

## ***Topic: HCBS Transition Plan***

### ***Questions discussed during the forum:***

What questions were asked during the sessions?

- What is the timeline of this Transition Plan and the comprehensive Transition Plan? Would there be a separate transition plan for the Aging waiver or would the Transition Plan submitted by DDRS cover Aging as well?
- Questions and Comments were received regarding the specific components of the Provider Survey in the Transition Plan and the importance of evaluating settings at an individual level.
- Questions and Comments (perceived compliance status, barriers, and potential solutions) were received regarding the CMS regulations, What is an integrated setting? How we can measure/document/ensure individual choice in regards to settings, services, and employment? How can we measure/document/ensure that people have privacy and are treated with dignity and respect in their home?

### ***Next Steps:***

BDDS staff have reviewed and categorized the feedback into sections. While the specific feedback regarding the provider survey and assessment of settings at an individual were not incorporated in the high-level transition plan, the specific suggestions will be reviewed by Stakeholders and the Transition Taskforce during the development of survey(s) and the HCBS Setting Compliance inventory. The anecdotal feedback received regarding Indiana's perceived compliance status, system barriers, and potential solutions, will be utilized during the review of qualitative data in order to supplement the quantitative data review and identify potential remedial strategies.

## **Feedback**

### **Integrated settings: Comments and Questions**

- One that's not entirely inhabited with people with developmental disabilities, a more diverse social group/environment
- People are being put together because they have a disability, for budget purpose
- Community at large
- Is there indicator such as 70% vs 30% to determine if that is an integrated setting?
- Should staff members be counted as the non-disabled?
- Do people have friends do they go to church do they have access to neighbors
- People can be placed in an apartment that is all in a larger neighborhood and they have access, is that integrated
- Not only are people present, but are people strength to the setting or just an entity
- Will it work for me, would I will live there

- What happens in the settings that create institutional like tendencies?
- Being able to support the physical needs of the individual, can the city support accessible housing, bus route
- Does the neighborhood know the house is present?
- Realize the sky is not the limit, and it is difficult to balance person centered approaches when budget constraints come in to factor. System constraints hinder person centered services i.e. allocations, Algo scores
- Allocations have made it less and less possible for individuals to make choices, due to budgets and the support needs.
- People are expecting the state for PCP, and the provider's needs to look outside the box
- Comments ranged from one that a person or family has chosen, to living with roommates or not, freedom of choice of where and whom to live with.
- Barriers noted were living arrangements based on OBA, client mix (such as one has moved, or passed away) and how it effects the others remaining, or how to choose a roommate.
- How can we facilitate and support individuals in these situations?
- How do we support those who choose to live alone when there are financial restrictions in place?
- Freedom of Choice can be a barrier due to the system.
- There is a need to identify if these are global issues or things that come up once in a while.
- As a system, how can we facilitate the conversation?
- Policy and procedure will need to address integrated setting requirements.
- Other barriers noted are rural vs. populated areas. People may move to more populated areas in order to get the supports they need.
- There can be a dependence on the current setting structure that does not allow for integrated settings.
- Issues happen when roommates are lost.
- Providers will not give more than is allowed in the budget.
- Health and Welfare can also be an issue in these situations. In order to get to true integrated settings, the focus should be on natural supports.
- To get to integrated settings, other options could be explored, such as college students needing roommates.
- If we decide someone requires 24 hour care and they do not want it, how do we support that choice? How do we determine if someone truly needs 24 hour care?
- More teams seem to be developing integrated settings with the FSW due to the funding limitations. Options are available, and require looking at plans and assessing if the services are appropriate to the individual.
- There is a very prescribed system. CIH has become known as a 24 hour type setting. The system has become either/or, there is not a continuum of services available.
- Rate structure is also an issue, as well as documentation standards. Participants stated the system is out of control. There is no room for creativity. Creativity in natural supports can be limited by regulatory requirements.

