Protect the Homes and Health and Rights of Adults with I/DD[1]

In 2022, ODDS[2] finalized OAR 411-450-0060(6) which affected all people with I/DD who live and receive hourly attendant care, i.e., care *outside of residential care facilities*. The new rule restricts where people with I/DD can live and makes them **ineligible** for the hourly attendant care they need and otherwise qualify for simply because of who owns the property where their rental unit is located. If one of their caregivers owns the property, ODDS terminates them from the nonresidential care program.

So far, ODDS has terminated 5 *severely* disabled adults with I/DD, namely, Andrew, Wesley, Timothy, Corinna, and Crystal, from their nonresidential care program because the **homes *that they rent*** are owned by one of their caregivers.

ODDS **terminated their attendant care services** because they refused to relinquish their right to live in their rental homes where they have lived for many years and refused to relinquish their right to choose their Medicaid hourly attendant caregivers. None of these individuals can survive without their attendant care services.

- Oregon and Federal law recognize that Medicaid beneficiaries are not required to relinquish their **right to access housing** that other people may access or to relinquish their **right to receive care from any qualified Medicaid caregiver** that they choose.

- Oregon is **paying Department of Justice attorneys tens to hundreds of thousands of dollars in taxpayer funds** to defend the lawsuits filed over ODDS's rule change.

- Please rescind ODDS's new (illegal) language and reinstate the original language at OAR 411-450-0060(6) that has been in place since 2016.

- Please amend the outdated statutory definition of "foster care home" to protect the right of people with I/DD (and all other Medicaid beneficiaries) to live in any home that they choose, including the home of a caregiver, when they choose to receive hourly attendant care as opposed to residential care.

[1] Intellectual and Developmental Disabilities
[2] The Department of Human Services Office of Developmental Disabilities Services

CONTINUED...

THE RULES COMMITTEES, THE HEALTHCARE AND HUMAN SERVICES COMMITTEES, AND THE HOUSING COMMITTEES:

1. The Department of Human Services (DHS) ***Denies*** by administrative rule ***access to housing*** for people with intellectual and developmental disabilities (I/DD) that the Oregon Legislature ***Grants them*** in Statute.
2. People with I/DD are unnecessarily dumped into **hospital emergency rooms** and experience unnecessary **extended stays in hospitals** because of DHS administrative rules and policies that keep them there.
3. Oregon legislators believe **they have no authority** to **correct administrative rules** and department policies that **thwart statutes duly passed by the legislature**.
4. The Administrative Procedures Act is **ineffective in protecting Oregonians** because it does not assist Oregonians to prevent departments from **promulgating and finalizing rules that directly conflict with Oregon statutes** and consequently **harm innocent Oregonians**.

People with Intellectual and Developmental Disabilities, I/DD, among other Oregonians with disabilities are crushed by these four problems. The following describes how this occurs and offers solutions.

Oregon's History of Residential Care for people with I/DD

Historically, people with intellectual and developmental disabilities, I/DD, were "placed" in an institution in Salem called Fairview to receive the attendant care they needed to accomplish basic activities of daily living such as toileting, eating and recreating.

In the 1970's and 80's, Oregon began to offer other 24-hour residential care options besides Fairview for people with I/DD and in 1983 the Oregon legislature passed SB 22 which instituted adult foster care homes.

In 1985, the legislature began to require the licensure of adult foster care homes which the legislature defined at ORS 443.705 as:

> *"any family home or facility in which 24-hour care is provided for five or fewer adults who are not related to the provider by blood or marriage"*

In 1987, the legislature changed the adult foster home definition from

> **"***any family home or facility in which **24-hour care** is provided for five or fewer adults who are not related to the provider by blood or marriage* **"**

TO

> "*any family home or facility in which **residential** care is provided for five or fewer adults who are not related to the provider by blood or marriage*"

"Residential care" was then defined as

> **"***the provision of **room and board and services** that assist the resident in activities of daily living..."*

The statutory definition of adult foster home did not distinguish how "room and board and services" were to be provided. Specifically, it did not answer the question of whether separate entities could furnish room and board and services and still be considered a foster care home. Nor did the definition make it clear that *24-hour care and supervision* was required of an adult foster care home provider because the statue only required the provision of an undetermined amount of "services".

