

## HB 23-1197: Stakeholder Process for Oversight of Host Homes

Kari Easterly, Executive Director, Arc of Adams County

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Hello,

My name is Kari Easterly, and I am the Executive Director of The Arc of Adams County. Our organization advocates for and with children and adults with intellectual and developmental disabilities. Given the recent report that was published by the Department of Regulatory Agencies regarding the regulation of host homes, I am writing in favor of HB 23-1197. Please accept this written testimony.

For over 20 years I have been advocating for quality services and supports for adults with intellectual and developmental disabilities. For some people with intellectual and developmental disabilities to be successful in the community, they need support 24 hours per day, 7 days a week. Some of the care needed is very intensive, and some individuals are very vulnerable and cannot speak up for themselves. For some people, the supports they need are provided in a host home setting. This setting is typically a family setting in which the host home provider is paid by the State to provide the needed supports for the person. These are very vital services for people who need that level of care, and this level of care also prevents people from living in a nursing home or institution. Not only providing people the opportunity to in the community, but this saves the State a significant amount of money when the services are provided in the community.

While most people with disabilities can speak up for themselves, there are others who cannot. They are fully dependent on the people paid to provide care for them. It is important that people who cannot speak up for themselves are receiving the care they need and there is oversight to make sure that quality care is happening.

I know many, many host home providers that are not only providing exemplary care, but also go above and beyond. Many host home providers are very caring people, and they work for agencies who follow all procedures set out by the State who have their own great policies in addition to what can be found in rules and regulations. I know several people with IDD who have lived with the same host home/family for 20+ years and are doing well. I would like to commend those host home providers and the agencies that support them. They know what they are doing and shows in the care they provide.

But not all host home providers and agencies that support them are created equal and fall short of meeting the needs of the individual leaving the person at risk of serious harm. Our office receives referrals for some individuals in these situations, and we see firsthand the unsafe situations and deplorable care. As the Sunrise report identifies, some people have died as the result of this care.

In my twenty plus years of advocating for individuals in these situations, I believe this is the result of a few factors:

1. **Lack of oversight and authority.** Who really has authority and what are the consequences of not meeting the needs of the people receiving host home services? Case managers are required to monitor the services in the home quarterly and can make recommendations, they but have no authority to enforce changes. I have seen host home providers deny a case manager entry into the home in which individuals live. I have seen host home providers and agencies deny

individuals the right to have visitors including advocates and guardians. For example, agencies are required to complete background checks and other state level checks prior to contracting with potential providers. There are regulations about CAPS checks and what is acceptable, but there is little oversight to make sure agencies are not hiring people who are showing up on CAPS checks. There needs to be quality standards for a host home provider and oversight.

2. **Lack of training.** Agencies (often new ones that are new to the field), do not know the regulations. The process for approving agencies requires very minimal training or certification. There is little to no oversight of those agencies before being approved as an agency. Most state reviews of agencies happen every 3-5 years after approval. Many host home providers are never surveyed by the state. And the on the ground oversight that does exist, such as case management monitoring, does not have the authority to enforce recommendations if concerns are noted.
3. **Some regulations are not strong enough.** Host home providers contract directly with agencies (PASAs) to provide services. The State provides direction that a contract is needed, but there are few criteria for those contracts. Contracts are not regulated and are up to the agency/host home provider to come to an agreement. There are hundreds of host home providers and service agencies. Some contracts have criteria such as health and safety standards, training needs, compliance requirements and consequences if those things are not met including fines, withholding of payments, and termination. Other contracts do not have any criteria and some even state that the agency will not have any responsibility to train or provide oversight on how the host home operates.
4. **Money.** This is Medicaid money and there should be oversight. Provider/Agency contracts and rates in which the host home provider gets paid are not standardized. The State gives the residential agency a daily rate to provide residential services. The agency in turn then contracts with a host home provider to provide those services. Host home providers are not paid an hourly rate; they are given a daily rate based on the agreement in the contract. The agency can withhold any portion of the HCBS rate for administrative and oversight purposes, this varies anywhere from about 20%-50% of the rate. This has created host home providers “shopping” for agencies that will give them more money and the least amount of oversight from the agency. This harms the individual with IDD because they need an agency to provide oversight to make sure they are getting what they need. This harms good agencies because they are providing needed training and oversight like nursing care and that takes money to pay a coordinator or a nurse. There are also agencies who withhold a major part of the rate and are not providing oversight. Regulations around contracts and the rates would help eliminate provider shopping, and provide accountability and stability.

