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No Wrong Door
Frontline Staff Focus Groups
Transcripts and Participants List
February 18, 2015

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Transcript

What follows is a compilation of unedited transcripts from three focus groups conducted with consumers and caregivers between 2/2/2015 and 2/16/2015

Tell me about the biggest issue facing agencies like yours these days.

- For us, we run into eligibility issues – making sure and finding CCB's that are using the same eligibility standards
- In addition to get assistance to CM to locate appropriate resources
- I would second that and say that there are resources that aren't available like housing
- Agreed
- Uhuh
- MH is really tough as well
- I find that more rural areas don't know about HCBS programs as well = I've sent patients to different social service agencies and they are told that the program doesn't apply to this part of the state
- And the Medicaid buyin program has been a real program with the counties – getting it rolling
- I think turnover in our area = we see a lot of that and it creates a ripple effect – a CM is working on something – we find ourselves recreating the wheel a lot
- We see that a lot in our area, too – even within the CCT program- we've changed ICM's three times now for a couple of our clients – that's within the SEP
- Our SEP here has had a lot of staffing issues – behind on intakes
- More need and fewer resources
- One of my biggest issues is when clients are institutionalized and then leave, they go home without services because the process is lagging; or the nursing home doesn't seem aware of the process
- We see that in SE CO – they are home before we even find out they are going home

- A couple of things that jump out to me, the scope of the services – the person has to be almost debilitated before they qualify – there's a need before that – before they are just about to get into a nursing home
- Need a broader spectrum of who can get services
- I would definitely second that – it is challenging doing these assessments and exactly that – a client who needs just a bit of assistance because their laundry is downstairs – she's going to be under the same functional criteria as someone who needs a nursing facility – there's no level
- If you don't meet that, you have access to nothing
- One of the other issues we run into in our SEP is that we are only able to manage the functional side – working with counties on the financial side of the approval – if the county loses paperwork or the client is confused – they might close a case and not let us know
- Not much we can do to manage that communication
- I work with ILC – and there needs to be something in between to keep people in their homes longer – you wait until there is a crisis
- We're downstream – we aren't upstream
- A lot of applications don't make it start to finish – I think in part there's no relationship with someone who can help them, help them understand what that letter from the county means
- A lot of people give up, it is complicated
- I'd add that HCBS isn't contacted before someone leaves a facility – also when someone needs to go to a nursing facility – if they have high-needs, especially behavior issues – there's very little space. We'll spend hours trying to find someone who will take that client
- I've had many who've ended up in homeless shelters
- What I'm working with are several families with teenage and close to adult children with autism and there is no place that they can have services right now. There are several waivers that exclude the diagnosis of autism.
- That's the way some of the waivers are going. I don't have anywhere to put these people. I can argue that they need higher hours so that their parent caregivers can get paid more or that they have other disabilities I can hang services on. But there's no way to get them the 24-hour care they need for this condition.
- That's the most frustrating thing that I face
- Not having anywhere to send these families

- I think we face similar challenges – we often interact with families and individuals either when they are stuck in the enrollment process; when they've been denied; don't know how to fill out the forms.
- We get them when they are stuck or they have never heard about the services and supports. Never interacted with a knowledgeable teacher or doctor.
- Often find that once we get them to the right place, they know to reach back to us if they get stuck
- Definitely families who move into CO from others states are pretty overwhelmed when they come here and are trying to put together services. Don't know where to go first.
- We are portioned and there is wait time to even get in for initial intake
- Definitely more since the recession – lots of families moving to CO (Jefferson Co.)
- And seniors who are now financially eligible – they don't know the vocabulary, the differences between Medicare and Medicaid. Esp. if they don't have internet access
- I agree with the not knowing Medicare from Medicaid. Mostly it is a lack of information
- Yes
- When I say I'm calling from Medicaid RCCO – they don't know what I am, or that there is a service center
- I'm nodding over here
- The targeting of waiver – we have to turn away people who have DD diagnosis – they don't qualify for our help
- And if someone is younger than 65 years old, if they have memory issues they don't qualify
- Also short on people to provide services – lots of waiting lists on lots of the agencies
- Want to jump on the issue of intellectual disability system – the entire intake and enrollment process to get people into any of the DD waivers are unreasonably complicated – there are so many places that people can fall through the cracks, lose motivation – I don't know how anyone gets through that system
- It takes so many pieces – some of which seem redundant - and by the time they get into the adult system, they have already had to get to know more systems
- Definitely
- Nodding
- Nodding
- All nodding

