

## **Missouri Home and Community-Based Service Settings Transition Plan Public Comments**

This document contains a summary of the public comments collected in response to the Missouri Statewide Transition Plan for the Home and Community Based Services (HCBS) Final Rule. Public comment was taken from December 30, 2014 through January 30, 2015. A notice regarding the Statewide Transition Plan was posted in The Columbia Tribune, Independence Examiner, Kansas City Star, Springfield News-Leader and The St. Louis Post Dispatch on December 29 and 30, 2014. The Missouri Statewide Transition Plan was available to the public on December 29, 2014. There were two public forums held. In accordance with Centers for Medicare and Medicaid Services (CMS) guidance, the Transition Plan was made available for public comment for 30 days after December 30, 2014 to allow all consumers, providers and stakeholders an opportunity to provide input to the plan. Paper copies of the State's HCBS Settings Transition Plan were distributed to Missouri Regional Offices and at the public forms. Additionally, Braille copies and American Sign Language (ASL) interpreters were available at the public forums.

During the public comment period, MO HealthNet Division (MHD), Department of Mental Health (DMH) and the Department of Health and Senior Services (DHSS) received comments from:

- Emmaus Homes, Inc.
- Missouri Developmentally Disabled Coalition
- Cole County Residential
- United Cerebral Palsy of Northwest Missouri
- Integrity Home Care
- UMKC Institute for Human Development
- Emmaus Homes Supporters
- United Cerebral Palsy of Northwest Missouri Supporters
- Missouri Developmental Disabilities Council (MODDC)

The following represents a summary of letters received from Emmaus Homes, United Cerebral Palsy of Northwest Missouri supporters, and MODDC.

The Emmaus Homes Campus has been in existence for one hundred years and many of the residents have resided there for over thirty years. There were three hundred and twelve (312) letters received from Emmaus Homes supporters including:

- Parents and Guardians
- State of Missouri Senator
- Local professionals
- Local business owners
- Community members
- Providers of services
- Educators

- Non-profit organizations
- Medicaid providers to Emmaus Homes residents
- Clergy and church members
- Washington, MO Chamber of Commerce
- City of Washington
- Friends and Family

The letters include support of Emmaus Homes staying open and fully funded. The letters reflect the thoughts and strong feelings that Emmaus Homes provide exactly what the individual needs. The individuals are fully integrated into surrounding communities. Most of the individuals have been at the Emmaus Homes for many years.

The Emmaus Homes staff and individuals are like family. Emmaus Homes individuals are safe, happy and content. The Emmaus Homes staff goes out of their way to enrich the lives of the individuals. One letter received indicates concern that not all developmentally disabled residents are “social.” The individuals have choice, friends and independence. They always have someone to interact with and the Emmaus staff is helpful and friendly.

One submitter feels that there will be great costs to implement changes to comply with the HCBS rule.

The Marthasville campus offers several housing opportunities such as apartments, five group homes, (two ISL’s) and larger housing units. One commenter writes that the Emmaus Homes individuals have freedom of choice and that the individuals would choose to stay in Emmaus Homes. There is safety and freedom on campus and individuals can come and go as they please. They are safe at the Emmaus Homes and can participate in campus activities. The individuals have created life-long relationships. The community of Washington has embraced these individuals and they are able to take part in city functions. They volunteer with YMCA programs, Meals on Wheels and raise money for local charities. They attend and are a part of local churches; such as playing in the hand bell choir. The local churches and community are likewise supportive of the campus as the Washington community embraces the facility by volunteering and conducting fundraisers in support of Emmaus Homes. Washington considers Emmaus Homes a part of the community. Each year over \$70,000 is raised by the community in support of Emmaus Homes.

Individuals are their own consumers in this community. They shop and partake of local business. They support locally owned businesses. Emmaus Homes individuals visit Washington frequently and use many community programs and facilities.

Some commenters are concerned that if there are drastic changes, there will be changes in the health and behavior of the individuals. They feel that the facility is well integrated into the greater community. They are asking the State of Missouri to recognize Emmaus Homes as providing a funded, integrated community environment for individuals and ask that the facility be allowed to stay open.

Eleven (11) letters were received in support of United Cerebral Palsy of Northwest Missouri.

They included letters from:

- Employees
- Parents and Guardians
- Friends and family

Several voiced concern that the proposed regulations are restrictive to the individualized plan at the Adult Day Care. The activities are planned specifically for the individual's abilities and interests while taking into account health issues. UCP provides in an individualized fulfilling manner of care. A cookie cutter approach makes wrong assumptions.

Some parents of children with multiple physical and mental disabilities do not feel that individuals with disabilities coming together in one facility, isolates and segregates them from the broader community of individuals without disabilities. UCP strives to ensure the individuals are enjoying their daily lives, that they have access to the community by participating in activities of their choice and that the individuals have a voice in their life decisions.

