally delayed, cannot read or write, is on many medications, and works about 5 minutes in an hour. She is in a group home, comes home to parents every weekend, and works [redacted]

    She goes into the community with her home, with us and with her work [redacted]. I know the goal is to have her work and make minimal wage but she is not capable of doing it and is happy where she is. She is highly verbal, very social, loves to eat and kid around, but does not get along with many of her peers. She loves to help with others in wheel chairs and loves to do jobs she can handle, like getting the mail and taking messages to people at work. How can your plan possibly accommodate her? What I fear about the Olmstead Act is that all disabled people are painted with the same brush and I think it is great for higher functioning people but my daughter is not like that. I am not sure exactly what person centered planning would do for her and keep her in the safe and great place she is in now.

12. **From parent of individuals with disabilities in Rice County on 4/19/2017**
My concern with policy deployment regarding the Olmstead Act, is that solutions are based on an assumption that the DD population is more homogeneous that it really is. Our two sons with DD are ''asked'' for their opinion by social workers, and school administrators, because they have to ask. One son is nonverbal and autistic and has no idea anyone is even talking to him, much less understand the questions. My son needs 1:1 care on a 24/7 basis. A group setting is likely his best option for good care, but there is a bias against that. NOT EVERYONE SHOULD BE LIVING IN AN APARTMENT. One size doesn't fit all and DHS should recognize that a group setting may be the best environment for some individuals to flourish. All of the rules seem to tell us what we can't do. Allow exceptions that are value and quality of life based. Open up the parameters so that READ INDIVIDUALIZED care plans are allowed AND ENCOURAGED. This parenting thing is tough enough without having to ''swim against the current'' of RULES that only say no. Give us some flexibility to do what is best for the individuals, not what is easiest to administer.

13. **From a local government worker on 4/19/2017**
I have attended the person centered thinking and planning sessions. I found the thinking session helpful but found the planning session bordering on ridiculous. A disabled individual I felt was exploited for two days and hammered on what activities he enjoyed that he could translate to work. He was clearly not interested in work so I did not find this person centered. As a parting gift for his 2 days, he was allowed to choose the one he liked best of the cartoonish picture drawings the participants drew to represent his life. I found this extremely patronizing and abnormal. I remember a time when normalcy and inclusion where the focus. This does not seem at all normal. I don't go to the doctor for something I need help with and come away with a picture they feel represents my entire life. I am all about finding out a person's wants, needs, and preferences, but this is too much.

14. **From county worker in Crow Wing County on 4/19/2017**
I find most of the person-centered information seems basic or obvious. Also, a lot of what is asked for seems redundant.

15. **From a family member of a person with a disability in Rice County on 4/19/2017**
The Minnesota Olmsted Plan and the Federal Olmsted decision ensures that people with disabilities are not denied access to the community because of their disabilities. The Supreme Court ruling states that people with disabilities must receive services and supports in the community as appropriate for the person. If this is what the law states, then why is my 25 year old daughter with a diagnosis of autism sitting at home more isolated than she has ever been before? As her constant caregivers, we too have become more isolated with the enormous amount of responsibility that we carry because she simply doesn't have the appropriate supports and services she need to live in her community. Due to low reimbursement rates we are not able to find qualified, reliable staff. It is better to go without the support staff than to put our daughter at risk. As a result, neither of us are living a life of our choosing. Some of the ongoing issues we she faces is finding reliable transportation, independent living support, employment, affordable housing options and consistent, knowledgeable case management. We were on a waiting list for 9 years before she got a waiver and even with the waiver we continued to advocate for years to get approval for basic services. Recently she was assigned a new case manager through the county, her 5th in the last 3 years and we try to

remain hopeful.  I could go on. Bottom line, as her parents, we simply cannot continue to solely and indefinitely provide the level of care for our daughter.  She needs to live a life of her choosing and so do we.

16. **From a service provider in Hennepin County on 4/20/2017**

    What is working well with person-centered practices: There is an expanding awareness of them. There are ample opportunities to learn about them and connect with those who willing and committed to use them.

    Opportunities for improvement: the vast majority of providers, case managers, guardians that I interact with when facilitating person centered plans, do not see ways that they can and need to make level 1, 2, or 3 changes. Many see PC thinking and planning, as a ''more'' or a ''must do'' and do not get to the heart of the matter. It would be an improvement if people participating really understood how to implement the concepts into action. Even those who take the 2 day person centered thinking training, often do not apply it to their position/life. Many guardians are conducting themselves in positions of power over, rather than helping/supporting decisions. Example: recently was facilitating a plan in which an adult daughter wanted to grow her hair out and the parents/guardians replied absolutely not. There is a need for guardians to assist with or make final decisions but over hairstyle is not one of them. This is but one example that facilitators often encounter.

    What would I like the subcabinet to know: there is a great deal of mind changing and action steps that needs to occur before people move on the continuum to community life. This includes individuals receiving support and the general public. I met a young man who considers his life as ok and better because he is no longer homeless. He is now living in adult foster care and thinks this is pretty much as good as it can be for him. Yet his life is void of any meaningful places to go, things to do, or people who mutually care and respect each other. He stays home 24 hours a day and occasionally goes to the store with his support staff. The support staff's understanding and belief of being person-centered is: I leave him alone and if he asks for something I will try to do.

    I do see some heartwarming things happening in peoples' lives too. Moving into one's own apartment and as a result becoming a happier and more independent person. I do see people saying I don't want to work at a DT & H, and teams rallying around to find competitive employment. However, these stories are too few.

    Having a policy on a topic and a training record on a topic, does not necessarily translate into an improved quality of life.

    I am hopeful that with continued efforts more and more people will experience a life that is in balance with what is important to and for them. And that those involved in their life will fully embrace person-centered thinking and actions.

17. **From a service provider in Cass County on 4/20/2017**

    I agree with the premise of person-centered planning.  I have been doing it for 20 plus years with the individuals that I work with, however, here in lies the problem that I see.  People who work with disabled individuals have to use good judgement with the concepts of ''important to'' and ''important for.''  I think that we have gone overboard with the important to and gone away with the important for.  For example, staff are afraid to tell someone that they can't eat 20 Twinkies in a day because that's what the individual wants. We have to remember that yes the individuals have a choice, but maybe it would be prudent to only have 1 Twinkie a day?? Isn't that why these individuals have guardians and teams members? To help make good decisions for the individuals when they are not able to make those good decisions. I hope those at the legislative level realize that if our disabled individuals are given to much control and not enough guidance, then we are not doing our job at keeping these individuals safe and healthy.

18. **From family member of person with a disability in McLeod County on 4/21/2017**
Having a Certified Assessor who is a stranger rather than the case manager who knows the client completing their MN Choices Assessment is not person centered at all. Having less professionals need to get one's personal information would be a better way as this is very intrusive.

19. **From a family member of a person with a disability in Otter Tail County on 4/21/2017**
In the 1980's I worked for the Grafton State School in Grafton North Dakota. I was hired just before the federal law suit, and worked at the state school for many years under the court's supervision. Before the law suit, personal care provided for the residents included straight jacket restraint, 4 or 5 point restraint in their beds, blanket wraps, basket holds, placement in steel cages for sleeping, unlockable seat belts for wheel chairs, the use of chains and locks to restrict movement in wheelchairs by residents, as well as tube feeding. All of these things were done for the health and safety of the residents. As horrible as this sounds, believe me when I tell you the day to day living conditions were much worse. You would see residents some clothed, some naked or near naked in rooms with little furniture, linoleum floors that had pools of urine and human waste on them, and maybe a direct care staff member or a janitor leaning on a mop would be present. It was not uncommon to have the staff person in attendance not even be able to speak English. Resident to resident rape and physical abuse was common. Before the law suit, staff interaction with residents would have been minimal at best, and that's to put a good face on it. All of this took place at a state institution where the state cared for those individuals 24 hours a day, 7 days a week, 12 months a year. Mercifully, the federal law suit changed everything. The residents had rights. Their day to day lives were to be directed by their individual needs as written in their education or habilitation plans. All staff that worked with a given resident needed to be trained in the resident's education/ habilitation plan's specific procedures, so that the specific resident centered care could be administered correctly as specified in the individual's plan. As an example, a resident may have a speech language goal in their plan which requires the use of specific sign language to accomplish the goal. All staff working with that individual would be trained as to when and where to use that sign language with that given resident who has that in their plan. That same consistency would apply to any OT, PT, vocational, social, or activities of daily living goals identified in the individual's plan. Staff would be required to in real time, as opportunities naturally occurred throughout the day/night, to perform the training methods identified in the individual's plan. This kind of person centered care not only became the new norm at the school, but followed the residents to ANY environment they were in. These plans didn't stop at the boundaries of the school; they carried over into the community, work place, dentist's office, and hospital/infirmary. After these changes were required to be made, by court order, it would be inconceivable to think a resident would be placed in any environment without his or her support staff. Doing that would be abuse.

In the 1980's, after the wave of federal law suits that swept across this country, and changed every state's institutional care; the States started to evaluate how to deinstitutionalize resident care. Institutional care was extremely expensive. Under the heading of "normalization", States moved the majority of their resident populations from institutions to group homes, this saved money. No longer did they have to provide for everything from physical up keep, to power plants, maintenance crews, educational staff, recreational therapists, administrative staff, security staff, medical staff to include doctors, nurses, psychologists, Adaptive equipment specialists, PT, OT and their assistants, as well as direct care staff for all the personal care needs. The States were able to further save money by providing incentives to families who would take back their family members and provide care for them in their homes. Family members were told they would be paid for providing said care; they would also not have to worry about any of the medical costs involved with that care. These families were not, and are not, paid to provide 24 hour care, 7 days a week, 12 months a year. Primary care givers are paid for 40 hours a week, plus an additional 30 hours a week for personal care assistant/respite care. Out of the 168 hours in a week, the state is now only paying for 70. That's a significant savings.

It seems cruel to me that at a vulnerable time, to add an unfair burden to these families by not allowing them to continue to be paid weekly wages for unique, necessary personal care, for the cognitively disabled person, is unjust and poses a real danger for the person hospitalized.

For the last few years, my family and I have tried to make this assistance available for all people with disabilities who are currently provide personal care assistance on a DD wavier. Our belief is that individual's that are being provided personal care assistance to assist in or perform those functions the individual cannot perform on their own, should not be restricted from receiving that assistance in a hospital setting. The intimate knowledge that the personal caregiver has concerning an individual's care would be invaluable in providing care that would otherwise not happen. Case in point, my son is severely and profoundly cognitively disabled, has CP, autism, with chewing and swallowing difficulties. His food has to be blended to the consistency of applesauce in order for him to be able to swallow it. That being done, he will only eat the food from someone he recognizes. NO doctor or nurse is going to get him to eat it, or take oral medicine for that matter. Going back to the term abuse, let me give you a few real-life examples of what has gone on with my son. After surgery at Sanford hospital in Fargo, it came time to order food for my son, I told the kitchen he needed his food pureed to the consistency of applesauce, and was told by their staff that they did not customize orders, all pureed food is done in one consistency. The food that came was like a thick paste, my son could not eat it. We had to have his sister blender his food at her apartment and bring it to the hospital so he could have something to eat. If my son didn't have someone there to oversee what was being done, I can't even tell you the number of times he would have gone without eating/nutrition or would have been poisoned by being given foods or medicines he is allergic to. He has gone in to have his central line replaced, had it replaced, taken to dialysis for a run, and when it came time to disconnect, I told the staff person he needed a heprin lock and to not use citrate, just to have the staff person disregard what I told them, used citrate instead of heprin, and by his next dialysis run, his central line was plugged. Another time my son was in the hospital in Fargo, his condition was getting worse, I was asking for help from the doctors and nurses, [redacted] was having seizures, the doctor wouldn't come to help, the nurse didn't agree he was having seizures, I fought to have him life flighted to Children's hospital where I was told by the ICU doctor that had we waited 10 to 12 more hours [redacted] would have died from dehydration. If you talk to families that have someone on a DD wavier plan they will all have their own horror stories to tell.