- Those folks that are doing the intake are basically told that it's in the clients/ family's hands to provide the info – to get the evaluations from the school or MH system, almost impossible; so people go out and spend hundreds of dollars on those evaluation
- I think additionally if it is an adult or a person who had lived pretty independently or someone without a lot of community connections - some folks don't have their testing information available. We spend a lot of time collecting information from 20 years ago to prove – or we have to get something diagnosed that is glaringly obvious
- We have what 15 or 16 different waivers – to get someone enrolled in the right program, you need to know enough about each of them to make a decision about what is best
- I have a family that migrates between DD and MH – their adult child has both diagnoses. I'm amazed at how much the family has to learn and stay on top of in order to manage this. It makes them play the system instead of getting the benefits they should be eligible fore
- I'm a little concerned that some of our most vulnerable populations have the least recourse – the TBI and the MH – you almost have to be in the hospital w/ a BI diagnosis to be eligible. If it was diagnosed later – you are SOL. With MH, the services are needed, they've never been robust enough
- All of these systems tend to be run by service providers – in many cases, not all – are threatened by the fact the people they serve – if we have input – they say, what do you know about it?
- When those of us who receive services stand up and say this is what you need to do to make this service work, we get patted on the head. The prejudice against our status since we aren't Master's degree holders or something like that.

How do those impact your day-to-day work?

- On my end, I see an incredible amount of frustration, esp. re: lack of housing and MH – I tell folks they have to look outside our county – that's really hard on them
- A lot of my guys end up in shelters, they don't know what else to do
- It's hard to see it, to have to tell people that I don't have anything to offer them
- To fight with waitlists for CCB – I thought the supportive living waitlist was gone, but that's not my experience
- We used to call that Bureaucratic Fatigue – that's for FLS and client
- I think it's a lot of hurry up and waiting – you're just waiting – progress is put on hold waiting to see if something works

- When we find a resource that works for us, we hold onto it
- And you keep it secret
- You don't tell people about it
- That's huge – those little wins are what keeps us going
- And so often it is an urgent situation – someone who is homeless or they just lost their primary caregiver – you have calls out and still have to tell them something
- People tell you to send them to the ER
- We have an emergency fund we can tap into if we have to (nonprofit)
- Here in Pueblo, we have Posada and Spanish Peaks Hospital – we have some partners to work with
- Housing does have a waiting list
- They all assist
- And we have Catholic Charities here in town, everyone in town goes to them, they help with like shut off notices
- It is hard enough getting someone to accept help – but then to go through all these hoops and then sometimes not get it – I can't help them – I sound like I don't know what I'm talking about – the trust gets lost
- The CM's will go out and when we talk about the scoring – if you look at their medical records and you know that there will be a decline and we can't score them, but it's just a matter of time – if we could have had them already on services, we could have avoided that crisis
- A lot of unnecessary crisis management – hard to manage work flow
- A revolving door
- If we could use our expertise – you know what's coming but you have to wait for the crisis
- I definitely agree with that – a lot of crises that could be avoided. As an ongoing CM, my clients are already on services
- In terms of day-to-day, there are a lot of people in the community who don't have supports to navigate these systems, they get all this paperwork and they are in the midst of a health decline and no one to walk them through it
- And they get all this paperwork from other agencies and we can't say anything about it except – well, call the county
- And our caseload is such that we can't really help with those
- There's not enough community resources for those who don't have family support
- If someone has home services and they are declining – there's no one to take them to do tours of assisted living facilities, etc. There are gaps there.

