



# Indiana Long Term Care Transformation Stakeholder Workgroup Meeting 2 Minutes

Monday, November 6, 2017, 9:00 am - 1:00 pm

**In Attendance:**

Core Members

First Name	Last Name	Organization
Debbie	Carriveau	Alzheimer's & Dementia Services of Northern Indiana
Liz	Carroll	Indiana Assisted Living Association
Zach	Cattell	Indiana Health Care Association
Steve	Counsell	Indiana Division on Aging
Erin	Davis	Case Manager Representative (SWIRCA)
Karen	Gilliland	Long Term Care Ombudsman
Laura	Holscher	ADRC Representative
Melissa	Keyes	Indiana Disability Rights
Kristen	LaFace	Indiana Associations of Area Agencies on Aging
Ambre	Marr	AARP Indiana
Amber	O'Haver	Indiana Council on Independent Living
Debbie	Pierson	Indiana Division on Aging
Matt	Rayburn	Indiana Housing & Community Development Authority
Evan	Reinhardt	Indiana Association of Home and Hospice Care
Marc	Sherman	Consumer Representative
Yonda	Snyder	Indiana Division on Aging
Jennifer	Trowbridge	Caregiver Homes
Terry	Whitson	Indiana State Department of Health

Observers

First Name	Last Name	Organization
Joshua	Bougie	OMPP
Laura	Brown	Krieg DeVault
Mark	Laubacher	Silver Birch Living
Terry	Miller	Hoosier Owners and Providers for the Elderly
Amy	Rapp	Division of Aging
Mike	Reinbold	Leading Age
Michael	Sullivan	Alzheimer's Association
Jessie	Wyatt	Division of Aging

Facilitators

First Name	Last Name	Organization
Erika	Robbins	The Lewin Group
Tiffany	Tsay	The Lewin Group



Welcome – Yonda Snyder (Division of Aging)

Review of Workgroup Ground Rules and Responsibilities – Erika Robbins (The Lewin Group)

October Stakeholder Meeting Review – Erika Robbins (The Lewin Group)

Follow-Up on Last Month's Commitments – Erika Robbins (The Lewin Group)

- Steve Counsell – Commitment was to look up regulations for hospitals and SNFs requiring some options counseling, notification information about LTSS or referral to the local AAA.
  - Found the rule language from 2010 but expired in 2011. It was under auspices of DA and not under hospital or SNF rules. Looking at how to revisit that.
  - There are some regulations in hospital and SNF that would allow for opportunity upon admission to hospital or SNF to flag those who may need options counseling.
  - There is also a requirement for discharge planning but it does not specifically talk about referral to AAA. Opportunity to include brochure or additional information.
  - CMS IMPACT act – requirements for discharge planning. Help hospitals/SNFs implement those requirements given the increased focus on integration. CMS/ACL focus on connection with community-based organizations.
  - Amber O'Haver: That connection at discharge is not just to AAAs but should be to other entities as well.
  - Karen Gilliland – Can use the ADRC network as an entry point
- Karen Gilliland – contacted state of IA and MI on their consumer-directed programs. Both states are in flux. IA hasn't gotten back to her on specifics. MI is re-evaluating program whether they're going to put more constraints on it. Concerned about families mis-using (e.g. person being paid is not really doing the care, person being paid gets a job and doesn't tell) - management system concerns.

Revisiting HEA 1493 Report

**What stood out to you that you liked?**

- Jennifer Trowbridge: The data itself; never had access to some of the numbers before, very enlightening.
- Evan Reinhardt: Commitment to looking at everything in terms of change thought need to prioritize within that. Everything's on the table to take a look at is a positive.
- Liz Carroll: A lot of information. A lot of data.
- Ambre Marr: Appreciate that caregiving is a definite goal throughout report; what does caregiving look like, happy to see that.