In 1987 though, it didn't matter that the statute failed to clarify that a single provider was required to furnish room and board and 24-hour care and supervision because that was the standard practice for "residential care" and nobody questioned it.

The last person moved out of Fairview in 2000 but the only places that Oregon had for people with I/DD to go to receive attendant care in Oregon communities was in 24-hour residential care facilities such as group homes and adult foster care homes.

Oregon Institutes *Nonresidential* Care for People with I/DD

It took the *Staley* lawsuit in 2000 for the Department of Human Services Office of Developmental Disabilities, DHS, to institute ***nonresidential*** care in the community for Oregonians with I/DD.

Under the *Staley* settlement, people with I/DD were no longer forced to move into a **residential care** facility such as a foster care home or group home to get the attendant care they needed. ***Nonresidential*** care was finally available. DHS offered ***nonresidential*** care services to people with I/DD by paying for attendant care by the hour. People with I/DD could choose hourly attendant caregivers to come to their own homes and could choose multiple caregivers from a variety of attendant care providers.

No longer were people with I/DD restricted to receive residential care, i.e., attendant care from a single 24-hour residential care provider in the provider's home where the person with I/DD must live to access the provider's attendant care services.

Eligibility for Nonresidential Care

The only eligibility criteria for Medicaid beneficiaries with I/DD to get into the ***nonresidential*** care program, called the "Community Living Supports" program, was for the person with I/DD to live in their own home i.e., they **could not** live in a ***residential*** care facility.

The eligibility rule for the Community Living Supports program had been virtually the same from 2000 until 2022:

> *"An individual who lives in their own home or family home is eligible for the community living supports described in these rules..."* OAR 411-450-0060(6)(a)

By administrative rule, a person's "home" was understood to mean *any residence* that **was not** a residential care setting:

> *"Home" means the primary residence for an individual that is not under contract with the Department to provide services certified as a foster home for children... licensed as a foster home for adults... or a licensed or certified residential care facility, assisted living facility, nursing facility, or* ***other residential setting***. OAR 411-317-0000(100)

The Oregon Legislature Clarifies the Right of Oregonians with I/DD to Live Where They Decide and the Right to Receive Hourly Attendant Care Where They Live.

In 2019, the Senate Committee On Human Services passed SB 20 to codify in statute that people with I/DD could no longer be "placed" by government officials into the residential or nonresidential settings that officials thought best, but instead secured **to the person with I/DD** the right to decide to live in the **residential** or **nonresidential** community living setting *of their choice*.

The language that the Senate Committee On Human Services used to express this right for people with I/DD cannot be clearer:

> **"An adult has the right to choose the adult's community living setting.** The Department of Human Services or the department's designee **shall present** to an adult at least three types of community living settings**,** ***including an option for services in the adult's own or family home*** each year, prior to authorizing services in a community

living setting for the adult and *w*hen an adult is moving from one community living setting to another community living setting." (Emphasis added) Or. Rev. Stat. § 427.121

To make sure that a person with I/DD could access the attendant care services where the person chose to live, the statutory language states:

" The Department of Human Services, in carrying out the legislative policy declared in ORS 427.007 and 430.610, subject to the availability of funds, **shall** ... **ensure** that:

Persons with intellectual or developmental disabilities ***have the supports necessary to reside in the setting that they choose***" ORS 430.662(1)(a)(A)

To further highlight the legislative intent to give people with I/DD the choice of where they may live and receive services, the legislature made the distinction between the **residential** and **nonresidential** community living settings from which a person with I/DD has the right to choose, ORS 427.101(1):

"Community living setting" means:
(a) A residential setting;
(b) An individual's home or the home of the individual's family; or
(c) Other nonresidential setting"

Based on these statutes, people with I/DD who **do not** choose to live in a residential care setting have the same right to live in any dwelling in the community as do people who are not Medicaid beneficiaries. Honoring their choice of dwelling assures equal access to housing for people with I/DD and equal access to **nonresidential** care through the Community Living Supports program.