- Those gaps create crises that could be avoided
- I don't know with the paperwork – for housing, for Medicaid, for SNAP, if they already have the information, why couldn't it be transferred over? That would really nice to do it once
- I would agree
- I think what ends up happening – the frustration – by the time the person gets to you, it takes a lot to just get them to where they have unloaded enough of the angst, there's a lot of listening and rebuilding – and then you have to tell them the bad news that it's not you who have all the services – that you can review things with them
- You are looking for people to work with someone who is a basket case – all of that before you can get them to write down any information
- Doing this whole PR piece to assure folks that we do believe them
- Totally agree with that
- Nodding
- All nodding
- It's about building trust
- And the extremely naive family who comes in with an older person who needs services – and they think it just took a phone call – they don't realize all that they have to go through – they are kind of flabbergasted
- In the old days, it was more straight forward
- Esp. in CO where we have so many fragmented families – who get into crisis and move their family here and they are overwhelmed
- The system is so broken and we have band aids
- These are people who really need to sit down with someone and get a plan going – you hope someone is available to do that and that they will be able to listen to them
- And there's a lot of misinformation out there. We spend a lot of time doing education with the hospitals and schools around us to try to get better info out

Your clients?

- A lot of waiting
- Because they don't have the resources – they often end up on the streets
- Some turn to crime – what started with asking for services is a legal issue
- I've seen a lot of that
- Like getting charged with trespassing
- A lot of times people get handed back and forth between agencies where there's not an easy answer

- And we've seen bed bugs – we are always triaging and most situations become urgent
- You are really depending on your relationships that you have to work with to provide some kind of safety net
- We had a gal with some furniture that had bed bugs, the caregiver couldn't come in – so the police department and someone else paid for the fumigation – that's hours of coordination
- I've had similar situation – the time you've had me working on it you could have done that instead
- I would say at least 25-30% of my interactions with families and clients is them being in crisis – they get some form that says their case will close and they call me – but with caseloads, it is hard to follow up – we don't have enough time
- I've had family members call me crying – I can't help them, can't you fix this
- It can be really stressful, when you can't help them
- The NORC model (naturally occurring retirement community) – you stick a social working in the midst of the community to help with all of that process, and we are just missing that. People who don't have family – or even the family doesn't understand what to do
- It's about relationships, you need to have a relationship with the person
- Our families are already stressed to the gills, and then they are given a Medicaid packet and told to register with Social Security
- And we know there are a lot of benefits once you get in the door – but there are so many more hurdles than open doors
- Many of us are lifelong advocates or social workers – it is frustrating on our end, too
- To have to go through an appeals process for a basic service, especially when a family is in crisis – we have a big problem and not many to support it
- I had a meeting with an 80-year old man – he said that these are the state's best kept secrets – and the state keeps them secret
- They are trying to figure out what magic word to say
- And a huge problem with people who are under-insured who are left out there with an HMO who says no – don't have anyone to advocate for them
- To be in that place, we have Child and Family Mental Health Oversight Groups that try to make sure they have covered everyone for Medicaid kids – but for privately insured kids are left with nothing.
- You're supposed to be able to afford all of this stuff – and if not, relinquish your child
- Those of us who live in the benefits system as part of what you do – not only that you have to impoverish yourself. I didn't start out wanting to be that way – I worked for

11 years. But then I got injured and I got right on. And now I don't dare try to get off of benefits because I can't work full time

- The other aspect of this having to prove how broken your child is – that's so counter to what you are trying to do for your child – you are trying to normalize them – but then they have to be beside you while you make the case that you are broken
- It is inherently dis-empowering
- I can't let me son start to see himself as not acceptable
- It's a huge barrier
- Nodding
- Nodding
- The impact on clients, what I see is a very large number of people who need services are not getting them at all – they either can't get through the system – or they aren't getting the appropriate services, they are based on the regulations of the waiver, not based on your goals
- Nodding
- Nodding
- Nodding

As you work to successfully connect clients to the services they need, what are the most critical factors (i.e. these things need to happen for success)? What does it look like when everything works like it's supposed to?