**What is the one thing in the report that could have the greatest impact on people?**

- Liz Carroll: expansion of waiver authority such as a 1915(i)
- Erin Davis: moving to integrate person-centered best practices, caregiver support
- Steve Counsell: increasing access to services. Previously focused on cost and spend. There are opportunities to grow community-based supports



- Zach Cattell: Good opportunities. What I saw as positive was the focus on people served. Balancing based on people served and not dollars spent. People served is also important to focus on. Meeting the need that exists. Dollars come later in terms of how it is financed. To the point of expansion of waiver authority, how do we do that smartly so that budget agency doesn't immediately say no to woodwork effect? A conservative state may not want to fund without caps in place under a 1915(i). How do you do that within eligibility criteria for those needs – whether it is social and medical?
- Erika Robbins: Important if you can tell the story that budget people can understand. Change the story slightly for people who you are getting the buy-in from.
- Zach Cattell: Skeptical about Lewin's analysis between delta between institutions and community-based services. Skeptical that it is so different, not aligned with previous reports released. Would like to see it refined and looked at again, in context of prior assessment.
- Liz Carroll: LeadingAge, IHCA, INALA, HOPE, SilverBirch Management got together and reviewed report; brought copies of comments on HEA1493 report for everyone.
- Debbie/Yonda: we will post comments on the HEA1493 report to the website. We will huddle internally to determine what amendments need to be made, what areas we need to spotlight. Official deadline has passed but if people get to us before we post, we can take them. In order to be considered in any amendment to the report, people need to get them in as soon as possible.

#### **Are there pieces that you wish were in the report that were not there? Anything that was left out?**

- Amber O'Haver: Piece that I see is missing is that living in the community as a right. Not just an opportunity that is going to save the state money. It's a right. Busy looking at data and numbers.
- Erika Robbins: Would you all agree that is a thread that can be strengthened?
- Jennifer Trowbridge: There was some data on wanting to stay home, value of that concept. Perhaps not the "right" word.
- Amber O'Haver: It could be enhanced for the report.
- Evan Reinhardt: 95% of people feel it is very important to them to remain in their home, that's where the starting point should be for these conversations. To Zach's point on budget constraints, for our group – we look at that and we look at reimbursement rates and workforce development. All of those things will have to be put together in a perfect formula to continue to build. There's a long way to get to a system that reflects what consumers are indicating are their preferences.
- Zach Cattell: Rate-setting. All providers - whether that is case managers, adult day. There wasn't enough discussion about creating a predictable reimbursement system to allow entities to invest in providing services. Building spaceship as we're flying it – a lot of things happening at the same time. Providing enough network capacity for people that go through case management and expanding waiver authority takes people who are willing to take risk and invest in service providers. Rate setting component was lacking.
- Evan Reinhardt: We think family caregiving is vital part of this. It's not going to solve all the problems that will come up. There has to be other supports and safety nets in the system. If we don't have capacity, not increasing rates, even over a 10-year period, no methodology to at least reflect what is going on at the front lines, we will be continuing to talk about things as opposed to being in action. Got to have more progress on that – reimbursement and methodology.



- Zach Cattell: Said this last time. For consumers and providers, comes down to predictability. Making sure whatever we put out publically is as predictable for end user and provider. Meet each other in the middle, in the community. Predictability is a word that means a lot to our members but also family members. Knowing someone is willing to provide the services to their loved ones.
- Karen Gilliland: issue of protecting residents regardless of where they are, quality assurance. Be sure that people are making choices based on quality of care. Would like to see that strengthened.
- Debbie Carriveau: Haven't seen report but does the report look at the impact of dementia care?
- Erika: Yes.
- Liz Carroll: one of the things as we talk about predictability. Different things that we will want to achieve. Struck me that report could have spent more time talking about how state agencies are going to achieve these very ambitious goals. Don't know if resources exist to do all of these goals and do them well. Prioritization is going to be real important. Didn't feel to me that the report did that.
- Evan Reinhardt: Not only how they're going to tackle those thing. Where they're going to be in the future.
- Erika Robbins: Good segue into next section where we talk about some of the prioritization of those action steps identified in the report.
- Evan Reinhardt: At least I didn't see it mentioned in there, would look at AAA reps in the room to see if this data is available but number of hours that are authorized but go unused would be interesting measure. Allow us to see where we're missing the boat. Our feedback from agencies is they get calls from AAAs that someone is ready to go but they can't staff. Would ask if AAA representatives would echo sentiments?
- Debbie/Yonda: Working on making that data available in consistent and available form.
- Erika Robbins: Before you build more and make problem worse, understand what baseline looks like.

