

Dave Cocagne
Silver Birch Living
JCARR Opponent Testimony on Rule 5160-1-06.5
December 11, 2023

Chairperson Callendar, Chairperson Gavarone, and members of JCARR,

My name is Dave Cocagne, and I am chairman of Silver Birch Living. We're the largest owner/operator of affordable assisted living in Indiana, and one of the chief proponents of the assisted living waiver provisions in H.B. 33 as adopted by the House and Senate.

I have provided voluminous testimony over the last several years on the role that affordable assisted living can play in expanding choice and access for thousands of Ohio seniors while saving the state's Medicaid program hundreds of millions of dollars annually and generating wide-scale investment in the state.

I will not replicate that testimony here today. Through H.B. 33, the legislature decided the merit of that policy and incorporated the critical access rate into the rates for Medicaid assisted living waiver providers.

The question before JCARR today is whether the proposed rule package meets the criteria that JCARR considers. I submit to you that it does not. In particular, it conflicts with the legislative intent of H.B. 33, and it will have an adverse impact on business in the state which the agency fails to address. Let me elaborate.

H.B. 33 incorporated 3 rates for assisted living waiver providers - a base rate, a critical access rate, and a memory care rate. In designing the contours of H.B. 33, the legislature sought not only to assist existing providers by raising the base rate but also to enable wide-scale expansion of affordable assisted living through creation of the critical access rate. The legislature recognized that the status quo isn't good enough, and it sought a fundamentally different set of option for Ohio seniors, options that seniors in many other states such as Indiana enjoy.

In his veto message, the Governor recognized the value of these increases, saying "The Ohio Department of Medicaid...and the Ohio Department of Aging are supportive of and will work to implement the proposed legislative rate increases...". Of course, legislative intent is determined by the legislature, not the Governor, but his words further validate the importance of this initiative.

ODM was not only aware of this effort, it in fact suggested that industry participants approach the legislature about seeking additional funding. Indeed, it has been extensively consulted over many years.

Notwithstanding this, ODM has proposed a rule that includes only 2 of 3 rates. Specifically, ODM has omitted the critical access rate.

These rates were never intended to be separated. Rather than raising the base rate for all providers, the legislature sought to minimize the fiscal impact and create a separate critical access rate that would only apply to providers who focus predominantly on Medicaid residents. As Rep. Carruthers stated recently, "It was not my intent to bifurcate the base rate from the critical access rate. It was laid out clearly in the budget." The proposed rule package defeats this intent and is expressly contrary to H.B. 33.

Not only does the rule package not adhere to H.B. 33's intent and express provisions, in omitting the critical access rate it will have an adverse impact on business.

Right now, Silver Birch has 4 sites under contract and an additional 5 in contract negotiation for construction of new assisted living communities in Ohio. These are in Mansfield, Cleveland, Akron, Canton, and Columbus. Each community that we build represents \$35 million of investment in Ohio, 40-50 jobs, and tens of millions of dollars of Medicaid savings. Each one. Not only will the omission of the critical access rate have an adverse impact on the revenue of these communities, it will ensure most of them are never built. Of the 4 under contract, only 1 would be built because it can access additional federal incentives. The other 3 cannot. Across those 4 sites alone, \$140 million of investment just became \$35 million. 200 jobs just became 50. Tens of millions of dollars in Medicaid savings became just a few.

We have approached ODM about these concerns on numerous occasions since it released the proposed waiver amendment to CMS in July. We have submitted written comment letters twice and testified at ODM's November hearing on the proposed rule package. In its hearing summary report, ODM indicates that "the department is solely focused on implementing simple rate increase in order to hit a January 1, 2024 deadline for *all* providers across the board."

Despite this statement, ODM is implementing a new memory care rate, which is anything but simple. In fact, it is far more complex than the critical access rate. Furthermore, it does not benefit all providers. It benefits only those that offer memory care.

Just as it has with the memory care rate, ODM has had 5 months since the budget passed to incorporate the critical access rate into the rules package; it has known for many more months than that the critical access rate was a legislative priority.

As these contradictions demonstrate, ODM is picking and choosing and is claiming for itself the legislature's authority to decide the state's fiscal policy. It is ignoring not only the legislative intent of H.B. 33 but also its express provisions. In doing so, it is harming business in this state, destroying new jobs, eviscerating new investment, and foregoing hundreds of millions of dollars in savings to the state budget.