- A person who returns calls.
- Able to establish a connection with the client
- Sometimes it's just your lucky day
- It feels like in our community we have the wealthiest and the most impoverished – and it seems like those who speak English as their first language
- Who are connected it the community or have a high level of education
- Don't know if that makes it easier to navigate the system or that the system is more inclined to work with them
- I'd like to argue that having an advocate helps – but sometimes it feels like we do everything 100% right, it still doesn't work
- Definitely about English speakers
- Also when clients have a stronger support or advocate – that helps. I see a lot of churches active in it.
- Those without families seem to have the biggest challenges.

- In addition, the advocate allows the parent to process the IEP or plan – the parent doesn't have to take notes, etc. They aren't as overwhelmed during those interactions with the system. The parent can absorb the content of the conversation. Frees up ability to negotiate.
- Even being there to hold their hand is enough
- And advocacy is teaching them how to do it – a lot of times it's just my presence. At some of these IEP's you are up against 20 specialists. And the parent is cast as overprotective or the client as overwhelmed
- And you can react to something that is out of bounds – the individual doesn't know when to challenge
- And if there's another body in the room, it keeps people on their toes – and they get a lot more creative and much more polite
- And that's the disappointing part – I think there's always a role for advocacy – it is disappointing that it takes an advocate being in the room for things to go that way
- And it continues the reliance on an advocate vs. "we're working together to resolve this for you/ your family member."
- I think families rely on advocacy – they don't trust the system
- I agree
- We need to help clients advocate for themselves
- This is important that you embrace this concept – someone needs to advocate for you for the rest of your life – it might as well be you
- This is not just a one-time shot for any of these families
- And you get better with practice
- I think we are touchstones – we are letting the families know where they need to go to get more assistance; depending on where they go, they are going to meet a lot of resistance – because the services they need are coming out of someone's budget.
- This is where you have to do some coaching so they develop some confidence in it
- The ARC doesn't need to step in – we can back off and close the case
- Limited amount of time
- That's rare
- We do an intake, we get them connected, in three months it's good to go – but that's not the norm
- If the process was easier for the person to navigate so they didn't need us to advocate for them so much

- I'm in a unique position so I work with long-term injured folks, they tell me about resources that work well – I hear about good resources and they are out there – they want to help each other and telling each other
- That kind of peer support definitely happens
- I work with families and come up with action plans – I educate them about the services – the parts that work the best is they call, they get to talk to someone, and it works like I told them it was supposed to. I don't have to get on the phone with them. I don't have to run out and get back up documents
- They have a contact person who they can contact
- And they get a call back
- A lot of VM
- Or the endless automated system – and you don't know what extension to press
- The other piece is transportation – that can be a real challenge with folks, too
- Second that
- In Pueblo, I agree with that – we have a contract with the cab company and they are so overwhelmed with all the clients –
- More demand than supply
- And we even have the medical transportation and even that is where you leave a VM and it is passed on to the cab company – it is very frustrating
- I'm hoping that since I'm a new supervisor, we can figure something out with them
- Here in Denver the Medicaid transportation just shifted to a new company, it went okay.
- They now require the doctors to certify that a person can't catch a bus and it takes three weeks to get them processed and approved
- I spend all my time on the phone
- That does happen sometimes – and the clients are usually grateful – but that doesn't happen very often
- We do see it – usually because there's another entity helping the client along – a family member, an advocacy group – it's usually never just the client alone
- And the client isn't doing a transition period (hospital t community; HS t adulthood)
- I agree – if they have a really proactive family or if the senior center helps- then it is smooth
- It's few and far between
- We have service coordinator – if they get homecare, they get to keep their housing – otherwise they are in danger – but when it workers, they get to stay in home until the age of 90