Employees states the UCP individuals are part of the community including volunteer involvement such as:

- Filling backpack for school kids for the Backpack Buddy program
- Filling bags for the children's Fair and handing them out at the Civic arena
- Washing tables and serving meals at the Open Door Food Kitchen
- Picking up litter at local parks and river walks
- Pick up recycling
- Deliver with Meals on Wheels
- Visiting, playing bingo, caroling, providing gifts for nursing homes
- Collecting schools supplies at local Wal-Mart for "STUFF THE BUS."
- Going to garage sales
- Decorating Christmas Tree at County Court house
- Going to museums, rec centers, libraries, eating out and shopping

Out of town trips to Kansas City Zoo, Farmstead in KS, Pumpkin Patch in Kearny, Watkins Mills State park are made each year. UCP provides in house speakers such as Fire Department and Zumba classes. UCP provides too many activities to list.

There was concern mentioned that a large part of the community still treat people with different abilities quite differently and it is not pleasant for the individual. The individuals have safety, protection and comfort during outings with UCP staff.

Letters implore the state to look closely at each provider's mission and how they implement said mission before lumping all in the same basket. The prior authorization

contract is not person centered and does not allow for flexible movement or spontaneity within the set units of day habilitation prior authorization.

The following addresses the questions, comments and letters received during the two public forums and public comment period.

### **I. Individual Initiative, Autonomy, and Independence in Making Life Choices –**

Comments and questions in this section center on requirements in the HCBS rule that seek to ensure individuals receiving Medicaid funded HCBS have full opportunity to make choices and exercise optimal control over all aspects of their daily living. As such, many comments do not specifically address the Missouri transition plan per se, but rather are seeking clarification or expressing concern with the HCBS rule. No changes were made to the Statewide Transition Plan as the result of any comments in this section.

**COMMENT:** Provider via telephone questions the portion of the rule which states every home should have a private place other than bedroom that person can receive visitors or phone calls? She states that it could be a financial burden on providers such as theirs and that most homes at Emmaus do not have a private area other than a bedroom. Commenter asks if there was a place on the campus that provided privacy; would that satisfy the requirement.

**RESPONSE:** The rule requires they have space for privacy, however, the rule does not specifically state that it has to be a separate room. When the state completes on site assessments, privacy will be determined. Regarding the question to having a separate place on campus for privacy, the State does not think that would be compliant. Having a separate place would require individuals to leave their home for privacy, which the State believes is not the intent of the rule.

**II. Provider Owned or Controlled Settings –** No comments were received.

**III. Community Integration versus Settings with the Effect of Isolating Individuals from the Broader Community –** Comments in this section center on the requirements in the HCBS rule that seek to ensure that HCBS is provided in settings integrated in the greater community and supports full access to the greater community to the same degree as individuals not receiving Medicaid funded HCBS. As such, many comments do not specifically address the Missouri transition plan itself, but are seeking clarification or expressing concern with the HCBS rule. No changes were made to the Statewide Transition Plan as the result of any comments in this section.

**COMMENT:** The following comments address concerns with an individuals' availability of choice and settings in which they live.

1. I am writing in support of keeping campus settings open and fully funded. The campus has provided services to individuals with developmental and physical

disabilities for over 100 years. Some residents have resided there over 30 years. The campus setting offers several housing opportunities such as: apartments, group homes, ISLs and larger housing units. The “final rule” talks about the need for individuals with disabilities to be an “integral” part of a community. The residents have freedom and safety on that campus that is not possible in the community. If they choose to take a walk, they can leave their residence and go next door to visit a neighbor or friend. Residents can walk to pottery classes and other activities, or walk to work at the sheltered workshop. Residents can always find a staff member to talk to; whether it is someone in the Administration office or an employee cutting the grass, there is always someone to interact with. In the community, a resident would not have the ability to leave their house without supervision. They would not be able to visit a friend next door without supervision or have the independence to interact with others on their own. If an emergency arises on campus, many staff are available to respond, not so in an individual home in the community. The rule addresses choice; each person should have the ability to choose where they live, although the rule states they should not live with “all disabled people”. Does that mean that senior citizens living in a facility should lose their Medicaid because they are together? Or that people of the same faith, race or economic status should not live together? Is it fair to move someone from a loved home where they have lived for 20 or more years because of the “new rule”? The campus setting not only provides exceptional care, but enriches the lives of their residents. These residents are embraced by the community.