- Other burdens include the need for the CIH to work; a person must have 2-3 roommates. It is not made for living alone.
- Continuum continues to be problem. Participants suggested building the plan first and then build a budget around it. Other suggestions include a daily note for documentation rather than the 15 minute documentation.
- Other barriers noted were health and safety issues. For instance if a person falls or trips, it should not always require a fall risk plan and all persons coming in contact with that individual to be trained on it. The paperwork and documentation required may take away from the quality of care. It also has the effect of limiting people's ability to choose to take risks.
- Wellness coordination should assist in taking a common sense approach.
- There is a general assumption that all providers are not doing a great job; some don't, but it is not fair to assume all do not have the best interest of the clients in mind.
  - Suggestions include revamping the IR process and having a more common sense approach to risk plans. The expectations of health and welfare are not realistic.
  - This creates its own segregation, as people need risks and choices. The system is set up to limit choices. Often times the closest companions are paid staff.
- Independent Living Centers encourages individuals to remain in their community, but do not have the means to do so.
- Most families have never experienced the system and when parents get older they do not even know where to begin.
- Our society has changed so much that the folks who have had family support find the services too restrictive.
  - The question was raised if the state was exploring services that were not Medicaid funded to allow for more flexibility. Also, will Aging waiver rates align with DDRS rates?
  - The comment was made that integrated settings should not be isolated. The settings should be around people and involved in activities. There may be a need to push back on regulation in order to meet intent.
  - How can CMS be made aware that regulations may counteract their intent? Regulations may have limited community involvement. Regulations make it difficult for people to have opportunity.
- How does integrated settings apply to provider owned settings? res services
- Pre vocational - Options for some adults are limited. It's not realistic to think that everyone can be employed
- Integrated settings are a catalyst to drive bigger ideas. The federal regs can assist us in driving the change for opportunities
- There needs to be a funding mechanism to help drive it.
- PCP with fidelity
- Concern with how policy, etc is communicated to management staff and ultimately, DSPs Staff are not educated, trained or informed

- State staff development: we need to begin to train all our staffs looking at professional development all the way thru the infrastructure
- Issues around the quantity of DSPs - More community services means a need for more DSP.
- Integrated setting require us to examine outcomes ,enlist everyone in that person's life and identify natural and paid supports
- We need to use data in a meaningful way
- A simulation of what an integrated setting it might look like would be helpful.
- Better education with families and individuals about informed choice and what this means.
- How will we help families understand the transition. How do we help them see the value in it. How can we help them understand the expectations of the system. Our transition plan did not address this but we are not certain how to address it. This goes for entire communities as well
  - It really is community dependent.
  - How does technology fit into this whole plan?
  - Management must help to break down the barriers and facilitate the process
- Having the VR agency under DDRS is a unique opportunity. The conversation should be starting with First Steps.
- Looking at the system and the person holistically.
  - Are we bringing all the resources in?
  - Most important thing we can do is to simplify. Stop making more rules and forms and simplify and add quality to what we have?
  - Collectively putting resources together to have a comprehensive training system
- Can we get conceptual agreement that this is what good PCP would be?
- PCP must be a living thing it is not and should not be a document.
- How will CMS be looking at cost neutrality and how this will cost more and what that looks like down the road.
- In community- choice of roommates, loss or roommates affect services. Necessity of roommates to received hours/services needed
- "Stuck" in a setting- budget does not support the wishes of the client- location, roommates, and services
- Living with people with and without disabilities including a true integrated setting. Community Activities
- Hoping for more fluid environment that allows flexibility in truly allowing integration to happen without being over regulated.
- Are services needed or desired by client? Such as 24 hour, staffing, state regulations are very strict
- Transportation- access depending on community (Urban vs. Rural)?
- Outside input from guardians, family, etc.
- Definition of outing- rural vs. urban, park is a given to some people, Zoo in Evansville or Indy is an outing
- Expectation being outlined more concretely- what is considered normal in terms of frequency's it realistic/normal for someone to go to the zoo one time a month?

- Building resources in the community
- Goals that are less scripted and more person centered
- Are individuals given opportunities and are they realistic?