### Moving to Action – Debbie Pierson (Division of Aging)

- Phase 1 – 1915(c) waiver renewal in July 2018 may be appropriate for some changes but waiver language has to be ready by mid-January, limitations for what we can get in terms of software changes both for our case management system and MMIS for providers to bill new services. Still some timing challenges.
- Phase 2 – Work on some of that stuff that might not be ready for July 2018. May include some reimbursement pieces. Could be some short-term reimbursement pieces that can be implemented. Some studying of current reimbursement rates and where we need to go.
- Phase 3 – Bigger more systemic changes. 1915(i) or 1115 authority. We are targeting July 2019. Coming out of Phase 1 and 2 activities, see what's left. Zach mentioned delicate balance between reaching out to people with lower eligibility standards that might result in woodwork effect or uncontrolled growth that won't scare off budget agency. Something that will help shift our system to HCBS.
- Liz Carroll: to paraphrase to ensure our understanding. Phase 1 1915(c). Phase 2 probably some amendments to 1915(c) and Phase 3 preparing for new authority.



- Debbie Pierson: Yes. Certainly opportunity to make some short-term gains right now.

### Parameters of Initial Design – Debbie Pierson (Division of Aging)

- NF LOC or just before NF LOC. Age 22+. Not talking about kids at this point. Actively working with DDRS and DMHA and OMPP and Lewin on a children's services waiver. Not sure what our timeline is yet. Hoping that is a waiver that starts in 2018 or early 2019 so we can move our kids off into that authority. Probably a 1915(c) waiver. We will talk more about that in Jan/Feb meetings as that starts to take shape internally.
- TBI waiver – very small waiver. Less than 200 with 30-40 waitlist. Can fold into A&D waiver with some added services such as behavior management, supported employment, residential habilitation. Behavior management could be helpful for dementia. Challenge for TBI waiver is that not everyone on TBI has NF LOC. Some have IID institutional level of care so we are working closely with DDRS on this. Some individuals would roll into CIH waiver. Some preliminary agreement to do that. Will need to work a lot on individual cases. Not sharing this too publicly, don't want to alarm any participants or families. Don't want anyone to suffer, want to ensure access the same services.
- Marc Sherman: Is TBI waiver is going to cease?
- Debbie Pierson: TBI waiver would end once we have all the services are represented in the other waivers. There is already a huge overlap with services between CIH and TBI. Impact is minimal. We want that time to go case by case with DDRS to ensure everyone can transfer without adverse impact. Maybe if a provider is not enrolled on that side yet, make sure that happens before termination. Many on TBI waitlist are already on A&D waiver, we are already serving them anyway but they just don't have access to specialized services offered on TBI waiver.
- Marc Sherman: When is TBI going to stop?
- Debbie Pierson: Hoping to do it in July with A&D renewal. We'll know in a few months. Goal is no adverse impact. We can add the services to A&D and let TBI run another year. Whatever we think is appropriate to transition those folks to A&D.
- Marc Sherman – I have some clients getting ready to sign them up for waiver services, transitioning from facilities. Would it make more sense to sign up for A&D or TBI?
- Debbie Pierson: ADRC will go through those options with them. Even if they're going to MFP, they're going to get same options. If they qualify for both A&D and TBI, the ADRC will offer both options – one is open, the other has a waiting list, etc.
- Amber - How do mental services play into all of this?
- Debbie – it doesn't. we don't have any mental health services. For children's, hopefully we can do that as an experiment, regardless of disability, include all services.
- Lots of waiver participants that get other mental health supports. With TBI, take a more universal approach with our waivers. A number of A&D waiver participants that are still working age, perhaps they would be interested in supported employment.
- Amber – those 6 individuals, are they VR services?
- Debbie – discuss with Amy what differs from our supported employment and voc rehab services
- Any new approaches and programs that we're looking at, keep CMS HCBS settings rule in mind. Remember there are other parts of that rule in addition to the settings rule. Requirements for person-centered planning, conflict-free case management.