2. Simply put, the CMS “final rule” regulations which are designed to ensure that society offers him what he already has, community integration, may ultimately remove him from his community where he is firmly rooted, as there is no guarantee that a new home would be in the area. He will lose the many life-long friends and numerous peer activities that he participates in on a nearly daily basis, plus the many times through the year that community friends and family attend functions on campus. The irony of this situation, the Federal and State intent to close campus-style “congregate settings” in favor of residential life, is that there will be an unnecessary and especially cruel outcome. Also, there is the idea that providing a life which includes close proximity and bonding with “peers” (i.e. “disabled”) neighbors is a form of “discrimination”. Isn’t that what “we” in the non-disabled world expect for ourselves, don’t we live in a community of our peers? Why would we try to limit any person’s choice of neighborhood and community? Are we going to limit choices for disabled persons, when we as a society, protect and legislate choice for the non-disabled? I am asking that the State and Federal governments recognize my brother’s deep-rooted life among his peers and community, and that they let him choose to remain at the campus for the remainder of his life. This can only happen if the State and Federal governments recognize that a rural community of disabled persons can also provide full community integration. Ultimately the campus is where my brother chooses to live. We should ask ourselves not what he will gain from

- the move but what he will lose by moving away from his peers and community of over 45 years. The sad result will be that he will live a diminished life compared to what he has now.
3. The Rule, probably well intentioned, says that a campus setting isolates our daughter from the greater community. That she should rather live in some house in the community among non-disabled citizens, managed by a caregiver. This rule may be okay for higher functioning developmentally disabled; it is not, however, appropriate for our daughter. She would no longer be with her present extended friends and staff in adjoining group homes. Our daughter would be truly isolated in a standalone house on some community street. She will not be able to go out the door without a caregiver hovering by her, unlike the freedom and safety she enjoys on the campus. This does not enhance her quality of life. Her life would be diminished without her 17 years of friends and staff in nearby group homes. The most concerning thing about this final rule is that: The final rule is written and intended to allow the developmentally disabled to have almost unlimited choices. However, when fully implemented, it takes away choices. It takes away her present choice of nearby group homes of staff and friends. It takes away the community she feels on campus. It takes her away from the people she has socialized with for 17 years. Do not forget, our daughter has chosen to live at the campus because it provides her with the least restrictive, loving, caring, safe environment to live in. She does not belong in a standalone home in some community. And we should not expect to move her from the wonderful group homes on the campus. The final rule cannot be applied to any and all developmentally disabled persons on a “one shoe fits all” basis. That is impossible. All developmentally disabled persons do not fit the same mold.
  4. I am writing in regards to the new regulations regarding persons with disabilities. I understand this will affect the wonderful adult program my daughter attends. This program allows my daughter access to a community and resources not available at home. Transportation is an issue in getting my daughter back and forth from this program but we have figured that out with family and friends. Living in the rural area we live in there are no programs, work opportunities, or resources available for families with children that have disabilities. Transportation is the biggest problem.
  5. You are making decisions that greatly affect so many people, not just the individual needing extra help, but I believe a very small percentage of you, if any at all, have someone in your life that will be affected by the changes you are wanting. I have 2 children with special needs, now young adults, both attend the adult program and very much enjoy it. It is my understanding that your group wants to integrate persons with special needs into the community in all areas. That sounds great on paper; however, in real life it is not at all great. My children have “peers” and friends in their own social settings and these peers and friends are just as good for them as your peers and friends

- are for you. My children know they are safe and secure when they attend the adult program, they are not viewed as different, and they are not made fun of.
6. As parents of a 37 year old son who was born with multiple physical and mental disabilities, we would like to comment on the transition plan the State of Missouri is proposing to meet the new Medicaid regulations regarding person with disabilities. We do not share the belief that individuals with disabilities coming together in one facility, isolates and segregates them from the broader community of individuals without disabilities. Our son has attended the adult program since 1999; we feel they strive to ensure the attendees are enjoying their daily lives, that they have access to the community by participating in activities of their choice, and that the individuals have a voice in their life decisions. The adult program is continually looking for new community activities individuals may participate in if they so choose.
  7. I am writing in regards to Missouri's transition plan. My grandson attends the adult program and has since he was 21. He loves it there and enjoys everything he does, he goes out into the community but he is not able to work out in the public. My grandson would not be happy anywhere else, he does not do very well anywhere else. If there are others attending the adult program that are able or want to go out, then by all means, let them go, but do not force those who are attending to change their routine.

**RESPONSE: Any setting in which HCBS services are provided is required to be compliant with the HCBS rule for all services provided in the setting.**

**The Transition Plan is the process for the State to become compliant with the HCBS rule. The DMH individualized assessment process will determine if the individual's choices and needs are met and are supported and documented in their Person-Centered Plan.**

**We are aware that there will be some settings that appear to isolate from the broader community and will fall under the heightened scrutiny review for submission to CMS for approval. The DMH will conduct onsite assessments of heightened scrutiny settings to evaluate compliance with the HCBS rule. Compliance will be determined based on the opportunities and experiences of the individual receiving HCBS, according to the standards set in the HCBS rule, including but not limited to whether the individual has selected the setting from all available choices; whether the individual's rights to privacy, dignity and respect, and freedom from coercion are protected; whether the individual has choice in services and providers; whether the setting is integrated in and facilitates the individuals access to the greater community.**

**Through the assessment process any settings requiring remediation will be afforded the opportunity to ensure compliance with the HCBS rule.**