I am in support of HB 23-1197 and the development of a stakeholder process to address these concerns. Thank you for the opportunity to submit written testimony.

Kari Easterly, The Arc of Adams County

The following is an account of the experiences I had in one host home in the Intellectual and Developmental Disabilities system in Colorado. I have been a client in Colorado's IDD system for four decades. I have had Cerebral Palsy since birth due to prolonged anoxia. My mind is fine, but I have severe muscular problems which make it impossible for me to perform any part of my own care. I am able to move a little, so I can cooperate while my staff are bathing and dressing me, but I can't actually move well enough to do any activities of daily living or instrumental activities of daily living. I am a very independent person in terms of knowing what is appropriate to wear, what I want to wear, and when I need staff to assist me. I know what medications I need and when I need them, and can direct my staff regarding my care. I am also very independent in that I have volunteer job as a disability advocate and can direct my assistant regarding what work I need to do and what help I need to do it. So I'm very easy to care for in that I am cooperative and that I am aware of what I need and can make my needs known despite having a severe speech impairment. My physical care needs, however, are many due to my muscular disability.

I have only lived in one host home, but it proved to be a nightmare. It was in 2003, when I was forty-two years old. Due to my extensive physical care needs, I had been living in a group home where I had been getting good care. After about a year of living there, the agency decided to close that home. They needed the clients to move out quickly, so I was only given one choice of host home provider. There was no time to explore options or get to know a variety of potential providers; I just had the choice to live in a particular host home or be homeless.

The host home providers were a man and wife. They had a teenage son with emotional problems living with them, and already had one total-care client they were providing services for. I'm not sure who thought this was a workable placement. It would be hard enough on a couple to meet the needs of an emotionally volatile teen. To add in one total-care client would be inadvisable, and to add in two total-care clients was insanity.

The woman, whom we'll call "Martha", was always angry about the amount of care the other client and I needed. I would have been mad, too – it was an impossible situation – but she had the option to say she wasn't able to take on a second host home client, yet decided to care for me anyway.

Martha was mad about everything from the beginning. Early on, I asked a friend of mine to come over and help me explain some aspects of my care since my speech impairment makes it impossible for people to understand what I'm saying unless they've gotten to know me. I told Martha about what I needed done and how it worked

best to do it for me, with my friend acting as an interpreter. Martha seemed to be ok during this discussion, but after my friend left, Martha confronted me and demanded to know who my friend was to come into her house and tell her her job. I was floored because that's not at all what had happened. I had asked a friend to interpret for me so I could tell my brand-new provider what I needed. I was terrified because of how angry and threatening Martha was. I have no ability to defend myself physically, or even to move away from someone who is threatening to me. I have no ability to care for any of my needs. I didn't know what to do. I couldn't go back home and live with my mom because she was no longer able to lift me. I didn't know how I was going to live with Martha's rage.

Martha also seemed to be paranoid. Clients in the IDD system have the right to privacy. It's stated clearly in each client's Individualized Plan. One day, my friend came over and I asked to talk to her in my room with the door shut. Neither my friend nor I thought anything of this; it's a guaranteed right. But after my friend left, Martha again confronted me and demanded to know what my friend and I had to talk about that we couldn't say in front of her. I was an adult; sometimes adults want to talk about things in private. It shouldn't have been a big deal. It shouldn't have been any kind of deal at all; it's a right. But Martha was enraged nonetheless.

I think it's hard for able-bodied people to understand just how scary it is to be completely dependent on an abusive person, and how scary it is to be unable to move away from someone who is angry and threatening. It's terrifying when you have no independent ability to get help. This, unfortunately, is how many clients in the I/DD system spend their lives. We're all too often captives in abusive systems we can't escape, and to make matters worse, the public has no clue about what's going on behind closed doors.

It was clear that the host home placement wasn't working. I was afraid to say anything in front of Martha, so I asked my day program staff (this was before I got my volunteer job) if I could make a call. I had thought that I could call the agency and get help finding somewhere else to live. But I got in trouble with the day program staff for merely asking to make a call. I wasn't ever allowed to call the agency to report that there was a problem. I'm unable to use a phone without assistance. The only staff I had to turn to – the day program staff – were just as bad as Martha. I was, in every sense of the word, a prisoner in that host home and day program. There was no way to get help; there was no way out. I just had to live with the abuse.

