

No Wrong Door
Consumer and Caregiver Focus Groups
Transcripts and Participants List
February 18, 2015

Transcript

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

What kind of non-medical services do you use regularly?

- Caregiver for my elderly mother; I'm on CDASS
- Work for AOI as a caregiver
- Employment program, group home
- I have 2 adult sons and a granddaughter diagnosed with mental illness who are being treated in Colorado's mental health system
- Transitioned from a nursing home
- My wife uses the WR Senior Resource Center – there are 2 or 3 in the area – it is set up for people with memory care concerns – for my wife it provides her an outlet and a chance to interact with other people and to participate in activities
- Also gives me about 20 hours of respite
- C.N.A. comes in in the morning and evening for an hour at a time and a nurse for an hour once a week and a homemaker for 2 hours once a week to do the laundry and some slight shopping; I'm in a wheelchair, I transitioned from a nursing home in 2009 and that's about it
- My wife is a beneficiary of CDASS program.
- We currently have at school, a PT, OT, Speech and Early Educator. I supplement PT weekly through Children's Hospital and Speech once a month at our home.
- Jeanne access total care through the total waiver; she was grandfathered into the DD system even though she has no cognitive disability – she has all of her cognitive abilities; she uses a touch talker and has difficulties getting training for the touch talker. Had to go to the DIDD; her PCB was refusing to let her have services to let her use her touch talker and computer together – she's not able to use it for speech – she

uses it for writing. That's a serious communication means she was cut off from. There are others who need those services – it's hard to get folks to understand that they are worth the money, but it is really about basic communication

- The nonmedical things – it is truly hard to find respite care. The ramps are considered non-medical; and technology modifications – that what we've experience
- I'd interject that my son, even though he meets the criteria for using a community board, he doesn't meet a CES waiver, so everything that we do is out of pocket and as a single mom – so I pay for respite out of pocket
- What's a CES?
- Children's Extensive Services waiver; the targeting criteria is that the person can't sleep through the night
- That disqualifies him
- My son does use the CES but it comes with a lot of restrictions about what you can and can't use so I access respite and I pay for myself; my son uses the community services – rec centers, library, community access
- Christopher Rowe – the Home Modification Team; 303-864-7831
- I come to the day program and work with teachers here
- We do meals on wheels
- Eldershare, medicine horse, I work at ASP
- At night, I live with my stepmom and dad and she helps me learn cooking – although I already know a lot; and we go shopping together; I don't need anyone doing cleaning or anything
- Employment access support
- Gary coordinates where I live
- Residential support from Imagine – I've got enough support from them, didn't like Carmel; I have some friends here and it's where I live
- I have 2 sisters, I live in Boulder independently
- I've got a new counselor and her name is Cody and she's really nice to me
- I go shopping every Friday and we go out on Sunday to do outings and then I go out by myself on Saturdays – anywhere I want to – usually for lunch
- My dad was angry with Carmel, because they didn't treat me right – he took me out right away
- I wasn't too happy either
- People first does my housing
- They also help me with my financial, like budgeting money, my counselor helped me
- I like when people are there to help with my selections

- He helped me to save money to get a new TV and IPAD
- I like my services, but then again I don't. My disability will get in my way – I don't think often before I act and some of the services I have I have to do a behavioral therapist and he's really good – my stepmom is a godsend, and Community Link is really good, too
- I'm really proud of myself, I've been home for a year and 2 months – before I was homeless and I didn't know how to get out of it
- And the people I've met here – very supportive, kept me very safe, no issues with the teachers at all, students are very friendly
- Before that I didn't have the services I had now – didn't have family support, I didn't have nothing
- I've gotten a lot further that if I didn't get these services
- I used to be in Special Olympics and I'd like to do that again – I don't care who it is with – go out into the community more and make more money or doing something where I'm not doing the same thing over and over again
- We want to be able to get out and do things
- If we stay back, we stare at the walls – if there's nothing to do, it gets really boring
- If Colorado would realize that we want to do something
- Seriously
- Lots of laughter
- We are mentally disabled, but we are also people, we are smart, we are active, we want to go out and do things
- Every person in this building would agree with me
- I agree with you
- We don't want to sit
- Want to go out and communicate
- I don't like show that much
- Me either
- A whole lot of agreement here – they talk for awhile
- You want to go out and live where you want to live
- Important thing to do is one-on-one – I agree with that, too. One person at a time
- It's harder with 5 people
- Yes, with 1 staff, we all have to pick what we want to do on our choice day and we can't always choose the same thing
- If we had more staff
- There are 60some kids here

- Freedom
- I agree with you
- I agree
- I live independently and I have meals on wheels 5 days a week
- My sister helps with my finances and my mom takes me grocery shopping; I'm on food stamps so I have to be careful on my budget
- My services I have a staff person she helps me with everything like personal care, homemaker, and cleaning; my mom helps with my checkbook; I do sell MaryKay and there are a lot of things with that
- I love everything about electronics
- I'm on the ACS Board – I go there for meetings and take notes and that and they email me notes and I type them up
- I don't like any new groups – I'm with my other friends; my mom and I go to swim class near Longmont
- My son is using homecare services
- Through Ft. Logan they started homecare – they come in and clean
- I receive respite care – 59 hours a month
- I have some concerns for myself – 22 years after my injury – I haven't had services for 18 years – and now the services I need aren't covered by insurance and it's too expensive out of pocket
- I've participated in some group programs through RM Human Services and I have a counselor through them – they check in once a month or so
- Real problems with access to transportation
- I agree on transportation
- I have a 6 year old so we access a lot of therapy and my husband and I are caregivers
- I do as well
- My daughter is 3, we used a lot of the services – now through preschool
- Been involved in a lot of different committees too, anyway that we can help you out that won't take forever
- I work at Foothills, mostly unhappily, we don't get fair wages; everyone is lumped together and we have a host home that I use
- In services my whole life; right now have a host home and it's pretty stable now – did move around a lot in the past; parents had to step in so that it stayed stable – to enforce his choice
- That's new the past 2-3 years
- Victim of a past CCB that ignored a lot of medical issues