**COMMENT:** The following comments address concerns with the setting in which they live.

1. The rule does not provide for individuals with developmental disabilities considering the needs for senior residential settings that meet the needs of their age, capacity and high quality of life. Disrupting their lives with moves into housing in unknown, unfamiliar areas with limited freedom of movement in the community and living among strangers seems to be unethical, lack of kindness, compassion, and caring for our fellow men and women. The current rule as written may have been well intended to serve developmentally disabled adults who live in undesirable settings. However, the unintended consequence of interpreting this rule to include placing of residents at various other communities is detrimental to the purpose of best practice care.
2. In the community setting on campus my sister has thrived. We visit her and take her out monthly and she comes to my house on some weekends to visit. My sister has much freedom of movement at the campus and it is much safer than a home on a cul-de-sac. Living in a group home in the community would make her more isolated. She would miss all her friends and her job. My sister has a very active social life and is a great part of the surrounding communities. I don't know what a move to a different area would do to her. Just like the rest of us, she has a hard time with change. She is part of the most vulnerable of our State and it feels like they don't care what happens to her. She has rights and I feel the State is just making decisions without regard to the people involved. The residents that live at the campus are all thriving because of the superior staff which provide care and truly are concerned about their well-being.
3. The "final rule" talks about the need for individuals with disabilities to be an "integral" part of a community. The surrounding community embraces these residents as they take part in city functions, participate in city activities, attend local church services and are consumers. The residents have freedom and safety on that campus that is not possible in the community. If they choose to take a walk, they can leave their residence and go next door to visit a neighbor or friend. In the community, a resident would not have the ability to leave their house without supervision. They would not be able to visit a friend next door without supervision or have the independence to interact with other on their own.

**RESPONSE:** Any setting in which HCBS services are provided is required to be compliant with the HCBS rule for all services provided in the setting.

**Settings that appear to isolate from the broader community will fall under the heightened scrutiny review for submission to CMS for approval. The DMH will conduct onsite assessments of heightened scrutiny settings to evaluate compliance with the HCBS rule. Compliance will be determined based on the opportunities and experiences of the Individuals receiving**



**HCBS, according to the standards set in the HCBS rule, including but not limited to whether the individual has selected the setting from all available choices; whether the individual’s rights to privacy, dignity and respect, and freedom from coercion are protected; whether the individual has choice in services and providers; whether the setting is integrated in and facilitates the individuals access to the greater community.**

**COMMENT:** Two commenters posed questions regarding the definition of setting such as four homes in a cul-de-sac with different addresses; would GIS show four locations? There was concern regarding rural settings vs. urban settings. Commenter also asked how many settings are in Missouri.

**RESPONSE:** The State will assess how the individual is integrated into the community. Each waiver individual should have the same integration opportunities as a person not enrolled in an HCBS waiver.

**There are approximately 2,200 DMH settings in Missouri. DMH will complete assessments based on a 95% confidence level derived from a statistically random sampling. Initial assessments are due to be completed April 2016. However, each individual assessment will be completed within six months of the starting date.**

**COMMENT:** Comment was received regarding integration and in particular a provider that houses a ceramics workshop; are individuals selling ceramics in the community considered “integration”? A question arose regarding when outside youth organizations came to utilize their campus for retreats would this constitute integration?

**RESPONSE:** The State asked the commenter for clarification on whether the individuals went out to community to sell or whether the community came to the campus. It was determined that selling ceramics to provider staff would not be considered selling wares to community and would not display community integration. A youth organization using additional buildings on a provider campus is not integration.

**COMMENT:** Public comment was made regarding settings and heightened scrutiny. The letters submitted by Emmaus Homes supporters indicate our opinion that our setting is not “isolated”.

**RESPONSE:** DMH will take into account all evidence during the assessment process. DMH will compile all evidence, including the comments, into the assessment report which will be submitted to CMS.

**COMMENT:** Public Commenter asked if state will be looking at the number of outings available for the participant per month.

**RESPONSE: No. The State will assess whether the individual had choice to go out into the community in order to meet their needs and access the greater community.**

**COMMENT:** Commenter poses question stating, “Integration is not based on numbers, correct?”

**RESPONSE: Correct, integration is not based on numbers. It is based on choice.**

**IV. Transition Plan: Settings Analysis** - No comments were received.

**V. Transition Plan: Assessment** - Comments in this section are centered on the assessment portion of the draft transition plan, excluding the settings analysis which is addressed in the previous section of this document. No changes were made to the Statewide Transition Plan as the result of any comments in this section.

**COMMENT:** Four comments regarding legal guardians being present during assessments: Will you complete the participant survey if no guardian is present and how can you ask a resident if the participant is not legally able to respond given the participant has a legal guardian? Public Commenter stated it is awkward and cumbersome for individuals to receive a letter regarding upcoming assessments. The United States Postal Service (USPS) is not dependable especially with recent news of USPS restructures. Could the participant receive an email? Can the participant be notified before three days?