- In terms of the issues we experience with communication gaps with the county, what I've seen as most affective, is that counties who still have individuals assigned to a client's case- then there's a specific person the client can reach out to
- But they are shifting to a team model – no one direct person to work with – just a main customer service line
- In an emergency, we can reach out to a supervisor – but we don't have a specific person to work with
- I see the team model in Boulder
- Housing helps us a lot, they refer to us and help them through it
- If they have a strong family support it works
- We don't have a RICO, etc. We don't have that here.
- I didn't CM for Chaffee and Lake Counties – and working with their counties, it was much easier. They only have 2 techs processing paperwork – I could call them directly
- Here it is customer service you have to go through
- It's hugely heartening when it does
- Yes
- It's a total relief
- Many of the families I'm dealing with have this kid to care for 24 hours a day. If I can plug them into any service that helps them go on, they are in tears.
- I have a woman who'd husband left because the child needed all the attention – she calls me up and says that I'm the only person who's with me through this
- I don't know if I'll be able to plug her into a robust enough package for her to survive
- Using that as an example, having you there is important for the family
- That's what I envision – there's always someone there to support
- When it goes well, the sky's the limit
- When there are barriers, just having someone there for referral, someone who will pick up the line.
- That wrap around feel,
- And it builds confidence, sense of worth
- I work with the CCT program and it doesn't work
- The options counseling is supposed to be done with ADRC, but the contract is still on HCFP's, so someone has to do that first step, so it falls to other agencies
- The state has it outlined that the options counseling would happen with the ADRC
- And the measure of success is that the person has to be out living for 6 months before you get reimbursed?

- Is that right?
- No
- I have trouble getting reimbursed
- I haven't had that problem, we've been reimbursed really timely manner for transitions – we already had the ADRC doing our options counseling
- It is frustrating that the ADRC wants to do it,
- The counselor is supposed to refer them to where their options are
- What's supposed to happen ideally is the options counseling takes place, the consumer choses what path they want to take – if they chose CCT the counselor tells them about the TC agencies and they beginning their processes, ideally

What are the ongoing obstacles to doing that?

- ADRC contract delay
- For most CTA's, the reimbursement process has been non-existent
- The problem is that you're required to front the money, you spend that amount and then you are sitting on that - one agency stopped doing the transitions because they were owed $16,000 dollars
- Until that's worked out, no one will be willing to front all that money
- Most that talk about joining, once they learn about that, no one in their right mind would take it on
- One thing we run into with people with comprehensive services – one person started to deteriorate quickly and looking at home health care to help him stay at home, it was a nightmare; no matter what we did to communicate the need about what was needed– it was called double-dipping because he was already on a HCBS waiver
- I'd second that; where we have family members who are caretakers and they have a health is and we need to get care in there
- Another issue is that when folks are trying to go back to work and navigating the system there is very frustrating
- Voc rehab counselors don't have the training to do it
- Folks stop trying and give up wanting to go back to work
- I think that's true – you start all over again when someone is turned down that you know they are eligible for
- Almost every time someone applies for social security
- Does anyone get it the first time
- They do at Craig – but they break their neck
- Is that what you have to do?

- Well you have to do it right ☺
- Brain injuries are hard to prove that things are bad enough – I have to do the full advocacy for that person – if I lose track on any step – if someone gets a phone call and doesn't return it, the get kicked out
- One of my clients brings me all his mail from Medicaid so I can check things
- We've all seen these letters – we can't understand them – how can they
- I agree – for some reason it seems like there are letters going out left and right – I don't know what they mean, how do my 90 year old client know what they mean?
- I know here at DSS, we work at the same floor with the technicians who set up those reup periods. Protocol is that they are supposed to give us a heads up – they need a bank statement or whatever – but they aren't all good at that.
- We can support that to go get stuff from clients, but it's hard to get things from clients sometimes
- Everyone has horrible caseloads
- It's hard for people to find transportation to connect with those advocates
- And fear to reach out to help from someone new
- From a management standpoint – it's funding – it's not funded to do that advocacy
- If we do that kind of hand holding there – we run out of funding
- There are hundreds of CM's touching these client, but it (the funding structure)
- We pass them on – one duty begins and ends with a payment structure
- It's really silo'ed
- Absolutely, like Sara was saying, we have a lot of clients with more needs than we can really offer them time – needs outside the scope of our jobs – we can't do wrap-around on those more intensive-needs
- If we don't have a community resource to refer them to, they fall through the cracks
- Not a community resource, or not enough of them – like the advocacy organization – like the centers for disability, or senior housing SW on site, someone like that.
- Not connected to those resources, and no family supports,
- You are dealing with people who are independent and they hear home care and they hear nursing home
- If they need help, they are afraid they will get institutionalized
- Absolutely
- That's their fear
- Yeah
- The relationship of an advocate is important – and do we want to keep advocating people through a broken system

- Having these systems that are ridiculous to navigate
- They could create a roadmap or trail map. If you go into a national park – there's a map. Even if it is just basic.

