

PAD-CO

PARENTS OF ADULTS WITH DISABILITIES IN COLORADO

December 2013

“For the discussion of the unique problems, concerns, joys and successes of parents of adults and older children with disabilities. And for finding goals and directions which we can voice to others to further the progress of our children with disabilities.”

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Introduction to the Guest Editorials Presented by Parents of Adults with Disabilities in Colorado – (PAD-CO)

How do parents of adults with disabilities express their thoughts to others, state and agency employees and the public about the myriad systems with which they deal?

Mostly, their time and efforts are consumed by 24/7 care of their child – and sometimes children. Exhausted, and with full schedules, they are unable to attend meetings – even those designed for so-called “stakeholder input.”

Sometimes opinions, ideas, criticisms and thanks can only be provided through writing. Yet, parents are constantly worried about retribution, intimidation and retaliation from those who control the purse strings and wait lists. So, they remain quiet.

To provide an opportunity for parents to safely express some strong, and perhaps controversial, viewpoints, PAD-CO developed “Guest Editorials” – published anonymously on the PAD-CO web page (<http://pad-co.info>).

During July - December, 2013, twelve Guest Editorials were uploaded. An announcement of each editorial was sent to about 900 Colorado legislators, leaders, policy makers and citizens (eventually certain organizations blocked the announcement emails, evidently not wanting to hear any controversial viewpoints).

The editorials are presented in the following pages. In addition, information is provided about PAD-CO and IssuesPAD-CO (the policy study group for PAD-CO).



Then and Now



Back in the day, adults with developmental disabilities lived either with their parents until the parents died and siblings took over or they were placed in institutions. Many institutions were exposed as being houses of horrors. People evolved in their thinking about the rights of people with disabilities. The feds mandated the closing institutions in favor of community living. The problem was that community living was not fully funded to support everyone who needed it and not provided as a right.

So where are we now? In Colorado, there is a disparity between where officials think we are and the reality of the lives of families across the state. First, many families have simply been forced to keep their loved ones living at home with aging parents basically forever, because very few resources are allocated for community living. No matter if the adult children are violent. No matter if the parents can no longer lift them out of their beds. No matter if the persons with disabilities are doing anything meaningful whatsoever. No matter if there are any jobs for people with developmental disabilities. No matter if the parent has cancer. No matter if there are no siblings or family members to help. No matter what happens...parents are forced to keep their adult children at home because there are no resources.

Second, the stresses and financial crush of having no resources is destroying marriages and severely limiting the earning power of parents to support their entire family, not only the person with the disability. Other children in the family get less attention and much less financial support from parents to go to college. When we reach crisis mode, we are told the only way to get help is if our loved ones are homeless. We are quitting our jobs, have no money for retirement of our own, and our adult children are languishing away. Unless

parents are wealthy enough to pay for services out of pocket, they are

providing 24 hour care for their adult children AND trying to earn enough money to survive. Many parents get very little sleep while trying to do it all.



Regardless of all the kudos the government likes to give themselves for changing the world for people with developmental disabilities, the reality does not match the rhetoric. Everyone loves to toss around their “inclusion” and “self-

directed care” terms, as if they are actually happening. They are not happening, and it is time that somebody faced it.

There needs to be a single case manager for this – to know the unknowable

By a PAD-CO parent of an adult child with disabilities

When I think of all the things I had to know in order to help my son it is mind boggling.

- First, I had to know what his diagnosis was. In spite of telling doctors for years that something was wrong, we didn’t get a diagnosis until he was ten. It turned out, that didn’t help me

much, because nobody knew anything about this condition. More on the later

- Then I had to know special education law, backward and forward
- I had to learn how to advocate for him when schools constantly called me a work to “come get him”
- I had to know about alternative schools, which nobody told me about.
- I had to know that I was supposed to get him on the adult waiting list for DD services when he was 14
- I had to know about the transitions program
- I had to know about Community Centered Boards (CCB’s)
- Medicaid and Medicare
- SSI
- SSDI
- Food Stamps
- Telephone assistance program
- Medicaid Waivers
- I had to know about special needs trusts.
- How to buy a property where he could live
- How to protect him
- And so very much more
- Then I had to become an expert on his medical condition because nobody knew anything about that.

So I gathered other parents on the Internet and we collected information. We took it to a doctor, started a nonprofit organization and had a broad medical study done to document his condition. By the time I got that done, he was already an adult. All the while, I had to raise another child as well and work full-time.

Why isn’t there a single “case management” agency where you walk in and say “this is my problem” and they sit with you and explain it all, help you apply for all, help you navigate it all and basically HELP YOU? People think that exists, but it does not.

My plea: Help to make life easier for parents of children and adults with disabilities.



People Flying Desks and Pushing Paper Get Far Too Large a Share of the Pie

By a PAD-CO parent of an Older Child with a Disability

The Community Centered Boards (CCB's)/Program Approved Service Agencies (PASA's) issues are huge. What I told the legislators and the Denver Post last year is true. The results of firing the Independent Contractors (IC's) by some CCB's is that the \$30 per hour that the IC caretakers used to get for hands on Community Connector care of our loved ones now only yields, at most \$15 per hour, and that is only if they are an employee of the CCB's newly established "Alter Ego Corporations." The other \$15 per hour for EVERY Community Connector hour worked by a 'Personal Care Worker' goes

to pay overhead costs. We all know what that means! Executive and staff salaries, benefits, buildings and bonuses among other things.