**RESPONSE: DMH will be scheduling the assessments with the individual three business days prior to the assessment date; guardians will be notified one business day prior. The individual can let the guardian know an assessment was scheduled; however, guardians are not required to be present at the assessment. The DMH reiterated that the assessment is about the individual and their services. Contact information in State systems will be utilized for scheduling.**

**COMMENT:** Two commenters posed questions regarding the availability of instruments that will be used for assessment; *Missouri Exploratory Questions and Missouri-Settings with the potential effect of Isolation*. Another commenter inquired about the experience of the developer of the instruments.

**RESPONSE: The instruments are available on the State’s website. The State sent out an email blast on December 31, 2014 making them available. The instruments were developed with references and language based off the initial rule and cross-walked with exploratory questions. There will be training for support coordinators, provider relations staff and other staff who will be completing the assessments.**

**COMMENT:** Comment was received regarding the assessments and non-verbal individuals.

**RESPONSE:** For those who are non-verbal, DMH will be using “communication kits” (picture books, crayons...) during assessments. DMH will be asking individuals questions regarding personal choice such as, “Would you like your own bedroom?”

**COMMENT:** A public commenter via telephone inquired if assessments for residential and day programs will be done at the same time.

**RESPONSE:** When the State completes an assessment for an individual, both residential and day programs will be completed at the same time.

**COMMENT:** Commenter via telephone asked if there will be an appeal process for assessment.

**RESPONSE:** The state will present findings and then providers can remediate.

**Comment:** Five documents specific to the new rule were not included in the materials posted to the websites of the Division of MO HealthNet, the Division of Developmental Disabilities, or the Division of Senior and Disability Services. Tools used to implement the plan, once developed, should be released for public comment to ensure transparency, and that they fully and accurately measure compliance with the rule.

**Response:** The 2014 Provider Self-Assessment Survey was open for a period of time August 21, 2014 through September 10, 2014 as indicated in the MO HealthNet Provider Bulletin dated August 22, 2014. As indicated in the transition plan the survey will be available for providers to complete again from January 1 to April 1 annually beginning January 1, 2016. Results will be shared with the public by May 15 annually.

The Initial Settings Assessment Tool (also referred to as the On-Site Assessment Tool) and the Provider Relations Heightened Scrutiny Settings Analysis are internal compliance tools that are utilized to ensure compliance with the final HCBS rule. This instrument was developed utilizing the CMS Final Rule and the CMS Exploratory Questions, which are posted on the MO HealthNet Division and Division of Developmental Disability websites.

The Missouri HCBS Waiver Settings Analysis document was posted on the MO HealthNet and the Division of Developmental Disabilities website on December 29, 2014.

**Comment:** The Council has concerns that the single assessment tool that will exclusively incorporate the opinions of people being served, in the draft plan, is an online survey. They also have concerns that a participant survey, which is exclusively online, will not capture a substantial number of persons because they lack access to the Internet, including the necessary assistive technology to make it usable, or the technological literacy to complete an online survey. A written explanation of how the survey is being made available to individuals in these situations is needed.

**Response:** The participant survey is not the single assessment tool. It is one form of an assessment tool to ensure compliance with HCBS. The initial on-site assessment tool is another instrument that obtains information from the consumer during the on-site assessment process.

The survey is available on line in both Word format and Survey Monkey. In addition, division representatives will be attending various constituent conferences throughout the year offering individuals the opportunity to participate in the survey. By being available in Word format, the survey is available for any stakeholder organizations to distribute.

**Comment:** The participant survey should also include a question asking whether a visitor can come to the individual's living area or bedroom for a visit.

**Response:** The participant survey addresses the individuals' choice to have visitors at any time in their home.

**Comment:** The State may also explore other ways to reach individuals that may not have a full understanding of written English. A video discussing the concepts of the new rule, and what it means in plain English, may be beneficial to some individuals being served, as well as educating the public at large.

**Response:** The Division of Developmental Disabilities is in the process of developing a video for social media that will address educating the public at large.

**Comment:** The Council recognized the reference to 330 initial on-site assessments on pages 5-6 of the draft plan for the action item, "Systemic Initial On-Site Assessment." The Council indicated that their understanding is that the actual number will be more than 900 settings to account for a 95% confidence interval in each setting type, in each of the five DMH waivers. This is a welcome change from the draft plan that was made public; however, these modifications need to be made public, in writing, as well.

**Response:** The Division of Developmental Disabilities has expanded from the sample size referenced in the transition plan of approximately 330 to assessing over 900 individuals at this time receiving HCBS services. This

**number will continue to grow as individuals continue to request assessments in addition to the random sampling.**

#### **VI. Transition Plan: Remediation Strategies and Public Comment Period -**

Comments in this section are centered on the remediation strategies and public comment period portions of the draft transition plan. No changes were made to the Statewide Transition Plan as the result of any comments in this section.

