

House Health & Insurance
 03/21/2023 Upon Adjournment
 HB23-1197 Stakeholder Process For Oversight Of Host Home Providers
 Typed Text of Testimony Submitted

Name, Position, Representing	Typed Text of Testimony
Lloyd Lewis For himself	<p>Written Testimony of Lloyd Lewis</p> <p>Before the Committee, House Health & Insurance HB23-1197 (Stakeholder Process For Oversight of Host Home Providers (Young))</p> <p>State of Colorado House of Representatives March 20th, 2023 Testimony</p> <p>As the father of a son with Down syndrome and the CEO of arc Thrift Stores, a nonprofit retail thrift operation that employs over 450 individuals living with intellectual and developmental disabilities (I/DD), it is of pronounced importance that people like my son and arc Thrift employees have safe and comfortable host home opportunities to live and thrive. The environment, the duties, and responsibilities of host home providers should be a compliant process with defined accountability to ensure one’s safety.</p> <p>The unfortunate reality is that the current system lacks accountability that leaves residents at risk of neglect and abuse, and I support to change the current system. The outline of 2022 Sunrise Review, produced by DORA, highlights many examples of neglect and abuse to host home residents that further identifies the need for more host home oversight and regulation. I am in favor of HB23-1197. I feel strongly that Colorado should prioritize the safety of host home residents. I want to ensure my son and arc Thrift employees living with I/DD have a greater level of protection and safety if living in a host home environment.</p> <p>And, I feel it is reasonable to expect those receiving payment for caring for those with I/DD meet minimum standards of care that are clearly defined and outlined in rule. Furthermore, Program Approved Service Agencies, PASA’s, and ethical host home providers also deserve to have clear and detailed rules that they can follow. I propose the rules clearly outline: Host home provider and PASA responsibilities, avenues for complaints, consequences should detrimental neglect and abuse be found against the host home provider or PASA, and ensure compliance of a host home when a corrective plan is filed.</p> <p>Ultimately, the safety of Colorado residents living with I/DD living in host home environments should be a basic right and rule. I thank you for your consideration and urge the committee to support HB23-1197.</p>



*For people with intellectual
and developmental disabilities*

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HB 23-1197: Stakeholder Process for Oversight of Host Homes
Kari Easterly, Executive Director, Arc of Adams County
March 21, 2023

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, 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 include 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

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

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

March 21, 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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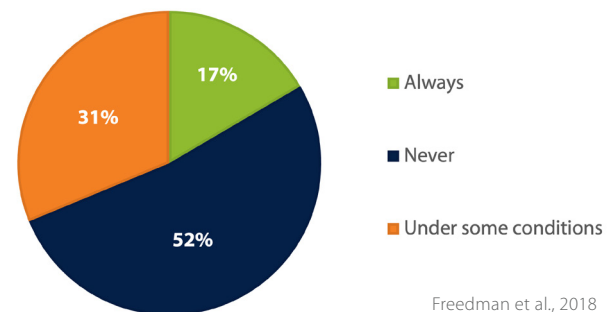
Key Points:

- Most women believe that hospitals should not be able restrict access to reproductive health care based on religion and that it is unacceptable for hospitals to restrict reproductive health care because of religion.
- Many women were not able to identify the religious affiliation of their hospital when seeking reproductive care.
- When choosing a hospital for reproductive care, some women believed the hospital's religious affiliation is important among other reasons, but less than one percent of women believed that religion is the most important consideration.
- The majority of women expect to be able to receive reproductive services regardless of the religion of the hospital.

In a national survey investigating patient awareness of the presence of Catholic hospitals and the implications on reproductive health care, **1,430 women were asked, "should hospitals be able to restrict care based on religion?" 83% said never or only under certain conditions.**

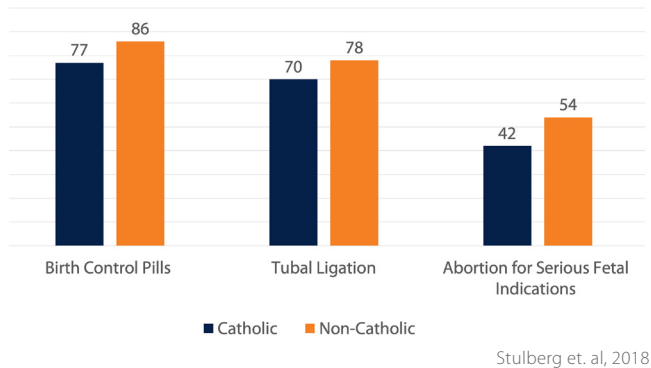
80.7% feel that knowing about a hospital's religious restrictions on care is important before deciding on where to get care.

More than two thirds of women find it unacceptable for hospitals to restrict information and treatment options for miscarriage because of religion.¹ The majority of women expect to be able to receive services regardless of which hospital they attend.