- Transitioned from a nursing home 9 years; I use homemaker services and C.N.A. in the morning and evening;
- I served in the state legislature – was on the HHS Committee in the Senate; also the authorized rep for over 30 clients – I can move faster than an ARC or something as a volunteer – to help someone get the services they need – the idea is that the client’s choice is paramount
- I’ve helped at least 15 clients move from places that they want to – you still have some residential agencies and CCB’s where it is, “We know what’s best for him...”; as an authorized rep
- When you wanted services for your kid 60 years ago, you had to go to a judge and say “I’m a terrible mom,” and they would then get services; I try to educate families about what their choices are
- I’ve had folks fire her agency, her ARC rep – it can happen that fast; respecting choices and ensuring health and safety
- I have CP, too
- I’ve been in the Medicaid system since an injury in 1983; in all sorts of services and processes; I started working for the home health agency 25 years ago; doing the Medicaid Buy In to continue to work and still receive services; we bring in a lot of people across the age range – people need to have the choice of services that not only fit their diagnosis and their needs
- Most of our clients want a choice and want the transparency to move between waivers – they are limited by age
- How seniors vs. people with disabilities and how they see them differently – in the disability culture, people don’t want people making referrals to social services about your welfare because it can put you in a nursing home or somewhere you want to be; folks assume an institutional setting is your best option once you are disabled – but I disagree
- I’ve done a lot of legislation liaison work; that work is really important – one way to measure a society is how they treat their most vulnerable citizens
- The word safe keeps coming up – who decides what is safe? The provider or the person getting the service?
- Dignity of risk
- I’m novice to the waivers, but I’m learning a lot quickly. My mother was blind and never got services. I watched 4 of my husband’s siblings go through being a caregiver – they could have gotten waivers but no one told them about it
- They never found out about the choices

- I couldn't leave him alone - and no one told me this best kept secret
- This is my 6th day on the job – we are health care services – predominantly in the rural areas
- We'll be in every county in Colorado
- Moved here from CA

What do you remember about how you first got connected to those services? Where did you go? What was it like? How long did it take?

- I was really fortunate – through a man whose daughter had MS he referred me to someone who had worked at Medicaid on the state and federal level and he had a business that helped people with the process – not only did he help expedite the process, he also sat down with me and said here are some other things you'd want to consider – I think that's unusual – I had to pay for his service – so it wasn't through a government agency;
- I also go to all the meetings at the Senior Resource Center – caregiver information sessions; Congressman Perlmutter had a session where I met a lot of agencies, etc. I got a lot of info on services and programs.
- She got into the DD waiver when she was about 14 – she doesn't remember what her parents had to do to get into it – but there was nothing appropriate to her needs – she needed total physical care but has full cognitive abilities – she was in a day program for 29 years where she didn't do anything – they just let her sit there. It was isolated in a different building than the rest of the CCB and it was very abusive. She now has a day program alternative which supplies her aid – the Supportive Community Connector Program; she has 2 connectors because she's so advocate
- Compared to what others have gone through, my experience is insignificant; I think it still needs to be said – all of you make me feel like I shouldn't even be here; I am blind and I'm only telling you that because it relates to the services I have received. Since I'm retired and I wanted to keep on learning things. The DVR – there's a move to have it relocated from DHS – they have a program where there are professionals who are trained to teach blind adults – they come to your home – provided that you can demonstrate that with this help you'll be more self-sufficient – I don't qualify for Medicaid so it's not covered; the point is that because what I needed to learn did demonstrate that I'd be more self-sufficient, I was eligible and the teacher comes and she's very good. I don't think she comes enough – but when we live in the country, we're happy to get any services AT ALL. I know how to get services the DVR in my opinion is in such a political mess that the people who need the services are

secondary to everyone scrambling to keep their positions, to keep their authority. I've been told that the DVR counselors spend 80% of their time doing paperwork and 20% of their time seeing human beings. That's the kind of thing that interferes with people achieving their goals and I'd imagine it goes on in other services also.

- The rehab services for the parents on the line here could be such a wonderful resource, but there really needs to be some change so that we don't get caught in things that have nothing to do with being helped
- I'm a caregiver for my 3-year old who has autism. I've experienced a lot of waiting – that's the hardest part – and the paperwork. Our journey to getting the CES waiver. I knew something was going on with my son last year. I paid privately for speech therapy – about \$10K last year. I went through IMAGINE and went through the whole waiting to have the evaluation – and they said, we don't know if they have autism or not. So they said we'll start giving some services and if it doesn't progress, we'll get more. They gave us 1 day of speech therapy, OT, and an early learning

- Teacher once a week. So I have to supplement. I didn't stop fighting. I had him evaluated privately and I kept him in speech therapy. At that point, I should have been told about these waivers, but no one told me about that. I went back and did research and thought he might qualify for CES – I average 3 hours of sleep a night. I called IMAGINE back, once I knew what to do and where to go. Once you know what waiver to go after. I was evaluated in August and I hounded them every week. He is now qualified – took about a month. At your initial appointment, they should say “here's the Medicaid application, here's the information you're going to need...” If I hadn't been on top of it, it would have taken a lot longer. I was always – what's my next step. They don't willingly give you your next step.
- He's making really great progress now that he's getting services
- I've been talking with other families, giving advice – telling them what to ask for – I learned the hard way, but there are families who lose out on 6 months of services
- That can be bridged – at the first appointment – fill these out, don't know if you qualify, but you can do this application now
- The websites are confusing – and I'm pretty tech-savvy.
- And the process is so intimidating
- There's no uniformity. There ought to be, and there could be if people weren't so damn territorial – once you fill out – everything in this day and age everything is done electronically, once you're in some system somewhere and it's the State of Colorado – that information ought to be available when you want it to be.
- There's a whole history of this state getting big software – the places where software for DHS was piloted, it didn't work, and they did it anyway. The same thing happened in DVR
- A uniform form could be developed so people couldn't get the run around
- Jeanne: many staff in the DD don't have the intelligence to do the job; like leaving someone at the top of the ramp without the brakes on; and the staff who did this talked openly about using drugs and alcohol. I was sexually harassed by a staff member – he talked about sexual scenarios he thought about with me. I complained every day and was still sent out to do one-on-one things in the community. This was in a CCB day program. This is what happens when you pay people minimum wage to work with human beings. Many of the bad staff go out and become buddies and no one wants to call their friends out on things. It is paid as if it is an unskilled job.
- My route was a little bit more traditional; my son went to the CO School for the Deaf and Blind, they saw the delays and brought in a doctor to do assessments. Through them we got connected to the CCB. There's no consistency in the system. When we

moved to Denver, the CCB's work very differently. A lot of inconsistencies. Unless you are willing to do the work – I've had to jump in with both feet in the past 8 years just to be able to know how to navigate the system. And lots of folks can't invest the kind of time it takes.