While the CCB's and their "Alter Ego Corporation's" management will continue to try to delude themselves that THEY ARE part of the care of our loved ones, I would dispute this notion completely. They bring zero value to the care equation in my view. I have said on many occasions, cut CCB's out completely and send my son the funding that the legislators voted to provide to him and I will make sure he gets the services he wants and needs. I could care less if the CCB's mgmt.'s kids go to college on the dollars that should have gone to my son's care!!!

Many outsiders call what our loved ones get in funding, 'welfare'. I would propose that the people who are raping the taxpayers are the people working in the system who make a living off of the funds that are supposed to go to the special populations that the legislators originally designated as recipients. Sadly, people flying desks and pushing paper get far too large a share of the pie, In My Humble Opinion.

Does anyone care? Is anyone listening?

Our current top 5 challenges:

1. Options for long term care. Case workers instantly offer standard responses to the search for long term care, like "Can you provide the long term care? What about family members or neighbors or friends? Maybe a group home, or host home – and then there are nursing homes." For my child, none of these are an option and so the quest goes unanswered. This does not even address the funding for long term care as my child is on the waitlist.

2. Critical/Urgent situations. If a family encounters this situation, there isn't a system who can/will respond. We're told to call 911 for emergencies, but there isn't a phone number to get help when a critical situation arises (need immediate out of home placement, need backup care when sole caregiver becomes ill/needs emergency care, need immediate respite). We're told to call back on the next business day, which could be 3 days away as some case management entities work only 4 days a week.

3. Decreasing Supply of Providers. Ever need to find a new Medicaid provider because you moved or the current doctor has retired or the day program closed? For adults with disabilities, there are fewer doctors, dentists, or other providers (respite and day programs for medically fragile) willing to accept Medicaid or desirous to meet all the government rules, regulations, and restrictions. When there isn't a provider, our family



- members do not receive preventive care, or have minor health issues addressed, or acceptable day program environments, etc.
4. Lack of System Experts. Because the system is so complex and the "experts" are not fully trained, parents have to continually research and learn the myriad of programs and rules, and how they might connect to provide needed services.
5. Rate of Pay for Waiver Programs. It used to be that the rate of pay was negotiated with providers (like day programs) but a few

years ago the State instituted “rate setting.” A specific rate was set for each service and for each waiver level. This rate change caused major issues for families and the level and quantity of care for their family member. For example, my child is a level 6 and used to get day program services for \$16/hour; new SIS required rate for level 6 is \$24/hour, but there was no increase in funding amount. Total result is substantially less services for my child, but my child’s service needs did not decrease.

Is anyone listening – does anyone care about our family members?

A comment August 8th, 2013, from an influential Colorado State Senator

"I am listening and I do care. As a legislator, we are working on this and hopefully we can come up with a solution that will decrease the waiting list."



I Want to Share My Daily Schedule

A typical day for this 66 year-old mom with her 18 year old adopted son who has a developmental disability and cerebral palsy secondary to premature birth due to cocaine use by his birth mother. He also has Post Traumatic Stress Disorder, and intermittent rage disorder as a result of abuse and neglect in foster care.

7:00 AM

Alarm rings and I go to gently get him up. If he is startled, the whole day is lost. The room that was picked up last night has had another “Dorothy - our name for a “tornado” that causes all the clothes and other items to be on the floor again.” I just walk through them for now. The clean clothes that are supposed to be on the bathroom counter and to be worn today are partially wet because he got up in the night and sprayed them while he was washing his hands.

He comes out of his room again in his diaper although he knows you do not walk around in your diaper with no pants. I tell him to cover himself up from bedroom to bathroom. At least it is better than when he used to walk into the living room naked. He jumps up and down (5’10 and 145 lbs), saying “it is not fair.” I remind him he will not get to ride the bus with his friends if he does not focus.



I go into his brother’s room to re-cover him and close the doors so he can’t hear the noise in the hall. His sister has already yelled at him to be quiet and to leave her alone because she was up late writing a term paper.

We get the diaper off and find some underwear. He had thrown most of the clean clothes into the dirty laundry yesterday so he would not need to put them into his drawers. The ones we set aside are un-wearable. He has a bowel movement and I assist with wiping, which he cannot do by himself.

I stand-by while he takes his shower. I make sure all of the less sanitary parts are thoroughly washed. Luckily he has just had a haircut so there is no soap to get out of his hair. He accidentally pulls the shower curtain down and water sprays all over the bathroom. I turn off the water and guide him out of the tub (clean-up comes later).

He gets on his underwear, pants and shirt, although the shirt is inside out and backwards. I watch him do his teeth, wash his face (sensory integration problems mean he won't wash his face in the shower). He has lost his deodorant again (deodorant and tooth brushes are a staple item in our supply closet). He wants to use his sister's deodorant and his brother's tooth paste. It is like living in an echo chamber. The answer is no.

He goes through the daily recitation of the mean, demanding para at his school, starts talking about events that are months away, complains about people who hurt him in the past, demands I find his telephone that he lost again (in between the mattress and the wall). I tell him no again and that he needs to put it on his dresser at night to charge so he can find it. (This is TRACphone # 4 this year. The last one got urine on it when he wet through his diaper although I get the most absorbent ones I can.)

7:45 AM

We get his socks on and I remind him to put his dirty diapers in the trash and then rewash his hands. He wants to go on Facebook, but I tell him he still needs to eat breakfast and get on his foot orthotics. He also needs his bathing suit and towel today, but the bag we hung on the door last night with them in it is not there. When I ask him where it is he shrugs.

I help with the belt, any buckles, buttoning if there is any. His bedroom smells strongly of urine because he changed his own diaper in the middle of the night and left the used one on the floor on top of what used to be some clean clothes.