DHS Circumvents the Oregon Legislature Through Rulemaking

On December 20, 2022, through its rulemaking powers, DHS **terminated** eligibility for the Community Living Supports program based on who owns or rents the dwellings where a person with I/DD lives.

Under the new language at OAR 411-450-0060(6), people with I/DD no longer enjoy equal access to housing because DHS excludes all people with I/DD from the Community Living Supports program who live in any of the following dwellings:

- Any house, apartment, or condominium that is owned or rented by a caregiver, the caregiver's spouse or any employee of a caregiving agency.

- Any portion of a house, such as a basement or a garage, even when remodeled to be used as a separate dwelling that is owned or rented by a caregiver, a caregiver's spouse, or any employee of a caregiving agency.
- A trailer or mobile home that is owned or rented by a caregiver, a caregiver's spouse, or any employee of a caregiving agency
- A duplex that is owned or rented by a caregiver, a caregiver's spouse, or any employee of a caregiving agency unless the structure displays a separate address from the other residential unit and was originally built as a duplex.

Even people with I/DD **who are homeless lose eligibility** if they secure housing with a caregiver. Under DHS's rule, a person with I/DD *with no permanent address* is eligible for the Community Living Supports program, but if that person is fortunate enough to move into housing associated with a caregiver, DHS **terminates** their Community Living Supports, OAR 411-450-0060(6)(a) (2022).

How Could DHS Write Rules Contrary to Statutes?

It only took *one person* to upend the legislature's carefully worded language--- Mike Parr, a rule-writer in the Office of Developmental Disabilities Services.

The legislature does not terminate eligibility for the **nonresidential** care program based on the dwellings where people with I/DD choose to live, but Mike Parr did and ***the administrative rules that Mr. Parr wrote function as law*.**

It is unclear how Mr. Parr justified writing rules to thwart statutory protections for people with I/DD, protections that assure that they can live anywhere that people without I/DD can live. Curiously, he stated that the rules would "prevent unlicensed foster care", but it was curious because it was without a solid foundation. DHS already had rules in place to prevent "unlicensed foster care" and he failed to elucidate any kind of "unlicensed foster care" problems that DHS faced, nor did he explain how this rule would solve the seemingly nonexistent "problem" of unlicensed foster care. Importantly, the restrictions to housing Mr. Parr wrote into the rule did not accomplish that purpose.

Instead, Mr. Parr's rule violated not only Oregon's statutory rights for people with I/DD, but also their civil rights under the Federal Fair Housing Act and Title II of the Americans with Disabilities Act.

Mr. Parr single-handedly determined that *unlicensed foster care* is delivered in a person's home when the person lives in a unit that is owned by a caregiver, a caregiver's spouse, or the employee of a caregiving agency. The fact that the person with I/DD receives **nonresidential**

care in the home---hourly attendant care delivered by any providers the individual chooses--- did not dissuade Mr. Parr from his belief that the individual was receiving unlicensed foster care.

Mr. Parr simply failed to examine the legislative differences between *residential* care in an adult foster care home and *nonresidential* care in the Community Living Supports program.

Instead, Mr. Parr depended on the outdated statutory definition of "foster care home" which at this time in history, fails to identify adult foster care homes as homes that are required to deliver 24-hour care and supervision from a single provider of services who must also furnish room and board for the person.

The distinctions between nonresidential care and adult foster care are clear for people who must decide between them, but for the rest of us, the distinctions become clearer when two questions are asked and answered:

1. **Does the person rent their own dwelling?** If yes, the person lives is their own home, they do not live in a foster care home. Under a **rental agreement,** a person determines with whom they wish to live, if anyone, and they are fully protected by Oregon's landlord/tenant laws. A person's rental home where they receive nonresidential hourly attendant care is not an adult foster care home because *people cannot rent a foster care home.* A person who chooses the foster care program is required to sign a **residency agreement with the foster care provider** as a condition of entering the adult foster care home. Under a residency agreement the person has no substantial control over their home including what residents enter or leave the adult foster care home--- the foster care provider has control over the home and makes these decisions.