What's the 80:20? If you could change just one thing, what would make the biggest difference for you? For your clients?

- I would be able to make a list of phone numbers that when people called that someone would answer the phone or return the call and explain what they do
- That's so true – when I call folks back, they are surprised that someone called them
- I don't know if you'd agree, but to me it seems like if there was a standardized form or application that could be passed along when they do refer – you spend hours and hours doing intakes and then there's a lot of wasted time. We're all doing intake processes on the same person over and over
- I agree with that
- Then they would have a single form for housing to get on all the waitlists
- Part of the struggle with the SEP is the IT system – if we can somehow the community people can enter that referral and it pops into the county that is appropriate so we aren't duplicating work that would be nice
- I can see the privacy laws, having them sign a bunch of releases – people might be hesitant to do that – so it might take some effort to get permission
- Streamline the application process
- Yup
- Um huh
- I agree with that
- Make it simpler – when they walk in and get that application – it is 23 pages – and it includes things that don't apply to them
- It can induce panic
- Communication with all the social services, nursing home, county, etc.
- I agree with that. I think communication is the biggest issue
- And getting clients to accept the services
- And to know the services that are available to them
- I agree with streamlining the application
- The other thing is waiver simplification – so many waivers with so many rules and regulations – combining it with waiver simplification
- A broader span of people who can qualify for care so you can help people upstream instead of waiting until they are really debilitated

- A basic, introductory, easy-to-read that a family could look to for a clearer understanding of what this process is about
- I just had this experience – one of my clients was appealing a denial by a SEP on a specific waiver. The first time, they denied her over the phone without her ever having her come in. Then she found out that an in-person review was her right – she demanded that. The denial said "does not meet target population" – she had applied for a specific waiver. In talking with them, they wouldn't talk with us about other options unless we dropped the appeal. And there was another service that this person was qualified – they knew where she could get help and didn't bother to tell her.
- They didn't want to deal with anyone outside their client base
- I wonder if they were overwhelmed by their caseload – I often know of things that some clients would benefit from but I don't have capacity to do that
- It's supposed to be family friendly, you're supposed to be able to do this without an advocate.
- It would be nice to have a good community foundation and understanding between all the agencies – it's almost easier to turn someone when you are overwhelmed – but if you knew all the other agencies, you could refer better.
- A collaborative approach- that we are all working together
- Going back to the roadmap – there was a program in JeffCo with youth corrections and the dual diagnosis kids – they developed some programs and came up with a lot of ideas – and they did create this roadmap. Focused on ways to turn things around. One of the things that happened is that the court system got a lot more engaged around this roadmap. Because sometimes the agencies that seem to have all the agencies are so overworked, they don't understand the whole. It made it more obvious that some of the processes are unreasonable. A lot of new agreements were made and they are still in place.
- There was a lot of cohesiveness between these groups who wanted to help these kids – and it really help them see all that was expected of the families
- Help folks get a real birds-eye view
- I think there needs to be a collaboration between the service and enrollment and everything under disability and aging – between these agencies and school districts. Something expected, routine, and regular rather than a resource fair. An ongoing relationship between agencies
- And to flatten the system – for the goal to be accessibility to users rather than over-regulation because we are worried about fraud