I ask him what he wants to eat and he says just a few grapes because he ate 3/4 of a box of his favorite cereal yesterday and used all of the milk. Today I don't argue about it.

I give him his antidepressant so he won't rage like he did over the weekend (my hand has scars where he reached out to grab me. I found out at the hospital that he had looked up his former foster mother on Facebook and it set him off. I have only had to use Ativan once since the doctor gave it to me to give to him if nothing else works. They said they wanted to avoid the expense of another hospital stay).

I put on his orthotics, tie his shoes (while asking him not to kick me because he is excited about his gymnastics meet next week - special needs team). I throw away a few more socks in the sock-box because he has chewed through the toes. I have already discarded this week's crop of shirts that he chewed through (sensory integration issues).

He has been talking about anything and everything for the last 45 minutes. My head is working overtime to answer or ignore as needed.

He gets his coat, but he can't wear it because he spilled food down the front yesterday at the baby sitter's. So we find another coat although he has a tantrum because I won't let him wear mine. He has lost three hats, two pairs of gloves and one coat so far this season.

I write out another check for \$50 for his lunch program and pin it to his shirt so they will see it. I have told the teachers not to fuss over him



wanting to eat at least two lunches each day. His body is never relaxed and he remains thin and muscular in spite of consuming at least 3000 to 4000 calories

each day. He complains that the lunch room teacher will not let him have two bananas with his lunch.

I see the swim bag sticking out from under a couch cushion and make a note to check under the couch to see what else is there.

8:05 AM

His daily routine includes feeding the dogs their dry food three times a day (I do the water since his muscle spasticity makes pouring water a risky business). Today I do the whole thing after I sit on the front porch with him until his bus comes. He decides he is hungry after all and I give a “light” peanut butter and jelly sandwich so he can’t squeeze the contents out and get them all over his clothes just before the bus comes.

If it has been a good day, he will also have unloaded the dishwasher. Loading it is too hard, requires spatial planning skills he doesn’t have. Today it is my job. He runs (more like leaps because of his gait issues) towards the bus and his friends.

4:02 PM

I pick him up at the baby sitter’s house. She said he ate 5 grilled cheese sandwiches, but the first thing he says is that he is hungry. Half way to home he says he needs to go to the bathroom NOW.

Today he is agitated because the para who reminds him of his former foster mom (I adopted him when he was 8) yelled at him today about how he ate at lunch. I can see how he ate by looking at his clothes. I have asked them to provide a mirror so he can see himself when he is eating and a damp cloth so he can wipe his face. So far not done. It is also time to replace the patch on his neck so his drooling is less and he doesn’t sneeze over a five foot radius.

We take off his orthotics and start dinner. He washes his face and hands - the second time when I am watching he uses soap. He eats again and then goes on Facebook although I ask him to “fold” the clothes in the clothes basket as he is

supposed to do. I will try again later when he is less agitated. He does not feed the dogs. So I do that in between putting dinner away, cleaning the table and loading the dishwasher.

I ask him where his towel and swimsuit are. He says they are in the car, so I go get them since he does not have his orthotics on.

7:15 PM

Time to start our evening routine. Pick out clothes for tomorrow and place them on the counter.

Have a snack. Take off the dirty clothes and put on pajamas and diaper after he takes another shower if he needs one. Put the dirty clothes into his clothes basket. Put the shoes and orthotics next to his desk.

He did not make it on time to the toilet so I mop the bathroom floor. I do an emergency repair on one of his orthotics. The teacher told him to get them on himself and he ripped one of the straps. He is not supposed to put on his own orthotics because he cannot position them properly or put the straps on correctly. SIGH!!!

I wash some areas where he has acne on his face and put on some medicine to reduce the spread of infection. We brush his teeth and his tongue. He wants to use his sister's mouthwash but I say no.

On the way to feed the dogs, he sees the flashing lights outside our house. The police/fire department/ambulance are at our neighbor's house again and he is jumping and screaming. He sees the police force the neighbor's son out of his wheelchair and onto a stretcher. The young man has a "no spit" mask on his face. It takes 8 police officers and two firemen. They drive away silently.

The neighbor's son has mental illness, a developmental disability and a severe medical condition but has attacked his father trying to hit his father at the site of his heart surgery. My son is terrified of the young man who

can be very aggressive and threatening to everyone in the neighborhood. It also brings back memories about the police having to put handcuffs on my son because after two hours of trying to talk him down, he was still threatening. My son cries and says he doesn't want to be like the young man across the street. I assure him that the doctors are helping him to learn to manage his anxiety and fear and that he will be OK.

I trim his finger and toe nails. It is hard for him to sit still long enough and he continues to ask me questions while I try to do a neat job while he is moving around. We feed the dogs together. I shave his beard. We look for his favorite stuffed animal. I watch him remake his bed which I sprayed with a cleaner this morning and then search for a pillow case to replace the one that has mysteriously disappeared. We find another comforter and cover and put them on together. I tell him it is too early in the season to start listening to Christmas Carols on YouTube.

I sweep his room after he "picks up" his toys, pictures and clothes. I find some food dishes from a "midnight run" he made on some leftovers and a mostly empty pop cans. He knows he cannot have soda but snuck one into the house when he came from his gymnastics practice.

I find some papers folded in his pocket that I needed to sign for a field trip and an announcement of an upcoming party he wants to attend. I tell him we have a dentist appointment tomorrow and that I will bring him to school after that. He still goes to a children's dentist who is also trained to treat people with disabilities. He is not happy about the appointment because tomorrow is post office day at school. I tell him I will try to get him there before they leave.