- I'd like to throw out a resource that's pretty new – Colorado Consumer Directed Attendant Support Services – it's been the safety net that's helped me stay as my wife's caretaker. It lets me draw a salary while I care for my wife.
- It has limited applicability
- Is that the same as CDAWS?
- Yes, exactly.
- I lost thread of the question;
- I was in a nursing home; they are supposed to ask you every 3 months if you want to leave; they did that for 9 months and I asked the social worker who they were working for – me or the hospital. Then I got a brochure to the local ILC and that's how I got out. I still had a GI tube – that's a feeding tube. I asked to get out and it's a lot better being out in the community.
- I think the worst part of all this is for my son's waiver – he's supposed to automatically supposed to qualify for Medicaid – but it is a dual process – so I have to do the applications twice – should have only had to fill out one – IMAGINE should have talked with MEDICAID. I had to do all the paperwork with IMAGINE. Then I had to physically take my son to Medicaid so they could see him and then do all the paperwork again.
- The way the system talks to each other
- And then people lose out on services
- There almost needs to be education on the front end of the people who are on the front end of the process – if that doesn't change – at least the FLS can say, you're going to have to do this again – be really clear about what the process entails
- No one wants to take the extra step to give that information to the caregiver
- I agree
- They don't tell you the next step because THEY DON'T KNOW IT
- The guy you go to for the services - #1 Colorado is ranked very low on how much it spends on services, that translates to people having tremendous workloads; their deal is CYA – yes they want to help people, but if they don't get their paperwork done by a certain day – they don't have time to sit with you and explain the next step.
- And not only that, but for my son, we waited a month after we got a letter than he qualified for CES, the letter was dated 9/9, but I got the letter 10/9. My initial meeting

with the Case Manager wasn't until early November. A 2-month gap for someone who needed early intervention.

- Those of us who can pay for things really are at a disadvantage – we don't get told about services; when my husband was in the nursing home, we didn't qualify for Medicaid – Medicare covers some and then you pay out of pocket. The nursing home was getting the money from me, so no one came and told me about hospice care. You'd think too clearly when you are grieving. No one told me I could have hospice care and Medicare could help with that.
- Like Ed was saying they don't tell you can get out until you asked
- We should be at least be given information about what services are available if we can see if any of them are for us
- A list of the community-based services and the acronyms – that would be a start
- For me, it was a continual struggle just to make ends meet and becoming aware of services through people that I talked to when it should have been coming more directly from Developmental Pathways with is our community-based agency; then going through the misunderstanding about what services are, what they do, what is covered, how to get them; Going through that a little bit at a time
- I think I went way too long without services because I didn't know what the services where
- I went through Developmental Pathways –but even that was confusing to me and it didn't go as they should; I do what moms do – you can't really approach it that way; what I found out is that as a caregiver to have that safety net I had to look at it from another perspective – someone who doesn't know my daughter and taking care of what she needs to be successful – so I didn't represent the need as strongly as it really was
- So it kept cycling through, losing time at work, thinking I'm going to get fired, but not having a safety net
- I relate to that dilemma. 11 years ago my mother had a diabetic seizure – she had it for 4 hours and it gave her short-term memory loss and the dementia really came to the fore. I didn't know about her income, etc. And then she wasn't able to tell me any of that
- I did lose my job – I was demoted over it because her getting ill turned my world upside down; they released her too early from the hospital with no one to care for her. I went out and hired someone and they stole from her. I had no idea that she had any services

- Her doctor told me she had Medicaid – got me in touch with a CM – wish the hospital would have done that
- The frustration was trying to find out what was available for her
- And when she moved in with me, she moved counties and we had to reapply again
- The Jefferson Co. CM did put in touch with a daycare and with a home health person to come up to help – but they often didn't come often
- Lots of “uh huh's”
- And having to trust them to work with her and lock up my house
- Some of them were good, some of them weren't; however I felt that her CM continually threatened to take away services – it came to did I have to choose between the daycare and in-home care – I had to do one or the other; so I ended up retiring. I felt there's no way I can pay for the daycare out of my own pocket.
- CM has changed and the new one is wonderful – when my mother was diagnosed with Parkinson's so I called her and told her I needed specialty care and she put me in touch with Access on Independence
- There wasn't a lot of discussion about how to proceed – it was just AOI will come over – and it was applying for a job (I didn't know that) – I get \$15/ hour 6 hours a day, 7 days a week.
- This is a pretty new program
- Depending on who you get on a CM – we went through being threatened that they would put my mom in a nursing home – afraid that they will take her away – instead of here are your choices.
- With Medicare and Medicaid, this year I had to get medical power of attorney because an insurance policy showed up on my mother's record and they needed to know about it in order to keep her benefits – it was a life insurance policy that was \$600 too much, they almost took away her benefits over it
- Lots of “uh huh's”
- The fear of losing her benefits – I can afford the meds she's on; and AOI would go away
- Since she's diabetic, I can't clip her toenails, but she's homebound. They can send a C.N.A. over to cut her nails – but I'm basically a C.N.A. and I could lose AOI if they think I'm duplicating services
- I called SRC the daycare to see if they can help with transportation – and they told me about Medicaid rides for medical appointments – nobody tells you this
- That's the frustration
- If you could have a directory – that would be great