Like I said before, my family has tried for years to help with this problem. Originally, we were told these are federal regulations and need to be changed at the federal level. We went to a state senator and asked for his help in crafting legislation to allow for personal caregiver assistance in hospitals. CMS told the senator's staff person that there was no need to create new legislation when there was legislation that already provided for this. That's when we were guided to the Olmstead plan. Under the Olmstead Plan, personal assistance retainer payments would allow for continued payment to personal caregivers under the waiver while a person is hospitalized or absent from his or her home. We thought great, the fight is over. Well not really. Come to find out the state of Minnesota did not include that in their 1915c waiver plan. So, we went to an Olmstead committee meeting, told them our concerns, just to be told the wavier in the Olmstead plan paid not to have the caregiver provided services in the hospital setting, but paid them to not quit and move on to someone that wasn't in a hospital. To me this is beyond belief. The person who came up with that idea must have worked for the agricultural department. They are the only ones I know that are used to paying farmers for not putting fields in production. This totally runs counter to the individual's needs. This doesn't help. It adds unnecessary cost. The money that is used to pay the personal caregiver is already budgeted for in their annual plan. We don't need the state to come up with separate money to pay for someone not to work. To get paid a bonus not to move on to another needy person. The person in the hospital NEEDS someone there who knows them! I beg you on behalf of all individuals who rely on their caregivers, stop blocking their caregivers paid service. No one is double dipping. These are unique services that cannot be duplicated by hospital staff. These are not patients that understand what's going on with them. They don't understand why they hurt, why they have to have all these lines running in and out of them. They can't use the call button. They can't change the TV channels. They can't call someone or entertain themselves. They are being addressed by people they don't know, and may not even be able to communicate with.

Imagine taking your own 2 or 3 year old child to the hospital, and after registration, you tell the desk person to call me when it's time to pick them up. How do think that would go over? Even if the hospital would except responsibility for your child, can you imagine the number of pages upon pages of documentation (required by CMS) to explain the medical necessity for examinations and assessments attempted, and billed for, but not able to be completed because of the child's lack of cooperation.

We have gone to State and Federal governmental entities only to be told by the respective sources that it's the other governmental agency's concern. State of Minnesota, we have been told by Senator Franken's office that the ability to change these rules is in the State's hands. If that is not correct, would you please help us. My belief is that having someone speaking for the State, about a State's concern, will have a far better chance of effecting change then me continuing to ride this merry-go-round. Someone needs to see there are two different populations here. One group of Medicare patients that are not cognitively impaired, and another group that is cognitively impaired. The one group can effectively communicate their need to hospital staff, the other can't. Please-help change these rules.

20. **From a family member of a person with a disability on 4/22/2017**
    You have created rigidity in the ''person centered'' way of planning. True options for living arrangements are not available and a family can't create the life I would like for my son.

21. **From a family member of a person with a disability from Steele County on 4/22/2017**
The intention behind the Olmstead Plan does not recognize my son's needs because he lives in an ICF-MR. His vocational program supports will soon end due to funding. If he moved to a waiver home, he could get the vocational support funding he needs. Why should he have to move from home of 10 years. His, and others needs are met at this ICFMR. Doesn't feel like person centered planning applies to him.

22. **From a parent of a person with a disability from Rice County on 4/22/2017**
When the Olmstead planning process was coming together in 2015, I was an active contributor to the discussion. I was pleased with the report that concluded that stage, in large part due to the clear and central commitment to person-centered planning. It was only through that emphasis that those of us who live and work within the system could look forward with confidence to the operation of a system of services for developmentally disabled individuals that would not attempt to force everyone into a "one size fits all" model of service delivery. Now, only two years later, we see evidence that not everyone means the same thing, apparently, when they use the phrase "person-centered planning," and that is creating problems.

Person-centered planning means to me that the team in charge of the services for an individual is able to come together and plan for that individual's life thinking only of what is best for that particular person. Some families and individuals prefer to live in four-person community homes, others prefer a well-designed ICF-DD. It seems elementary to me that the choice of one housing option or another should not bar a person from incorporating other particular services into his or her plan. My son lives in a cottage at [redacted] His plan for services has always been put together in that way. However, I have recently learned that another resident in his cottage is being denied some options in his employment program because he and his family have chosen [redacted] as his housing option. They are now facing the choice of leaving [redacted], which they do not want to do, or accepting limitations on his day program. To me this is particularly offensive because, in addition to the injury to this young man and his family, it perpetuates an ancient prejudice in the Department of Human Services against ICF-DD placement. DHS protested in the Olmstead report two years ago that they were not interested in closing off housing options, but when families see that by choosing an ICF for their developmentally disabled son or daughter they will be denied access to the full range of services, the ICF portion of housing services will shrink. Truly person-centered planning can prevent that. Minnesota cannot afford to shut down organizations that play a vital role in the provision of services for this population.

23. **From family member of a person with a disability from Rice County on 4/22/2017**
It is depressing to me that the staff who provide support to those with disabilities to be successful contributors to the community are so little valued. How can we possibly expect to attract the kind of people we truly want to be working with our family members when they're paid so poorly. It's not sustainable. We have created a staffing model that is inherently unsustainable...as a state we have to recognize that caregiving is not a minimum wage endeavor. We have to do better.

24. **Received from a person with a disability on 4/22/2017 (also spoke at Subcabinet)**
Person-Centered Planning is the fundamental principle that government and service providers must listen to people about what is important to them, to create or maintain a life they enjoy in the community. Person-centered planning therefore, logically, involves helping us maintain our health, and get healthier, if that is an option.

Two issues: First, don't divert your thinking into a discrimination pattern. It's come to my attention that the Transition Services part of the plan is discriminatory. On page 42, under measurable goals, it states under (B), that "people under the age of 65" will be helped to move to more integrated settings. Friends, you are required to help someone no matter their age. If someone 71 wishes to leave a nursing home or assisted living, you are required to help them. Or else you are opening yourselves up to another lawsuit.

Secondly. In my experience, there are some differences between what Person-Centered Planning means to you, and what the county and its agents believed is required of them. For example: last year I had to fight with my Elder Waiver program to provide me more homemaker hours when there were NO PCA's available through my agency.

Another issue is that many of us DO know what we need to maintain our health, or improve it; and if the money is there, why not provide it? Example: I've been needing pool therapy at the Courage Center for over 3 years. Once we are past the limited period when a doctor refers us for rehab, we are required to pay for pool passes to continue. I cannot afford to do that. Also, I need particular swimwear. Some of us cannot use bathing suits because of substantial damage to muscles, joints and connective tissue and spine. Pool therapy often is the best way to keep our bodies in the best possible working order. The professional company that makes swimwear, up in New England, called H20 (which I was told about years ago by a CADI worker) provides physical comfort. It is easier to get a two-piece on, keeps my muscle structure warm, is moderately inexpensive, and will allow me to actually do pool therapy.

Why interfere with providing the supports we need to keep our bodies functioning? If the supports are prosthetics or respiratory equipment, that is what someone needs. If it's pool therapy or appropriate medical swimwear, that is what we need.

The language in the Dept. of Human Services manual, referring to providers of medical supplies, identifies providing medical equipment and supplies which are "a necessary adjunct to the direct treatment of a recipient's condition."

Finally, again, don't let your prejudices, fear, or prior misconceptions about age, cause you to discriminate. Many of us from the Baby-Boomer generation are those who work worked for Civil Rights, stopped the war in Vietnam, worked on the Grape and Lettuce boycotts for Cesar Chavez, and still doing same.

Some of us worked in the medical system. We are not going away. Nor are we going to allow society to treat us like we are a disposable group because there may be some people who are afraid there will not be enough money. 10 years ago, the AARP (American Association of Retired Persons) predicted that by the end of this decade, 25% of the U.S. population will be 65 or older. Don't warehouse anyone. Don't assume this society is not ours or anyone's to participate in and change. We are your sisters and brothers, your aunts and uncles and cousins, your neighbors and friends. If you add the number of younger people with disabilities, perhaps 30% of the population might eventually be disabled.

This is the time to request funding for ALL persons, so that we all can live our lives in the communities of our choice.

**25. From an anonymous person on 4/23/2017**

I just hope that the Olmstead group members keep in the front of their minds the fact that folks with developmental disabilities span a wide spectrum, from people who are able to live and work in the community without a lot of assistance to people who literally need assistance 24/7 and cannot fend for themselves or fill out comment forms like this one. One size does NOT fit all, and I hope that your policymaking will take this into account explicitly. Thanks.

**26. From parent of a person with a disability from Ramsey County on 4/23/2017**

My daughter has worked with 4 different DT&H programs during the last 8 years following High School. Because of her level of support needs, she has had limited ''outside'' job opportunities because she will always need to be on a ''crew'' or have a job coach with her in her jobs. She has successfully worked at a grocery store, a manufacturer where she tested a cap for leaks, and during the last year with current DT&H Program, has only been given outside opportunities involving cleaning. She doesn't like cleaning and we've been told that unless she can work toward being totally independent on a job, they don’t have options for her to do any other work with a supervised ''crew.'' She stays in-house for packaging, shredding and CLEANING the center. She likes structure, and working and does like it to some extent, being in-house, in order to have a ''job'' BUT also she is mixed with significant lower level functioning coworkers (in the program) which is stressful for her. This also can sort of trigger her increased behaviors with the dynamic going on there. Improvements could include: look at each individual and see capability and options for work; don’t get so comfortable, workshop job developers, with just working with the same employers and keeping status quo, at the expense of clients who deserve the right to try various settings and work over their work life. There is still a need for many individuals to have a highly supervised and comprehensive vocational and recreational program, so please don't get rid of these because people will be ''sitting home.'' The DT&H''s have a big challenge with addressing the diverse needs, and for the most part, do a good job with what resources they have; Devote resources at upper level to do outreach to employers, explore tax credits for hiring persons with disabilities and OJTs; keep exploring labor market opportunities to help gear placement for persons with disabilities. Thank you.

**27. From parent of a person with a disability on 4/23/2017**

My 29 year-old son [redacted] has disabilities. I am writing to encourage you to support people like [redacted] with the decision you will be making in the near future with the Olmstead Act.

[redacted] was born two months prematurely and had an intra-ventricular hemorrhage when he was 10 days old. Due to medical science, he survived this life-changing event but now suffers from Cerebral Palsy and Mental Retardation, which has left him with many disabilities. Under the care of many doctors, [redacted] has had numerous surgeries followed by much physical and occupational therapy. He attended school from the time he turned two years old until he was 21, beginning with Early Childhood Special Education and graduating from the [redacted]. Through inclusion and special education classes, [redacted] has been able to accomplish more than was first believed possible. He does, however, have an IQ of 45 and functions at the same level as a 2 to 3 year old.

Because of his CP, [redacted] has many physical needs, also. He is able to walk short distances with his walker; needs assistance in all areas of daily living, including being taken to the bathroom every hour and a half to two hours, showering, food prep, etc.; needs assistance with transfers, and needs 24 hour care. [redacted] now works five days a week at [redacted] a center-based Day Training and

Habilitation (DT& H) program [redacted]

[redacted] is a happy and well-adjusted young man. He enjoys nature; music; ball activities, especially playing catch and bowling; watching airplanes; boating; horseback riding (through We Can Ride, a therapeutic horseback riding program); adaptive swimming lessons; going on outings; and going to work.

As [redacted] graduated from high school, his neurologist encouraged us to start looking for, and placing [redacted] in a group home. He stated that even children like [redacted] should be leaving home at 18-25 years of age, the same age as "normal" children otherwise it would be harder for [redacted] later in his life when we, his parents, might not be able to care for him anymore. So when our social worker told us about a room in a handicapped accessible group home that had become available, we decided to try it.

[redacted] enjoys spending time with his peers and the staff he knows at his group home. They play ball and other games that [redacted] likes; watch the Twins, Vikings, and Wild together; and go on outings that interest [redacted] and that he helps to plan. Staff that knows [redacted] well have thought of some very creative outings for [redacted]. They will take him along to "the Target store" if they need to do any shopping. They have taken him to places Sea Life Aquarium, the MN Landscape Arboretum, apple orchards, nurseries where he can enjoy the plants, flowers, and fish. Because staff knows he likes airplanes, he was taken to an airshow. [redacted] also enjoys going movies, museums, church, and sporting events. Since moving [redacted] he has been able to participate in Special Olympic Bowling in the Fall and Special Olympics Track and Field events-wheelchair race, walker race, and softball throw-in the spring. He enjoys Tuesday at the Acres, activities such as decorating t-shirts, planting a flower for mom for Mother's Day, or a carnival; Showstoppers, a dance activity-yes, even people in wheelchair can dance; Glee Club; and going to the Lake in McGregor for a few days in the summer, all things that [redacted] offers for their clients. All of these things are part of the Individual Outcome Formal and Informal Goals [redacted] and his Team set each year at his annual meeting.