#### How do natural supports fit into our integrated settings?

- We are challenged by trying to meet the paper shuffle, and finding roommates
- Force more natural supports, i.e. check of list of who you contacted
- Even in the settings are integrating the individuals i.e. churches created segregated class rooms, etc.
- We have developed several congregated settings. Providers are building their own complexes, i.e. shared doors to doubles or apartments. But do the individuals engage in the community, are they out of the settings
- We have to make sure as we define this by starting with the consumer. What does the individual want, where do they want to live?
- Be aware of the language we are using. Make sure we are defining to families and individuals know what we are talking about
- Volunteer regs are very restrictive.
- Look at measurements that will support the whole system.
  - If you are talking about people having a life and being in the community and how does the system support this. For example the IR system could be a barrier as to what we need to achieve. More natural supports mean there may be more health and safety issues that would add a burden to reporting

#### How do we work with people to find out where they want live?

- People contact based on the assumption that they need roommates, similar to group home placement without packet
- Where do we go for affordable rent?
- Accessible and meets the housing needs of the individual physically
- House is built by providers because accessible homes/apartments are not available.
- Providers are committed to allowing the individual to choose
- Because of budget people are making choices based on who they can tolerate to live with
- Families are paid to provide support, in the family home it is discouraged by state or system because of barriers
- Natural supports are not family, it's the person at the church that stops and picks you up
- We are getting parents and family caregivers that are worn out or have unreliable care givers and families are at risk of losing their jobs.

In an individual's current setting, how are we ensuring that people have privacy and are treated with dignity and respect in their home?

- How can we have privacy when we have such frequent DSP turnover?
- When waiver was small and funding was based on the PCP, there was a core philosophy in the state. There were mission statements we need to all be in the same page philosophy. Every time administration changes we have a change in philosophy
- Providers that are landlords shouldn't be able to discriminate if individual changes provider separate housing from support.
- People are always putting out fires; there is no time to put together a common philosophy and a mission by the state
- Sometimes agencies must purchase a house so that individuals don't have to the fear of eviction.
- Has the state let quantity be more important than quality. We are so focused reducing the waiting list, we are trying to do the Cadillac. We are going to big.
- Orientation training staff and clients
- Review BSP, team tries to "fix it" by restricting individuals
- HRC's are as neutral in some cases
- Other public comment received stated the process for making an anonymous complaint was identified as an underlying issue.
- Other areas noted were keeping health information private, ensuring a feeling of safety, and choice regarding services and supports.
- OBA may limit choice due to buckets limitations.
- It's also difficult to make any changes as the Case Manager is the only one who can update the budgets and this takes time. There is a need for a more fluid system.
- There should be more collaboration between case managers and providers.

How are people making autonomous decisions and choices? How do we enhance choice?

- Recognize we have more and more children coming into the system and providers need to be available evenings and weekends.
- Providers need to modify services to meet the needs of school age children
- Services are initiated in the home, less facility based services
- Providers needs to have services for families of middle and high school kids
- Pick lists needs to indicate who is open to serve the individual. Much time is spending trying to call around and ask who has opening and can provide services.
- Providers are chosen from pick list and the provider has not information or referral. NOA arrives and provider doesn't know they were going to use.
- Safety and health over weighs choice

- When serving individuals with behaviors and they get evicted then we struggle to find housing and landlords that will rent to the individual
- When we look across the year's families and individuals are more educated than ever before. We need to build on that with better systems
- Where does accrediting bodies fall within the plan?
- We need clear guideline on how we move thru the system
- Barriers noted included affordability, location, and transportation and housing providers. Clients don't always get to say no to chosen living situations.
- How do we look at affordability and how do we support that? How do we get housing providers to buy into this as well?
- There is a need to be more creative and look at resources such as collaboration with grant programs like Section 8.
- Education is needed beyond providers as well in order to get out of the mindset. There is a need to educate on choice.
  - Suggestions include training for legal guardians to explain intent of guardianship and choice.
  - Explain what it means to be a guardian by upholding an individual's choice. This can be accomplished by laying the groundwork to understand a person's wants and needs.
  - Independent Living Centers can be tapped into.
  - More education can be accomplished by utilizing more resources in the community.

Making services individualized should be part of the conversation on choosing services.

- How do we assure people can spend their monies as they wish?
- Choice can be limited when people are taken out in groups and not all what to do the same activity.
- The past showed more flexibility when dollars were not attached to Medicaid. This allowed for more freedom.
- Suggestions included looking at annual amounts and figuring out outcomes at the end, by creating more quality outcomes.
- There is a need to enable folks to have a better day tomorrow by getting back to basics and not being so academic in what is trying to be accomplished.