- You stumble across the services
- I can identify on so many levels
- I think similarly, only in the sense of frustration – the runaround that we get and the lack of caring of service providers. That’s across the board no matter where you are.
- I agree.
- And for me personally, one of my frustrations is that last January I had to go into a nursing home because I fell at the end of December and that was a total wakeup call. It was a shock. All I could think about was getting out. It was terrifying.
- It was like pulling teeth trying to get them to tell me what could be provided – I finally signed myself out – I wasn’t getting any services
- And I have to reapply for CDAWS
- Same frustrations with agencies – if they would come, if they would be on time, if they would steal from me, if the person was able to care for me – basically just helping me with a shower – but it was amazing how many people would say – I don’t touch anyone
- Now I have an attendant from CDAWS program – it was all encompassing trying to get on that. It’s hard to hire my own people – people who are really willing to actually work. Even people who will vacuum the rug – didn’t I vacuum it last week?
- I was raised with a really strong work ethic, so that attitude is really a culture shock
- And I can’t get anyone to cook anything
- And you have to find out if things are available – then are they for me – then what the process
- There’s a couple things – in terms of the NWD concept – one of the things that needs to happen, the short answer to some of this is to get rid of all these silos so you have to run around all over
- If we all came up with a message – even just in terms of transition – if everyone was speaking the same language it would be easier
- When you go to one door, they can help you with a piece of it, but you run around to get the other piece
- There’s a lot of duplication of services; I’m very frustrated with that and with throwing money at new agencies that do what others have been doing for years
- If we could get rid of the siloes it would help
- I ended up deciding with my employer to leave – I was going to work every day and fielding calls from doctors and concerned caregivers and others who thought maybe my mother should be in a nursing home because her gait was uncertain. That stress. In this country, it’s getting better with home and community based services

- People have to choose between poverty and caring for the people they love
- There's got to be a way to come together with the common goal of taking care of people across the age spectrum
- And getting people the information they need when they need it
- Absolutely
- Yeah – I agree
- Thank you for saying that
- The struggle with my daughter is after her father left and took everything – when I could have really used these services – I had no way of knowing about them except through Developmental Pathways – I think I fell into that lousy CM slot – they knew what was going on, I went for 4 months with no income and I should have been offered a comprehensive slot for her and they didn't tell me
- It might be that they don't have the training as well – we've had 5 different CM's in 11 years – I don't know what kind of information they get when they come on board
- That might be where it starts
- I don't think they don't have all the tools that they need to give me a choice – the one who was threatening to cut my services – it felt like she was on a quota or something – I feel like she really wasn't well-trained
- But applying for the Medicaid again this year, it was frightening to think she might lose her services
- It starts through the CM – they need a list of all the things that are available – that would help us all – you don't know if you don't know
- Something like a common intake process – it needs to be the same for everyone – they should be able to tell them your life circumstance and they can tell you what that means
- I didn't realize the emotion this conversation would bring up for me
- I'm seeing it in this rural area – some of this community services stuff is a real paradigm shift. Just because HCPF and others have woken up to this shift, doesn't mean that all these SW or CM's haven't had this paradigm shift, so you have some of these folks out there who don't think that these models of care are appropriate.
- I think the aging tsunami because we are scared of the massive number of elders coming who will need care
- You may or may not get the full menu of service based on what lens your CM is looking through; the way you can address that is make it clear that these are the directions we are going in – there are new and innovative programs. Get the message that this is happening – this is where you go.

- It starts with the feds and state saying this is the direction we are going in – and then you get the minions to follow that.
- You have to get everyone on the same chapter in the book – if not on the same page.
- They are now in the position of having to implement a program that a few years ago they thought was a little askew
- When I first got to the SEP here – she’s changed her tune, but she used to not believe in community services and thought the state was paying too much on transitions
- That can be a real impediment – if that person is in a position of power, especially in a rural area
- My daughter was diagnosed at 9 months so Children’s Hospital got me in touch with Developmental pathways, that’s how we got initially connected
- They came to the house and evaluated her and based on their recommendations and we decided to move forward – speech, OT, early ed – then they went back to their providers and found folks for us. They came to the house.
- When she turned three, she switched to school – did another evaluation – with the teacher and Child Sign – asked all the questions – created the IEP
- I supplement
- My experience is the same
- That continues each year – meet, go over services, every year
- We were on a waitlist for a CES waiver for four years
- You get some therapies – but then once you get in the program, it’s great
- Mine is the same – Children’s put me in contact with DDRC. We didn’t run into a waitlist, but that was 10 years ago
- My son his treatment plan through MH Center
- One of the problems – when I was trying to get him help – they said that he had to call – but he was so sick, there was no way he could call
- They came up with some of the treatments – they helped him with SSI, with Section 8 – I don’t know what I would have done
- But I had to keep on it
- There were times they dropped him – he’d go in and say he didn’t need a therapist and they’d drop him. But he wasn’t well enough to make that decision – he’d end up in the hospital
- It seems like this time is different – they came up with a more thorough plan
- And there are so many papers to fill out – so many different papers I get – there’s no way he can fill them out – but if I’m not here, what happens? If they aren’t filled out, he loses them. That’s a part I don’t understand

- We had an issue where our neighbor was in Afghanistan and it went to his house, and we got cut off – and no one contacted us, we were cut off
- And another time, I received a letter – if you want to continue the services, we need a face to face interview – but I called and called and got a message that VM was full. I finally got to leave a message and said he was ill and couldn't go
- I would like to bring up the issue of insurance plans – I know this is a national issue – but my personal insurance is KP and I have researched to find anywhere I can go to get support for TBI – the most they can do
- TBI isn't mentioned in their index. They might give you an MRI, but that doesn't always give you a diagnosis.
- Then you spend months trying to figure out “what's wrong with me?”
- Then at treatment, they have OT – that's more if you have physical difficulties, but not all the nuance that people with TBI – there are so many different levels and the lower level TBI are harder to discern
- If we could address that at the state level – what insurance plans do to address TBI, that would really be a start – my problems started when initially insurance companies wouldn't recognize what I had – they didn't have a category for it
- They tapped dance all around it – I spent thousands on an attorney to get treatment – then the insurance company kicked me out
- As I look back on that – had I not had a TBI, I'd be at a different place in my life. It affects my decision making, ability to focus and concentrate, etc.
- And it's difficult when you have the TBI – you have no endurance and lose your patience and end up in an emotional ball – there's no ombudsman there to help you through
- People with a disability of any source – if they have to depend on Access-a-Ride for transportation, they are real issues with how they are treated from pick up to delivery – I have a friend, she gave an address and they didn't pass the information to the driver, so she lost her ride and was left stranded
- Every door was closed – or not quite open. A lot of false information – even the CCB. No one could tell me if I needed to apply for MC and the waiver separately. Iowa has CDAWS for kids and that was an easy, streamlined way to lump the services together
- The application process took 4-5 months – I knew more about their system than they did – she qualified for the medical part of MC; but not the services part; I called the Governor's offices; Colorado Access couldn't go to anyone until the “computer glitch” was done; We were denied for CES – it was a no brainer to everyone but the county – I had my doctor write a letter saying “here's what you missed” – the day