2. **Does a person have their choice of multiple providers and provider types?** If yes, their residence is their own home, it is not an adult foster care home. People who choose ***nonresidential*** care are free to hire and fire providers at will regardless of where they live. In contrast, a person who chooses ***residential care*** including foster care, are contractually restricted to receive 24-hour attendant care services from their residential care (foster care) provider. People who choose residential care must move out of their foster care home to change providers. People who live in their own homes and receive nonresidential care are under no compulsion to move out of their home simply to change or add providers of hourly attendant care services.

The Administrative Procedures Act that oversees how departments promulgate administrative rules does not protect Oregonians from administrative rules that violate Oregon Statutes.

For example, the rules advisory committee that Mike Parr facilitated to promulgate the rule at issue had no one on it whose services would be terminated by the rule, so their voices simply were not heard.

Additionally, I personally sent in comments to the rule that demonstrated how the rule violated the rights of people with I/DD, but the rules advisory committee could not see these comments. Comments to the rule are only allowed to be submitted *after* the rules advisory committee meetings are concluded so the committee is not appraised of public comments or concerns, only the department staff are cognizant of public comments to the rule.

Further, the identities of the rules advisory committee members were not publicly available, and because the committee meetings were not open to the public, the public could not ask questions or comment during the meetings. I do not know if anyone other than DHS staff saw any comments made to the rule, including mine, prior to the finalization of the rule.

In the past week, I brought this problem to several legislators. Each explained to me that they had no power over an administrative rule that defies statutory language. The only power that our legislators believe they have is to write laws, they cannot correct an administrative rule that conflicts with statutes even though these rules ***function as a law.***

Seemingly, Mr. Parr failed to update his knowledge of the Oregon statutes, most importantly, SB 20 in 2019, before undertaking writing DHS rules.

Perhaps had Mr. Parr been trained to read the statues, he would have understood the rights that Oregon gives to people with I/DD; rights for which he did not have the authority to write a rule to take away. After all, Mr. Parr is not an elected member of the legislature.

The crisis that ensued in the lives of the five people with I/DD that my company cares for was almost unbearable. They all received Notices of Planned Action that terminated their services 17 days after the date of the notice. Their caregivers would have to take them to a hospital emergency room on the 18th day because DHS terminated their services.

It was the kindness of an attorney who agreed to contest their termination notices before an administrative law judge that initially saved the five people with I/DD from a hospital emergency room.

Unfortunately, the judge who oversaw the case was a recent employee of the Department of Human Services as a rules coordinator. Nobody knew of the judge's conflict of interest until after the judge issued his order and unsurprisingly his order sided with DHS. The judge's order did not address any statutes except those that granted the department the authority to write rules.

Based on the department's authority to write rules and the judge's determination that the department followed the correct process, he validated the rules.

The Administrative Procedures Act should make it very clear that an administrative law judge is not allowed to conduct hearings between the department in which he was recently employed and an Oregonian who depends on that same department for the care they need to survive unless the judge at the very least admits the conflict of interest before he commences the hearing.

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1. PROBLEM: The Department of Human Services (DHS) ***Denies*** by administrative rule ***access to housing*** for people with intellectual and developmental disabilities (I/DD) that the Oregon Legislature ***Grants them*** in Statute.

   SOLUTIONS:

   Pass SB 58 to open additional housing for Oregonians and assure that seniors, people with I/DD, and other vulnerable populations are not barred by administrative rule from accessing SB 58 units.

   Require DHS to restore OAR 411-450-0060(6) to its original language and intent to align DHS's administrative rules with Oregon statutes that secure the right of people with I/DD to live in nonresidential care settings including settings that caregivers own.

2. PROBLEM: People with I/DD are unnecessarily dumped into hospital emergency rooms and experience unnecessary extended stays in hospitals because of DHS administrative rules and policies that keep them there.

   SOLUTIONS:

   Review all DHS rules and policies that effect people with I/DD and modify them as necessary to assure that DHS rules and policies no longer needlessly put or keep people with I/DD in hospitals. This review should not be tasked to DHS because of DHS's inherent conflict of interest.