We were so glad to find [redacted]. The staff there is friendly and caring. They have a vested interest in their clients and are genuinely happy to be at work. [redacted] has nursing care on-site, which has been beneficial to [redacted] on several occasions. [redacted] loves his job, loves to work, and is very proud of what he accomplishes. When there is 2-piece gasket work, [redacted] works on gaskets. Other times he shreds paper. [redacted] keeps their clients very busy in addition to work. [redacted] is involved in the many activities that are provided for the clients such as concerts, presentations, magic shows, discussion groups, and dances. Volunteers also read to him and play games with him. He has been able to go on outings, his favorite being the zoo. There is never a time that we see [redacted] that he doesn't say, "I had fun at work!" and then he proudly tells us what he did there. [redacted] also has goals at [redacted]. Through these goals, established by [redacted] and his Team, he has learned to ask for help or more work when needed. He sees an OT for listening therapy, which helps him to remain focused and on-task for longer periods of time. He does meaningful walking during the day to help maintain his limited mobility. We had worked hard for the first 21 years of [redacted] life to help him have the best quality of life possible. We see [redacted] as partners, with the same goals as we have for [redacted].

We considered ourselves fortunate to be living in Minnesota and especially Carver County when [redacted] was born, because of all the progressive services the state and county had to offer to help with his needs. From the week he came home from the hospital, we had OT's and PT's come to our home to work with [redacted] and to train us so we could help him have the best quality of life possible. We have a super Social Worker who has helped us navigate through this sometimes, difficult journey. While [redacted] was young we received an In-home Family Support Grant to help with his many needs, buy equipment to help with his therapy, and help with his medical bills. [redacted] is now on the DD waiver, and receives SSI. We are very grateful for these services.

Unfortunately, now we are hearing that services [redacted] receives through the DD waiver like his DT&H program and his residential services are facing some serious challenges through CMS and through the Olmstead Act. This is very troubling to us as parents. The way I understand it, there is a push to use “Person Centered Planning” and “Informed Choice” to transition people with disabilities into more integrated and competitively paid setting. A goal has been established to move people with disabilities out of center-based programs by 2019 and into community based competitively paid positions. People like [redacted], who are currently being served by a DT&H program, will be exposed to safety problems and transportation issues which will lead to tremendous anxiety in his life. I also understand that [redacted], like most DT&H programs, holds a certificate that allows them to provide compensation according to the actual productivity that occurs. Each individual is measured against what a typical person would perform and is paid accordingly. This allows DT&H programs to attract work in a very competitive market. If the special wage provisions are eliminated and everyone is required to be compensated at minimum wage, DT&H programs will not be competitive and customers will bring their work back inside or find alternative outsourcing services. [redacted] as well as many other DT&H programs in Minnesota have crews go out into the community and perform work for employers. They are NOT “settings that isolate.” During [redacted] schooling, he was exposed to different work options. He delivered mail at the [redacted] Nursing Home, washed chairs at a local restaurant, did some sorting, and did lots of paper shredding. Only one of those jobs worked for [redacted]. He was most successful, happy, and productive doing shredding.

Having [redacted] end up sitting at home with no day program, after all the successes and happiness he has enjoyed with the [redacted] center-based DT&H program is totally unacceptable. It is much better for people like [redacted] to work at a pace he can accomplish and receive a regular paycheck, than not have work to do and not receive paychecks however modest.

America is the land of the free. The freedoms [redacted] needs to live his life are just as important for him as for everyone else. Because of his disabilities, he needs to live and work in a place where he has something so simple as someone who is there to help him out of bed each morning and out of a chair or wheelchair throughout the day. He needs someone to take him to the bathroom at regular intervals throughout the day. He needs someone to prepare his food and make sure it is in bite-sized pieces so that he doesn’t choke while eating. He needs someone to be with him to protect him and keep him safe from abuse, the elements, traffic, and other hazards. Those are the just some of the things that help [redacted] to be as independent as possible and living in the community.

Funding is also critical to ensure that high quality services for people like [redacted] are available, stable, and sustainable. It will help them to live as independently as possible in the community and continue to help them find employment, which helps them feel productive and positive about themselves. When agencies like [redacted] can’t pay staff in a group home competitive wages, care, quality, and stability are compromised.

We are very upset with the dangerous effects underway to destabilize these vital programs that are serving over 15,00 people with disabilities in MN.

I invite you to take the time to visit [redacted] at his work place and in his home so you can see firsthand how valuable these services are to [redacted] and many other individuals with disabilities before you make any decisions affecting this population.

**28. From parent of a person with a disability on 4/24/2017:**

What is working well:

- We have used person centered language with our son for all of his 28 years of life. Unfortunately, many other people, organizations, and systems in his life may have used the terminology, but they often failed to either follow through or truly apply the concepts in actual practice. This produced in [redacted], a lack of trust for those offering their support, and his own value in society. This breakdown in practice included my husband and I as well as his other immediate family. Even though we worked hard alongside [redacted] to develop a solid and affirming future plan, we found the resources unavailable to move the plan to action. What little trust and sense of self-determination we had instilled in [redacted] fell flat when he transitioned to adulthood and his person-centered plan could not be implemented. With Minnesota's Olmstead plan in now in place, we have seen an encouraging trend towards real action and systems evolution. [redacted] actively engages in his meeting now and is often the primary planner. With his lock-trap memory he delights in organizing, sending reminders, and following up with folks on "their" action items. Leading with strengths is thus recognized and rewarded, and the outcome for [redacted] is a growing set of skills to nurture and bring to fruition the self-determined life he wants and we dream of for him.

- [redacted] currently lives in a group home but has the skills to live more independently. Given his autism, he adheres to his routines and predictable world, so the thought of moving has been traditionally one of "staying put." As his support providers learn to communicate in more person-centered ways, we've noticed him talking about living in his own place, eating what he wants and hanging out with his girlfriend. While this sends up alarm bells and whistles for his family, we too are learning. There is always some risk when we decide what is important to us and what choices we will make. He too must learn from his successes and failures. The Olmstead plan has encouraged all of us who love and support him, to focus on what he wants rather than just what we need for him. This is a positive evolution for all of us.

- Lastly, [redacted] has always wanted to work in his community, just as we and his siblings do. He is currently doing team work through a local DT&H, but the Olmstead Plan's push toward customized employment promises [redacted] the opportunity to pursue work and community options of his own choice aligned well with his skills and interests where he will thrive, rather than just survive in a world where folks like him are often treated like second class citizens.

What are some opportunities for improvement?

- As a parent who takes full responsibility for being a good steward of our tax payer dollars, I feel the next big step toward implementation of Minnesota's Olmstead plan is giving family and individuals with disabilities more control over the funds that support them. Our family has experienced many times the limitations of the current system, and have found them to be foundational in not being able to implement his person-centered plan. Several years ago we hired professionals to support the development of a small business for/with [redacted]. Our plan addressed his skills, his need to move in order to focus, his enjoyment of being on a team, his sensory challenges, his commitment to serve others, and the wage he would need to earn to support himself as he would earn out of SSI and SSDI. Because the funds he would need for even a DT&H day program for employment and the added costs of his residential setting, we were forced move from our CDCS waiver to a traditional DD waiver to meet his financial requirements. While this offered him additional financial resources, it took all control of those funds away from [redacted] and his family. When [redacted] was supported with a CDCS waiver, we were actually returning some money to the county each year. Now he is isolated in a group home, working through a DT&H, living in poverty, and costing the county a great deal without the flexibility to use these resources in the most productive way, his plan cannot be implemented. *I would ask that you consider augmenting the CDCS waiver to cover employment support to the same funding level as the DD waiver currently provides. The recent augmentation was generous, but it still would not cover his costs to live a self-determined life in his community. I would also ask that you consider offering more flexibility around using DD waiver funds to support employment needs.*

- The other factor limiting us in implementing [redacted] person-centered plan is transportation. We live two blocks inside the Anoka County border. Metro mobility would not transport him to his job in Ramsey county unless he would walk the two blocks and wait there 30-45 minutes alone for a ride. Given his vulnerability that was not an option. For one position 11 miles from our home I ended up purchasing special transportation through our waiver for $42 per day for a three hour shift at Target. He also landed a great job downtown for $9.10 per hour which was very good for three years ago at an entry level position. Our only recourse was for me to take him prior to going to my own job (during rush hours). Depending on traffic I was on the road an extra 2-3 hours a day and after three months we had to let the position go. [redacted] has been offered 2 other jobs, but we have been unable to arrange the necessary transportation so, as I mentioned above, he now attends a DT&H for his day services as they provide transportation where others won't. Given living a self-determined life as outlined in the Olmstead Plan depends on being able to access the community for services, recreation, and employment, reliable and affordable transportation is essential for goals and dreams to be achieved. *I would suggest Minnesota investigates models recently employed in other cities (San Francisco being one) to work alongside the rideshare companies in developing options for individuals with different needs. I would also recommend that MNDOT and DHS ensure that vehicle regulations and standards are as similar as possible between different programs. MDOT has generally higher standards that are not as flexible, especially in using smaller vehicles (such as cars and vans) which presents barriers. Lastly PLEASE address policies regulations that do not allow transportation to cross county lines.*

**29. From a family member of a person with a disability on 4/24/2017**

Person centered: Understanding the comprehensive needs of the person including mental health, cognitive ability, physical ability and vocational ability as it impacts the person in areas of life including residential, community, spirituality and vocational health of the individual advocating or being advocated for. Voices at a table uniting as one for the betterment of the person being served.

30. **From an anonymous community member on 4/24/2017**
I care deeply about persons with developmental disabilities and their families and caregivers. For the last 15 years I have been a volunteer Board member of [redacted] which serves the whole spectrum of the DD population and advocates for individualized services. My professional background includes 4 decades as an MSW social worker-- in child welfare, the schools and in mental health. Please listen carefully to the professionals serving this population and to the pleas from parents struggling to provide for their adult children as each generation grows older and resources are scarce. Thank you!

31. **Received from an anonymous stakeholder on OIO voicemail on 4/24/2017:**
My comment, as a parent/guardian, with regards to the Olmstead Plan, and the directive that people with disabilities have more choices available. . .the new laws that have been passed and go into effect in January 2019, my daughter, who lives in a group home, and goes a DT&H program during the day, her group home said, "We'll close in January 2019, due to the new disability waiver rate system rate changes that are going into effect at that time." Her group home is losing 40% of its funding and it will be forced to close, along with my daughter's program is going to be reduced, mostly with a 21% reduction. The one comment I would like to make, after reading the Olmstead Plan, would be that my daughter is losing much of the choices that she's had in the past. To lose funding with cuts, with the changes that Medicaid has mandated for the state of Minnesota, which, in my estimation, is a violation of the Olmstead Plan. Thank you.

32. **Received from a parent of adult with disabilities, PCP facilitator, and disability researcher during Subcabinet meeting on 4/24/2017:**

**Preamble:** The following information is provided from two perspectives: That of a parent of [redacted], a 38-year-old man with Fragile X syndrome and mental health issues, and that of a professional Person-Centered Facilitator involved in Person Centered planning for individuals receiving DD waivered services in Minnesota counties.

**What is working well from a Person-Centered standpoint?**
**Personal:** Hennepin County has authorized Person-Centered Planning (PCP) for all receiving waivered services (DD services) in this county

Hennepin County is very interested in PCP—and encouraging all Case Managers to get on board. From a personal perspective and a resident of Hennepin County, as is my son, [redacted], this change in direction toward person-first thinking and planning is so promising. I hope this direction can be sustained.

**Professional:** There have been a number of free trainings for Person Centered Thinking and PCP-Picture of a Life specifically. ICI (Institute on Community Integration/University of Minnesota) through funding provided by DHS has been the organization offering these opportunities. In addition to county case managers and other key persons plus support organization leads, I am hoping that the counties will also encourage direct support professionals (DSPs) from various agencies to attend these trainings. DSPs are valuable members of an individual's team and often have great insight into needs and desires of the person who is being planned for.