Martha's rage only grew the longer I was there. I had a cushion for my wheelchair seat because I'm at risk of skin breakdown due to not being able to move much. One day, my diaper leaked and the cushion got wet. Martha yelled at me that if I was going to pee on the cushion, I couldn't have it anymore. She acted like I deliberately made my diaper leak, like I was going out of my way to make her life difficult. Martha had no business working with people with disabilities. If we didn't require care and clean-up, we wouldn't be disabled. Martha was not only being ridiculous by taking away the cushion, she was actively putting my life at risk. Skin breakdown can be fatal, but Martha didn't care. This is how bad the lack of oversight in the I/DD system is. Providers can literally threaten the lives of those they serve, and no one outside the system has any way of finding out about it. No one told Martha she couldn't take the cushion away. My day program staff didn't even notice it wasn't there anymore. So many clients are in situations like this where no one is looking out for them.

Just before I moved into the host home, I had found out about the Colorado Cross-Disability Coalition and a couple of local groups that did disability advocacy. I had wanted to get involved. I had always wanted a volunteer job where I could use my experiences to help others, and here was my first real opportunity to do so. I asked a friend and a woman from CCDC to come to my staffing at Martha's because I wanted to tell my team about CCDC and my decision to become a volunteer advocate. I met my case manager, who was new, about five minutes before the staffing started. I talked about CCDC and the meetings I wanted to go to so that I could be an advocate. My friend interpreted for me as I talked about my plans. The woman from CCDC explained about when the meetings were to take place and where. Martha got angry and said that my friend and the woman from CCDC were railroading me into making this decision. Martha convinced my case manager that my friend and the CCDC representative were trying to exploit me. Martha stated that I was forty-two years old, and that made me too old to get a volunteer job. She told my case manager that it was time for me to "start slowing down". My case manager, who knew absolutely nothing about me, agreed and said that I wasn't allowed to go to advocacy meetings "for my own good". It's interesting that though I was "too old" to have a volunteer job, I wasn't too old to be forced to go to a day program where I sat all day with nothing to do.

Martha also got angry about preparing my food. Since I can't chew and have trouble swallowing coarse food, I needed my meals to be pureed to baby-food consistency. Martha had a food processor, so this wasn't hard, or time-consuming. But she objected to it, anyway. After I had been living in her home for about nine months, she told me that she was through feeding me and that I needed to get a g-tube or she'd kick me out and leave me on the curb. I didn't want a g-tube, and I didn't need a g-tube. I just

needed my food prepared correctly. Luckily, I was able to tell a friend what was going on. I was scared to tell because I was afraid Martha would hurt me, but I was also afraid of dying. My friend was very supportive and helped me get the courage to leave the host home. I went to visit my mom for Thanksgiving, and just never went back.

To this day, I'm scared of ever trying a host home again. I might consider being in a host home if I already knew the provider well and trusted them, but after Martha, even if I trusted the provider, I'd still be scared. I don't know if I'll ever be over it.

An outsider would think that a situation like this could never happen. The problem is that it can happen, and does all the time. This is what happens when IDD services try to operate on a "business model" template. The IDD system has tried to promote itself as a business in which clients hire agencies and caregivers to meet their needs. In truth, the business model is flawed because people with IDD aren't truly consumers in the strict sense of the word. In the normal world, if a consumer (in the business sense) is unsatisfied with the products one company provides, they can vote with their feet and go to a different company. If one is unhappy with Wal-Mart, they can simply drive a few blocks to Target or Kmart. They have the awareness that they aren't receiving the treatment they should be, they have an array of easily accessible alternatives, they can independently access those alternatives, and they are empowered enough to make the decision to switch. This is not true of clients in the IDD system. We are essentially a captive population. The business model of IDD services holds that agencies which provide poor-quality services will lose customers and close, leaving only quality agencies providing services. What actually happens is that poor-quality agencies simply end up with the clients who have the least advocacy. These poor-quality agencies don't die a quiet death by their own hand as the business model states; they instead thrive economically while simultaneously becoming pits of endless despair for the clients trapped in them. There is a critical need for oversight of host homes in the IDD system.

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DeAnn Major – Director of Adult Advocacy, The Arc of Adams County

April 20, 2023

Good afternoon, Committee Members:

My name is DeAnn Major, and I have worked in the field of Intellectual and Developmental Disabilities for the past twenty plus years working directly with people living in host home settings. In my current position as the Director of Adult Advocacy, I conduct intakes of all possible new cases in Adams County as well as work on my own individual advocacy cases. By working with people in services and their family members closely, advocates can establish relationships and get closer to the truth of what services look like when we aren't visiting with people in their host home. We understand that every conversation, and in-person interaction may reveal more of what is happening, including (unfortunately) possible neglect or abuse. People in services may start to expect and/or accept this type of treatment because it is all they have known, or they are unable to speak for themselves, and that is truly heartbreaking.