I had hoped after discussion that the agency would revise these rules prior to filing, but it has not. In the absence of changes or further economic impact analysis, I understand that asking you to recommend is our only remedy.

December 4, 2023

Joint Committee on Agency Rule Review
The Ohio General Assembly
Vern Riffe Center
77 South High Street
Columbus, OH 43215

Dear JCARR Committee Members,

I appreciate the opportunity to testify on the matter of the proposed family caregiver rule, Ohio Administrative Code 5160-44-32. It is a critical issue that affects countless families across our state.

Recently, I was heartened to hear CMS Deputy Administrator and Director Daniel Tsai refer to paid parents and spouses as "the silver lining of the pandemic." The dedication of family caregivers allowed individuals to remain safe in the comfort of their homes and communities during the worst caregiver shortage in our nation's history. While I strongly support Ohio's implementation of a permanent policy for compensating legally responsible caregivers, the current draft of the rule contains a line that violates two of JCARR's prongs, and therefore this line must be invalidated from the rule. 5160-44-32 (E)(1)(a) both conflicts with an existing rule and implements a federal rule in a manner that is more stringent than the federal rule requires. Additionally, several other stipulations violate JCARR's prong regarding implementing federal rules in a manner that is more burdensome than the federal requirements dictate.

First, 5160-44-32 (E)(1)(a) directly contradicts state free choice of provider laws, including OAC 5160-41-08 and OAC 5123-9-11, which mandate adherence to federal free choice of provider regulations, namely 42 C.F.R. 431.51. The free choice of provider is a fundamental principle that empowers disabled individuals to select the most suitable caregiver based on their unique preferences and needs, protecting their dignity and humanity. Section (E)(1)(a) of 5160-44-32 states that a spouse or minor child cannot freely choose their spouse or parent, respectively, as their caregiver. Instead, they are required to accept any willing and able job applicant. This restriction directly contradicts the essence of free choice and places unnecessary barriers on individuals seeking the most suitable caregivers for their specific circumstances.

Despite raising this concern with the Ohio Department of Medicaid (ODM) and the Ohio Department of Developmental Disabilities (DODD) on multiple occasions, the response provided is unsatisfactory: "Prior to the COVID-19 public health emergency, parents were not permitted to be paid providers of services to their minor children nor could spouses be paid providers of services...Rule 5160-44-32 reflects expanded flexibility for individuals and families who receive services." While the agencies rightly state that the new rule now includes parents and spouses in the provider pool, they fail to address the core issue of limiting care recipients' free choice of provider. In essence, the addition of caregivers to the applicant pool, coupled with the restriction on individuals' ability to choose those caregivers freely, stands in clear violation of

free choice of provider laws. This issue requires careful reconsideration to ensure that the rights and preferences of individuals receiving services are upheld.

DODD and ODM's additional response to the free choice of provider issue is to challenge disabled individuals to a game of "chicken" when it comes to their care. DODD writes, "The parent/guardian has the right to choose from all willing and able providers, which includes the right to reject all willing and able providers. Rejection of all willing and able providers does not make the parent eligible to be a paid provider." This approach forces disabled individuals into an untenable situation in which they are compelled to accept providers who do not meet their specific needs and preferences. For example, if the disabled individual maintains a nonsmoking household and the sole applicant is a heavy smoker, the individual is left with no alternative but to accept this unsuitable candidate. Failure to do so would mandate the individual's spouse or parent to render services without compensation. Similarly, consider a scenario in which a young woman strongly prefers assistance from a female caregiver for bathing and menstrual care. If the sole applicant is male, she is left with the distressing choice of compromising her comfort and privacy or begging a female family member to provide these services without pay. This approach constitutes a clear infringement on the waiver recipient's ability to freely choose a caregiver aligned with her specific needs. It creates an unfair and wholly unnecessary dilemma that undermines the principle of individual autonomy in the selection of care providers.

Furthermore, from a practical standpoint, the implementation of Section (E)(1)(a) has serious consequences. Individuals who have received services from providers they freely chose for almost four years now (since April of 2020) face the prospect of having their freely chosen, experienced, qualified caregivers removed due to the requirement to fire their spouse or parent and replace them with any stranger the county board manages to find.