**COMMENT:** A public commenter inquired if CMS will extend the public comment time?

**RESPONSE:** There has been no indication from CMS that the transition plans' due date will be extended.

**Comment:** DMH providers and DHSS providers are treated differently in the draft transition plan in ways that may lead to uneven compliance between the waivers administered by each department/division. The Council understands that although the transition plan treats the two sets of providers differently, in practice, providers in both systems will be given the same amount of flexibility and leeway. However, this is not apparent from the transition plan, and should be in writing. Examples included references to MMAC responsibilities for DHSS but no specification for DMH, and remediation resolutions for prolonged non-compliance outside of the identified time frame.

**Response:** DMH and DHSS are two separate departments that operate under different service delivery systems and compliance structures. The transition plan accounts for the different structures by separating action items between DMH and DHSS. DHSS identifies MMAC specifically because MMAC is a separate agency whose responsibilities include enrollment and monitoring for DHSS; whereas DMH functions are internal.

**Additionally, the transition plan does address remediation resolutions for prolonged non-compliance. Providers that fail to remediate non-compliant settings timely may be subject to sanctions in accordance with 13 CSR 70-3.030 and/or 9 CSR 45-5.060.**

**VII. Transition Plan: General Questions and Comments -** Comments in this section are centered on the draft transition plan or the assessment and remediation process. No changes were made to the Statewide Transition Plan as the result of any comments in this section.

**COMMENT:** The following comments address concerns with an individuals' availability of choice and settings in which they live.

1. This plan however effective or applicable it may be to mildly disabled adults does not take into consideration the needs of the severely disabled. Those who have very low IQs do not have the ability to speak for themselves as far as their needs and wants. If the severely disabled residents are forced to make the changes this plan recommends, there will be drastic changes in their health and behavior, negatively affecting them and those around them. The safe and secure environment provided for residents would not be able to be duplicated with many recommendations of this plan. This plan seems to focus on the fact that these residents are adults when in fact most residents in a campus setting function more like a young child. Given this, many of these suggestions would prove to be more harmful than helpful. These residents thrive in a setting that provides consistency and familiarity. Many of the recommendations of the transition plan do not take this into account. If the plan intention is to provide the least restrictive environment as well as a community atmosphere, many of us feel that a campus setting already does just that, in the best interest of its residents. It is imperative that the legal guardians and family members of the residents are heard and taken into consideration. No one knows and understands the needs and wishes of the residents as well as their loved ones.
2. This letter is in reference to the Final HCBS rule. Last year our community project was remodeling one of the homes for residents. Over \$100,000 was donated by contractors, business owners, and volunteers in the form of labor and other assistance. Over \$40,000 was raised with two fund raising events for the project. We encourage community activities for residents and staff by donating funding for special events and chaperone expenses. Our support is directed to our mission, which is to make a difference in the lives of residents and staff that have made a choice to live and work in the campus setting. It is my sincere hope that you and other members of the Division of Developmental Disabilities, Department of Mental Health take the opportunity you now have to support the individuals who maybe cannot speak for themselves but deserve all the rights guaranteed them by the Olmstead Decision that their "choice" is preserved. For some residents that choice was made over 40 years ago. They want to continue to live in a community where they can enjoy the freedom to ride a bike, drive a golf cart, walk to work, visit friends next door, spend time with families in their homes, celebrate special events, and enjoy easy access to other community activities. They don't want to be treated differently but rather like everyone else, like all of us who freely make a choice of where to live and what we want to do in our life. Please preserve and honor their "Choice" of home.
3. My son is happy and independent. He can go to the house next to him to visit a friend, visit the office staff on campus, participate in pottery class, and attend church with a staff member; the list goes on and on. When a staff person that he cares for leaves, he knows that he can still be surrounded by staff that he knows and trusts. The community of

Washington is like no other community I have ever lived in or experienced. They embrace the residents of the campus and truly want them in their community. There isn't a Sunday that we visit and take him to lunch that he doesn't know someone in the community. He lives a full and satisfying life. The campus has existed for more than 100 years and is supported by the churches and local community. It should not close, we need your help to keep the campus open and allow my son and the other residents the dignity and freedom of choice.

4. I have experience in participating and observing not only programs and facilities, but choices, freedom and opportunities available to residents, families, guardians, and community. Without a doubt the choices and freedom for residents, parents, and guardians far exceed the other options and are demonstrated daily at the campus. While I am not a parent or guardian, I am part of the community that embraces the quality of life on the campus.
5. Our son made his own decision to move to the campus. He should have the same options as any other adults to decide for himself where he wants to live. It will put undue stress on him and other residents if they are forced to move into environments that are not of their choosing.
6. The rule addresses choice; each person should have the ability to choose where they live, although the rule states they should not live with "all disabled people". Does that mean that senior citizens living in a facility should lose their Medicaid because they are together? Or that people of the same faith, race or economic status should not live together? Freedom of choice means choice.
7. I am using this as an opportunity to speak for those who can't speak for themselves. Either the residents or their guardians have chosen the campus as the home they want. They choose to live in a community with others like them. Having several homes in close proximity to each other helps keep them safe. If there is a problem or improper care, it can be acted on immediately with help from staff from one of the houses nearby. My son is safe and has a wonderful life where home staff helps him live up to his full potential. If the final rule can take away my son's choice to live in a congregate setting, who's to say down the road that other choices won't be taken away.
8. My daughter attends the adult program, and I am so thankful for places such as these, they have helped her learn to walk, talk to the best of her abilities, feed herself, and sign language. I have to admit, I do not believe I could have brought her this far without programs such as this. They have also helped her be a part of her community, which I am very thankful for. People are cruel, they like to stare, and make fun of others if they are different. My daughter has been through a lot in her life, so please don't take away these programs, for it is the very thing that helps bring joy in her life. I believe the adult program is her best chance of progress, happiness, and the feeling of belonging to something, other than her loving family.