   Write a statute that requires hospitals to identify people with I/DD and keep track of how long they are in the hospital past their date of discharge readiness. Provide a billing system for hospitals that allows the hospital to bill

DHS for the days people with I/DD are left in the hospital past their discharge readiness date. Require DHS to report to the Health Committees the costs DHS incurs from these hospital billings and require DHS to reduce these costs.

3. PROBLEM: Oregon legislators believe **they have no authority** to correct administrative rules and department policies that thwart statutes duly passed by the legislature.

   SOLUTIONS:

   Write a law (if there is not already a procedure) that provides Oregon's legislators with a reliable and efficient procedure at their disposal to rescind, nullify or modify administrative rules that thwart Oregon's laws.

   If a legislator rescinds or modifies a rule that a department believes supports legislative intent, the new procedure may allow the department to appeal to the Oregon Court of Appeals to uphold its rule. This element of the procedure would protect Oregonians from having to take administrative bodies to Court simply to be free to live under the laws passed by their elected officials.

4. PROBLEM: The Administrative Procedures Act is ineffective in protecting Oregonians because it does not assist Oregonians to prevent departments from promulgating and finalizing rules that directly conflict with Oregon statutes and consequently harm innocent Oregonians.

   SOLUTIONS:

   Pass HB 2692 and 3382 to allow Oregonians more meaningful access to administrative rule making so that Oregonians have a greater voice in the promulgation of administrative rules that have the power of law.

   Ensure that the finalization of administrative rules (unless they are needed for a specific emergency) take effect no sooner than 30 days upon the date of filing with the Secretary of State to allow enough time for Oregonians to inform their legislators of instances where an administrative rule thwarts, contradicts or imposes barriers to Oregon laws. This provision offers an efficient method to stop an unlawful administrative rule before it affects

Oregonians and it gives legislators time to investigate the issue and if needed, invoke the procedure in #3 above before the administrative rule takes effect.

Oregon Wastes Precious Tax-payer dollars to Defend DHS'S Illegal Rule

From the finalization of DHS's illegal rule in December of 2022, to the present, Oregon has been in litigation over the rule--- **wasting Department of Justice attorney time paid** with thousands of tax-payer dollars. To what purpose? To defend a DHS rule that punishes innocent and vulnerable people with I/DD for exercising their right to live where they wish to live and with whom they wish to live-- a right that the rest of us take for granted.

DHS refuses to reestablish the rule in its original form and settle three pending lawsuits and one lawsuit soon to be filed, all of which are a continuing and shameful waste of thousands of tax dollars by the State of Oregon:

- Case 3:22-cv-01957 filed in Federal Court in December of 2022. This case is ongoing.

- Five Contested Cases from DHS's December 2023 Notices of Planned Action that all five of the people with I/DD were issued. All five cases are ongoing.
    - Administrative Law Judge Ramey was assigned this case even though recently **he was a rules coordinator employed by the Department of Human Services.** ALJ Ramey did not disclose his affiliation with DHS nor did he recuse himself from the contested case.
    - ALJ Ramey opined that because DHS substantially complied with the *rulemaking procedures*, the rule is valid. This judge did not address the rule's violation of Oregon's stated legislative policy, the rule's violation of Federal Law or the rule's violations of the civil rights of people with I/DD.
    - This case is being appealed to the Oregon Court of Appeals

- Case A 183802 filed in March 2024 in the Oregon Court of Appeals

- The attorneys kindly representing Tim, Andrew, Wesley, Corinna and Crystal are preparing a brief to file in Federal Court to protect their civil rights.

Had a single person, in this case Mr. Parr, been trained to compare proposed rules to Oregon law before writing departmental rules, the rights that people with I/DD have under Oregon law would have been upheld by both Oregon law *and* administrative rule. Oregon would not be in litigation over the rule, the legislature would not have to deal with an illegal DHS administrative rule and the individuals with I/DD would be free from the fear of losing their homes and/or their caregivers (providers).