before the hearing, they decided to give it to us. What's so frustrating, I can't use Access for CES. They shouldn't have to go through hoops. I shouldn't have to be a C.N.A. to care for my daughter.

- It should be waived
- Yes
- It is ridiculous
- Yes, background checks, etc., but this C.N.A. is ridiculous
- We are working through the CES process – but we can't work with Access; my daughter is “class B” and all these great agencies, I can't use – I have one that I can use
- If all the SEP's, etc. all had the same set of rules – they all have their set of guidelines
- Can you put that in your notes
- If you are setting up a one stop shop, they all need to be the same
- You have to be proactive – if you aren't told options, you are going to get lost
- And you might know more about what the person you are talking to
- Some of the CM's are not trained
- There has to be one place where everyone can go whatever the waiver is – where they can walk in and people can tell them about it
- And if people like me could work wherever they wanted
- The Dept. of Healthcare Policy has an acronym list and everyone should get that right at the start – so you know what the different terms are
- There are many ways of doing it – I was in a nursing home and they are supposed to ask you the Question Q every 3 months – and I was in a nursing home for 9 months and they never asked me
- If you look at that waiver list and read all those contents, they are so confusing = look here for the age, here for the disability, here for the services – so hard to decide what waiver you want to be on
- And sometimes you get to choose between before you age out, or age in
- In my case, I knew I could get on the supported living services waiver and the DD waiver, but I was aware of the waiting list problem and that she was not going to get on the waitlist on the DD waiver unless we did it at a certain point – I knew if I did it them month after she'd be on the waitlist
- Lots of people don't advocate
- But they don't know that you can
- If you don't know the inner workings
- You have to learn how to work the system

- Yes
- Absolutely
- Yes
- Where does someone go to get the knowledge? I feel like the CM's at the nursing homes or the hospitals don't know what's out there
- And the turnover and they are so underpaid
- The waiver simplification group finished – the report should be out in about a month or so – then available for public comment for 30 days – but does everyone know that it is coming?
- We are in the public comment period about conflict-free CM – we've been out of compliance for 8 years – the Alliance and the CCB's are all the same
- How do we make sure an independent CM gets into CO
- You can read the conflict-free report – can we get that to everyone who is here?

What worked really well about that process?

- I've had a very good experience with IMAGINE. My take is, I didn't sign up for this, but it's my responsibility. There's so much you have to be an advocate. I would have liked to have some visuals – someone had said, start a notebook, write down everything – make a visual of who's in charge of what; the stuff to read. Especially in social media.
- I think includes people on waiting lists; we've been on one for almost 3 years; what do you do in the meantime while you're on the waiting list?
- We're still on the waiting list for Child Sign – we qualified – on the list for services
- That's terrible
- The beginning part would be great to have some information; but once you qualify – what are your options while you're in limbo
- I know everyone has diverse backgrounds – I was fortunate to have someone to side step the Medicaid process – my case manager at JeffCo has been really wonderful
- Is there enough variance in how programs are run county by county?
- You hired someone to do the paperwork – the staff need to be educated to educate the consumer to do the processes
- You rolled the dice and got a good CM
- If someone doesn't know the process themselves – they can't educate the consumer
- It's not a question of horror stories – but my CM's knew far less than I did

- And the turnover rate is so high – in the last 3 years, I’ve had 6 different CM’s
- I agree with the high turnover
- I’d agree with the overworked statement – I see that with our CM
- Ours has over 200 clients – how effective can you be
- You can’t get to know them
- There are going to have to be some changes in policy to get the locals aligned
- It did work really well when I went through my mother’s doctor – she was able to get my mother a hospital bed and a wheelchair and that worked really well – she just ordered that and it was a huge help to me
- I do a lot of community activities as well – I give each of my clients a list written out and they can hand it to the doctor so they get the information to the doctor
- It made me sad, there was someone who talked about not getting any help from the hospital – I think discharge planners could really help with this
- To me the NWD concept isn’t one entity provides all the information but that a lot of entities are all on the same page – from the discharge planner to the agency, etc.
- It would help, it’s so hard when you are getting someone out of the hospital and they are vulnerable – what happens in that interim?
- Remembering back to that, to not mention any services? When someone is released to a caregiver...
- It was as if I was talking to people who didn’t want to hear it
- I wondered sometimes if I was speaking English
- The people in the positions of taking care – they need to be people who want to help
- So many start out wanting to help, but they get burned out –they can’t or won’t leave
- I was going to say, my daughter, when they are disabled from birth – they are already in a bucket; you have a learning period to go through learning to help from others – I had to learn; but you don’t know what you need. But because she went on a list for services at 18; at the age of 43 she was told she could move into a home. But we don’t think we can let that happen. But they did come through and they did come up with a plan for how to keep her here and I do get paid for those hours. So as I’m getting older if she has to live somewhere, I know that there’s somewhere to pick up if we need it. I get frustrated with the information they need written out, but I know that someone will have that information about her – so some things do go right
- At Children’s Hospital, they started the C Center for Down’s syndrome and that’s where they manage all the things particular to Down’s at the different points of her life. All the care is coordinated service – that speaks to what we’re saying about having all of these services coordinated. So, like her CPAP machine has been broken

for 2 years and I haven't been able to get it fixed. I brought it to an appointment and they said this is going to get fixed – and at the end of the week it was fixed. So I think doctors are extremely important getting it started.