## Case Management – Erika Robbins (The Lewin Group)

- Review of case management examples and ideas from other states
- Review of Indiana A&D Waiver – Ideas for Integrated Medical and Social Care
  - Steve Counsell: Previous work involved looking at literature and best practices on integrating medical and social care. Workgroup with 9 out of the 16 AAA regions to discuss the role of case managers.
  - Co-location is happening in some places such as Eskenazi Health. Having an options counselor and case manager co-located. Hospital has provided support. Also done in other states
  - Steve Counsell - Healthcare coordination service required a nurse from a HHA, adds additional fragmentation and rules not well-defined.
  - Yonda Snyder: We removed the requirement that it had to be a HHA.
  - Erika Robbins: Has there been an increase in the use of the service yet?
  - Debbie Pierson: No. Haven't done any outreach yet.
- Liz Carroll: Thinking about assisted living and nurse healthcare coordination. Wondering could there be an issue with too many people trying to coordinate. In assisted living, individuals already get nurses who are responsible for providing care coordination and already have case manager. Adding another nurse for healthcare coordination.
- Steve Counsell: Not intended for assisted living but for home settings.
- Marc Sherman: Even in assisted living, need to have a go-to person. Allows more accountability. More eyes on the situation. There needs to be a go-to person. A case manager.
- Dr. Counsell: What are the differences for a case manager between in-home vs. assisted living?
- Group: They are the same.
- Erika: Not different in the service definition.
- Marc: They are different in reality.
- Amber O'Haver: My assumption here is that actual individual is in the loop on all of this. Agreed to share all this info with all of these individuals? My concern with all of this is that person is involved and understands what's going to happen.

### Case Management Round Table Activity

Question	Themes from Group Activity
<p><b>If you could only add 2-3 changes to the current definition and activities, what would they be?</b></p>	<ul style="list-style-type: none"> <li>• Tiered case management system based upon need               <ul style="list-style-type: none"> <li>○ Minimal tier may not need quarterly face-to-face assessments</li> <li>○ Question: what does CMS require for face-to-face case management assessments?</li> </ul> </li> <li>• Importance of longevity and stability of case management relationship (macro-system issues are more important than day to day of case management role)               <ul style="list-style-type: none"> <li>○ Concerns with reimbursement rates</li> <li>○ How do we reduce turnover?</li> <li>○ Case managers need knowledge to go into homes (lack of medical knowledge)</li> </ul> </li> <li>• Do consumers know that they can request a different case manager? Can people have choice of no case manager?</li> </ul>