**RESPONSE:** Any setting in which HCBS services are provided is required to be compliant with the HCBS rule for all services provided in the setting.

The Transition Plan is the process for the State to become compliant with the HCBS rule. The DMH individualized assessment process will determine if the individual's choices and needs are met and are supported and documented in their Person-Centered Plan.

We are aware that there will be some settings that appear to isolate from the broader community and will fall under the heightened scrutiny review for submission to CMS for approval. The DMH will conduct onsite assessments of heightened scrutiny settings to evaluate compliance with the HCBS rule. Compliance will be determined based on the opportunities and experiences of the individual receiving HCBS, according to the standards set in the HCBS rule, including but not limited to whether the individual has selected the setting from all available choices; whether the individual's rights to privacy, dignity and respect, and freedom from coercion are protected; whether the individual has choice in services and providers; whether the setting is integrated in and facilitates the individuals access to the greater community.

Through the assessment process any settings requiring remediation will be afforded the opportunity to ensure compliance with the HCBS rule.

**COMMENT:** I sincerely hope that the State of Missouri reconsiders and makes allowances for the few individuals who would not benefit by this "final rule." The campus setting has in the past and continues to provide a quality way of life for mentally and physically challenged individuals. While I understand that residency for campus living may be down, that doesn't mean there is no need. I urge you to reconsider the demands this "transition" is placing upon campuses.

**RESPONSE:** Any setting in which HCBS are provided is required to be compliant with the HCBS rule for all services provided in the setting.

Settings that appear to isolate from the broader community will fall under the heightened scrutiny review for submission to CMS for approval. The DMH will conduct onsite assessments of heightened scrutiny settings to evaluate compliance with the HCBS rule. Compliance will be determined based on the opportunities and experiences of the Individuals receiving HCBS, according to the standards set in the HCBS rule, including but not limited to whether the individual has selected the setting from all available choices; whether the individual's rights to privacy, dignity and respect, and freedom from coercion are protected; whether the individual has choice in services and providers; whether the setting is integrated in and facilitates the individuals access to the greater community.



**COMMENT:** Commenter asked for definition of public institution:

**RESPONSE:** A public institution is any government owned institution.

**COMMENT:** Commenter asked if a provider is judged to be a non-profit institution, subject to the sunshine law and is a quasi-public entity; are the properties owned considered as public ground?

**RESPONSE:** The state will have to do further research.

**COMMENT:** Two comments were made regarding a particular provider setting which insures their participant's safety. The biggest concern stated was how we plan to keep a congregate setting in compliance that the participant has known for up to 50 years. One commenter has a brother at Emmaus Homes. The community environment is important to him. Her brother will choose to live there. Integration is not possible without Emmaus house helping him get into the community. Choice is the key and the commenter hopes the state continues to take that into consideration.

**RESPONSE:** Compliance will be determined based on the opportunities and experiences of the individuals receiving HCB waiver services, according to the standards set in the HCBS rule, including but not limited to whether the individual has selected the setting from all available choices; whether the individual's rights to privacy, dignity and respect, and freedom from coercion are protected; whether the individual has choice in services and providers; whether the setting is integrated in and facilitates the individuals access to the greater community.

**COMMENT:** Comment from Franklin County Public Administrator regarding the lease requirement; "Does each person sign a lease? As a county appointed official, I'm not going to be able to sign a lease. If I'm signing a five year lease, my signature means nothing if I am not re-elected. There are other individuals that I perform duties for as Public Administrator. I want to make sure the guardians I serve choices are heard and that the individuals keep their funding."

**RESPONSE:** Per the HCBS rule, an individual will have a legally enforceable agreement providing similar responsibilities and protections from eviction that tenants have under landlord-tenant law of the state, county, city or other designated entity.

**COMMENT:** One commenter asked if the Individualized Plan has been updated for compliancy. The same commenter asked for clarification regarding waiver number (Mo. 0197) which he noticed on information in the transition plan document.

**RESPONSE:** Yes, Individualized Plans are being reviewed and updated. DMH will be requesting the individuals' current individualized plan before the assessment and will review the plan prior to the visit.