He goes back to the subject of the neighbor's son and how he chased him in his wheelchair and came up on our porch and pounded on the door. There are no legal remedies since the neighbor's son has been ruled incompetent.

I try changing the subject and succeed on the third try by reminding him he will eat at Arby's with his girlfriend and her mother after practice later in the week. He immediately is talking about what he will wear.

I get him into bed. He comes out about 15 minutes later wanting a glass of water he knows he is not allowed to have. Back to bed and then I notice a flickering light in the hall way and take away his keyboard so he can't get back on Facebook. He throws a tantrum.

I go to the bathroom, the "mean mother's haven." About 20 minutes later while he is apologizing over and over and trying to hug me, he goes to bed again and goes to sleep.

Post script from the author: "Although the story here is the grueling schedule, the real story of this young man and others in my family is that they function at all, that they love at all, have solos at school concerts, draw profoundly revealing self -portraits, participate in nationally recognized sports teams, draw out children with autism to speak for the first time and the teachers, therapists, coaches and others who make that special effort to help them reach past the barriers they experience. Without services, without people who reach out to them, they are lost."



Why Do Parents Trust Their Child's CCB Case Managers/Resource Coordinators?

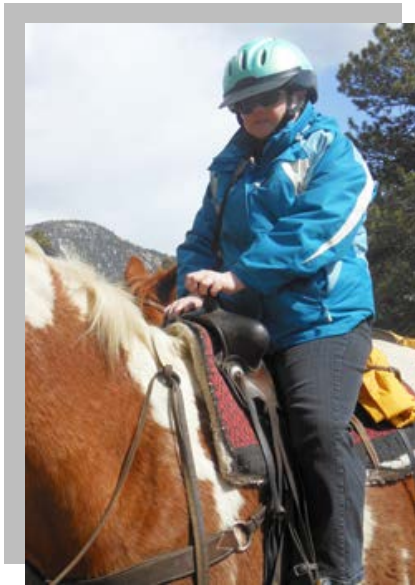
By a parent of an adult child with a disability

So many of us are misled into believing that what our child's case manager/RC with our CCB tells us is correct/true. We are lured into a false sense of trust that dissolves into harm being caused to our child when the information we are misled into believing/trusting turns out to be erroneous. Is the harm intentionally caused? That is for the individual family to determine. But as time goes on and we see because of the lack step outside of our searching for help eyes begin to open is happening.

One cannot dismiss one family hears manager/RC about be different or respect from what reports they heard

manager/RC (at the same or a different CCB) - such as how a person receives emergency comprehensive services - many times is a dilution, misrepresentation, or at the very worst, a falsehood/lie about how to receive those services or even if the person is qualified to receive those services.

How, we wonder, could such a dilution/misrepresentation or falsehood be perpetuated/happen to someone who is dependent on others' knowledge to help them live as independently as possible in their community, as the Olmstead Decision promises? What drives a CCB to mismanage, distort, ill-train, ill-prepare their case managers/RCs, who are disseminating this malicious deception, when the CCB most likely knows that the information given to



our children suffering of services, if we can exhaustion in for our children, our to the reality of what

the fact that what from their case a certain issue may varied in some another family from their case

families by their case managers/RCs is erroneous and possibly/probably causing harm?

Could it be that the money our loved ones bring into the CCB through their Medicaid standing is so impervious to federal oversight that CCBs simply do not care about the harm caused our loved ones through their own mismanagement of those funds by the misinformation put forth by their case managers/RCs?

And therein lies the harm - both to the individual with disabilities who is supposed to be supported by their CCB in receiving the appropriate services to meet their individual needs and how those needs continue to not be met because of false information.

Where is the accountability - by both the case manager/RCs and the CCB - for providing false/ misleading/harmful information that leads to harm to the individual and their family by services delayed, denied, ignored? Why do we, the parents of children with disabilities - whether they are still in school or now grown - continue to place so much trust in the individuals/case managers/RCs who represent the organizations/CCBs that are supposed to be knowledgeable and help us get our children the services they so desperately need - now, not later, not 10, 20, 30, even 80 years later, as some parents are reporting being told by their case managers/RCs?!

Why? Because we have been lured into a false sense of trust that needs to be broken open and revealed for what it truly is - a gaming of the system to benefit the CCBs, not what it is supposed to be - to help our children with disabilities lead a decent life.



A PAD-CO parent would like to say “Thank You” tosome of the many great people we’ve met on our journey



* The kindergarten teacher at a special education school (the only teacher there required to have a master's degree). She taught kids of all abilities and encouraged them to reach their full potential. She taught my non-verbal daughter to communicate - through looking left or right to indicate yes or no, to vocalize when she wanted the page turned during reading time, and she encouraged us to dream big for our child.



* Private therapist, Donna, who worked hard to teach my daughter how to control her muscles. She did this with kindness, smiles, and consistently and gently pushing my daughter to her limits - to the point my daughter was still smiling but couldn't hold her head up any more.

* The school therapist, Jenny, who advocated for my daughter to have warm water therapy and provided that therapy until the school found a way to prohibit it.

* The parents along this journey who provided emotional support. Including the fellow parent who provided guidance right after my daughter's first dire

diagnosis at 6 months, and the multitude of parents who have provided advice and guidance on the various therapies, schools, doctors, systems and programs.

- * My mother who is always there when we need assistance with well and sick appointments, errands, respite, sound advice, etc.; except that her health and age limits her to only providing emotional support now.

- * Other people with disabilities in school or day program that have looked after my daughter and become her friend; most of these friends put aside their own pains and worries to assist my daughter with her needs.