Secondly, several sections of 5160-44-32 run afoul of JCARR's final prong because they implement federal rules in a manner that is more burdensome than the federal rule requires. Federal guidelines regarding legally responsible individuals (LRIs) working as paid caregivers are outlined in CMS's "Instructions, Technical Guide, and Review Criteria" manual. CMS does indeed place certain restrictions on LRI caregiver work. For example, LRIs are only permitted to be paid for "extraordinary care," and OAC 5160-44-32 rightly complies with this requirement. However, ODM has added several more burdensome restrictions that are *not* required, encouraged, or endorsed by CMS. This includes the aforementioned (E)(1)(a) 'provider of last resort' clause, the arbitrary 40-hour limits in (E)(2)(c) and (E)(2)(d), the requirement that LRIs work as agency employees in (E)(2)(a) and (E)(2)(b), and the ability for county boards to reject any LRI for any reason with no appeal rights (J). In a meeting with our organization in May of 2023, CMS Deputy Administrator and Director Daniel Tsai stated, "We will tell states in extra bold letters that there are no federal barriers for paying parents and legal guardians as paid caretakers." Yet in this proposed rule, Ohio has piled on multiple barriers that federal rules do not require, placing undue and costly burdens on some of Ohio's most vulnerable families.

Because these specific stipulations violate one or more JCARR prongs, I urge the JCARR to invalidate 5160-44-32 (E)(1)(a), (E)(2)(a), (E)(2)(b), (E)(2)(c), (E)(2)(d), and (J) and keep the rest of the Rule in place.

Your thoughtful consideration is deeply appreciated. The support of the Ohio General Assembly is instrumental in ensuring that our state's most vulnerable individuals receive life-sustaining care from caregivers they trust, avoiding costly and unnecessary institutionalization. Thank you for championing the well-being of these individuals.

Sincerely,

Greg Carter - Father/Guardian/Advocate to Lauren Carter

Janemarie Sowers
2925 Telhurst Ct.
Moraine, OH 45439

December 8, 2023

Joint Committee on Agency Rule Reviews
The Ohio General Assembly
Vern Riffe Center
77 South High Street
Columbus, OH 43215

Dear JCARR Committee Members,

I appreciate the opportunity to testify on the matter of the proposed family caregiver rule, Ohio Administrative Code 5160-44-32. It is a critical issue that affects countless families across our state. I will reiterate what my fellow Parent Advocate Lindsey Sodano wrote because it is 100% correct.

Recently, I was heartened to hear CMS Deputy Administrator and Director Daniel Tsai refer to paid parents and spouses as "the silver lining of the pandemic." The dedication of family caregivers allowed individuals to remain safe in the comfort of their homes and communities during the worst caregiver shortage in our nation's history. While I strongly support Ohio's implementation of a permanent policy for compensating legally responsible caregivers, the current draft of the rule contains a line that violates two of JCARR's prongs, and therefore this line must be invalidated from the rule. 516-44-32(E)(1)(a) both conflicts with an existing rule and implements a federal rule in a manner that is more stringent than the federal rule requires. Additionally, several other stipulations violate JCARR's prong regarding implementing federal rules in a manner that is more burdensome than the federal requirements dictate.

First, 5160-44-32 (E)(1)(a) directly contradicts state free choice of provider laws, including OAC 516-41-08 and OAC 5123-9-11, which mandate adherence to federal free choice of provider regulations, namely 42 C.F.R. 431.51. The free choice of provider is a fundamental principle that empowers disabled individuals to select the most suitable caregiver based on their unique preferences and needs, protecting their dignity and humanity. OAC 5160-44-32(E)(1)(a) states that a spouse of minor child cannot freely choose their spouse or parent, respectively, as their caregiver. Instead, they are required to accept any willing and able job applicant. This restriction directly contradicts the essence of free choice and places unnecessary barriers on individuals seeking the most suitable caregivers for their specific circumstances.

Despite raising this concern with the Ohio Department of Medicaid (ODM) and the Ohio Department of Developmental Disabilities (DODD) on multiple occasions, the response provided is unsatisfactory: "Prior to the COVID-19 public health emergency, parents were not permitted to be paid providers of services to their minor children nor could spouses be paid providers of services...Rule 5160-44-32 reflects expanded flexibility for individuals and families who receive services." While the agencies rightly state

that the new rule now includes parents and spouses in the provider pool, they fail to address the core issue of limiting care recipients' free choice of provider. In essence, that addition of caregivers to the applicant pool, coupled with the restriction on individuals' ability to choose those caregivers freely, stands in clear violation of free choice of provider laws. This issue requires careful reconsideration to ensure that the rights and preferences of individuals receiving services are upheld.