**COMMENT:** One commenter questioned the fiscal impact and costs associated with implementing the transition plan; will CMS pay a federal match? There was concern noted that the statistical sample number was not enough.

**RESPONSE:** CMS will not pay a federal match for providers to make changes in order to come into compliance.. The State will be focusing on exploring ways to meet compliance without a fiscal impact.

**DMH responded that 300 individual assessments would be the minimum number assessed based on an early projection. However, the actual number of individual assessments will be over 900 settings.**

**COMMENT:** Commenter asked if completed provider surveys are available for public review.

**RESPONSE:** The completed provider surveys are not currently available for public review.

**COMMENT:** Commenter via telephone had questions regarding the provider surveys and time frames.

**RESPONSE:** The State sent notices to providers on June 23, 2014, with a follow-up notification sent in August 2014. The provider survey was closed September 10, 2014.

**If a provider did not complete a survey, the provider can go to the CMS exploratory questions document, which can be found on DMH website, and formulate responses and submit those to the State. However, they will not be incorporated with the provider surveys which were due in September 2014.**

**COMMENT:** Commenter via telephone asked if the paperwork that is included at this meeting is available on departmental website.

**RESPONSE:** The handouts can be found at the following websites:  
[www.dss.mo.gov/mhd](http://www.dss.mo.gov/mhd), [www.dmh.mo.gov](http://www.dmh.mo.gov).

**COMMENT:** Commenter asked if the participant survey can be filled out at this time and is there presently a method for folks who do not have technological literacy to gain access to the participant survey? Has this been discussed?

**RESPONSE:** Yes, the participant survey can be filled out at any time. The participant surveys will be available in the regional offices and made available to support coordinators as well. It is available in a Microsoft WORD document that can be submitted to DMH and will be available on-line in a Survey Monkey format in the very near future. Individuals are welcome to include their name and contact information, or the survey can be completed anonymously. Surveys should be sent to DMH Central Office rather than going through a provider.

**COMMENT:** A public commenter via telephone asked who the State's stakeholders are.

**RESPONSE:** The stakeholders include, but are not limited to, Missouri Association of County Developmental Disabilities Services (MACDDS), Missouri Association of Rehabilitation Facilities (MARF), Developmental Disabilities (DD) Council, People First, the ARC, Adult Day Care Association, and Leading Age.

**COMMENT:** A public comment was received asking where the Code of State Regulations (CSR) are located.

**RESPONSE:** Missouri's Code of State Regulations are found on The Secretary of State website which can be located at: [www.sos.mo.gov](http://www.sos.mo.gov)

**COMMENT:** Public commenter asks if the state anticipates any significant changes to the transition plan. Will comments be available to the public?

**RESPONSE:** No, the State does not anticipate any changes to the transition plan. At this point most of the concerns revolve around the implementation component rather than the transition process. All public comments will be summarized and shared with the public through posting on the State's websites.

**COMMENT:** Public commenter states that this is a well-intentioned plan, but was not thought through very well which is why the State has to work through all this. The implementation will be difficult and tedious.

**RESPONSE:** Statement, no response required.

**COMMENT:** Commenter via telephone asked if the state is making an effort to keep things the same at the Emmaus Home.

**RESPONSE:** The State is required to ensure that all service settings are in compliance with the HCBS rule. The State will work with individuals to remediate any findings based on the individual assessment. CMS will not

**federally fund service settings that are not in compliance with the HCBS rule.**

**COMMENT:** Commenter asked about the rigid guidelines for day service, on and off site prior authorized units. Provider is prohibited from taking them off site if all of the units are already used. Could there be a change to these on/off site guidelines to not be so rigid? Perhaps it would be possible to change the prior authorization codes to not differentiate between on and off site.

**RESPONSE:** This comment does not relate directly to the HCBS rule, no response.

**COMMENT:** Public Commenter stated that his brother has been at Emmaus for fifty years and he is worth \$10.00 a month and someone new comes in today and they are worth \$100.00. Why is there no consideration to bring my brother's dollars to meet the other persons as in compensatory rate? Does a higher rate given to administration of Emmaus encourage them to move off campus? There needs to be a blend between Emmaus and ISL or a blend of congregate and ISL. Be careful not to shift over too far to "integration into community".

**RESPONSE:** The State realizes there is general disparity in provider rates. As the State starts doing assessments, fiscal impact will be evaluated. Any identified fiscal impact will be addressed accordingly.

**COMMENT:** Public Commenter shared that their feeling is that their sons/daughters are much better off on Emmaus campus and that the individuals do have choices and are safe and secure at Emmaus Homes. His son let staff know that he wanted to move to a certain setting. There are some settings with less staffing available which in turn limits outings. Is this lack of staffing taken into consideration?

**RESPONSE:** As a part of the assessment process individual resources will be considered.

**COMMENT:** Public Comment via telephone asking if the state is considering choices/safety/comfort/general environment:

**RESPONSE:** Yes, these assurances will be addressed through the individual assessment process.

**VIII. Disability System Issues – No comments were received.**