	<ul style="list-style-type: none"> <li>○ Case manager needed for quality assurance</li> <li>○ Those who are independent could just need minimal case management</li> <li>● Case managers may not be providing sufficient education for informed decision making</li> <li>● Continuity of options counseling throughout their life, ensuring options counseling involved in all the steps (knowledge and skillset are often separate from case manager)</li> </ul>
<p><b>How can training requirements be enhanced for all case managers to ensure high quality case management?</b></p>	<ul style="list-style-type: none"> <li>● Training in options counseling skills</li> <li>● Training to empower consumer to be as independent as possible in least restrictive setting (focused care plan) – advocacy; less medical model and more social model</li> <li>● Technology – how technology can be brought into home           <ul style="list-style-type: none"> <li>○ Question: Do AAAs host provider fairs so that case managers/options counselors are aware of all providers, new resources, technology</li> <li>○ Yes, some regions still have provider fairs but are not required to in AAA contract</li> </ul> </li> <li>● Disability culture, aging culture</li> <li>● Retain flexibility of training to address localized issues</li> </ul>
<p><b>Should timeframe requirements be tiered based on acuity or need? Should case managers see individuals with greater needs more frequently? How would you design these tiers?</b></p>	<ul style="list-style-type: none"> <li>● Keep timeframes</li> <li>● Weight caseloads to support tiering; tiering based on strengths of case managers</li> <li>● Look more at outcomes – connecting highly trained case managers to individuals; specialization           <ul style="list-style-type: none"> <li>○ For backup purposes, training and knowledge for all but specialization may be challenging with some geographic regions</li> <li>○ Specialization may cause burn-out; some case managers may need some diversity in caseload</li> </ul> </li> <li>● Increase flexibility of what case manager can do instead of narrow windows of time for reassessment</li> <li>● Different timeframes between entry into system vs. ongoing (more stringent timeframes upon entry and more flexibility to be person-centered)</li> <li>● Set timeframes within control of case manager (e.g. 450B form, Medicaid eligibility)</li> </ul>

### Supported Services Across Settings – Erika Robbins (The Lewin Group)

- Review of supported services across settings framework:
  - Provider-Owned Congregate Settings (Assisted Living, Adult Family Care)
  - Participant-Controlled Settings (Permanent Supportive Housing, Section 811 Housing)
  - Participant-Owned or Family-Owned Settings (Family Home, Individual Apartment)
- Recap of what Assisted Living workgroup focused on last year
- Zach Cattell: Consistent theme through Assisted Living workgroup was flipping paradigm between perception of provider-driven outcomes to person-centered needs and directed





program. Balance between providers desires of predictability and need to manage risk and run a business vs. untethered personal choice.

- Review of supported services state examples

**Are there features of supported services that you feel DA should pursue such as revising the definition of room and board?**

- Liz Carroll: Can you explain what you mean by revising the definition of room and board? Is it what is covered under the ~\$730 dollars per month?
- Yonda Snyder: Definition of room and board. Payment of room and board, current limitations on that.
- Erika Robbins: Medicaid cannot cover the cost of groceries but it can cover the cost of someone preparing the food and serving the food because that is a service.
- Liz Carroll: Transportation to and from where those benefits (groceries) can be accessed might be helpful to some individuals.
- Zach Cattell: A lot of the items in the state examples are not objectionable. Many are contained in licensure requirements.
- Erika Robbins: Some of it is the use of language as well – assisted living is called “customized living” in Minnesota which has a more individualized meaning.
- Kristen LaEace: Services – what might be different other than a definition. Broad definition. Customized living vs. assisted living. What did survey reveal as to things we’re not incorporating?
- Erika Robbins: Transportation, delegation of nursing, mental health and cognitive support?
- Liz Carroll: Many are in licensure requirements.
- Zach Cattell: How are we providing medical services? Scope of practice. How are medical services being provided because of current licensure provided? Assisted living as we know it today, even if it is amended provides a higher level of coordinated medical services.
- Kristen LaEace: How do we provide menu in unlicensed settings? Cutting out all medical-related things unless it was brought in by outside home health provider.
- Amber O’Haver: What does license ensure? Quality standards?
- If allowed into unlicensed settings, possibility of quality control problems?
- Steve Counsell: But person’s home is not licensed.
- Karen Gilliland: More responsibility on case manager to monitor.
- Liz Carroll: But in unlicensed settings, health care delivered by licensed HHA.
- Amber O’Haver: it’s like living in an independent apartment complex.
- Kristen LaEace: There are so many other kinds of housing settings thought of as congregate (multifamily, 811 development). Some may be enhanced with various coordination, e.g. service coordinator in public housing complex. Not a big leap into allowing people to use a housing with services provider as their housing of choice and service provider. Unlicensed is like permanent supportive housing for older adults.
- Liz Carroll: One difference in unlicensed + HHA combination, one piece we don’t have now is provider is not also providing any type of services now such as home management tasks. Trying to think of who pays for what? What is the individual paying for? What is State of IN paying for?