- A real systemic change – I like the idea of No Wrong Door – a welcoming environment for families and individuals
- If we follow the timeline of someone being diagnosed to getting services, it's doable. As long as we have the bifurcation and things that undo other services
- Agreed
- I just want to say, the people, the messengers from these systems aren't bad people, but they are restricted by the practice vs. the policy issues
- They are put in a bad spot – but over time, it ultimately goes to what do you do when there's not enough services. For those folks to know that there are going to be gaps and start alerting people that more will be needed.
- If I walked into Colorado and I Googled services for my disabled child, there's no easy way to understand what my next step would be – make it easier to navigate – no peaks or ravines
- Practices/ procedures issues vs. Policy issues: times when we know that the way the process is being handled isn't what is mandated, it's in contradiction to what's mandated. Sort of like "it's how we've always done it"
- I think there are times when there are people – and maybe because we are far from Denver we think we can get away with more – people will bend the rules in the favor of someone getting services when a policy seems wrongheaded
- You know that the whole system started out when the people living in a specific nursing home in Denver decided they were going to move out on their own. The Housing Authority had a project they couldn't keep full – they modified some of their apartments. Medicaid agreed to look the other way so that people's home was identified as a place where someone could get services. The Atlantis Community.
- But now with the waivers and structures, the creativity has been lost.
- Often the people with Atlantis have been involved in advocating for specific waivers – but once the waivers set up a power structure that is the be all and end all rather than focus on getting people the help they need
- One thing that bothers me these days is the explosive growth of cottage industries being one more middle man to tell people lists of places they could try – not only is the person not being well served – But it's a bait and switch.
- And they get government money – I find that troubling.

What's the one thing people designing the NWD system MUST keep in mind about your clients?

- That with older adults and adults with disabilities we work with – the situation may be really urgent so the person isn't keeping track of who they are calling – they are calling everyone; the person's situation is probably urgent by the time they are calling so
- And they can be tagged as manipulative when the call a lot of places – but they are in crisis, they need help
- And if you called them back they wouldn't call you so much
- With our folks, I tell them that they have to educate all the time – that you have to tell them you are in a wheelchair, you have to tell folks what your needs are
- And I'd imagine that with more hidden disabilities, that can be harder to do, and harder to talk about
- Not assuming by what your eyes tell you
- I would say they need to know we are working with a lot of elderly clients who have trouble navigating tech
- And can get overwhelmed
- Many have memory impairment – and many don't realize it – they think they turned a form in, they need more coaching
- And they've already gone through a lot to get that paperwork together, be patient – they've had to do a lot already
- I would say too, a recognition that we are going to have clients who decline and then rebound
- So the issue between home/ community services and nursing home – there's difficulty transitioning between one and the other
- We're going to see that a lot so we need to make that process smoother (in both directions)
- I have a client who I had to close their case – she went to a nursing home – she's now back at home for 5 months – I can't help her because she's having to reapply for everything – 5 months without services at home

About front-line staff like you?

- Caseloads are really big
- Keeping in mind that the other organizations that we all work with are trying to do their best and that it can be frustrating when it seems like balls are being dropped
- That's some common ground and it can be difficult to find
- And even if we develop a network of knowing who's at different places so we know who to reach out to

- Don't have a lot of free time to develop a professional network
- Depending on the agency and their cash flow, the reimbursement lag can be frustrating – spend a couple of hours with a client and you are talking about all their options but at the end of the day you can't put out the money to transition that person out, you leave them waiting for a very long time with their hopes
- It's really hard – anyone who's worked in that arena has had to deal with that
- It is frustrating for staff and they know there might not be a result
- And it can be devastating for the client
- It is my understanding that some of the SILs (?) some have larger budgets, but here at CRS, we have a smaller budget and the reimbursement lag is very frustrating, but we aren't experiencing too much of that
- Return our phone calls
- We have exceedingly high caseloads – we are doing the best we can
- We are trying to help a lot of people
- Turnover seems to go up and down; more recently I came back from maternity leave and 3 people had left our 12 person team in 3 months
- We haven't been fully staffed for the last year – people get a full caseload when they arrive – 130 clients
- OMG
- It is overwhelming
- It's also hard for people who are here to train the new people, we are overwhelmed

What else do you want the Planning Group to know?