- * Doctors and nurses who found the best solutions to my daughter's needs; who also provided support to me when I stayed in the hospital with my daughter; for their kind touches and words; and their staff for working with us to coordinate the many appointments.

- * The pharmacy, who not only fills the orders but accommodates our preferred mode of communication, and who always checks to make sure we received the correct supplies.

- * The many advocates who have fought and persevered so that my daughter could benefit - even in ways that I do not realize.

- * The Colorado Legislators and State staff who truly care, who take the time to listen, and who search for ways to weave together the various programs to provide assistance to our family members.



* The people who stop to smile and say "Hi" when we go to church, dinner, or shopping - this means so much to my daughter. One time while shopping, a nice lady stopped to talk to us and, at the checkout counter the clerk gave my daughter a beautiful scarf and said it was from the nice lady. My daughter loved that scarf!

* Our long time care providers who have other full time jobs in the disability field, and who have their own health issues - you have always been there to meet my daughter's needs so I could work full time.

"Thank You" all as we could not have traveled this journey this far without you. Please keep up the good work and know that you have greatly touched our family.

The life story of Patrick exposes Seven Critical System Flaws

My son, Patrick, age 25, has a developmental disability (<http://www.angelman.org>) and a surgery-induced spinal cord injury. He requires 24/7 care. Patrick requires a wheelchair when he is not at home. Patrick received care initially through a Fort Collins, CO home care agency. After we trained over 70 Certified Nursing Assistants (CNA's) in a four year period, the agency "dumped us" and we were not able to find another agency to serve our son.

1. **CRITICAL SYSTEM FLAW EXPOSED:** Dumping of patients with complex needs by home health agencies is a life threatening event and needs to be prevented. Thankfully, in 2008, we fought for, and now receive, Consumer Directed Attendant Support Services (CDASS) through the Medicaid Home and Community Based Services - Elderly, Blind or Disabled (HCBS-EBD) waiver

option. We were also simultaneously offered the Supported Living Services Medicaid (SLS) waiver. Since CDASS was still a pilot, we were able to get on both CDASS and SLS together. Sadly, this wonderful combination is still not offered routinely, due to bureaucratic delays.



2. **CRITICAL SYSTEM FLAW EXPOSED**: Integrate CDASS into the waivers for people with developmental disabilities. Through CDASS, we get four hours of personal care attendant services each day, two hours in the morning to get him ready for his day in the community, and two hours in the afternoon/ evening to feed him, put him in the stander, wash him, get him ready for bed, and provide other personal care such as changing his brief, brushing teeth, etc. His brief is checked twice each 2 hour shift. During this whole process, Patrick must be redirected and requires constant supervision.

Supported Living Services (SLS) is a program offered by the State through regional Community Centered Boards (CCBs). Patrick has a SIS (supports intensity scale) of level 5. He should have had a level 6, but we would have had fewer hours with a more intense need. SIS was originally designed to rate the need for services and is now used to allocate funding, which it does badly. Makes 'NO' sense.

3. **CRITICAL SYSTEM FLAW EXPOSED**: Use a tool designed for the job of allocating funding, not a tool made for another purpose, such as the SIS. Through his SLS waiver funds, Patrick goes by public transportation to two volunteer jobs he's had for over five and four years respectively. He works at the CSU (Colorado State University) Greenhouse watering plants and at the City of Fort Collins Garden's on Spring Creek watering plants and assisting preschoolers in the drop in "read and seed" program. He does these jobs year round. It's meaningful and John, one of his attendants, helps him with his responsibilities, transportation, goals and objectives and communication. We are fortunate to have great providers. Michael,

Patrick's longest serving provider of five years, is a special education teacher. He has a full time job and used to do all Patrick's hours in the summer. When school started up, we added John who has been with us for four years. John, who provides most of Patrick's hours, is a father who has two daughters in college. The providers have to love what they do or they would not do it for the pay they receive, which is very little.

When Patrick is not working, he exercises at one of the city recreation centers, goes to free concerts, or goes bowling. He is known in our community and well liked. He doesn't sit home and get anxious about not having anything to do. He gets a little respite care, but mostly we private pay that because we prefer he's doing meaningful things in the community.

As for Patrick's other services under CDASS, my husband was laid off from his job, but we couldn't leave Colorado to get another job because we would have lost Patrick's existing services and gone on to another State's waiting list. So, my husband stays home and cares for Patrick, and is the Authorized Representative (A/R) who manages Patrick's CDASS. By law, he cannot be paid for those services. I work the available hours as Patrick's attendant for shifts we cannot cover with our two staff.

4. **CRITICAL SYSTEM FLAW EXPOSED**: Waiver services are not portable from State to State.

5. **CRITICAL SYSTEM FLAW EXPOSED**: The A/R cannot be a paid employee. So a parent who is an A/R can provide "natural supports" (meaning unpaid labor), but not receive pay. It is very hard to find a job flexible enough to accommodate the intense needs of our son.

Recently there has been a big change in the SLS (Supported Living Services) portion of Patrick's care. Patrick's CCB, through which all funds for all people with developmental disabilities are paid, has decided they will no longer work with Independent Contractors.

So, Patrick's SLS service providers (both independent contractors) each now have to become a PASA's (program approved service agency) Medicaid provider. This is costly and both our providers service only one or two individuals with intellectual and developmental disabilities. CCB's collect overhead from PASA's, meaning fewer dollars go to direct care of the individual like Patrick. The providers and the individuals being served lose the money and the CCBs get more.