Is it on the housing provider, home health provider? Who are we going to pay and whose responsibility is it?

- Zach Cattell: Current Medicaid recipients reside in licensed residential care facilities, higher acuity.

**Thinking about the concept of “supported services” with housing, what types of services could be included in this menu of services? Should it be core + optional services? Should the core be a small portion of the current assisted living definition?**

- Amber O’Haver: Why do we have to have menu of services? Why can’t it be based on what the person wants and needs?
- Kristen LaEace: Because CMS requires a service definition.
- Amber O’Haver: There may be huge menu but 2-3 that everybody needs.
- Kristen LaEace: You’re saying there shouldn’t be a core, everything should be on menu?
- Liz Carroll: And assign a different reimbursement factor to each of those services.
- Steve Counsell: Why should it be different than package available in the home? Difference is facility providing or home health providers.
- Kristen LaEace: Are there services an assisted living provides that you can’t get on A&D waiver? Other than locked dementia unit?
- Amber O’Haver: 24 hour support. Reality is does somebody need that?
- Kristen: What if we took whole list of what’s available in home on A&D waiver, and look to see what we need to add to that. Decide if things need to be core. Or do we want to have a core? You’d want to make sure the provider could do all those services.
- Steve: Counsell: Or bring them in.
- Kristen LaEace: Even laundry. Licensed assisted living may offer laundry service but a Section 811, a for profit laundry service could be picking up and delivering it back.
- Steve Counsell: Back to point on individuals requiring a higher level a service. Suddenly contradictory, this person needs a higher level of care.
- Liz Carroll: Beneficiaries all meet NF LOC.
- Zach Cattell: This was mentioned in 1493 report as well – high proportion of people with dementia in assisted living. There is high tolerance and ability to support non-exit seeking behavior. It is matter of efficiency and reason why there needs to be service definition – assisted living includes all of these things, ensure not duplicating payment. It is under scope within the license. Logical in these settings, able to do things in more efficient way with one roof to operate.
- Melissa: The more services that you require at facility level, less choice a person has without having to move. For example, I don’t like services provided there, I’d have to move in order to change provider. Whereas if it’s more just food and transportation, I would theoretically have the option to bring in who I want.
- Liz Carroll: Good but at the same time, there is value in when they pick “this”, knowing what “this” is. Assisted living term is very broad, it includes a range of congregate living settings.
- Erika Robbins: Do you think some people don’t know what they’re getting?
- Liz Carroll: when they first make the call, they may not. But once there’s some structure and context: easier to explain things.