A small group of PCP planners/facilitators (I volunteer my time with this group) have monthly meetings to discuss various topics in person-centered planning such as what's working from a billing standpoint, case studies, presenters—i.e., Angela Amado, Ph.D. from ICI discussing her research on how individuals can develop friendships and lasting connections in their communities beyond just being part of a "program." This is so important to understand for professional planners/facilitators because knowing how to help the thinking around expanding the social network and sustaining it for individuals with disabilities is critical to their leading the BEST life.

**Opportunities for Improvement**

**Personal:** What are my son's rights? He is given this list but it is not in an accessible format and not readily available. Olmstead can take the step of making the rights of individuals more readily available to individuals who have the right to receive them in more than one format (i.e., auditory, pictographs, video, etc.).

Work situation is not working and provider does not seem to want it to change. [redacted] is in his prime earning years and, in a good week, gets two hours of paid employment, with the rest of the week doing activities in a center or volunteering. Where is career exploration or customized employment? Employment should be strengths-based. In his specific case it is not. Person-centered planning could help in this if it has follow through. Other parents of individuals with IDD report having no idea that Person-Centered planning exists or how it might help their son or daughter.

The Case Manager for my son sent a list of planners for PCP (I am on the list) but didn't have any further suggestions. As a parent, it's hard to know who I would want to choose to do the planning. I am not sure the CM knew much about the planners either.

**Professional:** Secondary and post-secondary teachers and district administrators need to learn about PCP and how it can be used, especially for Transition. In at least one district this type of education appears to be lacking.

Navigation of what services are available is needed in PCP. There are myriad services, agencies, etc. available, yet people I work with and their guardians do not know what these are. Case Managers' knowledge of these services varies.

**What would I like the Sub-Cabinet to know about my experience with Person-Centered planning?**

**Personal:** Until recently we received no information from Hennepin County regarding PCP. However, we recently received a well-done information sheet on the topic from DHS titled "What does person-centered mean for me?" It's well done but, as a parent, I am not sure I know what to do with this. I am certain my son wouldn't know what the flyer means. Can this be made more accessible? Through video, etc.? Maybe a follow up call on this from the county or DHS?

**Professional:** It looks like Minnesota wants to use a checklist to rate plans and certify planners. No mention is made of the training necessary to become a planner. It might be a consideration to look at education and preparation as part of the qualifying process.

I am very happy Minnesota is going in the direction of person-centeredness. Let's make sure it stays focused on the individual and not just the paperwork. The best Person-Centered plan on paper as judged by a checklist can be a miserable failure if it is not appropriate and there is no follow through. Please consider this as Olmstead progresses in Minnesota.

33. **Received from a parent of an adult with disabilities at the Subcabinet meeting on 4/24/2017**
Son [redacted] 32 years old lives in group home today. Auto accident 10 years ago. 6 months in coma. Survives to have another brain injury in March of 2007. [redacted] lost his ability to speak and walk with other behavior issues. A tough man to have survived two serious brain injuries. Today he has a chance to live a more normal life as he understands far more than we thought possible. He uses technology and is competitive with board games and wants to engage people. Difficult for a person who cannot speak.

What works well? He has therapy and behaviorists and doctors who understand the disability from a medical perspective. The Direct care Staffing and providers do all they can but this is unstable.

Opportunity for Improvement - The whole Foster Care Program is struggling just to keep afloat. Providers are closing homes because they cannot staff the shifts. Specific: [redacted] calls me 3:00 AM. Grinding his teeth. Sounds like he is shivering. I call the house line and the phone is off the hook. Staff was sleeping, yet paid to be awake. [redacted] was laying in a bed of urine because they would not help him to the bathroom. [redacted] is continent but needs help to transfer. Staff fired causing Turn Over! Other Staff issues refusing to bring [redacted] to appointment because they get off work before they can return to the home in time for their shift end. The staff serving staff agenda rather than person centered.

This is nobody's fault. We cannot point a finger to blame somebody. This current Direct Care Staff crisis if effecting the ability of the providers to execute their contracts to provide the care plans.

What we need the Sub-cabinet to know:
I have learned from getting involved. Advocacy requires learning about the issues. Over the last ten years I have learned the many faces of disability. We have tremendous funding and process. But minimal process to see what we are doing on the front line of DCS activity and training. My advocacy with the BIA, DHS Summit follow up and life experience makes me aware of how we need to find a way to make it better. Use the knowledge and get it done. Improve training for Direct Care Staff. Find a way to bring the jobs to a livable wage. Plan now for the future of increased needs. Make the Olmsted Plan Work in the community. When we get out of bed in the morning what do we think about? I still think about it every day. Those who have to wait for a shift change or enough people who can help them get going. If nothing else, find the way to implement the Olmsted Plan and see it working the way intended. If the consumer and the staff are not aware of the PLAN how can we expect it to impact lives. The plan was written back in 2013.

34. **From a foster care provider at the Subcabinet meeting on 4/24/2017**
Olmsted Plan and Person-center care have their faults. For a number of years, I've worked with disabled individuals, primarily intellectually disabled, in a number of venues. I love working with this population. I've worked with those with spectrum disorders, Asperger, autistic, low functioning, downs syndrome mostly. For the last six years, my wife and I have done adult foster care and we have two low functioning, intellectually disabled ladies, now ages 27 and 28. I've read the Olmstead

Plan Implementation, both the June 2016 revision and the Feb 2017 revision, taken person-centered care training and learned all about the expectations of both the Federal government and state government in regards to the quality of life for those with special needs. However, I feel the state of Minnesota is doing our foster daughters a complete disservice. The Olmstead plan needs to be challenged because it is not raising the quality of life for some in this population, but lowering it. First, let me say that I am all about respecting and caring for those who have disabilities. I've always treated them like their needs come before my own. In many ways, I feel the state's recent posture has been an affront to those of use doing adult foster care because the DHS projects the feeling that we as caregivers are incapable of making good choices on behalf of the persons we do service for. I've always respected these disabled persons. But here are the reasons the Olmstead plan is letting down our disabled people and particularly those who are intellectually disabled.

**#1 – It is not individualized.** There are many if not most intellectually disabled individuals who are capable of making many or most of the decisions regarding their care. However, not all in this population can make good decisions and their decisions need to be guided. The Olmstead plan makes no provision for this. It is not taking into consideration there is a wide difference between all of these individuals. For example, the two adults we do foster care for are sweet, kind girls. But they are at a 5-year-old mind level that will never improve. That is why they are disabled. They do not have reasoning skills and don't seem to ever develop them. This is why they must be cared for. They cannot count money or even tell time or remember their address and we are told by the best doctors that they never will – they just can't. To expect that they will or could is like expecting a blind person to see or a quadriplegic to walk. Yet the State's posture on Person-centered care and the Olmstead plan is based on a premise that all disabled people are capable of making adult choices. Would you also let one with dementia walk around a city unsupervised just because they want to?

We had a lady who came to our house doing a quality of life survey and surveyed both girls. At first, I left the room and let them do the interview. Pretty soon I was called into the room because the girls could not understand the questions. I asked the interviewer to put the questions at a level the girls would understand. Her statement was that she was supposed to read the question as written. So, I told our clients to answer as best they could. Answers they gave were so out in left field it was clear they didn't understand the question. So the interviewer looked at me and asked me what they meant. I simply said, "If you must read the question as written, then you should also write the answers as answered. I'm staying out of this."

This was a prime example of the state sending an untrained person with little or no experience with some in this population to do a survey in a cookie cutter fashion – as if all in this population can be grouped together into one category. They can't.

I have friends with downs syndrome who would have understood the question as well as some with various levels of spectrum disorder. Some of those with downs syndrome could give intelligible answers. Some could not. When you group together those with intellectual disabilities and categorize them as being the same or like each other, you do them a tremendous disservice. Trained people know that. So having read the Olmstead implementation, I felt bothered that it appears that those who prepared it seemed to not understand the wide range of capabilities of those with intellectual disabilities.

**#2 – It is not healthy.** We have always offered our ladies healthy food options in our home and we used to just serve healthy meals. We do ask our ladies what they like to eat. However, we are told now we are to have food available to them 24/7 so that any time of the day they can indeed raid the kitchen and help themselves. Nowhere is there inability to make adult choices more prevalent than in their eating and health practices. Everything they want and like is unhealthy for them because in their minds they reason as children. They choose kids cereals. They choose the fill up on sweets. And they choose not to exercise. If you are the parent of a five-year-old, you guide them into proper eating and healthy exercise. But we have to read rights to our girls that tell them they don't have to eat what we want them to eat, they can eat what they choose and we they don't have to do the activities we recommend for them. Both of our ladies have gained 30 pounds in the last two or three years and there is little we can do about it because they choose as a child would. Our doctor says we need to control their diet. HCBS rules tell me I can't. That is why you are hurting the health of our clients. You are taking the wisdom behind their eating away from the caregivers and putting it into the hands of intellectually disabled ladies.

**#3 - They both are making less money, not more.** Both are in a day program here in town called [redacted]. Once upon a time, [redacted] could tell their clients what work to do and act as "bosses" to these clients. Now they have to give clients choices because they also have their "person centered care" rules. So clients can choose to work or not work. One of our foster daughters has gone from making $140 every other week to making $14 every other week. Why? Because when offered, she will choose the easiest job or to do no job at all – just to take a nap.

The state expects that our ladies can buy their own clothes and pay for their own haircuts, etc. But at this rate, our foster daughter doesn't make enough to cover her needs, meeting the guardians or we as foster parents have to kick in so that her wants and needs are taken care of. It's one thing to tell a person receiving services, "You have the right to choose what clothes you buy." But the state has not put them in a position where they cannot afford to buy them. So what should be a program that encourages advancement and independence is actually creating much less advancement and much less independence, working to the detriment of the person receiving services.

**#4 - Good wise people are getting out of foster care.** Believe me, I've been tempted myself. It hurts to watch this population be destroyed by rules made up by people who really have no clue what this population needs or what will best help them. Not to mention the paperwork is enormous. I have over 60 documents updated annually and changed at every whim of the state in order to comply with 245D and person-centered care. Mandates put on foster care givers and group homes have not come with more money to carry out the mandates. You want quality care, you need to pay money that will bring in workers with the capability to be trained in person-centered care. For example, many of the local group homes and even [redacted] are trying to hire employees for $11.50 per hour – exactly what McDonalds is paying for new employees who are 18 years old. As people say, "This is ridiculous, we are getting out of foster care," are you not pushing these intellectually disabled individuals back into institutions? The state wants those of us caring for these individuals to be professionals. Are you paying professional –level wages?

**#5 – Some individuals are being put out in general population too quickly.** Because one of our ladies is a good worker, the county chose to put her out into more independent living. Huge mistake. She was picked up twice by police because they didn't understand her disability and found her out wandering the streets because she was freaking out on a bus from her anxieties and the bus driver kicked her off the bus. She couldn't remember her address, so police locked her up until they social services came to pick her up. This was a case of people in social services not knowing their person and making decisions without good knowledge. Why would the state assume all intellectually disabled adults could handle the anxieties of a city bus ride or being lost in a town?

**My suggestions for better care for persons receiving services.**
**#1 -** Implement through the counties. You have case workers. Use them. They are more trained to do your quality assessments than interviewers you sent around door to door. Also, they can work to individualized a plan, much the way schools do with IEPs, plans that can take into consideration the capabilities of each individual person. Case workers see their clients two times every year. Put the onus on them to see that homes are providing person-centered care and providing a quality lifestyle for the persons receiving services.
**#2** - Let the foster care parents and the guardians work together to adopt guidelines for care for each individual person receiving services.
**#3** – Stop listening to the voices of a few and setting state policies based on the desires of a few rather than the needs of the many.

**35. From a family member of a person with a disability at Subcabinet meeting on 4/24/2017**
**What is Working?**
Awareness of choice for individuals with disabilities
DHS is starting to work together with providers

**What is Not Working?**
There is inadequate communication to families/guardians regarding changes and how it will affect their family member with disabilities now and into the future. They seem to only be made aware when services are going to change (VRA for employment)

How we identify choice….is it your vision or theirs. DHS/government has decided everyone is to work in the community. Some individuals cannot d/t physical limitations, medical issues, sensory deficits, behaviors. Some are happy and want to stay working in environments that they feel calm, safe, successful and supported by others they identify with. Who is advocating for them, where is their choice.

What is going to happen to the individuals that require more supervision and physical care…the rate structure seems to be following employment more. My brother has lived in 4 different environments. He moved from some as he gained more independence, another d/t poor services. What has been common in all is lack of consistent and well trained staff. Staff in many cases are paid fast food wages or less, in positions that require specialized skill and training.

