

Report to CLAG Regulatory Subcommittee
Survey Monkey created by Carol Meredith
Hopefully I have redacted the names of specific agencies (I tried)
This was an online survey only - it went out on Parent to Parent, PAD-CO, and several list serves of The Arc.

51 people responded to the survey - all were parents or siblings of people with disabilities.

When asked what waiver they were using for LTCSS supports and services, 47.5% replied CES Waiver, 9.5 said the CHCBS waiver, 0% said the CWLLIW, and 43% said the SLS waiver.

When asked if they were finding it difficult to access Personal Care or Respite services, 31% said Personal Care was a problem, 69% said they found it difficult or impossible to access respite.

When asked if they had been told that a licensed provider was necessary for care, 41% said yes, and 58% said no.

When asked if their son or daughter lost access to services in the past few years even though those services had been available to them in the past, 48% said yes, and 52% said no.

When asked if they had been told by providers that they are not licensed to provide personal care or respite - 56 % said yes and 46 % said no.

Free Comments:

The CCB seems to think Personal Care to medical appointment EXCLUDES any payment for safely accompanying SLS clients to medical appointments, even though PASA is not billing for the transportation cost.

I am actually the sibling of an individual with DD, not parent, but this wasn't an option. I also work for a PASA. The cost for PASAs to get license for PC and be monitored by a third party is difficult- we get varied responses on what is/isn't skilled care. It would be nice to have a more clear understanding of what PC under HCBS is available, but unfortunately, clients require both skilled/unskilled care during PC and therefore cannot access HCBS PC services.

My brother for whom I am a legal guardian is not able to access many programs because we can not afford to pay for them. Programs like Adult Day Programs, job coaching/supervision are cost prohibitive, and thus we do not have regular programs

that he can participate in. We have been able to work with Agency X to coordinate volunteering at the Nonprofit Y as well as different recreational activities that change with the season. This has kept him busy and engaged, but the opportunities are only a couple of times per week, and not as regular as we would like. He is a very capable, engaged, social, curious, and active young man. More programs to engage him would be good for him and for society.

We are a family in crisis. As our son has aged he is gotten more aggressive and much stronger. The only services we can access are the deputies to help restrain him and the local volunteer fire department to help transport him to Children's Hosp for emergency services. He runs from home sometimes, he attacks his father and me and he is oppositional and defiant. It is difficult to sleep at night because he frequently threatens to run away at night or hurt us while we sleep. It is also difficult to know what services might be available to us; we only find things out piecemeal if we happen to meet the right person or ask the right question. There should be some sort of clearing house set up to make information more available to parents. We moved to Colorado 7 1/2 years ago and are still struggling to get help for all of his needs (which have changed and grown as he has). We adopted our son 11 years ago and promptly lost his Medicaid. I can attest that there is no level of income that these children cannot outspend. He uses the bulk of the resources for a family of four and our insurance does not pay for residential treatment. We find ourselves in a very deep hole, I assure you.

More funding..it's been a very long wait.&.still waiting to get SLS.

I have been on the wait list approx 8 yrs

Our son has never been able to access CES because of the sleep issue. Respite, and behavioral therapists would have been helpful. We have had to pay out of pocket for all of this.

Our son is on the SLS waitlist

It was and continues to be a constant struggle to secure and retain respite care providers for those with autism. Consistency is of extreme importance these individuals and training is a long process. We need to value these caregivers, pay them well and keep them!

My son has been on the SLS waitlist for Agency X since 2001 and has yet to receive services. I am very frustrated with the system.

Even when given the waiver finding the people to fill the hours is impossible!

We are having trouble accessing respite care for our son because he is solely g-tube fed and takes medications. It is very difficult to find a provider who can do these things and has a contract with Agency X.

Had personal care covered in the past thru the Home Care Allowance. (It DOES NOT duplicate services we get under SLS!) Now doing it myself; I am facing recovery from surgery without any help to care for my son while I am supposed to be "resting," not driving, etc. Not having any luck finding help at all thru SLS. His funds are used for other services, leaving little available for this, and so far, no providers have responded to the RFP. Son will be eating p-nut butter out of a jar, unable to get to his supported employment job, and God help us if he needs medical attention while I am unable to drive.

There has been a huge problem with paperwork at CCB we use ; providers also have trouble with the level of paperwork, and often refuse to work through Agency X, we have found...even if they worked through Pathways at one time.