DODD and ODM's additional response to the free choice of provider issue is to challenge disabled individuals to a game of "chicken" when it comes to their care. DODD writes, "The parent/guardian has the right to choose from all willing and able providers, which includes the right to reject all willing and able providers. Rejection of all willing and able providers, does not make the parent eligible to be a paid provider." This approach forces disabled individuals into an untenable situation in which they are compelled to accept providers who do not meet their specific needs and preferences. For example, if the disabled individual maintains a nonsmoking household and the sole applicant is a heavy smoker, the individual is left with no alternative but to accept this unsuitable candidate. Failure to do so would mandate the individual's spouse or parent to render services without compensation. Similarly, consider a scenario in which a young woman strongly prefers assistance from a female caregiver for bathing and menstrual care. If the sole applicant is male, she is left with the distressing choice of compromising her comfort and privacy or begging a female family member to provide these services without pay. This approach constitutes a clear infringement on the waiver recipient's ability to freely choose a caregiver aligned with her specific needs. It creates an unfair and wholly unnecessary dilemma that undermines the principle of individual autonomy in the selection of care providers.

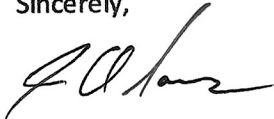
Furthermore, from a practical standpoint, the implementation of section (E)(1)(a) has serious consequences. Individuals who have received services from providers they freely chose for almost four years now (since April of 2020) face the prospect of having their freely chosen, experienced, qualified caregivers removed due to the requirement to fire their spouse or parent and replace them with any stranger the county board or ODM's case management agency manages to find.

Secondly, several sections of 5160-44-32 run afoul of JCARR's final prong because they implement federal rules in a manner that is more burdensome than the federal rule requires. Federal guidelines regarding legally responsible individuals (LRI's) working as paid caregivers are outlined in CMS's "Instructions, Technical Guide, and Review Criteria" manual. CMS does indeed place certain restrictions on LRI caregiver work. For example, LRIs are only permitted to be paid for "extraordinary care," and OAC 5160-44-32 rightly complies with this requirement. However, ODM has added several more burdensome restrictions that are NOT required, encouraged, or endorsed by CMS. This includes that aforementioned (E)(1)(a) 'provider of last resort clause', the arbitrary 40-hour limits in (E)(2)(c) and (E)(2)(d), the requirement that LRIs work as agency employees in (E)(2)(a) and (E)(2)(b), and the ability for county boards to reject any LRI for any reason with no appeal rights (J). In a meeting with our organization in May of 2023, CMS Deputy Administrator and Director Daniel Tsai stated, "we will tell

states in extra bold letters that there are no federal barriers for paying parents and legal guardians as paid caretakers." Yet in this proposed rule, Ohio has piled on multiple barriers that federal rules do not require, placing undue and costly burdens on some of Ohio's most vulnerable families. Because these specific stipulations violate one or more JCARR PRONGS, I urge the JCARR to invalidate 5160-44-32(E)(1)(a), (E)(2)(a), (E)(2)(b), (E)(2)(c), (E)(2)(d), and (J) and keep the rest of the rule in place.

Your thoughtful consideration is deeply appreciated. The support of the Ohio General Assembly is instrumental in ensuring that our state's most vulnerable individuals receive life-sustaining care from caregivers they trust, avoiding costly and unnecessary institutionalization. Thank you.

Sincerely,

A handwritten signature in black ink, appearing to read "Janemarie Sowers", written in a cursive style.

Janemarie Sowers

Jenni Wolfenbarger
1277 Woodmere Dr
Broadview Hts OH 44147

December 8, 2023

Joint Committee on Agency Rule Review
The Ohio General Assembly
Vern Riffe Center
77 South High Street
Columbus, OH 43215

Dear JCARR Committee Members,

I appreciate the opportunity to testify on the matter of the proposed family caregiver rule, Ohio Administrative Code 5160-44-32. It is a critical issue that affects countless families across our state.