Community integration has been given limits within the definition of DHS. This too should be a choice. We all participate in the community according to our own personal choice. I go to the library and am in a book club with individuals that share that interest. My mom is in a "senior community" because she feels comfortable and understood by those that share common ground. Our public schools have honor society, athletics, drama and speech club. Professionals (doctors, nurses, teachers) have professional groups. Not everyone is included in these groups.

**Press are writing and documenting negatively** towards day programs in general and employment. While you can't control what they print, you do have a strong voice. We all remember the individual picking garbage up at a waste facility in the Minneapolis Star & Tribune. There are no articles of individuals working successfully in the community or at day programs of their choice. Not all individuals choose competitive employment. Some enjoy the consistency, routine, positive environment at their DT & H Program. Some have tried and failed in the community, choosing to return to what they are happy and comfortable with.

By telling you this, I am not advocating for keeping the system as it is. All individuals should be given choices as to where they want to live, work and socialize as I do for my brother. It should be **THEIR** choice, not the state or federal governments interpretation of their choice.

36. **From a service provider from Ramsey County on 4/26/2017**
    I am concerned that there be sufficient options for people with disabilities--not all WANT to live in ''homes'' or designated unites but not all want to live isolated, either. Both should be available.

37. **From the parent of a person with a disability on 4/26/2017**
    With the new person centered planning, do you realize that this doesn't work for everyone with special needs. Housing, jobs, not everyone has the skills to work in the community. My daughter applied to get in a [redacted] supported home. My daughter is unable to live in the community in a supported apartment. She doesn't have the skills necessary and has challenging behaviors.

    What are you going to do for the kids out of school that are unable to work in the community and will need 24/7 care for the rest of their lives.

    Since the day ideas that go along with this act, an entire group of adults will be unable to leave accessible

    I am scared for the family's in the future. Kids will graduate for you but will be unable to get their own housing and job. How is this going to work with the low functioning kids. I'd like to hear your answer soon. Thanks.

**38. From county worker from Hennepin County on 4/27/2017**

What is working well with person-centered practices?

People with disabilities have opportunities to live life with true integration, and participate in their communities and this has happened and is good.

1. What are some opportunities for improvement?
    a. The MN Choice tool is too long (takes two and half hours to complete do the tool only if the client is able to answer the questions and not stray too far from the questions asked). The MN Choice tool does not have a guide if anyone is unsure what the question is asking. The MN Choice tool loses information, asks for the same answers to questions several times, and is very slow. Once the MN Choice tool is completed, the information has to be manually put into a CSP plan, uploaded to MMIS, time information put into SSIS, and forms uploaded to ECF. The servers are overwhelmed and these computer programs are frequently not available. Information acquired through the assessment but not able to type in is lost or forgotten.
    b. It was determined that foster homes were institutions. Anyone with a disability recognizes that having a disability comes with added costs and impairs your ability to make money or have a good income. Foster homes provided housing that our clients could afford, could be located in the communities they desire, have transportation to go to shopping centers with good prices. Now clients are encouraged to live in housing where they hold the lease. Our clients have a choice of HUD low income housing and apartments. These locations hold the disenfranchised populations in great numbers. Transportation is limited and some clients do not feel safe.
    c. Minnesota has created an environment where people from other areas leave their informal supports and come to Minnesota because we have good resources. Many of the people I assess, do not have informal supports in the state but most of their family lives in another state.
    d. Some housing resources seem to favor some populations over other populations in need. Entire high rise buildings appear to come from the same demographic group. Also why are disenfranchised populations living in tall urban apartment buildings. If I go out to the suburbs, the buildings are less tall but large for the suburb. Again, disenfranchised people all grouped together with providers of services coming and going.
    e. It sounds person-centered to ask questions what is important to the person, what is important for a person. What is important for the person, is patronizing. As professionals, we feel we need to tell a person what is important and say it is for the person. The individual know what is important and will work on it if it makes sense.
    f. The OPC did not have adequate time to address the following issues although other states did address these issues: such as individuals with disabilities in the corrections system, strategies for addressing the need for additional direct support staff, the needs of children with disabilities and their families, elderly and their special needs and individuals at the Minnesota Sex Offender Program. The also did not address the critically important issues of transportation. Because other states were able to address these issues and Minnesota was not, I am left to believe that different people should have been on the committee. Also, there is something about Minnesota politics that wants us to separate disabled disenfranchised people from the rest of the population. All of above issues could be addressed by different committee members and how Minnesota decides to work with communities and fund communities.

g. The resources need to be added that specifically address disenfranchised populations. Providers need to be trained in trauma. Trauma counseling resources need to be added and providers trained in the latest evidenced based treatment as it relates to trauma. Recreation opportunities and classes that address issues that disenfranchised people would benefit from, need to be added. Instead of building transportation systems build communities where everything you need is within walking distance, support and encourage small business. Have home delivered meals that address special diets (it will be costly ).

2. What would I like the Subcabinet Committee to know about your experience with person-centered practices?
My experience with person-centered practices that some of the assumptions what makes a practice person-centered was wrong. Telling a person what is important for them is patronizing. Addressing only the person-centered practices that are easy and keep with the status quo is not person-centered. There is a lot more work to be done as it relates to person-centered practices. Person-centered practices needs to start in all communities people live. Provide funding to build these supports in the communities where people live. Do not group all disenfranchised people together. Do not provide resources and benefits to people so that they feel leaving their families, friends, and other informal supports and locating to a place where they have no family, no friends, and no job is a good thing and will be better for them than staying where they are.

**39. From parent of two adults with disabilities on 4/30/2017**

I have two young adult sons with autism and one with cognitive disabilities as well. The schools are doing well with trying to find out what my sons want for their future.

We have two main problems. There is no good source to find resources specific to our situation to help with long term planning and finances. It is still hard to find help for my sons to be able to actually do any of the things they want for their future.

The second is that the planning can be impractical and therefore not actually helpful. For instance, my son had planning in high school for his dream of becoming a K9 police officer. But he did not have the intellectual ability to have the training needed for this; when he graduated from high school there was no other plan that had been proposed to him, and we were left in no better shape than if there had been no planning at all.

Thank you for asking for these comments.

**40. From parent of adult with disabilities on 5/4/2017**

Person Centered must be modeled by the agencies and all who provide services to those who receive or purchase your services. Taking about people and the programs that serve them without them exposes the underlying belief about what value or lack of value that is placed on the person or their input about the services that they receive. When meetings are set up to gather information about programs and services they should be “person centered” “person first”. Each member at the meeting has an equally valuable perspective and input to how things are, could be and should be designed, implemented and evaluated. Just because a person has a title that allows them the privilege of being of service to a vulnerable person does not mean their title equals more value. In fact if we are true to “Person Centered/Person First” their voice should hold the most value at the table.

We need to ensure that the receiver of services including the family and self-advocates voice is not over powered but is equal to the agency, providers or other partners contribution in the development, the implementation and or improvement of programs and services that are “Person Centered”. Seems to me it makes sense for “Person Centered programs include and demonstrate the importance of the “Person”. When you show a disregard for the “person” and that their input has less value then the agency/provider who is implementing the programs or services it creates a barrier to getting to solutions to resolving the problems or preventing the creation of the best possible programs and services that meets the need that the program is intended to meet. In fact it requires all parties at the table to come up with the best possible programs and services.

When it comes to Person Centered/Person First we cannot continue to do things the way they have always been done and expect a different result. As a leader you set the example to all those who follow you. If you want to improve the odds that the person with a disability will be treated with person centered principles and person first services, then the place it begins is with each and every one of us walking the talk. If we are Person Centered let’s start with the person.

## Comments received through survey

**41. From a family member or friend of PWD on 4/7/2017**

The planning is not the problem. The follow through is what's important. Follow up in 6 months to see if the Plan was followed.

**42. From a family member of PWD on 4/13/2017**

My son's PCP was an incredible, supportive, celebratory experience. Knowing my son, I helped to tweak the process to fit his needs so that he could participate to his fullest extent. The normal process is asking the client about their dreams but with my son, knowing that he needed help to expand what he could dream, I included a time where everyone got to write down on post-it notes possible dreams for him that he could consider. Each person came up and shared their dream or hope and put it on a wall. After all the post-it notes were up, my son went up to choose the ones he wanted on his Planning Map and we left the other post it notes for him to consider for the future. So the start of the meeting was adapted by his family and then the normal PCP process led by a PCP trained person came into play. It was a great team effort. WE had invited many friends, supports, and family and had a total of about 10 people who participated. Because my son needed to process this all, we didn't complete the entire process in one day but ended with the map and then the PCP leader worked over time with my son (and the members of his team) to flesh it out. He already accomplished his one goal of finding a new job!

43. **From a family member of PWD on 4/13/2017**
    We completed the process twice for our son: once when he was 4-5 years old and once when he was 18 years old. The special education school system did not know what to do with the information. As a parent, I was trying to show information to the IEP team, and felt ignored or discounted. PCP needs partners that are willing to take the information forward and special education needs to understand the value of the process and utilize the information. Parents spend valuable time dedicated to the process; providers from agencies need to help make sure the doors are open to make the steps happen.

44. **From a family member of PWD on 4/13/2017**
    That is why my mom chose me as her executor. Because I respected her as a person. Even when she got Alzheimer's. She was still included in the decision making process. Always.

45. **From a service provider on 4/13/2017**
    I think having access to Person Centered Planning is still limited. Would like to see expansion. Here in Duluth, I really believe many people do not always know what options and resources exist. I myself have worked long and hard to get my needs met, and am still trying to find good resources for dealing with organization in my living space. I also work as a Behavioral Aide in an Adult Foster Care facility (started in January 2017) and find that many of the clients do not have a good understanding / knowledge of their rights, especially as most are under some form of guardianship.

46. **From a person with a disability on 4/13/2017**
    It's only effective if the provider uses one and listens to what I think would help in my recovery. Most of my providers don't have or know how to access person centered planning form. I have only seen one out of 5 or more providers in the last year! Person centered planning doesn't do any good when the county and state don't have the funding to provide what would work best for me, or what I think I need to stay stable. That's just been my experience hear in Morrison county.

47. **From a service provider on 4/13/2017**
    What counts is following through with wishes.

48. **From a family member & service provider on 4/13/2017**
    The system is totally broken! It is controlled by the insurance companies, politicians, and pharmaceutical companies: who nothing about the how, what, or when of best practices or lived experiences. Person Centered Planning is great and is very much needed and used but hard to implement and follow through on for a lot of people's dreams and goals for their lives.

49. **From a service provider on 4/14/2017**
    Live work learn enjoy life...that's a lot to consider in a small amount of time.

50. **From a service provider on 4/14/2017**
    Each provider has its own PCP process, which can cause delays, a lack of coordination among providers and an inconsistent plan. As of today, most case managers still do not facilitate the PCP process so it falls to individual providers to approach the subject. From my 25 years' experience in this field (residential, vocational and as a guardian), the best thing so far to occur with Olmstead is mandating the consistent and progressive approach to incorporate as well as adhere to a plan. As far as the future goes, resources for individual providers as well as the individuals served must be equitable or person centered planning as intended will be lacking.

51. **From a service provider on 4/14/2017**
    I think clients have difficulty when they want something that is not available to them, especially when it comes to housing or certain programs. We have folks that want to live in a certain city or area and can't due to rents that are higher than what their subsidy will pay or their background causes difficulties and they aren't accepted where they want to be. We always try to give them at least 3 options to choose from.

52. **From a family member of a person with a disability on 4/14/2017**
    Seems like a big waste of money if no providers are available for respite and direct support staff are not capable of doing things that the person wants to do.

53. **From a service provider on 4/14/2017**
    I believe that AFC homes are best at this as our quality of life at home is dependent on the happy client so our homes run smoothly as we have to live with them it only makes sense. All the rules coming out are just common sense to us.

54. **From a service provider on 4/14/2017**
    We should not think this is a one fit all. I understand that this can help some individuals, but for some individuals it does more harm than good. I serve MICD residents and the Person centered /Olmstead planning makes it really difficult to help these residents, because they make choices which are not usually good ones and it usually sets the resident back even with guidance and encouragement to do the right thing. I have been seeing this happen over and over.

55. **From a friend of a person with a disability on 4/14/2017**
    This process made my friends life so much better because the staff in the group home where he lives stated thinking of him as a person, not a job.