We are waiting to see if Patrick's long time providers are going to be able to become PASA's. If they can't, then life will be irreparably altered. We would go back to the situation like we had when we were using an agency. With an existing CCB PASA or other large agency PASA, we would be back in that same unstable provider situation.

Our independent contractors are trusted and loyal providers who we know provide Patrick (who is non-verbal) a voice and care that is unsurpassed. The loss of our Independent Contractors will be an incredible loss!

6. **CRITICAL SYSTEM FLAW EXPOSED:** Independent Contractors forced to become PASAs in order to continue as providers. No benefit to Independent Contractors or their clients.

We have been waiting for eleven years for the Comprehensive DD Waiver, which provides more services than the SLS waiver, including residential services. We have been told it could be another ten to twenty years before we reach the top of the list. We need to plan for the future and it's hard to do that with no funding in sight. We are grateful for what we have, but are concerned about life



altering cuts in services that have happened before.

7. **CRITICAL SYSTEM FLAW EXPOSED:** Extremely long waiting lists for residential and other comprehensive service

Would you like a job?

That allows you to carefully select a Board of Directors that is compliant and supportive of you. A job where no one who strongly disagrees needs to be chosen. Where, if you are smart and careful and choose the right “Team,” it is a job for life.

Where you can convince that carefully selected Board of Directors to give you a huge salary to show how important and valuable you are, based on “stair-stepping” surveys by non-profit associations. Since you and most others are always superior (of course) to the survey’s “average” you and others will always have a salary higher than the “average,” thus boosting the average for the next year’s go around. What a deal!!

That besides some state contractual requirements and a couple of minor state laws, the state has NO control over your business, even though the state spends up to 10’s of millions of dollars through your organization. YOU ANSWER TO NO ONE EXCEPT YOUR PERSONALLY SELECTED, NON-COMMUNITY ELECTED, NON-REPRESENTATIVE BOARD OF DIRECTORS.

Where, despite the government spending millions and millions of \$\$ through your organization, you don’t have to respond to transparency requests, nor do you have to show any real budget figures and actual expenses to anyone

outside your organization. No citizen, such as you or I, has legal access to your itemized expenditures and income.

Where, unlike most other non-profits, you do not have to fundraise significant sums of \$\$, nor actually run a business. About 99% of your funding is guaranteed by county/local, state and federal funding. You just have to spend it all! What fun!

Where any money you raise can legally be used just and only to further increase your salary!

Where your business has no competition. You have a guaranteed clientele handcuffed to your business by state defined areas. Folks can only leave if another organization will accept them to provide services.

Where many only have to work 4 days per week.

Where there are 19 other government funded similar businesses strategically and regionally located in the state who regularly woo legislators, impress the legislators with "canned presentations" about their organization's "fine job" and assure that no laws are ever passed detrimental to their and your organization's status, power or empire.

Where you are a member of a taxpayer-supported trade group which protects you and your organization and, among other activities, publishes research "studies" beneficial to your trade group and its members, even when anyone who is "polarizing" is automatically excluded (by design) from the research, and the research participants are not properly sampled and therefore the results are not able to be generalized, even though the "studies" claim they are.

Where you can use taxpayer funds to hire private state lobbyists to further your and your organization's status and agenda at the legislature.

Where you are paid to attend numerous non-productive meetings, conferences and other functions as a representative of just one more unnecessary layer of bureaucracy.

If you would like a job like the above, then you should become the Executive Director of a Colorado Community Centered Board (CCB)!

The Community Centered Boards provide case management and services to individuals with intellectual and developmental disabilities in Colorado. They are codified as a quasi-governmental agency under CRS 27-10.5, but are not subject to Colorado open record laws.

Could YOU make this decision on the fly?

When my mother needed nursing home care because she had Alzheimer's and a broken hip, my family undertook a process to find the right place for her. She was on Medicaid. We obtained a list of facilities. I researched every one of them online. I obtained information on their locations relative to family members who would care for her, cleanliness, level of care, violations against them and even ratings by other patients. My sister and I visited every one of them until we found the right one for our mother.

The process for a person with a developmental disability in Colorado is nothing like that. You place your family member on a waiting list that lasts for many years for a Medicaid resource to pay for your adult child to live in the community. In the mean-time, you get no further information. Instead, I got a letter telling me to go to a meeting where we would decide which resource we wanted. When we arrived at that meeting, there were scores of other parents

there, also making the same decision. We filled out paperwork as a group. Questions were answered in front of everyone else.

We were told to choose a resource: Supported Living Services (SLS) or Comprehensive Services (COMP, which is now called something else). SLS was much less support than COMP. If we chose COMP, we were told we had two options: to place our adult child in a Host Home or Group Home. We were not told anything else about where these facilities might be, who might be the care providers, what the quality of such care would be, or where to find information in order to make an informed decision. We had to decide, right then, with a promise that we would get more information later.

It turns out, there were two other options that nobody told us: assisted apartments or to use the COMP services to serve our adult children in their own homes. Many parents turned down the opportunity for COMP services because of lack of information and choice. Some just weren't ready to make the decision that day or their adult children were too young. Those who did not make the decision that day lost their COMP resource until a future unknown date when the state might open more resources. For our family and that group of parents, that was 7 years ago. In the meantime, lives change and needs grow but no resources exist. Basically, it was our only chance because the waiting list only got worse after that.



We were not allowed the opportunity to learn what the ramifications would be of these two choices. We were not allowed to understand where we would be sending our loved ones if we chose "host home or group home." And with no information, we were supposed to send our adult children off into the sunset. I ask you, could you make that decision on the fly, with no information and virtually no choices?