During the pandemic, parent and spouse caregivers were praised for stepping up to provide care for their loved ones. Many of us lost our jobs to provide care to our vulnerable loved ones, but found hope and stability in the appendix k provision. While I strongly support Ohio's implementation of a permanent policy for compensating legally responsible caregivers, the **current draft of the rule contains a line that violates two of JCARR's prongs, and therefore this line must be invalidated from the rule.** 5160-44-32 (E)(1)(a) both conflicts with an existing rule and implements a federal rule in a manner that is more stringent than the federal rule requires. Additionally, several other stipulations violate JCARR's prong regarding implementing federal rules in a manner that is more burdensome than the federal requirements dictate.

First, 5160-44-32 (E)(1)(a) directly contradicts state free choice of provider laws, including OAC 5160-41-08 and OAC 5123-9-11, which mandate adherence to federal free choice of provider regulations, namely 42 C.F.R. 431.51. The free choice of provider is a fundamental principle that empowers disabled individuals to select the most suitable caregiver based on their unique preferences and needs, protecting their dignity and humanity. Section (E)(1)(a) of 5160-44-32 states that a spouse or minor child cannot freely choose their spouse or parent, respectively, as their caregiver. Instead, they are required to accept any willing and able job applicant. This restriction directly contradicts the essence of free choice and places unnecessary barriers on individuals seeking the most suitable caregivers for their specific circumstances.

Despite numerous parents raising this concern with the Ohio Department of Medicaid (ODM) and the Ohio Department of Developmental Disabilities (DODD), the response provided is unsatisfactory: "Prior to the COVID-19 public health emergency, parents were not permitted to be paid providers of services to their minor children nor could spouses be paid providers of services...Rule 5160-44-32 reflects expanded flexibility for individuals and families who receive services." While the agencies rightly state that the new rule now includes parents and spouses in the provider pool, they fail to address the core issue of limiting care recipients' free choice of

provider. In essence, the addition of caregivers to the applicant pool, coupled with the restriction on individuals' ability to choose those caregivers freely, stands in clear violation of free choice of provider laws. This issue requires careful reconsideration to ensure that the rights and preferences of individuals receiving services are upheld.

DODD has concluded that “The parent/guardian has the right to choose from all willing and able providers, which includes the right to reject all willing and able providers. Rejection of all willing and able providers does not make the parent eligible to be a paid provider.” This approach places our most vulnerable community members in a difficult situation having to accept any provider no matter how unsuitable for their needs or comfort level. This could include a provider who is a heavy smoker for an asthmatic client, a male provider when the client would prefer a female for toileting and intimate needs or providers that don’t have the experience in specific equipment, treatment or care.

Furthermore, from a practical standpoint, the implementation of Section (E)(1)(a) has serious consequences. Individuals who have received services from providers they freely chose for almost four years now (since April of 2020) face the prospect of having their freely chosen, experienced, qualified caregivers removed due to the requirement to fire their spouse or parent and replace them with any stranger the county board manages to find.

Secondly, several sections of 5160-44-32 run afoul of JCARR’s final prong because they implement federal rules in a manner that is more burdensome than the federal rule requires. Federal guidelines regarding legally responsible individuals (LRIs) working as paid caregivers are outlined in CMS’s “Instructions, Technical Guide, and Review Criteria” manual. CMS does indeed place certain restrictions on LRI caregiver work. For example, LRIs are only permitted to be paid for “extraordinary care,” and OAC 5160-44-32 rightly complies with this requirement. However, ODM has added several more burdensome restrictions that are *not* required, encouraged, or endorsed by CMS. This includes the aforementioned (E)(1)(a) ‘provider of last resort’ clause, the arbitrary 40-hour limits in (E)(2)(c) and (E)(2)(d), the requirement that LRIs work as agency employees in (E)(2)(a) and (E)(2)(b), and the ability for county boards to reject any LRI for any reason with no appeal rights (J).

