Responses to Questions from 12/9 Stakeholder Forum re: Paid Parent Caregivers

Compiled by Senator Sara Gelser Blouin. These answers reflect my understanding and should not be interpreted as the position of any other member, agency or organization.

Courtney Coleman: Do I understand it correctly that Knopp's proposal limits hours parents can claim?
As I understand it, the Knopp proposal does not propose to limit the total number of hours parents can be paid for in a month.

Courtney Coleman: This sounds very similar to how Colorado is providing paid parent PSW's. Does this mean your proposal also requires parents become CNA's?
This is actually very different than the Colorado program. The Colorado program is about home health services which are different than attendant care services. Attendant care services can be provided by people who are not licensed. Home health services generally cannot. Neither of the Oregon proposals requires parents to become a CNA.

Valentina: Medically involved is different than CIIS?
It is a specific part of what is generally referred to as the CIIS Program. There are three waivers under this umbrella term-- The Medically Fragile Waiver (hospital level of care), the Medically Involved Waiver (nursing home level of care) and then the Behavior Waiver (children with ID/DD that have very significant behavioral support needs.

Calli Ross: Can you discuss what "tier" level that would be based off the ONA Senator?
The reason the proposal doesn't use a number is because it depends on the age.

- 4-11 year olds have only 3 tiers (1- Very Low to Low, 2- Moderate and 3- High to Very High)
- 12-17 year olds have 5 tiers 1-Very Low 2-Low 3-Moderate 4-High and 5- Very High

The reason for the different tiers is because K Plan services (attendant care services) are based on needed supports for ADLs and IADLs. The ONA does a better job of this than the current system, because it will for the first time take into account the age of a child. For instance, even a typically developing birth to 3 year old is completely dependent on an adult to make it through the day. Typically developing 4-11 year olds can manage more of their needs on their own than infants and toddlers, and youth and adolescents typically take on even more independence.

The easiest example of this is toileting. Diapering, toilet training, support with bathroom hygiene, etc is a typical responsibility/task of all parents of birth to 3 year olds. It is not a typical responsibility for the parent of a 12 year old. For this reason, the ONA doesn't allocate paid supports to a 1 year old for being incontinent (because no 1 year old would be expected to toilet independently), but a teenager would.

More comprehensive information about the tiers can be found here:
https://www.oregon.gov/dhs/Compass-Project/Pages/Service-Groups.aspx

Kelsey Smith: Will there be an exception process?
This bill would require that any exceptions process be handled at ODDS. The proposal I drafted requires ODDS to develop rules about any exceptions process. However, they would not be able to grant exceptions to limitations written into statute.

Shasta Kearns Moore: There are three Medicaid waivers that make up the CIIS program: Medically Involved, Medically Fragile and Behavior
The only reason that the Medically Fragile and Medically Involved waivers are called out in my proposal is that some very high need children on those waivers are not eligible for DD services because they ID/DD. These categories were added to the eligibility list to ensure that all children receiving those services have access to paid parent caregiver hours if otherwise eligible.

The behavior waiver ***already*** requires that the child be eligible for ODDS services. That is not a change.

Valentina: How may we apply for CIIS?
This is a discussion to have with your service coordinator or case worker.

Tobi Rates, ASO (she/her): Why a limit of 60 hours per household, why not 40 per provider for example, like other PSW/DSP?
This was based on a couple of things:

- Equity: If it is based on 40 hours per provider, then two parent households have greater access to supports that have a direct financial benefit to the family than single parent households.

- Cost containment: No matter who provides the services, federal overtime laws apply. The cost of services increases substantially when overtime is used. Also, PSWs are currently limited in the ability to do overtime. Some agencies are now paying overtime, but they are still bound by their budget. The rate model pays the agency a set rate per hour, and from that rate the agency must cover regular wages, overtime, training, recruitment, sick time, benefits, agency overhead, etc.

- Existing policy: Most DSP/PSWs have been limited to 40 hours a week for quite some time.

- Parental duties vs. Paid duties: There are existing limitations on when attendant care services can be paid to ALL care providers. Prohibited times include while the child is sleeping and while the child is at school. In addition, attendant care cannot replace parental responsibility. All parents have a duty of care to their children, so there will logically be a limit of the number of hours in a day/week a parent would be paid for caring for their own minor child as there are hours of care that are simply parental responsibility. That number, of course, varies based on age. For instance, the parent of an infant or toddler is responsible for that child 24/7—and when the parent takes a break they must ensure another adult is providing for those needs in their absence.