- If there's an ombudsman, or someone to hold your hand, to help straighten out issues
- Children's Hospital did a great job handing off
- DDRC made my life easier – filling out paperwork, following up on paperwork, when we got canceled, they got him reinstated really quickly
- I know in the MH center, they have a group called the Navigators – they have a person from HS who has an office right in there – at one point we were having problems getting services and they pushed it through
- I got tremendous services at Boulder Community Hospital – Mapleton Center – they basically saved my life
- They had a lot of services – speech, group therapy, etc. They helped me understand what I was dealing with
- I wanted to say that I was surprised to find the resources that were available through KP – their online system let us email back and forth with my dad's doctor – I got responses really quickly and got referrals quickly
- I agree with the ombudsman comment – we had one and a navigator at a long-term care facility who were great to help us prepare – the questions to ask, things like that
- Advocacy
- Some groups
- The
- If we were to go to a blended rate for all services – that allows people to get what they need where they need it
- You don't need a PT or a C.N.A. to do some of these things
- One thing that has worked really well is CDAWS – consumer-directed support program – it's been changed and more people can get it
- What has also worked that the disability community has had to perfect is self-advocacy – I'd like to see the models we have shared with the aging community
- There's nothing like that in the aging community – no self-education system for adults who've never needed services and now all of a sudden do
- The model CCD has developed has been taken on by DU and that's something can get credit for
- The ADRC's could be doing it – they could be doing in with the ILC's
- The only benefit I see of Gateway is Stacy Taylor – she does classes for everyone and takes us out in the community once a week

- CDAWS and IHSS are quite similar and the benefit of those programs is that you can direct your own funding – there can be drawbacks; for the person who can't budget those funds adequately is IHSS can help. With CDAWS, they can pay their caregiver \$20/ hour or \$40/ hour – I'm still on the rope about that
- Expecting a SIS every three years
- Doesn't always happen
- A lot of things starting to happen – here's what's really been going on and changes are being made, now
- I got connected through Colorado BI Alliance – they have some supportive services through RM services – but not individual treatment
- I've been pretty lucky, haven't had any issues
- I agree
- It's worked out wonderfully
- Me, too
- Once I was able to find the resources – the issue for me was the time to do the resource search
- My other son, we had a hard time getting an appointment – he finally got on some meds, but then Medicaid dropped him; it was unbearable – it was a horrible experience
- I've never had to pay of anything
- Some therapies like music or equine that aren't covered – we cover those
- For us after the waitlist, it made everything so much easier – the advocates – they know so much, having them tell you what's out there is invaluable
- I'd have to say that we were trying to do the caregiving ourselves but it got to where we couldn't keep up; finding those resources enabled us to allow both of our parents age in place in their homes and have their end of life experience be a far greater quality – it made a huge difference for us
- In terms of the TBI, the BI Alliance is an excellent resource – it should be expanded – it is an excellent resource

What didn't work well? Or at all?

- My dad tried to get my SSDI together and my mom had to write a letter and that took quite a few months to get the ball rolling on that – but we finally got it
- With me, it took a little bit to get my diagnosis so I finally found out what it is – been waiting awhile to find out what my disability is; I didn't have any services to back up

the disability – all I have is Social Security – I didn't have anything – no counselors or therapists or anything

- Went to another program and it was a nightmare – didn't think I'd be able to walk out of there – it was very, very tough
- I'm with Imagine now and they treat me better; It was easy to switch – I told my sister and she thought it was a good idea to transfer
- I used to go see Eva if I got upset and get new ideas; I'm trying to get over my family
- When I was about 5 years old and had heart trouble, I had to go to the hospital and they gave me a surgery – they couldn't figure all these things out
- You used to live independently and now you have a host home provider, do you know why you were moved?
- No, it was hard for me to move from one place to another – I wish I could go back to independent living again, that's all I want to do
- I don't know why they moved me around
- We got moved back and forth to 4 houses – I didn't like that
- Our staff changes too often – our junior high and high school teachers got us connected to services until age 19
- How many got services after HS?
- I didn't get anything – I got shipped out on the street
- I hope now people are getting connected earlier – like Casey her teachers helped her get on the lists she needed to be on
- I have children and I don't get to see them, it is really hard for me to see them; they are actually with my mother and I'd like to be able to see my daughter more – every time we talk she throws a fit because she can't see me – it's been really hard on her; my son I haven't seen since he was maybe 2 years old – I'm hoping somehow I can get a way to do that
- I think the way that translates is that it is really important for you to have a chance to voice what is really important to you – if that's not happening in your IEP – that's not working for you
- I'm a parent, since I'm also an advisor, I see so many people who are needing jobs, and I don't know if we are ever going to get jobs for everyone – a little that there aren't a lot of jobs- but also folks don't get offered them
- The state hasn't prioritized funding for folks getting jobs – DVR has recently changed their funding to strongly support people getting jobs; but DIDD continues to not allow billing for the amount of services that are actually provided; so the number of folks who can do employment counseling

- Folks have a lot of interest in one and one and not in a group fashion
- As a parent, my son was enrolled in living situation –when he was in CES – that Medicaid waiver was able to fund one-to-one supports at a living wage for his support providers, but as soon as he went to the adult program – money went from \$15 to \$11 an hour
- That makes it that they people have to be served in groups or the provider gets paid minimum wage; a number of us have been advocating for the state to structure the funding in a way that #1 pays for employment services to be individualized and community support services
- People want to be served in a way that is individualized – that’s not what’s happening right now
- Legislature just did away with the waitlist and are putting a plan in place to end the waitlist in a 5 year period; community support services funding needs to be more flexible
- Counter to Olmstead and ADA – you have to be served in the most integrated setting possible
- Similar to what you’re saying about employment – all the regulations and funding pigeon-hole people so you have huge turnover – that’s one of the factors – and people’s needs changing over time – things are so rigid
- People have to change to fit into the system – they have to fit into whatever system or waiver there is instead of the person-centeredness
- As a parent, it’s really hard to see staff change again and again. Your child might have trouble getting to know someone and it’s hard. Every three to four months.
- When my daughter went into independent living, she wanted to live as independently as possible; but the roommates weren’t great, the staff wasn’t great; luckily we could buy a property; we then had to deal with roommates who would steal from her. That works well now.
- What resonates with me is that it is extremely difficult to find good support staff and as I mentioned before, the way the funding is arranged the pay is so low you can’t get good support staff.
- Some families if they like a person, they break the law and raise their hourly rate by paying them under the table. That’s the situation.
- It puts our sons and daughters are in constant turmoil – finding someone who’s going to steal or put someone at risk of abuse
- When parents of younger children have a misconception that there is a safety net for their child becoming an adult