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Sincerely,

Jenni Wolfenbarger

Laurie Simmons
9225 Echo Hill Ct
Columbus, Ohio 43240

December 4, 2023

Joint Committee on Agency Rule Review

The Ohio General Assembly

Vern Riffe Center

77 South High Street

Columbus, OH 43215

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DODD and ODM’s additional response to the free choice of provider issue is to challenge disabled individuals to a game of “chicken” when it comes to their care. DODD writes, “The parent/guardian has the right to choose from all willing and able providers, which includes the right to reject all willing and able providers. Rejection of all willing and able providers does not make the parent eligible to be a paid provider.” This approach forces disabled individuals into an untenable situation in which they are compelled to accept providers who do not meet their specific needs and preferences. For example, if the disabled individual maintains a nonsmoking household and the sole applicant is a heavy smoker, the individual is left with no alternative but to accept this unsuitable candidate. Failure to do so would mandate the individual’s spouse or parent to render services without compensation. Similarly, consider a scenario in which a young woman strongly prefers assistance from a female caregiver for bathing and menstrual care. If the sole applicant is male, she is left with the distressing choice of compromising her comfort and privacy or begging a female family member to provide these services without pay. This approach constitutes a clear infringement on the waiver recipient's ability to freely choose a caregiver aligned with her specific needs. It creates an unfair and wholly unnecessary dilemma that undermines the principle of individual autonomy in the selection of care providers.

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Sincerely,

Laurie Simmons

Lindsey Sodano
6381 Rosewood Ln.
Mason, OH 45040

December 6, 2023

Joint Committee on Agency Rule Review
The Ohio General Assembly
Vern Riffe Center
77 South High Street
Columbus, OH 43215

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DODD and ODM's additional response to the free choice of provider issue is to challenge disabled individuals to a game of "chicken" when it comes to their care. DODD writes, "The parent/guardian has the right to choose from all willing and able providers, which includes the right to reject all willing and able providers. Rejection of all willing and able providers does not make the parent eligible to be a paid provider." This approach forces disabled individuals into an untenable situation in which they are compelled to accept providers who do not meet their specific needs and preferences, precisely the situation the free choice of provider laws strive to avoid. For example, if the disabled individual maintains a nonsmoking household and the sole applicant is a heavy smoker, the individual is left with no alternative but to accept this unsuitable candidate. Failure to do so would mandate the individual's spouse or parent to render services without compensation. Similarly, consider a scenario in which a young woman strongly prefers assistance from a female caregiver for bathing and menstrual care. If the sole applicant is male, she is left with the distressing choice of compromising her comfort and privacy or begging a female family member to provide these services without pay. This approach constitutes a clear infringement on the waiver recipient's ability to freely choose a caregiver aligned with her specific needs. It creates an unfair and wholly unnecessary dilemma that undermines the principle of individual autonomy in the selection of care providers.

Furthermore, from a practical standpoint, the implementation of Section (E)(1)(a) has serious consequences. Individuals who have received services from providers they freely chose for almost four years now (since April of 2020) face the prospect of having their freely chosen, experienced, qualified caregivers removed due to the requirement to fire their spouse or parent and replace them with any stranger the county board manages to find.

Secondly, several sections of 5160-44-32 run afoul of JCARR's final prong because they implement federal rules in a manner that is more burdensome than the federal rule requires. Federal guidelines regarding legally responsible individuals (LRIs) working as paid caregivers are outlined in CMS's "Instructions, Technical Guide, and Review Criteria" manual. CMS does indeed place certain restrictions on LRI caregiver work. For example, LRIs are only permitted to be paid for "extraordinary care," and OAC 5160-44-32 rightly complies with this requirement. However, ODM has added several more burdensome restrictions that are *not* required, encouraged, or endorsed by CMS. This includes the aforementioned (E)(1)(a) 'provider of last resort' clause, the arbitrary 40-hour limits in (E)(2)(c) and (E)(2)(d), the requirement that LRIs work as agency employees in (E)(2)(a) and (E)(2)(b), and the ability for county boards to reject any LRI for any reason with no appeal rights (J). In a meeting with our organization in May of 2023, CMS Deputy Administrator and Director Daniel Tsai stated, "We will tell states in extra bold letters that there are no federal barriers for paying parents and legal guardians as paid caretakers." Yet in this proposed rule, Ohio has piled on multiple barriers that federal rules do not require, placing undue and costly burdens on some of Ohio's most vulnerable families.

Because these specific stipulations violate one or more JCARR prongs, I urge the JCARR to invalidate 5160-44-32 (E)(1)(a), (E)(2)(a), (E)(2)(b), (E)(2)(c), (E)(2)(d), and (J) and keep the rest of the Rule in place.

Your thoughtful consideration is deeply appreciated. The support of the Ohio General Assembly is instrumental in ensuring that our state's most vulnerable individuals receive life-sustaining care from caregivers they trust, avoiding costly and unnecessary institutionalization and hospitalization. Thank you for championing the well-being of these individuals.