If we calculate that a child might sleep for a minimum of 6 hours a day (not necessarily sequentially), the school day for 5 year olds plus is 6 hours a day, and 60 hours a week of service works out to just over 8.5 hours of services each day. In a 24 hour period, that would leave just 3.5 hours of billable hours unpaid to the child's parent/parents within a 24 hour period. As a matter of policy, 3.5 unpaid hours of care to a minor child each day would strike many people as fairly reasonable. Particularly since, if the child has additional hours allocated, those hours can still be reimbursed for care provided by a third party. (*Obviously, the sleep hours and the reality of access to school is not the same for all children and I don't mean to suggest that these calculations apply to every child or situation*)

- Data: The information ODHS provided to the Senate Human Services Committee demonstrates that the majority of children currently paying their parents are paying 60 or fewer hours a week to their parents. (This information is posted in OLIS)

- Service tiers: Under the new rate model, for individuals under 18, only adolescents with very high needs would be allocated more than 60 hours per week of attendant care services (this is not the same as nursing services and personal care hours which are additional services within CIIS for medically involved and medically fragile kids). There will be a process for exceptions, and exceptions will be granted--- but the vast majority of families would be left with very few hours they would need to choose to fill with paid providers OR provide to their child without being paid.

Jenny (she/her): What number does it correspond to on the ONA scale? "Very high needs"

It is the highest tier. Children 4-11 years old only have three tier levels, so in that group it would be Tier 3. 12-17 year olds have 5 tiers, so that would be Tier 5. However, a child can still receive the services available to someone in that "Very High" tier if they meet the eligibility requirements of either the medical support need assessment or the behavior support need assessment.

Nancy Berge, The Arc Lane County: Are there any consideration for the back log of two years for onboarding to the CIIS program?

That is outside the scope of these measures. A child doesn't need to be enrolled in CIIS to access the opportunity to pay their parents (unless they do not have a developmental disability and are eligible due to being medically fragile or medically involved). For instance, right now even when people are waiting to receive services on the behavior waiver, they can still receive in home services that are paid through out of the K Plan. Some kids have services paid for through a blend of different funding streams.

Romi Ross: If a parent is capable of providing care to two disabled children with very high needs at one time, why are they not capable of providing sufficient care to one qualifying child while also caring for a non-disabled sibling?
The issue isn't about capability, but rather the contracted work. When a parent is being paid, they are being paid to provide care to the client (or clients). This simply means that the provider (like other providers) must only be doing the tasks for which they are paid while they are on the clock.

Jade Christensen: I'm wanting clarification on why budget is continually being brought up, when we aren't talking about increasing hours for disabled kiddos, we are talking about adding in another option of carers for them unless the total number of hours assigned to disabled kids were never intended to be fully met in the first place. The budget conversation here, dismisses the fact that the plan is already in place, but ODDS isn't able to satisfy the full requirements of the plan if it were to be executed efficiently whether it was PSW's filling the role or parents
This is how the budgeting process has always worked in Oregon for human services programs like these. For instance, adults with DD (who CAN pay their parents) also don't use all assessed hours (when looked at collectively). The budget is based on usage not on the hours that are in an assessment. The assessment is not an allocation of hours, just a measure of assessment of the number of hours in a day for which an individual will likely need assistance (from paid supports AND natural supports) to complete ADLs and IADLs. It does not account for assistance with ADLs and IADLs that would occur during normal parenting activities. For instance, at dinner, it is not unusual for a parent to assist children with cutting their food. While getting kids out the door, even if a child can't zip their own coat, a parent can accomplish that while fulfilling the parenting obligation of taking the child to school.

The reason the budget comes up is that the Legislature cannot pass initiatives without allocating the funding to pay for them—we can't print or borrow money. The estimated cost to simply expand paid parent caregiver eligibility to every child eligible for DD services would ***more than double the current cost of the entire program paying for ALL children*** receiving in home support services, even if only a minority of eligible families participate. That could have significant consequences on the level of services available to all people with ID/DD as well as to other areas of the state budget. The budget process is challenging and involves weighing the very real and serious needs of Oregonians and deciding how to most equitably and effectively divide up the pie.