Parent comment:

I would love to have more information...WHO sent you the letter, WHO sat you, and those families in that room and gave you those "choices?" I hear similar stories almost daily...the withholding of critical information (mostly by CCB's) when families are suddenly given a SLS or DD comp resource. Most people don't even know what they are being offered! And yes, many do turn them down because of the lack of guidance and information. Criminal.

Another parent's comment:

Years ago we were offered - on a Friday - an opening (a comp "slot") in far Southwest Colorado (100's of miles away), and our child was supposed to be there the next day - Saturday - and we knew NOTHING about the placement, who our child would live with, medical facilities, etc., etc. We turned it down as we were not going to place our child in such a haphazard way. Subsequently, I heard that we were roundly and publicly criticized by the staff at the CCB and DDD for not taking this "opening." It got so bad that finally a letter was sent to the CCB and to DDD to get this criticism of this child's parents stopped, and to tell our side of the story.

A comment by a 3rd parent:

I am a sibling to a younger sister by 7 years who has DD. Both of us are "senior citizens." Did you know that if you do take "opening" and place your family in a host home, that host home can drop your family member back on your doorstep, giving you no notice and no reason? It's in their contracts that they can "terminate" your family member if it doesn't work out for their families.

This happened to us. After living with me on SLS, my sister got a "slot" for CLS and we placed her in a host home 5 miles from us. I picked her up on the way home from work every Friday for the weekend. After 1 year, she became ill and needed extensive medical care. Within a week of her diagnosis I found all her belongings on my front porch in black trash bags and got a call from the Director of Quality Life Services that she had been terminated by the host home and would be home permanently that evening. Sorry.

This was three years ago. Thank God, by then the Family Caregiver Act had been passed. This is the solution. Parker Personal Care Homes, a progressive "for-profit" agency, took us on as partners in self-determined DD care and services. I have been paid as a family caregiver employee since then; so as her guardian I can manage and monitor my sister's CLS budget and funds, hire through them the people and home health care services she and I need to stay alive have actual quality lives. Never again will we turn our lives over to "the system". I know many families who turn down the resources because they think you can't have it and maintain quality control over the life of your vulnerable lived one. You can. You just need to know the law, how the system works, and not be intimidated by it. This works!

A comment by a 4th parent:

Great comparison and parent comments! It's sad that these are the norm and not the exception. We were given 2 weeks to decide on SLS versus EBD, all the services needed, and to have the day program picked! Unreasonable timeframes, no useful info, and we are all on our own to figure out the maze details.

What Happened to SLS?

When my adult child was provided with a Supported Living Services resource, it provided great supports to enable my loved one to live independently, with many supports. Since that time, the state cut our resource in half, cut the rates paid to providers (which caused us to lose our excellent provider), and cut many things out of the program that helped support people with disabilities who either live independently or with support from their families.

The end result of the cuts in SLS have been devastating for many families. In our case, we had a provider who visited my loved one several times per week. We had 1:1 support to continue to allow my loved one to live

independently in the community. It was not 24 hour care, but it was several times each week. Instead, we were forced into group activities that we did not want and 1:1 support was cut to a couple of hours per week.

Other families, who relied on SLS to provide meaningful activities for their adult children while they work full time, lost at least one day of day program. That loss means that many parents can no longer work full time to support their entire family. Furthermore, there are NO other resources for these families because of the adult waiver waiting list.

SLS was working so well for my loved one for a couple of years. Then the axe fell. We had built our entire lives around these supports, only to have them systematically cut.

Does the state realize what they did to us? Do they know that we had built our whole lives and the lives of our adult children around what SLS provided? By making those cuts, they jeopardized the jobs of parents and any kind of meaningful community life for adults with developmental disabilities. They took away our great providers. They forced our adult children into group activities, rather than “normal” community living.

DECEMBER 2, 2013

Attention - Individuals Drafting the Bill to End the Wait List for Individuals with Intellectual and Developmental Disabilities in Colorado.

PAD-CO (Parents of Adults with Disabilities in Colorado) was not invited to participate in the drafting of this bill, nor has our review of this bill and input been requested. However, the IssuesPAD-CO group has taken considerable

time to study the bill and raise some questions about the bill and the processes of developing the bill and the suggested method(s) of ending the waitlist.

The most recent draft available to PAD-CO is:

<http://www.ourwebs.info/EndWaitListDraft102831.pdf>

Certainly PAD-CO supports all realistic endeavors to end the waitlist, and, indeed, was a prime sponsor of the NOEWAIT (National Organization to End the Waitlists) efforts to end waitlists nationally, and gain portability of services between states. This effort can be viewed at <http://www.noewait.net>. NOEWAIT was also not asked to provide any input into the current efforts to end the waitlist in Colorado.

We are concerned about aspects of this bill. Our questions and concerns are listed below.

Thank you,

Denver C. Fox, Ed.D.
Moderator, PAD-CO

Questions for the “Bill Drafters to End the Wait List”

1. Why can't DD eligible individuals and families keep the CCBs from being involved in the determination of the “right person/right services/right time”? CCB interference draws taxpayer money away from the individuals who need the funded services, and who could purchase their own services if they could have true Consumer Direction with authority over their budgets. I feel the CCBs are blocking true Consumer Direction for individuals with Intellectual/Developmental Disabilities. Consumer Direction is available in the Medicaid services for people with other disabilities.
2. Most important: OUTSIDE of this bill, which will mandate that a strategic

plan be made to end the waiting list by 2020, are there any legislators, such as yourself, who would be willing to draft a companion bill that would address a) the dismantling of the CCB system in favor of a more person-centered approach b) making DD services an ENTITLEMENT, like the Lanterman Act in California?