DHS Misrepresents New Rule Language to Senator Gelser-Blouin

On January 25, 2023, Joan Schrader sent Senators Gelser-Blouin and Mark Meek an email (attached) with the subject "Please Rescind Agency with Choice Rule OAR 411-450" advocating for the right of people with I/DD to exercise self-determination. She wrote:

> "DSPs and PSWs (caregivers) who are willing to share space in their personal homes with individuals in the Community Living Supports program provide needed housing for individuals with I/DD who choose to live outside of residential facilities such as foster homes and group homes. The new rule outlaws this kind of shared housing and makes anyone sharing housing ineligible for the Community Living Supports program. This means that an individual must move out of the home they share with one of their caregivers to be eligible to receive Community Living Supports! I believe we have enough homelessness in Oregon without adding people more with I/DD.
>
> DHS was ostensibly attempting to stop "unlicensed foster care" through the CLS rule. Of course it is important to prevent unlicensed care, however, sharing housing with a DSP or PSW does not turn that home into "unlicensed foster care". All DSPs and PSWs are qualified to provide care so no "unlicensed" care is occuring.
>
> Also, it is noteworthy that individuals in the Community Living Supports program retain their choice of providers regardless of where they live in contrast to foster care homes where securing the services of a foster provider is dependent upon living in the foster home.
>
> Not surprisingly, because the rules thwart Oregon statutes, the rules also violate the Fair Housing Act and the Americans with Disabilities Act for the individuals with I/DD in Oregon who choose to share housing with one of their caregivers."

On February 3, 2023, Senator Gelser-Blouin requested Justin Withem to contact DHS and obtain for herself and Senator Meek the background information from DHS regarding Mrs. Schrader's letter. Senator Gelser-Blouin stated,

> "I was wondering if the agency could provide some background on this for Senator Meek and me? I know we discussed this briefly with Anna at our last meeting but it would be helpful to have an email back for easy reference if similar questions and concerns are raised."

On February 3, 2023, DHS responded to Justin Withem that a "rule update" was made for "clarification purposes" and that nothing had changed in ***interpretation of statue*** or ***practice*****.**

The falsity of DHS's statements in response to Senator Gelser-Blouin is easily demonstrated because DHS changed both DHS's *interpretation of SB 20* (2019) and *changed DHS practices*.

Under the original rule that had been in place for many years at OAR 411-450-0060(6), all individuals with I/DD had been free to exercise self-determination and live safely in their rental homes and receive Community Living Supports from Community Living Supports providers of their choice.

To make its rule change, DHS had to *reinterpret* the statutory definition of "self-determination" that was incorporated into law in SB 20 (2019) to exclude the group of people with I/DD who rented their dwellings located in caregivers' homes because the language in SB 20 did not exclude any people with I/DD regardless of where they chose to live or from whom they received Community Living Supports services.

Under DHS's *new interpretation* of SB 20, DHS could change its rule language to deny the right of self-determination to any individuals with I/DD who chose nonresidential care services and chose to rent in a home owned or rented by a caregiver. Under the new language in DHS's rule, people with I/DD were excluded from their statutory right to self-determination, a clear *reinterpretation of statute.* Under DHS's interpretation, specific individuals with I/DD could not exercise their right to choose where and with whom they lived and receive Community Living Supports from their providers of choice.

In December of 2023, DHS issued Notices of Planned Action based on the new rule language in OAR 411-450-0060(6) to terminate the Community Living Supports services of five severely disabled individuals who share housing with their caregivers, *some of whom who have done so for over a decade.*

These notices of termination after all these years demonstrate that in fact, DHS *did change DHS "practices"* and the change in practice was directly based on DHS's new rule language.

The rule was not simply made to clarify, because the changes DHS made to OAR 411-450-0060(6) are what DHS relied upon to *terminate* Community Living Supports services, services for which people with I/DD had been eligible for many years--- under the same circumstances that DHS's new rule made them ineligible.

DHS claimed that their rule somehow "prevented unlicensed foster care". While this is an important function of DHS, foster care is a *residential care* service and the Community Living Supports service is a *nonresidential service*. DHS does not have the statutory authority to license nonresidential care services, only residential care services**--- another reinterpretation of statute that DHS must depend on to support its rule change.**

In DHS's email to Senator Gelser-Blouin, DHS misrepresented its position on SB 20 (2019), misrepresented its change in practices, and misrepresented residential foster care services as being Community Living Supports services.

It begs the question, what else has DHS misrepresented to Oregon's elected officials?