When Should Hospitals Be Able to Restrict Care Based on Religion?**Under which conditions?**

- No taxpayer funds are used to support the hospital
- Patients are informed of hospital's religious restrictions before visit
- Patients arriving by ambulance, unconscious, or in an emergency situation are offered transfer to another hospital

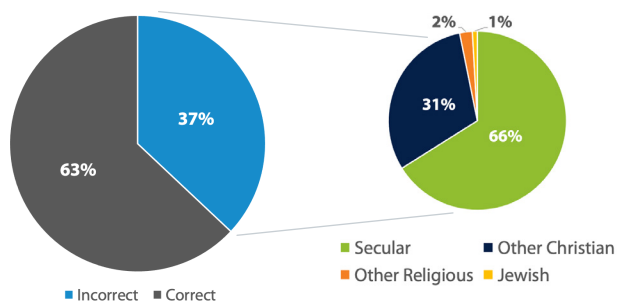
Expectations of Service Provision Based on Hospital Religion



Attending weekly religious services or being Catholic did not make women more or less likely to want information on their hospital's religion.

Women were more likely to correctly identify their hospital as Catholic when the hospital had a religious sounding name. **37% of women whose primary hospital is Catholic did not know the hospital was Catholic, and 66% who misidentified their Catholic hospital's affiliation, thought their hospital was secular.**²

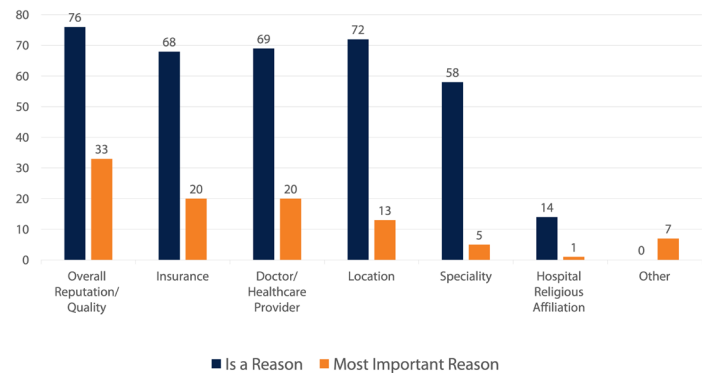
Percent of Women Who Misidentified Their Catholic Hospital and How the Hospital Was Classified



As household income increased, so did the respondents' likelihood to correctly identify a hospital as Catholic indicating **lower-income women may face more unexpected restrictions when seeking care.**³

When asked about their reasons for choosing a hospital for reproductive care, **13.6% checked the hospital's religion as one among several reasons, but 0.7% felt religion was the most important reason.**⁴

Reasons for Choosing a Hospital for Reproductive Care



References

1. Freedman LR, Hebert LE, Battistelli MF, Stulberg DB. Religious hospital policies on reproductive care: what do patients want to know? *Am J Obstet Gynecol.* 2018 Feb;218(2):251.e1-251.e9.
2. Wascher JM, Hebert LE, Freedman LR, Stulberg DB. Do women know whether their hospital is Catholic? Results from a national survey. *Contraception.* 2018 Dec;98(6):498-503.
3. Stulberg DB, Guiahi M, Hebert LE, Freedman LR. Women's Expectation of Receiving Reproductive Health Care at Catholic and Non-Catholic Hospitals. *Perspect Sex Reprod Health.* 2019 Sep;51(3):135-142.
4. Hebert LE, Freedman L, Stulberg DB. Choosing a hospital for obstetric, gynecologic, or reproductive healthcare: what matters most to patients? *Am J Obstet Gynecol MFM.* 2020 Feb;2(1):100067.

Written Testimony of Lloyd Lewis

Before the Committee, House Health & Insurance HB23-1197 (Stakeholder Process For Oversight of Host Home Providers (Young))

State of Colorado House of Representatives March 20th, 2023 Testimony

As the father of a son with Down syndrome and the CEO of arc Thrift Stores, a nonprofit retail thrift operation that employs over 450 individuals living with intellectual and developmental disabilities (I/DD), it is of pronounced importance that people like my son and arc Thrift employees have safe and comfortable host home opportunities to live and thrive. The environment, the duties, and responsibilities of host home providers should be a compliant process with defined accountability to ensure one's safety.

The unfortunate reality is that the current system lacks accountability that leaves residents at risk of neglect and abuse, and I support to change the current system. The outline of 2022 Sunrise Review, produced by DORA, highlights many examples of neglect and abuse to host home residents that further identifies the need for more host home oversight and regulation. I am in favor of HB23-1197. I feel strongly that Colorado should prioritize the safety of host home residents. I want to ensure my son and arc Thrift employees living with I/DD have a greater level of protection and safety if living in a host home environment.

And, I feel it is reasonable to expect those receiving payment for caring for those with I/DD meet minimum standards of care that are clearly defined and outlined in rule. Furthermore, Program Approved Service Agencies, PASA's, and ethical host home providers also deserve to have clear and detailed rules that they can follow. I propose the rules clearly outline: Host home provider and PASA responsibilities, avenues for complaints, consequences should detrimental neglect and abuse be found against the host home provider or PASA, and ensure compliance of a host home when a corrective plan is filed.

Ultimately, the safety of Colorado residents living with I/DD living in host home environments should be a basic right and rule. I thank you for your consideration and urge the committee to support HB23-1197.

Sincerely,

Lloyd Lewis