3. What is happening with the rewriting of the current waivers? Are the waivers truly being combined so as not to delineate the type of services available under each? For example, by "appropriate services when needed," does this mean that the person receives the real services they need, no matter which waiver (SLS or Adult) those services are currently covered under? Because "appropriate services" means, to us, "exactly what they need"...not a pared down version of what they need subject to an arbitrary cap set by a flawed SIS testing limit.

Or...

Does this really mean status quo in terms of what is offered under each waiver and that a person would not receive "appropriate services" because they would be limited to services available only under SLS if that is what they get? Because.... SLS is not currently providing "appropriate services." There are people receiving SLS for whom "appropriate services" would actually mean living outside the home and away from their parents, for example. But if they only have SLS, they are only receiving a very small amount of services they actually need.

4. Can we also ask the legislature/state to drop the entire SIS (Supports Intensity Scale) and funding cap process during this legislative session to go along with this bill so as to ensure "appropriate services when needed." This could actually save money, rather than increase spending now and in the long run.

5. The bill talks about the legislature appropriating the funds to meet the benchmarks of the plan each year. How much flexibility is there in the state budget to allocate more money than has been allocated in the past to open

"slots" on the waiting list? Is there a current projection that state income has risen to the point of actually allocating more funds to the DD system than before? Or, is it thought that the legislature will pursue a new referendum to raise taxes for the DD System? Or, is it projected that this new plan will be more cost effective and therefore open more slots?

6. How can a signed legislative bill (such as this bill) encumber future legislatures with responsibilities that will require potential (but as yet unknown) funding? We thought this was illegal under Colorado law.

7. How will the total number of person waiting be compiled? Will the number of persons currently being "underserved" be included?

8. Since the state department says it has no control over the CCBs (despite each CCB having to sign a contract with the state), how will the state department enforce any of the plan's provisions that affect the CCBs?

9. If the "right services at the right time," are real rather than the current "only services that we are willing to give you when we decide that we will offer you something," it would be a big step in the right direction. How can this be assured?

10. I've never understand how they kept a waitlist and who comes off the waitlist at what time and is it related to turning 14 years of age. If so, could someone coming into the state now, come off the waitlist before someone who has been waiting for 10 years? How do they make it fair, if that word exists in the CCB/DDD/HCPF vocabulary? How will this bill change this?

11. One problem with legislation is that if it is not specifically clear, then departments get to "interpret" the intent and then get to write the rules to the slant they want. How can this be prevented?



12. Why hasn't utilizing matching Medicaid funding for County Mill Levy funding been proposed. This is legal and would bring about an extra \$40 million into the system, making a marked effect on the waitlist, and directing these funds toward Consumer Directed Attendant Support and Services (CDASS).

13. Why was the representative from CCDC removed from the email distribution list after the second meeting?

In addition to a bill of this nature, PAD-CO strongly proposes that the legislature appropriate funding in 2014 to eliminate wait lists. Certainly the DDD/HCPF must have a good approximation of those not being served and those who are underserved. Why is a report from DDD/HCPF actually needed, when the waitlist could be attacked immediately by additional funding for CDASS programs?



ABOUT PAD-CO

PARENTS OF ADULTS WITH DISABILITIES IN COLORADO

We welcome parents or guardians of adults or older children with disabilities in Colorado to join our group!

Just send a member
request to:

PADCOWEB@aol.com



Please state that you are the
parent or guardian of a child
with a disability.

together

What is this IssuesPAD-CO group, anyway?

The Issues group was formed when it became apparent that we had folks on PAD-CO who were relaying our private conversations to CCB Executive Directors and others. At that time, I started a small group of folks who I felt could be trusted to not relay information, and who had great experience in the disabilities world both as parents and as activists.



We are now at 17 invited participants including some very well-known individuals - past presidents of this and that organization, former Executive Directors, activists with the legislature and the "system," folks who are not afraid to stand up in public and fight for the rights of individuals with disabilities and their families, folks with very special skills and knowledge. Anonymity is guaranteed.

IMHO, this group is THE outstanding group in Colorado as related to parent's knowledge of and awareness of the characteristics of the Individuals with Intellectual and Developmental Disabilities System.

We study issues carefully, write position papers based on those studies, speak out when necessary, and always have as our objective the best - as we can determine - for individuals with disabilities and their families. We almost always

present position papers and other writings to the entire PAD-CO group for comments before finalizing them.

We keep a low personal profile, but hope to have a high impact. Sometimes we make a difference and sometimes we don't, but we are always trying.

Being a totally non-funded organization, we are beholden to no one, which is unique, to our knowledge.

We thank you for your continued support.

Pad-CO can be contacted through padcoweb@aol.com



The printing for this booklet was paid for by hard-earned funds from parents of adults with disabilities, with a contribution from the Arc of Aurora (whose funding support does not necessarily reflect an agreement with the content).

Alphabet Soup– what does it all mean?

A/R	Authorized Representative
CCB	Community Centered Board
CM	Case manager
CDASS	Consumer Directed Attendant Support
COMP	Comprehensive services, now called DD Waiver (Developmental disability)
HCA	Home Care Allowance
HCBS - EBD	Medicaid Home and Community Based Services-Elderly, Blind or Disabled waiver option
IC	Independent Contractor
NOEWAIT	National Organization to End the Waitlists
PASAs	Program Approved Service Agencies
RC	Resource Coordinator
SIS	Supports Intensity Scale
SLS	Supported Living Services Program
24/7 Care	Someone who needs care 24-hours a day, 7 days a week
TRACphone	Pay-as-you-go telephone