Theresa Jahangir (she/her): it seems that your bill is extremely limiting, and will drop support and services to a large portion of children who are currently supported by paid parent caregiving. How do you plan to make sure these children don't end up in hospitals and foster care, costing the state more money than paid parent caregiving?

This measure is actually an expansion of current law AND of the temporary paid caregiver program. Most (if not all) of the children currently receiving services from a paid parent would be covered under this program, and additional children not currently eligible would be able to pay their parents for the first time.

We also know that these kids were not living in hospitals or foster care before the paid parent program. In addition, in some cases now, the cost of parents being paid to provide care exceeds the cost of supporting a child in DD foster care.

Jenny (she/her): If it's federal (the prohibition on hours during school, etc) why include the language in a state statute?
Because there is a fair amount of confusion and a LOT of different providers. The confusion has increased during the pandemic because of the exceptions. Consistent messaging is difficult in the DD System which is run by an independent entity in each county--- and when hours are overseen by dozens and dozens of provider agencies. This will ensure everyone understands the limitations of the law and protect Oregon from being required to pay back funds plus fines to the federal government if there is noncompliance.

Sarahreed: We homeschool and our hours are different than the local school and we shouldn't be punished that my son can't access his DD supports at that time.
It isn't a judgement or a punishment. It's simply that the federal government has already allocated resources to children through public schools. This is why CMS does not allow for Medicaid to pay for support services during school hours through an attendant care program. That is the responsibility of the school districts.

Tobi Rates, ASO (she/her): My reading is that a child who has an I/DD does NOT also have to qualify for CIIS but does need to meet the "very high" behavior/medical standard. Is that correct?
This is correct. CIIS waiver eligibility is not required for the paid parent program AT ALL as long as the child is otherwise eligible for ID/DD services.

When the behavior waiver was established, there was no other path to services for kids with high behaviors. That is because at that time, the only in home services available to children were through the medically fragile program. The Behavior Waiver was created in order to establish crisis diversion for kids who would leave their homes for foster home or group homes because there was effectively no access to respite, behavior support services or in home services for kids with significant behavior needs. At this time there were ZERO hours available if you were not a medically fragile child--- nor was respite, behavior specialists, equipment, supplies, training, etc. As a result, the only eligibility for the Behavior waiver was ID/DD eligibility.

The only reason that the medically fragile waiver and the medically involved waiver (which wasn't established until after 2007) are mentioned in the legislative concept is that those children don't have to meet DD eligibility and so we want to be sure that the minority of those kids that don't have DD eligibility are not excluded from the paid caregiving program. We do not need to call out the Behavior waiver in this way because you already have to have an ID/DD eligibility determination to be on that waiver.

Theresa Jahangir (she/her): do you plan for any stop gap funding for the limited number of children you're hoping to support through this bill? Or will those children also lose their support when the PHE is over?
There currently isn't authorization or funding to cover that gap. Unfortunately, like many programs that were instituted through the public health emergency (expanded Medicaid eligibility, expanded benefits eligibility, eviction protection, rental assistance, etc.) these will not be authorized or funded when the PHE ends unless and until there is legislative action and a budgetary appropriation.

It will be difficult to establish stop gap funding for the current paid parent program because upon the expiration of the public health emergency, the program would have to be operated without any federal matching funds--- that means it would nearly triple the cost to the state general fund. Because we are looking at inadequate funds to roll up currently established programs, it would be very difficult to access these funds. For instance, if the PHE ends on June 1, we would still likely be looking at 9-12 months before the new program could be implemented in the best case scenario. This is because the bill cannot be signed until July or August, then there is the required public process in the waiver application development, then the submission and then the approval from Medicaid. For just nine months, we would need a dedicated allocation of somewhere between $13 and $14 million of general fund. It is very difficult to get an unmatched general fund allocation of that size even for a very large program—and the benefit to this program would be limited to fewer than 350 children.

The other challenge is that this would be part of the overall budget discussion. The E-Board cannot meet while the Legislature is in session, so this would have to be considered as part of the regular budget process which will not be complete until sometime in June.

Lillieth Grand (she/her/s) Parent: Question -- what about the rule that only one parent can be the paid caregiver so the other can be the EOR?