As a result of our collective concerns about the deteriorating quality of host homes, over the past several years the Adult Advocacy Team in our office has tracked formal complaints that we have made on behalf of adults in services to the Colorado Department of Public Health and Environment (CDPHE) which is the regulatory agency that takes complaints against service agencies. We have also met with Health Care Policy and Financing department heads and collaborated with other advocacy organizations to examine who is responsible for the monitoring and accountability of host home providers and/or service agencies that are not providing quality services and even directly causing harm, including death, to people in services. We have been reviewing current rules and regulations set by the State to ensure quality standards and to identify where breakdowns are happening. Our organization also contributed to the Sunrise Review where the State examined what, if any, harm was happening to people in host homes and could it be addressed with additional regulations. The final report of the Review was beyond disappointing: it acknowledged harm had been done but no further regulations were needed. The examples I shared with the State were cited three times specifically in the Sunrise Review, but I was never contacted for further details, nor were the families I contacted that submitted their concerns.

In the most severe cases, there have been questionable deaths of people in services. This usually results in a Critical Incident Report being submitted to the State for review, but it is rarely investigated or probed any further. In my own experience, there is seldom an investigation from the service agency, the Community Centered Board, Adult Protective Services, State Health Department or even law enforcement. I have had conversations with detectives in various municipalities that have been bewildered as to why a potential case

wasn't opened, including sexual assault cases. Rarely are cases of abuse or neglect prosecuted, which leaves the provider free to continue working in the field.

In one particularly egregious case I had during the start of the COVID Public Health Emergency, I was removed as the person's advocate at the request of the host home provider (the person in services was easily coerced) who then proceeded to change the case manager, the service agency, and even the case management agency because financial exploitation was suspected of the person's trust fund. The host home provider chose a new service agency that would pay him a higher daily rate and with less paperwork (his words) and then proceeded to isolate the individual and not even let his family talk to him on the phone or see him in person even after the family was vaccinated. I was later contacted by the person's sister who shared significant health and safety concerns and disturbing details of his living conditions that came to light because she was finally able to see him in person. This only happened because he was in the hospital for a brain tumor and the sister could talk to him without the host home provider present. While isolated in the host home he had suffered a broken femur under suspicious reasons that even his family doctor questioned (he was immobile, but provider claimed he got up without supervision), had lost significant weight, and he wasn't taken to the ER for seizure activity that had recently started. Unfortunately, he died shortly after the removal of his brain tumor. The only reason there was an investigation into his death was a result of the sister and I making a formal complaint to the State Health Department together against the agency. Law enforcement even told the sister they wouldn't open the case because the victim was dead. It is apparent the State has no authority over host home providers, and even though the service agency in this case was cited **sixteen** times by the Colorado Department of Public Health and Environment for violations (including no monthly monitoring for a home with three people) it still operates today in good standing and the host home provider continues to get paid with Medicaid dollars. At this time, there is no agency or entity that can competently monitor or even penalize such outrageous acts against vulnerable people in services. Who has ultimate authority over host homes?

One can only imagine how incredibly frustrating and devastating this is to individuals and families that are trusting the system to do the right thing. **A system of checks and balances does exist for health and safety standards, but only in writing, and therein lies the danger.** Health Care Policy and Financing does have the authority to close agencies, but this is an extremely rare act so bad agencies continue to operate and/or bad host home providers hop from agency to agency.

The good, reputable agencies are also penalized because they see their hard work and actual monitoring seen as intrusive by some providers who will actively seek out an agency that requires less work. I have worked on a case where Adult Protective Services substantiated medical neglect due to sixty doses of medications being undocumented by a provider. Prior to this, the host home provider threatened legal action against the agency that was trying to do the right thing by terminating the contract. The provider claimed his livelihood was impacted and the agency was concerned about their ability to financially afford legal representation even though they were in the right. At times it seems there are no clear rules in how to handle a rogue host home provider. These cases are rarely investigated by Adult Protective Services so

host home providers are seldom placed on the CAPS list and prohibited from being hired in the field again.

The alarm bells are ringing: people are living in squalid conditions in many host homes where the most vulnerable of our community are placed to live. They are seen as an easy way to make money without much interference if the agency isn't invested in the person's care. This will undoubtedly result in more tragic deaths if oversight and monitoring are not increased, and serious penalties imposed for those repeat offenders.

Thank you for taking the time to read this,

DeAnn Major

Director of Adult Advocacy



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