56. **From a person with a disability and a service provider on 4/14/2017**
    If people are not their own guardians, the process is flawed. Parents often have legal and situational power over the person receiving services. If the guardian wants something different from the person receiving services, too often the power of decision making goes with the guardian. Since the guardian often receives monies to care for the person receiving services, there is also a conflict of

interest. If the person receiving services becomes independent, the guardian loses an income source. As a person with mental health disabilities, a person with an independent best friend who is his own guardian who makes his own choices, and a person who works in a DT & H I have seen multiple sides of this issue. From where I sit, people who are not their own guardians, who have guardians that rely on the monies received to care for them, have very little potential to actually create their own planning regardless of what the law says.

57. **From a parent of a person with a disability on 4/15/2017**
    They only did a part of the assessment, so my son’s needs were not fully addressed.

58. **From a service provider on 4/17/2017**
    As a children's mental health worker, my experience with this process has been with clients under the age of 18. The children seem to like having their wishes and goals included in the provider meetings and the care team does their best to help them reach these goals. However, there are many things that a child or teenager might want that is not appropriate for them due to their age or understanding of their abilities and challenges. This has led to concerns that the child could be at risk if their requests are followed to the letter. For example, a vulnerable teen who is at high risk for being sexually exploited or influenced to use drugs by peers wants to have unlimited phone contact with anyone they want. The teen does not understand his/her safety risks or how others may use him/her for their own needs. The teams have worked to try to mitigate these risks by writing specific rights restrictions but have found it difficult to meet all the DHS rules for PCP. I would want to see more guidelines developed for children and teenagers so that as we, as adults, can keep them safe.

59. **From a service provider on 4/17/2017**
    I completed the person centered thinking in November and have yet to have access to the person centered planning training. I am not aware of any training available anytime soon either that is even somewhat local to me.

60. **From a service provider on 4/17/2017**
    I think person centered practices are great and valuable. My concerns are more related to the implementation of the positive support rule as it applies to residential sites for juveniles. The statues and rules that are put into place are difficult for sites to implement as there are many statues and rules in place and create problems in implementation. Example would be the exhaustive list of training requirements that are expected be completed before a person assumes duties, in the real world implication is that staff would need over 3 weeks of training before being able to work. This causes numerous problems in staffing, costs, etc. I do not feel those that put this in did not have the foundation of what is already expected for residential sites and/or did not consult with those in the field prior to.

61. **From a service provider on 4/17/2017**
    This is basically what we did in the 80s and 90s just repackaged.

62. **From a service provider on 4/17/2017**
There is an overwhelming amount of paperwork that goes with person centered planning. In our county we have found that even if the person is heard the guardians are typically acting against the will of the individuals (especially private guardians). They have very little desire to actually acquiesce to the desires and dreams of the person especially in the DD world. This leaves the individual in this awkward state of now having voiced all this stuff but not being able to do a thing about it. Other providers are also mocking in this effort too. There is little movement from providers to actually start to staff their group homes for example in a way that enables people do what they want to do (go to work at 6am vs. day program all day).

63. **From a service provider on 4/17/2017**
Getting all service providers on board will be key. Some individuals have guardians for a reason. Many that do are not capable of self-directing and making safe, wise choices, hence guardianship. To lump all together in this process is going to result in many problems going forward that we're just beginning to see the start. Nothing is one size fits all in the disability world.

64. **From a family member or friend of a person with a disability and a service provider on 4/17/2017**
I am a family member/guardian for a person who receives IDD services and I am also a long-standing IDD social worker (who has been a case manager and is currently a MnCHOICES Assessor). If DHS believes that the MnCHOICES Assessment tool results in a person centered plan, you are fooling yourselves. The processes couldn't be more different. Well educated people and family members are the best assets to driving personal centered planning. Continued self-advocacy training and also training to family members about what PCP actually is, is critical to actually implementing the goals set out in Olmstead. Also experienced and well trained case managers and service providers are invaluable to the process. High turnover with the professionals involved with a person's services is one of the biggest obstacles to service planning with a person centered focus.

65. **From a family member or friend of a person with a disability on 4/17/2017**
Person-centered planning is a lovely phrase that implies opportunity for persons with disabilities, but which doesn't as easily align with reality. Person centered planning is dependent upon options and choices being made available to persons with disabilities. The (group home) housing moratorium leaves myriad persons on waiting lists for services. The low wage provided to disability workers ensures a constant turnover of short-term employees and implies a job that is not worth much in having or performing. The "opportunity" for families to pursue IHOs (independent housing options, otherwise known as the 'figure it out yourself option') is paramount with risk for families, and extremely difficult to find staff or providers for those arrangements because of the worker shortage, low wages and high turnover. The current "one size fits all" approach to disability services in the manner of day programs - not all persons with disabilities want to work in the community and many are best served and would choose to work at a consistent and supported work site. I'll believe in person centered planning when I see a level of respect and opportunity afforded this population

that makes REAL person centered planning a possibility. Otherwise, I'm simply stymied at the lack of change and vision and at the lack of resources for this population.

66. **From a service provider on 4/17/2017**
    At times, the questions seem too invasive for the person, especially when they ask why we need to know that. If the assessment has to take 2 to 3 hours to complete, that is not very person-centered for the elderly and/or disabled. And the amount of paperwork continues to increase, causing deadlines to come and go while trying to remain focused on each individual's needs and allow payment to the provider as they try to make ends meet as well.

67. **From a person with a disability on 4/17/2017**
    I have been ventilator dependent since I contacted childhood polio in 1952. Fortunately, I grew up in the Stillwater Area School District which provided me with a great education, which included a school to home telephone/intercom system through middle school and high school, because I was not strong enough to attend regular classes. I have always been a strong advocate for myself and I was able to graduate from college and law school long before there was a PCA or home care program supported by DHS and/or Medical Assistance. However, I have benefited from both the PCA and Nursing Care components of the Home Care Program. I feel very strongly that persons in my situation, as mandated by the Olmsted Case, should be provided with the necessary supports to live in the community and not be isolated in institutions at a much higher cost to the state and federal governments. Additionally, we should be heavily involved in the decision-making process so that we can live and thrive in the least restrictive alternative that provides for our care needs. Thank you.

68. **From a service provider on 4/17/2017**
    While the concepts and principles regarding Person Centered Planning are good, the associated policies in conjunction with them in the Positive Support Rule are cumbersome. The Person Centered Planning approach reflects what the true design of individualized treatment and care should be.

69. **From a service provider on 4/17/2017**
    I feel that service providers (at least the ones I know and work with) have been providing person centered programing for YEARS. The extra financial resources and trainings should be centered on community awareness and incentives to potential worksites/social organizations and not training service providers. It is pretty difficult to provide choices to those with disabilities and provide more social opportunities when the people not directly involved with disabilities are not well informed and do not find or understand benefit in such ideals. We as service providers help facilitate this bridge and have for years and will continue to do so. But again I feel resources should be directed on informing the public. Service providers can only do so much when jobs are not available to people

with disabilities, public is not accepting, and quality employees to work with those with disabilities are not available.

70. **From a service provider on 4/18/2017**
Meetings get to be too long for many consumers. Family members (guardians) and providers are concerned about the length of time and multiple meeting dates/times to complete assessments and service planning/authorization.

71. **From a parent of a person with a disability on 4/18/2017**
I am a full time employed Mother of an adult son with multiple disabilities, also a single parent. If it were not for these programs for my son I would not be able to work and support my family. Please do everything possible to keep these programs and instead improve them.

72. **From a service provider on 4/18/2017**
The model is complicated and not always realistic. I am a work experience coordinator. I work with young adults with disabilities. Some students are 'work ready', 'work invested', work able'; others are not. The model seems like an 'all or nothing model'... Families are not able to work with the Day Training Programs the way they once could - where, as the guardian, they make the best decision based on how they know their child / student / worker... Some families feel forced to go through the Vocational Rehab services when that model is not appropriate or desired... The other piece is that the funding will never match some of the needs of some young adults.. The 'all or nothing' never benefits anyone.

73. **From a service provider on 4/18/2017**
Most of the clients that have completed a formal or informal person centered plan seem to not find it useful. They do not reference the plan and it can be overwhelming and difficult to stay focused on an in depth plan. One visit from an outside provider discussing a person centered plan is not that helpful because they do not know the client and I have not seen follow through with the person centered provider once the plan is developed. A person centered plan can be completed but when there are barriers in funding or an agreement in appropriate services for a client, often the person's desires are not followed anyway. We should be person centered in our work with clients everyday but making a detailed plan about it is just more paperwork for providers to do that really may have little impact on the client.
74. **From a family member or a friend of a person with a disability on 4/18/2017**
It was very difficult to find someone to facilitate the process. I made numerous phone calls and searched resources online. When a facilitator was identified it took an additional ten weeks for approval from the county. The process itself was a wonderful opportunity to learn about my daughter's strengths, needs and dreams. It was a stark contrast to the service and system driven conversations we've had with our county case manager for the past several years. Person centered planning is a positive process that documents the needs of the individual. It's exciting and we're extremely thankful that we had an opportunity to utilize the process to plan for her future.

75. **From a service provider on 4/18/2017**
Financial and regulatory matters have been trumping person centered practices all over the state. At times if feels like person centered practices are more lip service than what is really occurring. It is a good direction but more action is needed. The current duality in practice makes me think it will take more court and legal challenges for this to be more than talk and philosophy. This has opened doors for higher functioning individuals but it has also closed doors and drawn the focus away from people that were appropriately served and have greater needs. We are pragmatically leaving lower functioning people behind as we struggle to implement person centered planning for lower functioning individuals.

76. **From a service provider on 4/18/2017**
Our staff in residential and employment services try hard to provide person centered services. We have seen great things from that in our programs. But The DAC is against it. The guardians don't understand it. And the case managers go with whatever the DAC and guardians say. How can I provide complete PC services when they know how to manipulate the individual into saying what they want them to say at meetings? Or talk them into other things??? My staff and I feel frustrated for the people we support because we know what these people want and we bring good solutions to the table.

77. **From a family member or a friend of a person with a disability on 4/18/2017**
Until larger service provider systems and funding streams are flexible enough to meet the specific needs and complexities of the people with disabilities who are supposed to be the center of the person centered planning, the process feels like a futile exercise with hardly any sense of empowerment.

78. **From a family member or friend of a person with a disability on 4/18/2017**
It is key to remember that Person Centered Planning is just that - centered around the person - to help the person plan their life and have the ability to make choices and decisions based on their own preferences. Person Centered Planning does not involve cookie cutter options for life or a one size fits all solution. It also does not mean that living in your own home or apartment instead of a campus environment is necessarily the best option when planning for the person's life journey and the supports necessary to implement the plan. You can have quality, individualized care and community in a campus environment.

79. **From a service provider on 4/18/2017**
The training requirements are too much. I cannot afford to send all my staff to 4 days of training. The expectations are exceedingly over rated and it is unreasonable to expect small minority disability service providers to do this. The college of direct supports offers the training and we are proceeding with this training for our staff.

80. **From a service provider on 4/19/2017**
    Very difficult to implement in the context of a 2-3 hour MnCHOICES assessment. Not able to spend any time on the planning process. Way too many requirements in paperwork that take away from any good care planning.

81. **From a service provider on 4/19/2017**
    It is frustrating knowing people should be able to make choices but sometimes there is only one opening for placement. So, they don't always have options; only to use whatever business or placement is available.

82. **From a service provider on 4/19/2017**
    It would be helpful for counties to address their lack of involvement with persons of need. Giving them all the necessary information to have option and make decisions is key. I have many individuals who need their case managers to provide time to them instead they rarely get calls back and sit waiting for someone to assist.

83. **From a service provider on 4/19/2017**
    Person centered planning is wonderful when it is done with respect and with the tools to implement what the individual wants/chooses. It's disrespectful to go through the person centered planning process if there is no plan, intent, resources to implement things based upon the person's wishes/choices.