- Parents don't know what's available
- Our family members are living on such a minimal amount of money from the government
- When we try to help our kid, we have to do it under the table – they will lose services if people are giving them gifts of money or whatever
- The complex nature of the system, because there are so many different places to go and lack of coordination – It has gotten a bit better – it still needs work
- It's still very much a puzzle – even if you have worked in this system for a long time
- Trying to figure out what's being offered and make decisions about what to do, it is so complicated
- It's here's what we have to offer so let's make it work for you
- I still don't know all the rules and programs and services – and what do people do who aren't as connected?
- We see a lot of adult self-advocates whose families aren't in the picture at all – so that leaves the self-advocates on their own to sort through the process. They are very dependent on the system and the staff and if those people aren't guiding them in the way that are best for them, they are stuck.
- Some issues are invisible – getting connected is harder
- You are under stress, interacting with a stressful process – it's harder
- Absolutely
- You are already at a point of being emotionally stressed –
- It's endemic – there's not a recognition of what the symptoms are that people go through for some conditions
- And you might be treated poorly instead of being supported or helped
- A sense of isolation – you're in this by yourself
- If you move between counties it is hard – we moved and it was hard – you have stuff for so long and you move one county over and you have to do everything over again – all applications and paperwork all the meetings all the approvals just to get what you had
- And different counties have waitlists and your last county maybe didn't
- I faced a similar challenge – from not being able to find the resources – I found out all the resources after I'd been doing caregiving for a long time. I didn't know what was available.
- One of the things the doctors might have been able to do better was address the behavioral health – some of the struggles with depression – they weren't comfortable asking for that assistance and their doctors didn't really talk about that

- Systems need to do a better job with the MH stuff – making it easier/ more comfortable to access that help – esp. the older populations – especially if you are looking at assisted living, depression can be high
- I agree – trying to find the resources that are available – my insurance covers a lot – but those that have to pay out of pocket – it would be nice if there was an easier way to obtain that information
- I'm in a family leadership program for FLTI (family leadership training institute) and one of our projects is to find something that will help our kids in our community – I'm working on easier access for grants for families
- Insurance coverage in general – it seems like reviewing any injury that affects the brain – that covers a lot; long-term impacts
- All the turnover in CM's
- You can make a comparison between the CCB's and the mafia

If we were starting from scratch, how would you have it work? If you could make just one thing easier about getting connected, what would it be?

- At the point of entry, there needs to be like commonalities as far as our situations – and from those what choices do we have and how do we access
- It has to start when you're loved one is rushed to the hospital you are so emotional, you can't think clearly. It has to start with the Social Worker. Before they are released, you get the information about what's available according to needs
- The doctor can figure out what the needs are – not some Social Worker who thinks it won't work
- Write the book – that says what's available and what's the next step
- Wouldn't it be nice if they were as well-versed in community-based solutions as they are in hospice and nursing home?
- Information available across the service provider continuum – the same message, the same language, parity – if it Suzy Q in Denver gets told that she has these options, people in rural areas should get that message, too.
- If the social workers were less of information sources but navigators of human need
- And a person on the other end of the number
- Yes!
- We each have basic human needs – housing, food, physical needs like a shower or a bath, our house cleaned, to feel loved, safe, and important
- It's pretty basic on making sure those resources can be sent out to people
- I've had a mother who had dementia and a cousin I took care of. People say – how can I help you? I found that if they did tell me, I had forgotten. Everything needs to

be timely, I don't feel like it can be handled well – there are so many needs you need today and you can't get help that fast.

- Kansas Model
- There were waiting periods that were mandated in the Medicaid process and that was disconcerting because as others have said, my wife needed the services as soon as she was approved, but we had a 2-month waiting period
- I think what I'd like to see, if the case workers could send out a monthly auto-email – if you haven't seen this information – here's some other resources. Something that simple to communicate information
- I agree on the checklist – just having right at the beginning a checklist if things to do – and if you have to apply two different was, you know that. Kind of a roadmap
- That's helpful for me – it helps bring people back to the process.
- I would modify the amount of duplicated paperwork that the CM's have to go through in order to give you services – there's got to be a way to streamline that – there's conflicts between the state and federal equipment
- I would ask for consistency. I know that's hard when you are dealing with people. When you train say the SEP vs. the CCB, you get very, very different answers. Why is there not consistency across the domain? Regardless of how I get into the system, everyone should have that same roadmap. If you go to a certain CCB, you might not even know that there's a CES. There are so many nuances to the systems – they should all have the same roadmap. It's all the government
- What has been difficult for me and reason why I'm my wife's primary caretaker – I couldn't keep a FT job and cover the things the system doesn't cover. There are a lot of areas where the coverage she gets doesn't provide any service. I could go back into the job market, but I'd have to take off so much time I don't think an employer would allow that.
- I'd agree – the majority of the waivers require forced poverty to qualify for services
- Amen
- There's no sliding scale. All the legislators complain that Medicaid is bankrupting the state, but they don't let us do anything else
- I looked at what it would take to have an agency take care of the other things – I'd have to make \$50/ hour or more.
- One of the things that I mapped out, as a parent, I've documented that I was required to take off 120 days last year to manage my child's needs.
- More funding – federal and state