This is one of the reasons why the program needs to be operated through an agency. In terms of conflict of interest, it does not make sense for the family to be the employer of record when they are financially benefitting from the employment relationship. Having the agency employ the parent removes this conflict. It also allows both parents to be paid as providers and ensures equity with single parent families who do not have another adult in the household to serve as an EOR.

Jenn Whitten: If a child attends a public charter school with an alternate schedule, why would another school get to dictate what hours are considered school hours?
Medicaid will only pay for services when there is no other service that is available. Children with disabilities are entitled to free full time, public education and the related services needed to

access that education. As a result, a child that is attending a school or whose parents consent to a program that has fewer hours than the local school is waiving a benefit of services. Medicaid will not step in to pay for that waived benefit or substitute for the responsibility of the school district. The same is true when a parent chooses to home school—the government is making services available and the school is responsible for providing services during school hours. If the parent declines those services, Medicaid will not substitute by paying for different services.

We can work on the language specific to the definition of the school day so that it is more carefully described as the same cumulative number of hours as the child's boundaried school rather than the exact same hours (such as 9am to 3pm) on a given day. That would pick up almost all charter school and private school situations, unless the parent consented to an abbreviated school day or the school district unilaterally imposed an abbreviated school day. In that case, Medicaid services are not available during that time that schools are responsible.

Roberta Lincoln (she/her): How will this work for kiddos with High Behavioral needs too – for example – DSP's require higher level of certification/training – will parents then be required to have higher level training? And will they be paid at a higher rate? How will it work in collaboration with a parent providing services at some times and another DSP organization at other times?
This bill does not speak to training. This bill grandfathers in those who are currently working as PSWs. Those wages and training requirements are set thorugh a collective bargaining agreement. The wages and training requirements through agencies are set through the provider agencies, consistent with the rules for all DSP service prociders. This bill DOES require that parent providers are paid the same wages as other providers employed by the same entity, including overtime. That would also include any rate differential for unique or enhanced needs that are paid to all other providers.

Roberta Lincoln (she/her): … or they can have been waiting to receive DSP services for YEARS, from a number of DSP companies, and none can be found to meet the needs of the kids…
My understanding is that the intention of this measure is to create some relief when non-parent providers cannot be found. Although this bill is capped at 60 hours a week, under the new rate model when the ONA is implemented, very few children will be eligible for more than 60 hours a week of attendant care services. (Keep in mind, attendant care services are not the same as nursing services—but paid parents cannot provide nursing services)

Roberta Lincoln (she/her): so paying parents because the state cannot locate other qualified people – would be helpful
That is what this bill is attempting to do. Because it allows up to 60 hours a week, it would replace income for a full time position if a parent is not able to work due to not being able to find a caregiver for their child. If it is one parent providing 60 hours through an agency, the parent would likely be paid approximately $1760 per week. That is calculated by assuming an hourly rate of $22/hour (consistent with current agency rates) for 40 hours, then $33/hour for

the additional 20 hours of overtime. ***That is approximately $7000 a month per family***. This will not diminish a child's access to other paid services, including to additional DSP hours if the child is allocated more than 60 hours in a week. It is my understanding that in most cases, parents will also not be taxed on this income due to the difficulty of care payment provision for caregiving wages of an individual that lives in the caregivers home. It will also not diminish the child's eligibility for SSDI payments.

Romi Ross: What they are doing today is a huge amount of unsupported caregiving that is well above and beyond parenting
This proposal would pay parents for up to 60 hours a week of attendant care services for their minor children with wages approximating $70,000 a month for a parent providing 60 hours a week of services.

Jenn Whitten: Why would thousands of parents go through qualifying for a program with yearly reviews if they didn't want services?
DSP services are not the only services available through the kids' DD program. Access to services includes secondary medical coverage, payment for things like gloves and diapers for older children with toileting needs, specialized equipment and assistive technology and home modifications. These parents might also be accessing respite care services or employment support services for teenagers. In some cases, a DD eligibility is required to access other programs, benefits and tax incentives. Others establish DD services early so that they are available should the child need them later, or to improve the continuity of services when a child transitions into adulthood.

Lisa Tschudi: What about potential savings to other areas of the state budget if parents are eligible to work as DSPs because families don't need other programs?
The Legislative Fiscal Office does not calculate things in that way. We have to look at what is required to operate a new program and cannot assume savings until they materialize. Further, savings in different areas may have different match rates and may also be offset by a decrease in revenue collections from the state on untaxed wages to parents or an increased need for public services by displaced non parent caregivers.