84. **From a parent of a person with a disability on 4/20/2017**
    We need to somehow get out training to Community Education and churches. Example my son attends Mass. He just gets up and walks to the next pew and sit down in the middle of church. We need to somehow train priests and pastors that this is ok. I would like my child to do first communion but I am not sure how this will work because he is not going to be able to memorize the prayers, etc. but my child believes in God. Children with autism, disabilities should be able to confirmation like the next person. It may look a bit different but should stop them. I think education on educational diagnosis VS medical diagnosis is something most families still don't get. Families don't want to pay the TEFRA fee or if they do pay the fee they don't want to sign the education part with the school district they feel that will up their usage report. We need to have a better roadmap for families who apply for TEFRA and use TEFRA. Many families who are on TEFRA still don't get how it exactly works. Families who are going through divorce need a roadmap itself should TEFRA be in the divorce settlement and who pays what. Kids that get both the medical and education tools are going to be better off when they turn to adults because they are going to be independent as possible. We need to give this access to our children now and really there should be no TEFRA fee. Many families cash out 401ks and walk away from their homes simply because they can't afford it. You should not have to go broke if your middle income and have a child with a disability. A person with a disability should be able to live in a home that is safe for them and gives them their own space. Home modifications should be allowed besides a person with a physical disability. As more and more adults and older Americans access supports we need to look to do more home modifications to keep them in their home and with their community. We need to have more support staff. Minnesota is in a crisis mode right now my son has not had a PCA for a year. We have

tried emailing colleges, walking around college campus putting up a picture and job description. I want my child experiencing the community by participating in things such as park events, and going to trails and going for walks, going bowling etc. As a Mom I can't run my house and do all the things that would benefit my child. We need to make sure we are listening to what people are saying such as what temperature they want their house to be? Do they like music when traveling in a car? Some people like to ride in the car in silence. When going to airports having more supports at the airports or other location to seek supports to ask questions. Having more City Councils understand the OLMSTEAD plan. My city council will not allow the autism sign to be put up in my neighborhood. We need to be training our city councils on what this looks like. I have given them examples about sidewalks in my area but I feel they are not listening. Not everyone is going to be able to drive. We need to access and safe access for those who don't drive to be able to get around in their community in a safe environment.

85. **From a service provider on 4/20/2017**
    It's been more talked about than implemented. I am so excited now that finally something seems to be happening.

86. **From a person with a disability and friend of person with disability on 4/20/2017**
    This has been a good starting point but by no means is a consistent thought across county lines or among providers. The theory of person centered planning is great, it’s the implementation that needs work. The variety of individuals involved in the process could be stream-lined and what person=centered means could be clarified for a more unified approach.

87. **From a person with a disability on 4/21/2017**
    It’s a good idea. I haven't directly experienced it yet.

88. **From a service provider on 4/21/2017**
    It's definitely the right process---so glad Minnesota is moving toward assuring all persons served have access to person centered planning.

89. **From a service provider on 4/21/2017:**
    Case managers are disregarding MnCHOICES assessment results and discussion to opt for easy work such as immediate move to a corporate foster care and not exploring option to live independently even when clearly identified in the assessment as a distinct possibility with correct support. I fully believe that this is not done because case managers do not want to take the time to develop a complicated plan for community living when it is much easier to just send / talk the person / guardian into foster care.

90. **From a service provider on 4/21/2017**
    Due to lack of affordable, safe housing for individuals with disabilities, these conversations are difficult when we are not able to help the person achieve their goals for more independent community living. The greater community is also not prepared for all people with disabilities to be competitively employed. Employer incentives such as tax breaks or required % of employees with disabilities to meet cultural competency plans would be helpful. The state of MN needs to do a much better job of communicating their goals to individuals outside of the disability community as none of the Olmstead goals can be achieved without community awareness and acceptance.

91. **From a service provider on 4/21/2017**
    I've found that the multiple barriers individuals face due to their disability, the choice in care, housing, and opportunities shrink. Many with disabilities have legal issues, present or past substance use, and have been mislead in the past on what decisions to make. Because of the lack of understanding and advocacy, many of the people I help feel they have no choices left but need to just get by instead of thrive.

92. **From a service provider on 4/21/2017**
    I've noticed that a lot of the time, people are spoken about like they aren't in the room. Sometimes things they want get vetoed without being really talked about. Like if they want to try a new job, a member of the family or other care providers would be like, not possible, instead of trying to find a way where they would be able to.

93. **From a friend or a family member of a person with a disability on 4/21/2017**
    Person centered planning goes in the right direction. I believe that too often, the process is controlled by the guardian and not the person. Often these guardians are family members. I also believe person centered is a big boost to the person and guardian who want to make progress and will devote the time to make this happen. If that push is not there, progress flounders. Case managers seem to now have more paperwork to fill out and less time to support individuals.

94. **From a service provider on 4/21/2017**
    As an employer, Person Centered Planning is a most important approach to all employees both with and without disabilities. Having person center planning and thinking as an overall approach treats everyone equally with dignity and respect and is fundamental to our collective success.

95. **From a service provider on 4/21/2017**
    I wanted to share what we have done at [redacted] in the last year. We have had all support staff attend person centered thinking training as well as provided a session for our employees with [redacted] with disabilities, emphasizing "What is important to and what is important for". We have also had two designated coordinators attend a two day person centered thinking training. Lastly we are working

to continue to think about our overall culture as an organization, to create a person centered organization as well.

96. **From a person with a disability and friend of person with a disability on 4/21/2017**
    Person Centered Planning should be about the Person, and thus include what is necessary, as determined by the Person and his/her Guardian/s-not as determined by what money is available or what policies the State has or doesn't have or does or doesn't want to include or what DHS does or doesn't want to include, etc.. If you truly want Person-Centered Planning and Practices to actually happen-stop only letting certain services be allowed in certain settings. . . . whatever services is needed, should be allowed to be provided how the Person needs the service provided and in the various settings the Person needs the service provided. PCA SERVICES NEED TO BE ALLOWED TO BE PROVIDED AND PAID FOR AS THEY REGULARALY ARE IN THE HOSPITAL SETTINGS. NOT ALLOWING FOR THIS IS CAUSING INHUMANE RESTRAINT, NEGLECT, ABUSE, LONG-TERM MENTAL/EMOTIONAL/SOCIAL DAMAGE, DECREASES IN HEALTH AND DEATH. DO THE RIGHT THING!!!

97. **From a family member of a person with a disability on 4/22/2017**
    Disabled person desires many things for independent living. Resources to reach these desires are not available. Affordable housing and staff for daily living including jobs are not in the county's budget.

98. **From a person with a disability and friend of a person with a disability on 4/22/2017**
    Many of the new laws passed in the last 3 years have made decisions on what's available for jobs more difficult!! Specifically 245D & DWRS.

99. **From a service provider on 4/23/2017**
    I think it is a great process. I am concerned that many DT&H agencies in Minnesota are not giving the people we serve a full choice when it comes to working in the community. The current WIOA legislation and process is great but I believe many sheltered workshops are influencing the decisions that people we serve and their guardians make. Many guardians and people we serve are choosing to stay working for subminimum wage. There is not enough information given to them that would influence their decision. They are worried about not enough staff, no jobs out there, safety, employer resistance to hiring people with disabilities and the risks involved. In most of the small towns in my area [LeSueur County] employers and companies have barely been tapped for job development for people with disabilities. I know this because I used to be a job developer and parents/guardians are being told there are no jobs in our area by DT&H providers, where in fact the provider has not researched job opportunities.

100. **From a parent of a person with a disability on 4/23/2017**
    My son is 28 years old and has cerebral palsy and mental retardation. His IQ is 45 and he functions at 2 to 3 years of age. He is present and consulted when decisions are being made that affect his living arrangements and work but is unable to make decisions by himself. He needs assistance with all areas of life-grooming, personal cares, dressing, meal prep., personal safety, clothing care, housekeeping,etc. He is very happy with his employment and is very proud of the fact that he shreds paper or works on gaskets. He enjoys the activities he does with the staff and his housemates at his group home.

**101. From a friend or family member of a person with a disability on 4/24/2017:**

I am glad that this is being discussed, and hopefully if it is required that people have to consider a person's wants and needs that the outcome will be better for that person. Really, we are talking about quality of life, and more than a check the box "yes we met the retirement of person centered planning," needs to be a leading with empathy and understanding but not paternalism. People with disabilities are capable, caring and competent. I am hopeful continued discussion will result in everyone believing this because the live, work and are in the community right alongside people with all abilities.

**102.** From a friend or family member of a person with a disability on 4/24/2017

It's a wonderful idea, but the state lacks the financial and political resources to make any reasonable difference in the lives of people with disabilities. I have several friends with disabilities whose entire lives are dictated not by them, but by overbearing family members (who are NOT legal guardians) and the case managers will always side with the family, never the person they are supposed to be working for. The state is light years from being "person-centered." Until people with disabilities get support to make decisions - whether good or bad decisions, they will get nowhere. We are not an inclusive society by any means.

**103. From a service provider on 4/24/2017**

I think that Transportation is going to be a problem for individuals to get jobs out in the community, and that it's something that needs to be addressed before giving individuals false hope of where they can work. The reality is many of them could easily work in the community, but getting there is put back on them and their responsibility, and they don't always have the means or resources to get to work.

**104. From a person with a disability on 4/24/2017**

I have Done some work with and done some practice with person center planning I recently did person center planning for myself so I'm still just learning about what person center planning is all about.

**105. From a friend or family member of a person with a disability on 4/24/2017**

(PCP) needs to be more accessible to self-advocates and their families need more training opportunities out of the metro area.

**106. From a parent of a person with a disability on 4/24/2017**

Kept my son out of a group home and allowed him to grow and learn with family, communication, computer use, have the same care taker and not have rotation of staff.

**107. From a service provider on 4/24/2017**

It is very difficult, as a service provider, to help the people I support feel like they are in control of their lives and that their wants and needs and desires are being heard and respected when the families are not being educated on this process and are therefore still living in the "dark ages." For example: I'm struggling with parents who try to make their 27 year-old son shave his beard, which he's never been allowed to have before. They are so set on controlling this that they bully him, have all of his brothers and sisters bully him, refuse to let him go on home visits if he doesn't shave etc. They have said "well, can't we just tell him his doctor said it's bad for his sensitive skin" or "Oh just make him do it...what's he going to do anyway? It's not like he's going to go running to his case manager and tell on us." (He might not, but I will!) They are angry with staff because they feel that we "don't care." Staff have told them it is his right, and that we care about his rights and are here to help ensure his rights aren't violated. It creates a lot of tension between the families and staff (and then wages come into play with staff saying "I don't get paid to deal with this) So I feel a LOT more needs to be done to educate the families. I also feel it might have been beneficial to all concerned if there was more of a transition phase to this whole process. I absolutely LOVE person centeredness... I've hated the way we used to tell people "you can't have that pop, it's bad for you," "you have to go to this activity whether you want to or not," "you can't date that person (or anyone) because your parents don't want you to" for example. But, I think this newfound freedom is hard for some to handle all at once and they don't know what to do with it. It's overwhelming for them and can cause unnecessary behaviors. We work with people who sometimes struggle with decision-making more than others do and work hard to build those skills. And we will continue to do so. It just would have been helpful to have a little more transition. Overall, I am elated that this has all happened! I love that we can actually help them live THEIR lives, not the lives others think they should have.

**108. From a person with a disability on 4/24/2017**

I wrote the plan myself. The problem was that the county altered my plan without my consent, refuses to approve the supports for the type and at the level I have in my plan and pressures me to use a support planner. They refuse to provide technical assistance. I have shown medical need for and proven is the least costly alternative -- met all of the criteria required by the State in the CDCS Consumer and Lead Agency Manuals. Hennepin County dismissed my plan items. (In addition to failing to provide a suite of commonly approvable supports and common ranges -- like the other counties in the metro region do.) I appealed Hennepin County's decisions and the MN DHS judge agreed with the decision. NONE of these processes have a check and balance for meeting the guidelines of the program NOR for the person-centeredness of the supports requested. The judge rules in favor of the county because they are "the experts in redirection." I do not wish to be redirected. The supports they are not permitting full access to are: Cab fare through the Metro Mobility Same Day Cab program (up to $15 discount and the ONLY means of independent transportation I can take due to my combination of disabilities.) Office supplies so I may compensate for deficiencies in visual tracking due to my Traumatic Brain Injury. The net result is that I'm confined to my home except for grocery shopping and to meet with a non-insurance billed professional. I have no access to the community for social or civic purposes independently.

**109. From a service provider on 4/26/2017**

More training for providers of AFC and ILS.