- More flexibility – in how to spend the money – if the Medicaid waiver system had some flexibility, then we could better cobble together the services that are needed; if we could pay a living wage so we could retain them, that would solve a lot of our problems
- A decade ago it was possible
- We are tied into congregated and segregated services by the system
- My biggest concern right now is that they keep raising the rent and I don't know if affordable housing will be something I can get into
- I don't know where the state stands on Section 8 – Casey has a Section 8 slot – it would be great to get Dan enrolled in that
- I would say care navigators and more SEP resources
- I agree
- I agree
- And of the ombudsman/ kind of oversight is important – so that you are treated well
- A way to address issues
- It's almost like you have to push, push, push, push, push
- Eliminate the CCB's – a lot of agreement
- Quit siloeing things into separate things –
- C.N.A. regulations
- I would changes Gateway so that more people got out in the community
- And what happened with the – they were going to help people in the community use the toilet and it was taken away?
- It was delayed, but it will come through
- It takes so long – it's way too complicated in this state
- We have a huge population of all different kinds of disabilities
- If some of that power could go to ILC's and other community-based models
- Wouldn't you say the CCB's are a community based model? They are little kingdoms – they are huge gangs that we were dealing with in the 80's and 90's
- They will have to split – CM and service delivery
- One had 13 deaths in a year and didn't report them to the state
- Need for more oversight in some areas – lots of abuse, etc.
- And other places the regulations and policies are too complex or aren't working well
- From in-person focus group – “ideal system”:

| | | | |
|---|---|--|---|
| <p>People hear about services from:</p> <ul style="list-style-type: none"> • Schools • County • Healthcare System • Nursing homes/ institutions • Etc. | <p>Everyone starts somewhere where the people have broad, universal knowledge and can refer you to the specialized knowledge/ help you need</p> | <p>People with personal experience/ content expertise relevant to your situation; specialists NAVIGATORS/ WELCOMING</p> | <ul style="list-style-type: none"> • Evaluation • Educate about options • Services that align to needs • Connections to peers • Connections to the community <p>UNDERSTANDING</p> |
|---|---|--|---|

Anything else?

- No
- Thanks for taking the time
- I appreciate someone listening
- Me too
- The lingo needs to be same, the same language
- Working with an ARC advocate, and the things I've been saying to Developmental Pathways over and over again – she says to say it this way and they say oh, okay. Like I'd say, what I do for her is not what they needed to here.
- The system doesn't respond to emotion
- We tend to minimize the situation and not say exactly what we need
- Maybe they don't agree with the model – but laughing shouldn't be on us
- We shouldn't have to have special training to have them understand us
- And what on earth – how do you go to school in a human service field and you can't fill in the blanks and understand that the parent with life-long needs help? That's so inherently wrong.
- When people get information when they need it – they save money.
- You said it!
- Thank you!
- I'd like to see more childcare avail be for kids with disabilities for parents who work
- Summer is coming up and daycare just is not available
- I agree
- I agree

- I'd like to see more education programs for caregivers – we found a support group with an education component – but we had so many questions about when to make certain decisions – like talking about stopping driving; resources to help manage those issues that come up
- I'd like to see more peer mentors for that
- That's a tremendous a resource and help
- We need general education like we have for heart disease – public information about a whole variety of things we've discussed – eldercare, TBI, etc.
- So that the general public has a better understanding of what families are facing – if people understand then they are much more open to providing services
- I'd like to say that I appreciate being on this call – this is a wonderful process and I hope that we see the end result down the road
- I think it is different for families with kids or adults – will there be several plans? Or will it all be lumped into one
- The transportation issue – that is huge for people getting services – even getting to the places to get services – the way those needs are addressed – for example my son has a taxi that's supposed to pick him up and it might be 3 hours late and that affects his mental health quite a bit
- It's all secondary injury, when his transportation doesn't arrive, he's injured again – he's left alone, his stress level increases – it compounds the injury
- My son panics when that happens
- So I want to fix that for him
- The voc rehab people – they hired a woman with a disability to be the director. And in less than a year of her being there, they torpedoed her. She did things no one had done like really work on eliminating the waitlist, redefining what the family is, etc. I would like people who are looking at this to realize that firing her was a huge mistake. What that said to a lot of people who have disabilities
- See more stakeholders involved in the process – if their experience with public policy and experience with entry points is really relevant
- Some of the CM's who don't have a medical background are making decisions on how much time is needed to do a task – I get that the budget influences that – but they aren't necessarily
- He's talking about how you deal with a CM – you can't call them names even if you want to; he as at Easter Seals and a CM from North Metro pulled him from Easter Seals to their day program. That CM didn't
- The most positive experience I had was the advocate at the Governor's office

- People don't know they have that route
- Our
- There are so many layers – you might have home health care, you might have the different provider over here – these rules for this department, and these other rules for this other department, and then you have folks fighting to give a service that should have been given 3 years ago
- I think there needs to be some collaboration
- And clarity
- And the opportunities for consumer choice have really increased in the last couple of years – once a client I had knew that he could leave the agency he was with, he said that he wanted to leave. They didn't want him to leave, but they finally let go – once they got the cops involved and threatened to call the press
- Tom Miller at CDPHE – he said point blank, if they want to move 4 times a day, they get to
- He had set a precedent
- I got to meet the Governor last October, I asked what he thought of substandard pay
- I'd like to see some of these recommendations go into the State Plan on Aging
- Seen things at this scale
- Colorado Choice Transitions Council and they have a draft going out now – I filled out a comment on it by the 25th of this month
- Is anybody got a vehicle they can give me a ride to Union Station?
- The other thing I was going to say is that the state has always been restricted with TABOR and Gallagher

Focus Group Participants – Consumers and Caregivers

- Emily
- Jan
- Lee
- Seven?
- Louise Apodaca
- Jeanie Benfield
- Cheri Bishop
- Casey C
- Mindy Catlin
- Andrea Clements
- Jen Cohrs
- Diana De La Renzo
- Angela DeBruyn
- Abby H
- Rob Hernandez
- Lisa Hertz
- Diane Hosier
- Charles J
- Linda J
- Christina Johnson
- Nancy Kepner
- Stephanie Klemp
- Chrissy Krum
- Dana Lange
- Bob Lawhead
- Kathy Ludlow
- Casey M
- Anna Martinez
- Edward Mc
- Ed Milewski
- Enid Miller
- Barbara Preskorn
- Chris R
- Michelle Ra Meredith
- Kevin Smith
- Pamela Stephens
- Dan T
- Greg Thomason
- Evelyn Tileston
- Danny V
- Patricia Ziegler
- Shannon Zimmerman