- The financial eligibility can be really rough for CCT – if we've found transition to be feasibility and they go to do that financial piece and find out the client has a medical trust that may not be set up right, suddenly the client is not transitioning, they are in danger of being sent out of the nursing home because they get tossed off Medicaid
- We run into those issues where the financial piece takes forever – mostly around the Medicaid buy in program – people don't really understand it; or they get approved and you are waiting for someone from HCBS and paying a premium in the meantime
- What did they do to the website – to PEAK? You could apply online for PEAK and now it is a nightmare – anyone else run into this?
- I think it was supposed to be an upgrade
- We've gone back to paper applications
- We've always done paper – we lost too many doing it online
- It was working really fast – hearing back from the county for a week or two

- One thing we've noticed in the last few months, people's situations are way more complicated than they used to be – like more people calling who are about to be evicted and in the meantime their HCBS has been dropped. More layers. Trying to get in home care, need counseling, power about to be turned off, etc.
- Can I ask, do you know what kinds of change they are looking at making
- One of the things I've heard over and over is more support for community agents – the folks working with folks – is there potential that they would fund NPO's or community agencies?
- I think we've covered it pretty well.
- Thank you
- I'm very grateful
- It can feel like you're the lone ranger – and I think have some good observations – and it is very refreshing to be looking for solution and future direction

Focus Group Participant List – Frontline Staff

First	Last	Position	Agency	County (s) Served
Kim	Bauknecht	Advocate	ARC of Adams County	Adams
Kristen	Castor	Advocate	Colorado Cross Disability Coalition	Pueblo
Delaine	Dunning	Supervisor, RN	Prowers/Baca Counties Options for Long Term Care	Prowers and Baca
Jill	Eelkema	Options Counselor	DRCOG AAA	Denver, Arapahoe, Gilpin, Clear Creek, Adams, Broomfield
Michelle	Gaumond	Case Manager	Rocky Mountain Options	El Paso, Park
Janna	Hartmann	Adult Program Supervisor	Pueblo County DSS, Options for LT Care	Pueblo
Kathy	Hulse	Social Worker	Craig Hospital	Nationwide
Raeann	Hund	Adult Program Supervisor	Pueblo County DSS, Options for LT Care	Pueblo
Cathy	Johnston	CCT Coordinator	Center for Independence	Delta, Eagle, Garfield, Gunnison, Hinsdale, Lake, Mesa, Montrose, Ouray, Pitkin, San Miguel, Chaffee

Alison	Joucovsky	Senior Connections Program Coord.	Jewish Family Services of Colorado, NORC	Cities of Wheat Ridge and Edgewater
Tara	Kiene	Director of Case Management	Community Connections, Inc.	Archuleta, La Plata, Dolores, Montezuma, San Juan
Saori	Kimura	SEP, functional assessments	Colorado Access, Long Term Support Solutions	Adams, Arapahoe, Elbert, Douglas, Denver
Kathleen	Kleinhuizen	Care Coordination Specialist	Community Care Central, RCCO Region 7	Elbert, El Paso, Park, Teller
Roman	Krafczyk	VP of Programs	Easter Seals of Colorado	Front Range
Jenne	Loffer	211 Program Supervisor	United Way of Larimer County	Grand, Larimer, Jackson, Moffat, Routt, Rio Blanco
Shelly	Miezwa	Lease Compliance Manager	Boulder Housing Partners	City of Boulder
Patrick	Miller	Transitions Specialist	The Center for People with Disabilities	Boulder, Broomfield, Longmont, North Metro Denver
Rachel	Moore	Case Manager	Colorado Access	Adams, Arapahoe, Elbert, Douglas, Denver
Maureen	Nicolais	Resource Nurse and Seniors Wellness	Jefferson County Public Health	Jefferson
Marissa	Petrochko	Case Manager	Colorado Access	Adams, Arapahoe, Elbert, Douglas, Denver
Sarah	Purdy	Case Manager	Colorado Access	Adams, Arapahoe, Elbert, Douglas, Denver
Hanni	Raley	Director of Systems Advocacy	ARC of Aurora	Aurora
Erica	Reich	Case Manager	Larimer County DHS	Larimer County
Linda	Rumney	ADRC Coordinator	Larimer County DHS	Larimer County
Jenny	Smith	SEP Manager	Colorado Access	Adams, Arapahoe, Elbert, Douglas, Denver
Lisa	Smith	Case Manager	Larimer County DHS	Larimer County
Donna	Wyant	CCT Program Manager	Disabled Resource Services	Larimer and Jackson Counties