- Karen Gilliland: Make expectations clearer. If you have outside services, puts emphasis on case manager to avoid fragmentation. Melissa's point is valid. As needs or wants change, do you have to move out of your residence, you don't want that kind of transition.
- Erin Davis: Someone who is privately paying for assisted living, if they run out of money can no longer afford assisted living - having ability to stay in their place of residence.
- Debbie Carriveau: That is a primary source of breakdowns for people with dementia in assisted living. It is a piece of the population that doesn't qualify right now for waiver services. They don't need an environment that is so restrictive as nursing facilities but don't necessarily qualify for waiver. They fall through the cracks. Can manage diseased symptoms in assisted living if agree on definition.
- Kristen LaEace: I'm hearing a dementia services waiver that does not require NF LOC.
- Karen Gilliland: How would structured family care work for these individuals?...It requires caregivers.
- Debbie Carriveau: At that point, a lot of family members are burnt out. More complicated than whether they have family or not.
- Erika: What I'm hearing is making sure it is person-centered. If we're going to make a menu – ensure people have flexibility. Thinking about services currently provided in assisted living 100% of the time – those would become core.
- Steve Counsell: Even among the core services, what ability do they have to get from another provider.
- Erika: The more you have that, the provider-owned congregate starts to look like the middle option (congregate, subsidized settings)
- Liz Carroll: There is a limitation of how much the provider can charge for room and board. Reimbursed for one service, you don't know that you'll still get a core amount of services. Can't afford to build it on \$730/month.
- Erika Robbins: Comes back to Zach's point of predictability.
- Karen Gilliland: What are you paying for - room and board is separate from that. What services are you paying for with the waiver as opposed to room and board?
- Erika Robbins: Attendant care, chore services, etc.
- Liz Carroll: Even within attendant care, what do we mean by attendant care? Medication oversight. Oversight or administration or cueing? Very different cost of providing. We need to be clear on our definitions.
- Evan Reinhardt: What happens in AL but also what happens in IN related to attendant care, homemaker, etc.
- Erika Robbins: So looking at service delivery across array of settings.
- Liz Carroll: With licensed RCF – current model – they are required to perform healthcare coordination services and provide medical care as part of licensure.
- Steve Counsell: Comes back to tiering.
- Zach Cattell: There is a requirement to coordinate residential nursing services and need for that. Idea that you're choosing. In the private market – people are choosing that level of service. Not an outcry of lack of choice or being in a provider owned and controlled setting. In private setting, you're choosing it. However, when government pays for it, it's restricting. Folks with different socioeconomic means have a different vantage point, how much leverage they have is different. Coming back to medical services dialogue. Tiered type thing. There is an efficiency in



provider directly responsible for nursing staff, aides, hands-on care (Alzheimer's/dementia) – even then, when does a home health agency come in? Medical needs are served in this particular way. If they don't choose it. If they choose the middle bracket, how do case managers coordinate all of those services?

- Steve Counsell: Healthcare coordinator role – should be core service as part of assisted living. if you're in other sites, pull in others.
- Zach Cattell: Some do it well today and some need to improve.

## Secure Memory Care in Nursing Facilities vs. Assisted Living – Erika Robbins (The Lewin Group)

- Review dementia/memory care examples from other states
- Review CMS guidance on dementia and secure memory care
- What are the characteristics that a “community” setting must have?

### Secure Memory Care Partner Sharing Activity

- Imagine that your family had a discussion with you and they want you to consider moving into an assisted living facility due to increasing memory problems and possible onset of dementia. What would you tell your family are the most important elements of a potential new home for you? Some things to consider:
  - Physical environment and location—Do you need to live in the city, suburbs, or the country? Do you need to have a place to garden? Do you want to live somewhere quiet or a bustling place?
  - Possessions—Are there particular items you own, such as family pictures, that must be present for a place to feel like home? Is your phone or computer your lifeline to your family? Do you have a favorite bathrobe, coffee mug, pillow, etc. that are important to your sense of home?
  - People who are present (or absent)—Who do you want to see regularly? Are there people you don't want to see? If you need someone to provide support, what qualities must be present or absent?
  - Daily routines—What time do you like to get up in the morning? Are you cheery and ready to take on the day, or do you need to hit snooze a few times and have a couple of cups of coffee before you're ready to see anyone? Do you need to triple check the door is locked before you go to bed? Do you need to clear off the kitchen table every night to eat dinner, or sit on the couch watching TV while you have a bite to eat?
  - Status and control—What in your life brings you meaning and a sense of purpose? How do you want others to recognize and acknowledge that? In what areas is it particularly important that you have control—when you wake up and go to bed? When you come and go from your home? What you eat? Who comes into your home?
- Now, thinking from the provider's viewpoint, what would keep you from honoring these things that are important to and for the person? What are the risks? What can be done to mitigate those risks?