I could go on and on. I have (had) 2 daughters with disabilities, born to me, both qualified for Personal Care Services, as well as respite. My youngest daughter passed away 9 years ago. Accessing services for her was difficult. I was told that only an agency could provide the services. It was difficult to determine how the allotted amount of hours were determined. I was told by the agency that we were accessing services through that they could not provide services on weekends, because it was too hard to staff. Additionally, the providers frequently did not show up; were late; were lacking in compassion for their jobs. I had a 7 year old at the time that could not dress, feed, or bathe herself. I was told by her provider that I was just looking for a babysitter. I understand that some of these issues were due to the lack of professionalism expected from this agency. It also seemed clear that because this was a family situation, we were last to receive regularly scheduled visits. I finally quit using personal care services (forget respite - it wasn't going to happen). Then a friend told me about Agency X. What a lifesaver! I would have preferred to have a reliable agency that provided qualified, compassionate caregivers. Since that was not the case, Agency X seemed to be the best alternative.

XX county is the worst county in the state to provide services for our kids with developmental disabilities. Always the same excuse "not enough money .PLEASE set better guidelines for training so that the staff has a clue what they are doing and for heaven's sake please give these programs sufficient funds so they can train them properly.

We have never been able to access respite care, because providers are not able to handle his behaviors.

We use "family recruited" service providers because we found the quality and commitment lacking for those staff available through agencies. At the \$11.00 per hour rate allowed for respite (under the SLS family-recruited program through Imagine!) it has been very difficult to find and maintain quality people for respite. Under the CES Waiver we were able to pay \$15 per hour for community connectors (this service is not offered under SLS except with a group of other people who need support). We

still ask respite staff to do community connections but at that level of pay it is almost impossible. SLS should allow for individualized supported community connections instead of the congregate and segregated services that are allowed presently.

It was also difficult to initiate services with OT & speech at the beginning. There are just not enough professionals with openings in their schedules, especially since I cannot have them deliver services in the school system. Once we found them, our lives have improved and our daughter's speech, writing, movement have significantly improved

My 16 year old son with Down Syndrome has not been able to qualify for any of the waivers you listed above. We have no help and desperately need help as he is unable to stay home alone and care for himself. No one seems to be able to find a way to help.

It is extremely difficult to find a new provider after one quits. I use to be able to find a worker and then send them to Agency X for training for a minimal cost. Not that cost is over \$300 I am told and no one want to absorb that. The agencies hem an haw about meds and difficulty of my high need teen.

Wait lists for ALL services are way too long

The rate reductions over the last 8 years have been drastic and tragic for the caregivers who have been providing services for our children - the number of changes that we have had to go through has been very difficult on our son - really sad when numerous personal care providers we have worked with can't make a living getting paid \$10 per hour for what they do - all have left the field to make a living elsewhere or will only work with small groups instead of individual care

my son had personal care and home making services, but these were removed from his care plan. I provided these services. I now pay an outside person to provide these services or I do them myself

The difficulty with finding a skilled, caring provider is that the pay is so low and no benefits are provided to these workers. The caregivers are specifically kept on part time hours so that the agency does not have to pay any benefits. So who can afford to do this kind of work??? This creates a situation where people are forced to look for other work and leave. This is sad for the person with disabilities who may have grown attached to their caregiver. It also means that the knowledge, skills and familiarity with the client's needs are lost, again and again.

It's frustrating that the CES Waiver has a respite benefit that my son is unable to access. My son is fed 100% via a feeding tube and has severe sleep apnea. When he sleeps he needs a bi-pap machine to help him breathe. G-tube feedings and bi-pap care fall under the scope of practice of an LPN or RN. The CES Waiver does not allow respite care by an LPN or an RN. We were advised that a care provider could be trained by an RN and provide g-tube care with "nurse oversight" however we have

done multiple searches and have been unable to find a provider. As a result we have had to pay on our own for respite care.

There don't seem to be people who provide these services. I am told that it is because of the low pay

It is hard to find qualified people to provide many of these services. So I do all but the respite care myself. I can't afford not to do them as I can't afford to work and get good care for my daughter. I am always afraid that the Government will take services away from her

As an employee of Agency X and a parent to a kiddo with DD, I am so shocked at how much incorrect information was given to me. My daughter receives services through RMHS. I work on the CES applications and my daughter would be a great candidate. However, our RC and Agency Y have denied the right to apply for CES and I am appalled that we have been turned down. We were told that she's not medically fragile, not enough to apply. What can I do? I would like to transfer her to DP.