Roberta Lincoln (she/her): And with high behaviors and CIIS – child qualifies through the CW program (Intercept) with high behavioral and DD needs – but is adopted and therefore qualifies… but not through OHA BH… it doesn't make sense – same kids, same issues – same local behavioral provider – but they can provide services from CW but not from OHA. DOESN'T MAKE ANY SENSE!
I can't speak to your specific situation. However, child welfare, ODDS and OHA are all distinct programs that operate under different federal eligibility criteria and regulations.

I am introducing a separate bill this session that will expand attendant care services to kids who are at risk of out of home placement due to mental health/psychiatric needs.

Sonja: My son has Autism spectrum disorder with global developmental delay? Would he qualify as having an intellectual disability?
I can't speak to your son's particular situation. This would depend on his individualized assessment. To qualify for ODDS services he can have either a developmental disability OR an intellectual disability.

Theresa Jahangir (she/her): so if you're writing a bill that is based on the NEW ONA, how will children qualify once the bill is passed, BEFORE the new ONA is implemented?
Children are now being evaluated with the ONA, the hour allocations just haven't been implemented yet. In order to implement the paid caregiver program contemplated in the measure, we simply need the service tier level that is generated by the ONA. That is available today.

Jade Christensen: Sonja yes, but to qualify as level 5 with an intellectual disability is significantly more complicated because Autism is experienced on a spectrum, and that varies monthly, weekly even daily depending on a multitude of internal and external factors. This system of deciding who is worthy of support, especially with behavior disabilities is ableist and incredibly subjective
The ONA is a validated tool that is approved by the federal government for the state to determine eligibility for ODDS services. In addition, the section of the ONA that specifically considers whether a child has high behavior support needs does in fact consider the child's experience and behaviors over the course of year rather than over the course of a week or month. The validated assessment tool provides information about the level of support needed and hours are allocated based on that information. Neither the assessment or the allocation of services is based on subjective criteria or a judgement of who is worthy and who is not.

Amy Haigh (parent): CHRIS WILCOX – YES! Qualified and reliable caregivers are the #1 problem with utilizing hours, not that people don't want to use them. Sen. Gelser does not understand the situation we face day in, day out.
I would never pretend to understand anyone else's situation. That said, I am also the parent of an adult son with intellectual and developmental disabilities. I share in the weekly challenge of filling caregiver slots, stepping in when there are caregiver vacancies or absences, or he is ill or has other needs that only I can manage. If you follow the session, you will undoubtedly see me at some point coming into a committee hearing or onto the Senate floor with my son beside me because he has a need only I can fill or a scheduled caregiver has called out for a shift. (And no, I am not paid as a DSP.)

Lisa Ledson: Is there an opportunity for situations like Ainslee is speaking about have an exceptions process allowing more than 60 hours per week?
There will be an exceptions process for the allocation of hours based on the ONA in terms of the total number of hours a child can access paid services in a week. That said, this proposal does not currently consider an exception to capping the number of hours that parents are paid to 60 hours a week. This is a substantial number of hours in a child's week, particularly if you

consider that caregivers cannot be paid for attendant care services while a child is sleeping or during school hours. That leaves only a handful of hours that a child can have paid services eligible for reimbursement to parents. Regardless of disability, parents do retain parental responsibility for uncompensated care and support for at least some time each week (how much time is dependent on age). With overtime, a parent providing 60 hours a week of paid services to their child will realize wages of approximately $7,000 a month which would compensate for a parent who had to leave their job due to lack of access to available paid caregivers.

Theresa Jahangir (she/her): There are other states doing this with OUT these limitations that are seeing a huge savings. Have you looked at those states and the huge savings they are seeing?
Yes. I have looked into these states. Oregon has a vastly more permissive structure for making children eligible to receive community based DD services. Many states that people talk about have much stricter criteria—for instance, children must be terminally ill to qualify for service or they must qualify for a hospital or nursing home level of care. There are children currently receiving services through the paid parent program that would not qualify for ANY in home services by ANY provider in these and other states. Other states also require kids to go into managed care or place limits on the quantity and type of services offered.

Oregon is unique in regard to its decision to disregard parental income, allow all children with ID/DD to be eligible for services, and capping access to services only based on need rather than at an arbitrary number of hours or dollar amount.