## Summary of comments from April 24th Subcabinet meeting

**(This summary of public comments from the April 24th Subcabinet Meeting is included in the meeting minutes posted on the Olmstead Plan website.)**

**110. Thomas Martini – Member of the Public**

Thomas Martini shared his experience working for organizations that provide in-home care under 245D and requested the State provide training materials, like a video, that could be used so that employees can better understand what to do with clients and to help organizations to standardize more in order to meet expectations from the state and to better serve patients.

**111. Dianne Naus – Member of the Public**

Diane Naus shared that the biggest issues she has faced with working with individuals with disabilities are transportation and independent housing options. She stated she hoped individuals, the State, and providers could continue to work together to increase opportunities for people to move around the community and live in a setting of their choice.

**112. Lilli Sprintz – Member of the Public**

Lilli Sprintz stated the government and service providers must listen to what is important to people with disabilities to hear what is important to them in order to create and maintain a life that they can enjoy in the community. She stated that this work logically includes helping people with disabilities to maintain their health and get healthier if that is an option and describe the financial challenges of receiving the services and equipment needed to accomplish this. She also stated the transition services portion of the Olmstead Plan was discriminatory because it states that people under 65 will be helped to move to more integrated settings, adding that all people no matter their age need to be helped or the state is setting itself up for another lawsuit. She also commented that person-centered planning has different meanings to different people and entities and that there is a Personal Care Assistant (PCA) crisis in the state. She stated there is abuse occurring in private settings and encouraged DHS and MDH to set up protocols for an oversight procedure for PCAs.

**113. Lisa Litchfield – Community Advocate presenting on behalf of Pat Eversole, Member of the Public**

Lisa Litchfield spoke on behalf of Pat Eversole and read a statement he had prepared. She described his life and the disabilities with which he lives. She stated that Pat would like to live somewhere other than a group home or an assisted living facility and would like to live somewhere with private and shared space. She stated that Pat would like to be treated with respect as an intelligent, knowledgeable and skillful person worth being around, adding that people have both disabilities and abilities.

**114. John St. Marie – Member of the Public**

John St. Marie stated he is a recipient of home care paid through medical assistance and that the thrust of Olmstead is to keep people like himself in their own homes and to get them out of nursing homes. He stated that the legislature does not see fit to increase the payment rate or the reimbursement rate for these services in order to pay nurses and PCAs livable wages. He described current pending legislation related to PCAs that would provide for higher level training and higher pay and asked that people support this legislation by contacting their legislators, adding that the legislation if passed would truly support the spirit of Olmstead and empty some nursing beds, getting people back in the community.

**115. Bradford Teslow – Olmstead Community Engagement Workgroup Member**

Bradford Teslow stated he was a member of the Olmstead Community Engagement Workgroup and was happy with all the work the Subcabinet is doing. He stated that he would like more clarity around person-centered planning and described his own person-centered planning process. He asked that the legislature be pressed to get the funding needed for DHS and other agencies to make the Olmstead Plan work. He described work he has done to make the environment better in his own workgroup and thanked MDHR, the US Department of Labor, and the media for their assistance with that work.

**116. Denise Neisz – Member of the Public**

Denise Neisz stated she had 30 years of experience with special education, multiple special needs and supports, and medical services and is also is a parent. She reminded the group that any person can have a life altering event that results in needing support services for daily living. She thanked the Subcabinet for revising the plan, rewriting the rulebook, asking stakeholders for input, and asked how the impact of individuals would be observed. She described the different ways input and understanding can be sought in order to achieve positive impact. She thanked those whose career paths positively impact those with disabilities and supports unique individuals to live their lives to their potential. Commissioner Roy (DOC) requested that her written comments be provided to the Subcabinet.

**117. Gerald Murray – Member of the Public**

Gerald Murray described his son’s living situation and the level of care needed by his son, as well as the challenges of finding qualified, consistent PCA care for him. He stated he did not believe the training provided to PCAs is appropriate and would like to see action from the various meetings regarding service providers and trainings for them. He also stated he would like to have livable wage certifications for direct care staff developed in order to support providers, including a way to give raises, stating they are valuable people who have some important people to help.

**118. Connie Jensen – Member of the Public**

Connie Jensen shared her background with the Subcabinet and expressed her challenges finding employment as an older person with disabilities. She stated the Olmstead Plan does not discuss a retirement age or a person who no longer wishes to be employed, stating it is her health and she should be allowed to decide if she can or cannot work because she knows best the state of her health. She invited Subcabinet members to her place of employment to witness the working conditions and the improvements needed.

**119. Pat Salmi - Mentor for Olmstead Academy, PCP Planner, and Parent**

Pat Salmi shared with the Subcabinet information about her son, who has Fragile X, cognitive disabilities, and autism spectrum disorder. She described her son's living situation and her challenges with the person-centered planning process in Hennepin County and shared that she felt more training opportunities need to be provided for both parents and providers. She stated that individuals with disabilities have rights, but there is a need to make information about those rights more accessible in a more public way. She also described challenges with the person-centered planning process as well as transition services in the schools and asked that the State rethink the person-centered planning checklist and look at the education and experience of the planner and consider the professional aspect of a qualified planner.

**120. Stephanie Peterson – Member of the Public**

Stephanie Peterson stated that housing options for those with disabilities are focused on independent living and providers of independent living facilities and group homes cannot provide the 24-hour care needed by some individuals. She added that the lack of support for increasing wages for direct support workers compounds the problems of providing services and finding reliable staff is nearly impossible due to the limitations of hours and wages for waivered services. She stated that the need to prove you cannot do competitive work is demeaning and limiting and stated day programs are important for those who cannot participate in competitive employment but want to participate and contribute. She stated that choices for her daughter have been reduced due to changes resulting from the Olmstead Plan.

**121. Kathy Austin – Member of the Public**

Kathy Austin stated she has been a social worker for 35 years and has experience with direct care, adult case management, and guardianship. She stated she appreciates the intention, spirit, and goals of Olmstead, but fulfilling the plan and offering services does not allow providers to pay livable wages; there was workforce crisis before and it has worsened with poor pay and turnover. She stated her son lives in an ICF and asked that the larger bed facilities be left as an option for people who require more staffing, stating her son is very much integrated in the community and is not segregated. She stated that she has been told her son must move to a waiver home because he receives ICF funding. She stated her son had lived in the same place for ten years and it is his community and his home and he should be able to stay there. She stated she has heard a lot about person-centered planning, but is not seeing it applied to people who live in an ICF setting and the inflexibility of the funding needs attention.

**122. Nancy Wagner – Member of the Public**

Nancy Wagner described her personal experience with person-centered planning for her son, stating it is difficult for parents, because they must read through day program and apartment program reports so that they can communicate with the other professionals and collaboration between the groups is missing and is more difficult to accomplish with person-centered planning. She stated she loved Olmstead and the spirit of what is trying to be accomplished and it helps to take responsibilities off parents who will not outlive their children and the work being done will help to care for her son when she is no longer here. She commended the Subcabinet for the work being done to make the Olmstead Plan the best plan possible.

**123. Joel Fox – Member of the Public**

Joel Fox described his challenges in finding and being trained for appropriate employment that includes his needed supports. He also described challenges with other residents in his permanent living situation.

**124. Paula Neisen – Member of the Public**

Paula Niesen stated that person-centered planning is working as far as awareness of choice and DHS working with providers but felt it is not working when it comes to adequate communication about how the changes will impact families now and in the future. People are not aware of all the changes until for example, they receive a Vocational Rehabilitation assessment notice in the mail. She questioned whose vision is represented in Olmstead and stated that the government has decided everyone should work in the community, which is not an appropriate setting for everyone; some people need to work in an environment where they are calm, safe, successful, and supported. She stated her brother has worked in different environments and settings, but all have had a lack of consistent and well-trained staff; staff require specialized skills and training and make less money. She stated that everyone participates in the community based on personal choices and preferences and gave examples. She commented that the press has written negatively about day programs and employment and opined that the Subcabinet has a strong voice about what goes in the media. She stated that her brother is proud of his job and Day Treatment & Habilitation (DT&H) programs are the best fit for him and where he is happiest; not all individuals want competitive employment. She stated all individuals should be given choices for how they work, live and socialize that is actual choice and not the government's interpretation of their choices.

**125. David Hammond – Member of the Public**

David Hammond stated he has worked with people with developmental disabilities, Down Syndrome, autism spectrum disorder, and intellectual disabilities for some time and has found five ways in which he feels person-centered planning has hurt them as individuals and their quality of life. He stated he feels there is not enough individualization for adults and described a woman for whom he provides care who did not have the needed level of intellect to understand and respond to the survey questions. He also described medical concerns resulting from individuals who make food choices that are not appropriate for themselves and individuals who choose employment that is not an actual option for them and lose income as a result. He stated that person-centered planning can push in a direction that can be hurtful or harmful to an individual and described a situation where a woman was put in the community too quickly to be independent and was put in jail because she did not know her address.

### 126. Bruce Ario – Member of the Public

Bruce Ario stated that peer support is a highly successful method for treating mental illness and having that support has prevented him from being hospitalized since 1983, when he had been hospitalized three times in two years prior to receiving that support. He stated that the Olmstead Plan states his employment is not competitive so his employer no longer receives reimbursements. He stated he felt it was highly competitive and the fact that all the employees have disabilities does not make it a non-competitive work environment and likened it to the NBA not having any NHL players there because it doesn't make sense. He stated that all the employees have a certain level of abilities and are a certain type of people and they work together successfully and he would like to see that regarded as working competitively.

### 127. Gerald Smith – Member of the Public

Gerald Smith described his concerns with changes that will be implemented by DHS during 2019, stating that the changes will result one of his daughters losing 41% of her housing funding and 21% of her DTH program at which she works during the day. He stated that many parents are not aware that these changes are coming and the home in which his daughter lives will close after the change is put in to effect. He stated that he feels these changes violate the Olmstead Plan because it prevents individuals in having choices about where they work and live. He stated that, if funding changes are not made, these changes will result in the closure of some group homes and many counties have not passed this information along to parents and guardians or individuals and clients.

### 128. Mary Kay Kennedy – Executive Director, Advocating Change Together

Mary Kay Kennedy stated that one issue that is coming out very strongly is the issues of guardianship and non-disabled family members being barriers and an increasing culture of fear and protectiveness. Guardians making the rules under which persons with disabilities live. She stated the relationship of power between the person with a disability and the non-disabled person is worth a discussion to think about cultural change over the next decade and think about what can be done to help families shift their thinking in their perception of their role in keeping someone safe. She stated it is easy to create the plan, but implementation of the plan is what is really important and that the outcome is what needs to be measured and she hoped there was a component to measure what is happening and the outcomes. She also inquired about the cost of services, stating if someone is getting $120,000 of service per year from providers, they ought to be able to receive the services they want and it needs to be a person-based model not a service-based model. She stated the importance of people coming together before a person-centered plan to think about what is possible and that a person who has a narrow idea of what is possible in their own lives, the series of meetings will not be long-term enough for them to see all of the possibilities.

### 129. Victoria Hickenbock - ARC Greater Twin Cities

Victoria Hickenbock stated the biggest challenges she sees is that there is not enough education about what person-centered planning really is and what person-centered means, stating it does not allow giving any choice someone wants, but is a balance between the things needed to be happy and successful and the things needed to keep someone safe. Person-centered planning is about making choices and having people who can support and educate to make those decisions. She stated there is a difference between the person-centered plan and the person-centered process and education is a big piece of understanding what each is and how to implement it. She stated this it is not about continuing to provide services that already exist and saying it is person-centered, but is about creating services around a person rather than trying to fit existing services around a person. She stated there is a lot of fear for families and parents and there is a need to educate them, adding that change doesn't happen overnight. Families need to be educated to understand that these changes are happening and they are not about taking away services or money.

**130. Katie Hedlund – Member of the Public**

Katie Hedlund stated that she feels the biggest barrier tends to be case management and guardians who are trying to do well and understand but do not fully understand what person-centered planning means. There are many barriers to allowing individuals the dignity of risk to let them do want they want to do in their lives and who may be talked out of their choices by guardians who know how to navigate an individual away from a choice, particularly when it comes to employment. She questioned how counties are held accountable to ensure that person-centered planning is happening. She also commented regarding the need for the legislature to support additional funding for direct support professionals, stated her organization spends much time and money training and retraining to go by person-centered planning but providers can't feed their families on the wages they are earning, which results in high turnover, which negatively impacts the people being supported, who need consistency in order to build relationships.