My daughter has significant daily needs which would qualify her for the CES waiver, but her nighttime needs are not so great. It would be helpful if we were able to access the respite and behavioral therapy and other services provided by the CES waiver that are not available through the HCBS waiver. It is frustrating that the only thing she doesn't qualify for are the "nighttime" commitment issues for the CES waiver and therefore we have to pay out of pocket for any respite and behavioral therapy that is needed (which we are currently doing at our own expense because she needs it)

Medicaid makes it very difficult to find and keep qualified providers!

I am a single parent CNA that has not had respite in 3 years. HELP!

When the hourly rates were set I lost house cleaning, I was using a service that wouldnt take the hourly rate. I lost carpet cleaning as well. I wish I could get someone to help with the more difficult tasks like laundry or cooking. I have respite it helps my child get out away from the family for a break but doesnt help me, I still have to care for my other child that doesnt quaify for CES.

I have been having a hard time with this since entering into adult services with my guardian child. It frustrates me when I know the money is there for my adult child and due to written word we can not access it. I have found myself lying about the services we need just so we can reach the money for the services we really need.

We had our budget for respite and personal care reduced by 50% when our daughter turned 18 years old and moved from the CES Waiver to the SLS Waiver. This was 3 years ago. This is the same time that our daughter is aging out of the school system and needs more coverage and supervision so we can continue to work.

While the CES Waiver is wonderful for the developmental aspect, it leaves medically fragile children behind because there is no skilled respite care. Respite pay rates and contracts with providers should be disability-based, not a single pay rate for all children.

When Agency X submitted an RFP for my son for respite/community connector, we received only 2 agencies. One agency was owned by the case manager's parents! (And, that agency never followed up / followed through on finding any providers.) We had to go with the other agency simply because there was no other choice. It took 4 months for a provider to be found and the only reason it will work is because we are doing day time respite where I will be home to supervise. The parents should be allowed to use common market systems (care.com) to find quality providers quickly. BUT, this is not an option as they have to become contractors through the agency owned by the case manager's parents.

Respite is not respite. It has been so difficult to find providers that I've practically given up. It seems like that is part of the government's plan-- so many barriers that we give up. We have a new one. She's available on weekdays and Wednesday evenings. My son is in 1st grade. It took 6 months to find her and get her qualified through the nursing agency. She is lovely but now we'll need to find someone who has time for us.

My son is 16 and very involved. We have always had services for him and have not had to reapply , etc. Although took us 5 years to get off the CES wait-list :). I do have concerns when we transition to SLS things will change dramatically.

As bad as not having providers after he finally got CES is, he is soon turning 18 and the lack of host homes, group homes that are qualified to care for Type 1 diabetics makes his future bleak. We are both in our 60's and he cannot live with us forever. We hope there will be options for him. My wife quit her (well paying) job when we adopted our son. We have two other children close to college, but the great majority of our time, energy, and finances are dedicated to our son. We have very little respite and we are just plain tired. We love him with all our hearts and continue to have hope he will be OK in the adult world. Living rather rurally it is difficult to find people to fill these services. It took me almost 3 years to find someone able to do the homemaker services for my daughter that would do it at a reasonable price (what the waiver would cover.) Many wanted funds in addition to what the waiver paid. With a severe special needs child, respite providers that are qualified to care for her are difficult to come by. Often the respite care relies on friends and family members who are not qualified per the state and cannot be hired by the agency that provides respite. This is increasingly burdensome when you don't live in "town" and travel to our house becomes an issue and professionals won't do it for the pay allocated by the waiver programs.

The questions are not geared toward the issues we have had, even though it said it covered things other than medical. Our issue is with personal assistants (mentors, etc) who quit providing service when the state cut provider rates. We haven't had decent providers since that time. The second is housekeeping. The rate paid for this is completely undoable. We ended up being forced to use the service of our CCB which was completely and utterly inadequate. Services have been cut steadily since my loved one got on SLS. We are down to almost nothing except mom and dad now.