**Additional Notes from Public Comment**

Privacy/Respect

- Hard to get when you have DSP turnover
- Core philosophy/mission/vision- what does this look like?
- Separating the "housing" from the support
- Growth/crisis tends to drive the system
- Individual needs
- Have we left quantity go before quality?

- Orientation/training for staff and clients
- We do not decide what it is the individuals do
- Language we use is jargon
- Roommate situation they can get into- visit, meet, “click”
- Centers around accessibility
- Subsidized housing - affordable rent
- Guardian protection (?) and where they live
- Neighborhoods - building in the same
- Landlord that will work with you
- Choice to stay with their family, family as paid caregiver
- Surrounding neighbors- do they know what is there? Too many people in the neighborhood
- Difficulty balance person centered approach with budgets, Algos, housemates, settings
- Systemic issues
- Clients rights, access, simplification
- Consistent training for Res Hab, CMCO, etc. important
- Person Centered Planning- measure the person vs. arbitrary plan
- Is there a reason a person is not able to have full privacy- outliers
- Data is the key! Measure what is intended to be measured
- PCP process needs to be better defined, must be individualized, tie into resources, reality based-rights and responsibilities of individuals and families
- Feels like we are doing things backwards: Should be PCP, services, then budget based on need/want
- Case management function needs to be better defined.

### Individual choice/Options

- Think outside the box
- Teams and families look at natural supports- but the focus is too much on bureaucracy
- Sometimes the community segregates
- We are having more congregate settings, shared hours, etc.
- Are people getting out?
- Paid staff does not count in a ratio
- Friends, church, community areas that are integrated
- Getting/Coordinating separate elements to have harmony between organizations or separate
- Strength in setting- positive impact in the setting
- Would it work for me? Would I live there?
- What is happening that creates an institution?
- Accessibility/Transportation/Budget Cuts
- Not inhibited by people with disabilities, rather a more diverse social community at large
- Emphasis on putting people together just because they have a disability
- Geographical congregation (7 apartments out of 8 have disabilities)

- Is there a percentage?
- BSP- “Fix it philosophy- some things we would not do in our own lives
- Paradigm Shift
- Children’s – 8-4 workday does not work
- Choice- capacity to serve has to be related to choice
- Information/Communication- how choice is made
- Safety/Health/Choice
- Rentals/Evictions due to behaviors
- Choice- more educated and committed
- How do we go about doing this?
- Getting to “Yes” clear guidelines
- Wanting services not paid for by the waiver or Medicaid
- Missing services under Medicaid (Dietician)
- Client does not know everything wanted and changing budget is complicated
- Need fluid system
- Case manager ability to finesse the system better than others do
- Case manager does not know the client
- Need advance collaboration and teamwork
- PCP completed before provider is aware of client
- Affordability?
- Finding providers based on clients income not choice of where they want to live
- Location
- Seems state sometimes encourages or mandates placement
- Reality of situation is the key- not everyone has unlimited choice? How to convey this to individuals
- Budget sometimes mandates the services (including housemates)
- Transportation availability

#### Regulations

- CIH needs 3-4 roommates to work
- Subdivide staff hours to bill each client
- Documentation required is too strict
- Continuum – looking at individuals needs not the budget
- IR’s- documentation; how do you really prevent accidents from happening? Staff are scared of accidents- worried about documenting when should focus on client need
- Restricting clients freedoms because of risks of incidents

#### Solutions for health and safety

- Don’t presume it’s the providers fault
- Wellness coordination (but what about dietitians)

- Trending- how often does it occur?
- Talk to the individual if applicable

#### What can we do?

- Training
- Guardians- to help understand what the choice is and how it effects the client
- Other agencies and organizations- utilizing all resources
- Coordinate with Attorney General and judges to know what it means to be a guardian
- Decisions based on the client's needs/wants
- Make sure the individual is involved in all discussion

#### Employment

- We have work to do as a state to ensure employment opportunity exists
- Cooperation/collaboration with employees needs enhancements
- Educating families earlier, school age about employment and life-long opportunities
- For someone who has been in a workshop for many years, it is difficult to get them into supported employment; VR counselors do not seem to find them employable