Themes from Partner Sharing Activity	Provider Viewpoint (Risks, Mitigation)
Control of schedule (e.g. eating when I choose even if middle of the night)	Liability – responsible to family; cater to majority of individual’s preferences (negotiate to compromise)
Pets/no pets (may not be allowed in NF)	Safety, allergies Small pets allowed for an additional fee
Quiet vs. constant socialization	Need for 1:1 supervision
Security – external and internal – sometimes conflict between what I want versus what my family thinks is best	Liability
Knowing individual as a person – life history	Gathering and documenting data Use of technology (Oasis)
Keep car/drive, Uber (may be harder in NF)	
Community options (e.g. hiking, kayaking), transportation to activities – ability to continue to do what I like	Staffing
Dietary interests (comparable in NF)	Cost of food/groceries
Proximity to family/friends versus far away - location	
Want to bring my favorite things with me (e.g. favorite chair, blankets, pictures)	

[Note: Due to time constraints, the Person-Centered Foundations discussion was moved to the following month’s agenda.]

## Commitments to Action

### What is the difference between community settings and institutions to you?

- Erin Davis: choice, control, privacy, flexibility.  
Commitment: Re-read the report again and look into different areas. Take back to the staff.  
Positive things for long-term future goals.
- Terry Whitson: No difference between community and institution, they can be individual-based.  
Commitment: No commitment.
- Ambre Marr: Difference between maintaining independence and individualized support system.  
Not reality to both be the same.  
Commitment: deeper dive into some of the information. Following up with all the information, need a minute to review and move forward.
- Melissa Keyes: Community implies person remains in control of their life and destiny. In institutions, don’t really have the control you do in community.  
Commitment: Read the report.
- Steve Counsell: Privacy and freedom.  
Commitment: Follow up on IMPACT Act.
- Zach Cattell: Differences in economic means and Medicaid is payer of last resort – it is a catch for whatever system you have breaks down. Whether it is family or your own dollars, difference



between what individuals can pay for or system provides. Institutions and community difference – depends on how you come at it.

Commitment: Structured family caregiving research.

- Jennifer Trowbridge: Limits in choices.  
Commitment: Call Zach.
- Karen Gilliland: Freedom – do what I want to do at this minute or not.  
Commitment Follow-up on two states on person-directed care.
- Laura Holscher: Flexibility and having control over own destiny.  
Commitment: Read the examples again – hard to glean what might be applicable before we had this discussion. Will go back and review again.
- Amber: True community is having absolute control and choice over every part of life.  
Commitment: Read examples, finish reading report
- Debbie Carriveau: Agree with Terry and Zach. People in either environment can have good quality of life. In congregate settings, can bring our culture change, can give people just as much freedom and choice but not the reality. Difference is between just existing and thriving. Many examples of really good quality of life, people thriving in congregate settings, all in approach and way we design things. Person-centered care in a barn and can be successful!  
Commitment: Talk to family caregivers, what are some of the community-based resources that might have allowed you to keep your loved one at home. And request a copy of the report.
- Kristen LaFace: Ditto Erin. control, choice, privacy, flexibility.  
Commitment: Review case management definition with our workgroup that is focused on looking at case management.
- Marc Sherman: Privacy and person-directed care. Dramatic difference between institutions and supported living. Some that are better than others.  
Commitment: Will commit to reading the report.
- Evan Reinhardt: Choice and freedom and presence of third party/third parties in those choices and limitations on those freedoms (e.g. play music as loud as you want to in your own home).  
Commitment: Be more specific on our feedback on case management, direction we'd like to advocate for those changes heading.
- Liz Carroll: Difference is where did a person chose to be. Where I didn't choose to live will be more institutional. Trying to create sense of community – if person doesn't like situation, more likely to find it to be institutional.  
Commitment – Provide feedback on case management and provider rule.
- Terry Miller: Have seen congregate housing to have community. Try to find what in that congregate community that made it so special. Extraordinary environment that didn't last forever, don't know what caused deterioration.
- Yonda Snyder: In one of our sessions last year on discussing settings rule issues, one of the communities said. Our residents fight us every day for their independence but our families look to us for their safety. Not a binary choice. Balance is important.