My son needs medications many times a day, and g-tube feedings 6 times a day. My son needs medications several times in the night as well. Legally, CNA's can not provide these services. As a result we ONLY use nurses for my son's care and as a result we use nurses for "brief" respite, a few hours in a day while a nurse is on shift. Legally we understand only a nurse can provide the services we need, so that I could physically be away from the house. As a result I have not left my son overnight in over 5 years. It would be helpful for my husband and I to get at least one night away from home, but this has not been possible. Finding nurses to fill the hours we have been given has also been a challenge. We recently got a new nurse who is willing to work all night, but we have only had her for a month. We had gone several years without any nurse willing to work at night. This means most nights we get interrupted sleep as well as caring for our high needs child in the day time. Respite is an interesting word in our case.

There needs to be some sort of data based maintained where providers both skilled and unskilled can list their contact info and the location they are available . My son recently went on consumer directed and I am his caregiver but he was eligible for services for 6 years prior but that was never revealed to me until late last year. Due to his dual diagnosis we felt this program was the best fit for his situation but getting any details or contact info for other programs and/or providers has been extremely difficult . My daughter has lupus and fibromyalgia - she's on Medicaid also and should qualify for some services as well but once she's approved I have no idea where to look for providers . I can't lift her by myself so it's a huge concern as to where are we going to find someone . I see parents posting all the time asking for assistance in finding providers. It just doesn't make much sense to have a program without a listing of possible caregivers or providers. I understand the state wouldn't want to be held liable or want the responsibility of screening caregivers but there's got to be a better way. Posting ads on Craigslist is not a good way to find help . Thank you for your assistance in resolving this problem .

I'm concerned if Personal Care goes under Medicaid and not HCBS, how this will affect PASAs and clients that receive this service. While it allows more access to all that require this support and opens up funds for HCBS, it makes it difficult to understand next steps in the CCB/PASA responsibility and what lies as the responsibility of the family member- the bureaucracy is difficult enough- SSI, Medicaid, Medicare, Housing, Medicaid Savings Program, Food Stamps, HCBS, Home Health, etc. I just wish there was a "one stop" for access and one-step application process where you checked off what you need, then the state determines what you're eligible for, and not so much

paperwork repetition when the qualifications are already so similar for all programs. I work full time and spend hours each week/month/year to ensure my sibling gets the supports to live as independently as possible. Then you get into HCBS- there are so many rules with each waiver. But I'm glad you're here to listen- we have come a long way and hopefully your voice will take us even further.

Thank you for sharing our stories.

Before, we had HCA coverage for up to 35 hrs/wk for services related to dressing, bathing, hygiene, eating, meal prep, housework, laundry, shopping, med. mgmt., appointment mgmt, \$\$ mgmt, access to resources, and telephone use assistance. Now none of these.

Thank you! I think parents are always looking for ways to get our voices heard to improve this system.

Tell XX county representatives to take a look at the other counties around Denver and see how they get things done so well and so fast. I know that the people in this county have been taken advantage of as far as tax hikes so they are reluctant to vote for more tax increases, but we have so many adults on waiting lists in this county and we need more revenue to create services for them whatever it takes to do so.

We need to revamp the XXX school system to include our children in the general education classrooms as the norm, not the exception. That way we can prepare our children with disabilities, as well as our community without disabilities to appreciate and support one another.

It is not our son's fault he is disabled. He is living in his own apt, working every day, riding the light rail to work and working extremely hard to be a part of our community, but he needs help meal planning and shopping for his food, cleaning and gaining access to the community with activities and transportation (light rail and bus) training. He does need support to remain living on his own. Please stand up for our son and other folks with disabilities - don't abandon them to their aging parents by further cutting their support.

For example, I've tried to find a younger male person to work with my teen son with autism. But competent younger people have career goals and will not hang around for a low waged, zero benefits job for long. A retiree is good but they don't have the physical stamina needed to really be a companion for an active teen with autism.

Committee members may not be aware respite isnt for parents to take a vacation. Children with autism require eyes on them constantly so they dont hurt themselves or others. I use my respite time to take a shower, which means I get one shower per week

Thanks and keep up the good work

Thanks Carol. Appreciate all that you do for the families. I'd be happy to come in person to any of these meetings and explain how difficult and frustrating this is for all parents.

please contact us with questions. This needs to get fixed. I have lots of stories. Thank you, Carol.

Good luck with that. All we parents ever do is fill out surveys saying the same thing and nobody fixes anything.