Rachel Bowman-Cryer: where did the 30 % of the child's hours can be used by parent idea come from. If I still can't get outside care that leaves 70% of hours unusable.
This is not 30% of the child's hours. 100% of a child's hours (up to 60 hours) can be paid to the parent.

The agency that EMPLOYS the parent must ensure that parent providers only comprise 30% of the hours they pay for attendant care services. This means that hours provided to any person over the age of 18 would count towards the other 70%-- as would every hour provided to any child by a nonparent.

Lisa Fugere: Can exceptions be made for DSPs to work during school hours? It took the school district where I live, half the year to figure out how to service my daughter for only 1 hour a week. We would seriously be hurting if we could not my use hours during the school day.
No. This is a federal rule. School districts are responsible during school hours.

I would be interested in talking with you about your school experience. We have additional legislation this session to hold districts accountable for meeting the needs of students with disabilities and providing full school days—including the supports necessary to make that safe.

Lillieth Grand (she/her/s) Parent: Has research been done, by our legislators and their staff, beyond what OUR committee has done, regarding what other states who say they have a successful program are doing and why they say it's successful?
Yes.

Jenn Whitten: Why does the program have to be a budgetary island? If you're reducing the costs of hospitalizations, foster care, etc, why is that not being considered on the front end?
That is not the way the Legislative Fiscal Office calculates fiscal impacts. We cannot count savings until we see them.

Jenn Whitten: Can you share where a school day is legally defined at a federal level?
This is basically the hours that the local public school is operating. The local public school is responsible for providing students with disabilities a full school day and a full school week and access to a free and appropriate public education.

Romi Ross: Do you have data you can share to support the 30% agency cap?
Under this proposal, about a third of all children eligible for in home services would be eligible to pay their parents. Only the attendant care hours for minor children that are paid to parents counts towards that 30% cap. Any hours provided by a non-parent provider to these children, all hours provided to children ineligible to pay parents and all hours provided to individuals over 18 would not fall under that 30% cap--- instead they would comprise the vast majority (likely far more than 70%) of all in home service hours.

This is intended to ensure that agencies continue to recruit, train and retain a workforce beyond the parent community. This is essential to the children and adults who need in home services and do not have a parent they can pay to provide their services.

Jessa Reinhardt: I would like clarification on the 1:2 option. PSWs are the only ones currently allowed to do so and receive no additional pay.
When I spoke to ODDS about this (both at the state level AND at my local level for my own planning for my son), I came to understand that there is a 1:2 option. There is a group rate that is paid to the DSP for providing support to multiple individuals at the same time. I believe the rate is slightly enhanced, but it is not double the rate for 1:1 care.

Karen Krieger: My son goes to PPS for a half day, that is all he can tolerate. So PPS will pay us for the other half day?? Did I understand that correctly?
If PPS has put your son on a half day program without your consent, that is illegal. PPS is responsible to provide your son as many hours of instruction as nondisabled children of the same age who attend your neighborhood school. If PPS wants your child to learn remotely, they are responsible to provide the related services and supports necessary for your son to succeed—including nursing, instructional assistant services, prompting, hand over hand support and access to synchronous learning with a licensed teacher.

This measure ***does not*** require the school district to pay you. However, it clarifies that nothing in this measure impacts your ability to ask them to do so, or ODE or the court's ability to direct the district to do so.

It is worth noting that just last week, during the budget rebalance, additional funds had to be allocated to ODDS to cover hours claimed during the school day which is allowed due to the public health emergency. Meanwhile, funds have not been clawed back from districts for their failure to serve the students for whom they receive funding.

There is a measure being introduced this session that will require school districts to reimburse parents for reasonable expenses, including lost wages, when the district has unilaterally placed a student on an abbreviated school day program.

Shasta Kearns Moore: If these are federal rules, why do they need to be enshrined in state statute rather than just sent out in a memo to social workers?
There is a lot of confusion, and having it clearly stated helps to unbundle that confusion. There is also substantial confusion with public schools who are not understanding their obligations, and continually trying to push their responsibilities onto the DD system. This language is needed to level set after the pandemic, protect caseworkers from the conflict and clearly signal to school districts that ODDS cannot make up for their failure to provide services. It is also intended to prevent parents from being stuck between two agencies giving them different advice about what can and can't be paid for by ODDS.

sarah kaplansky: school is not OIS trained
A school district is required to provide appropriate training to staff serving children. If staff need to receive a specific training in order to support a student, that should be written into the IEP and the training should be provided by the district. There is another bill this session that, if passed, would strengthen the requirements around quality appropriate training for protective interventions and/or restraints.