Sincerely,

A handwritten signature in black ink that reads "Lindsey E. Sodano". The script is fluid and cursive, with the first letters of the first and last names being capitalized and prominent.

Lindsey Sodano

Theresa Sweeny
14623 Bayes Avenue
Lakewood, Ohio 44107

December 6, 2023

Joint Committee on Agency Rule Review
The Ohio General Assembly
Vern Riffe Center
77 South High Street
Columbus, OH 43215

Dear JCARR Committee Members,

I appreciate the opportunity to testify on the matter of the proposed family caregiver rule, Ohio Administrative Code 5160-44-32. It is a critical issue that affects countless families across our state.

Recently, I was heartened to hear CMS Deputy Administrator and Director Daniel Tsai refer to paid parents and spouses as "the silver lining of the pandemic." The dedication of family caregivers allowed individuals to remain safe in the comfort of their homes and communities during the worst caregiver shortage in our nation's history. While I strongly support Ohio's implementation of a permanent policy for compensating legally responsible caregivers, the current draft of the rule contains a line that violates two of JCARR's prongs, and therefore this line must be invalidated from the rule. 5160-44-32 (E)(1)(a) both conflicts with an existing rule and implements a federal rule in a manner that is more stringent than the federal rule requires. Additionally, several other stipulations violate JCARR's prong regarding implementing federal rules in a manner that is more burdensome than the federal requirements dictate.

First, 5160-44-32 (E)(1)(a) directly contradicts state free choice of provider laws, including OAC 5160-41-08 and OAC 5123-9-11, which mandate adherence to federal free choice of provider regulations, namely 42 C.F.R. 431.51. The free choice of provider is a fundamental principle that empowers disabled individuals to select the most suitable caregiver based on their unique preferences and needs, protecting their dignity and humanity. Section (E)(1)(a) of 5160-44-32 states that a spouse or minor child cannot freely choose their spouse or parent, respectively, as their caregiver. Instead, they are required to accept any willing and able job applicant. This restriction directly contradicts the essence of free choice and places unnecessary barriers on individuals seeking the most suitable caregivers for their specific circumstances.

Despite raising this concern with the Ohio Department of Medicaid (ODM) and the Ohio Department of Developmental Disabilities (DODD) on multiple occasions, the response provided is unsatisfactory: "Prior to the COVID-19 public health emergency, parents were not permitted to be paid providers of services to their minor children nor could spouses be paid providers of services...Rule 5160-44-32 reflects expanded flexibility for individuals and families who receive services." While the agencies rightly state that the new rule now includes parents and spouses in the provider pool, they fail to address the core issue of limiting care recipients' free choice of provider. In essence, the addition of caregivers to the applicant pool, coupled with the restriction on individuals' ability to choose those caregivers freely, stands in clear violation of free choice of provider laws. This issue requires careful reconsideration to ensure that the rights and preferences of individuals receiving services are upheld. DODD and ODM's additional response to the free choice of provider issue is to challenge disabled individuals to a game of "chicken" when it comes to their care. DODD writes, "The parent/guardian has the right to choose from all willing and able providers, which includes the right to reject all willing and able providers. Rejection of all willing and able providers does not make the parent eligible to be a paid provider." This approach forces disabled individuals into an untenable situation in which

they are compelled to accept providers who do not meet their specific needs and preferences. For example, if the disabled individual maintains a nonsmoking household and the sole applicant is a heavy smoker, the individual is left with no alternative but to accept this unsuitable candidate. Failure to do so would mandate the individual's spouse or parent to render services without compensation. Similarly, consider a scenario in which a young woman strongly prefers assistance from a female caregiver for bathing and menstrual care. If the sole applicant is male, she is left with the distressing choice of compromising her comfort and privacy or begging a female family member to provide these services without pay. This approach constitutes a clear infringement on the waiver recipient's ability to freely choose a caregiver aligned with her specific needs. It creates an unfair and wholly unnecessary dilemma that undermines the principle of individual autonomy in the selection of care providers.

Furthermore, from a practical standpoint, the implementation of Section (E)(1)(a) has serious consequences. Individuals who have received services from providers they freely chose for almost four years now (since April of 2020) face the prospect of having their freely chosen, experienced, qualified caregivers removed due to the requirement to fire their spouse or parent and replace them with any stranger the county board manages to find.

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Sincerely,

Theresa Sweeny
Lakewood