Jenn Whitten: But per our IEP team the best placement was a charter school with an alternative schedule. The decision making power here is fuzzy.
Part of the intent of calling out the school language directly is to make the obligations and decision making LESS fuzzy. This is particularly important given concurrent legislation to address the chronic issue of schools illegally putting students on abbreviated school days. Even if the district makes the placement into an alternative school, that does not relieve the district of its responsibility to provide full day and full week of education to all students—including those attending schools that might have a shorter day than the neighborhood school.

Gabriel Triplett (Parent Advocate): How much would the State save on a 6 fold reduction in hospitalization cost of kids with I/DD? That's what Colorado saw after implementing a PP program. Will those sorts of savings be factored into the budget.

I have tried to find this data from the state of Colorado, but have not been able to do so. Can you share it with me? What I have found is an informal study from an in home care agency that talked about the impact to their clients. That is not a particularly good comparison to what we are talking about, however. That is because the Colorado program is not based on attendant care, but on in home health care and part of the benefit there was the training for family members that improved the ability to manage medically related tasks safely at home and with fewer complications related to infection, etc. In addition, that is a medically fragile population rather than a general population of kids with ID/DD.

Karen Krieger: Does anyone know how well do the PP programs in CA and CO work? And if they work, wouldn't they be good models, or improve on what maybe doesn't work.
Oregon and Colorado have very different service systems than Oregon does. We provide far more hours and services to children and families in addition to having much more broad eligibility criteria for children with ID/DD—including ignoring parental income and not requiring any level of medical need.

Tobi Rates, ASO (she/her): Meghan, is the 60 hours cap per provider or per household?
Per household.

Michael Paruch: It's important to note, that those of us who are parents to children who have chronic, complex medical conditions cannot just "place our children" in school environments due to the high rate of illnesses. This respiratory illnesses cause our child to have breathing suppression and status seizures. Thus, we have been forced to do extremely limited remote learning supports ourselves to keep her out of the ER from life threatening illnesses.
The bill does have an exception for medically directed absences. That said, the school is STILL responsible and should be providing services. For instance, during the pandemic, the school was legally obligated to provide the needed support services—including an instructional assistant—in the child's home if needed to support access to instruction. One of the problems that we have is that many of our school districts are out of compliance with state and federal law. Their lack of compliance grew exponentially during the pandemic and has been masked by the federal exception to provide some attendant care hours during school hours during the public health emergency. The impact of this failure is going to be shocking when the PHE ends. We need to be prepared to hold schools accountable and have them step up to meet their responsibilities to every child.

Shasta Kearns Moore: Then why not just amend the current waivers (fast) than create a new one (at least 2024)?
The current waiver cannot be amended—it is an 1115 waiver and will expire when the PHE ends. The K Plan is not a waiver. That is an informal reference to the community based services individuals can access under the community first choice act which was adopted into our State Medicaid Plan.

Courtney Coleman: I agree Meghan. I don't understand why we're trying to reinvent the wheel. There are states doing this. What in those states legislation (CA, AZ, MN, CO) is working well and what needs to be reevaluated?
The other states have very different base programs in terms of who is eligible for ID/DD services in the first place. Under the concept I have introduced, our plan would be very similar to those plans because it would make the paid parent program much more similar to the population in those states for whom parents are being paid. In addition, many of these states do operate this type of service on a waiver which is what I have proposed here. With the possible exception of Minnesota, there is no state that has made a paid parent program for attendant care service part of its state Medicaid plan which is accessible to every eligible individual.

Ainslee: What about families whose children get 2:1 services? Can both parents bill 60 hours per week EACH one as the 1:1 and the second parent as the 2:1? It's hard enough trying to find 1 PSW let alone two.
It is 60 hours per household per month.

Jade Christensen: Can someone clarify, whether someone has a medical or behavioral disability, is the ONA the same, or is it a different ONA evaluation?
There is one ONA. However, the ONA looks at three different things:

- The need for supports with ADLs and IADLs
- Medical support needs
- Behavioral support needs

An individual could have low overall need for support with ADLs and IADLs, but have a very high need for behavior supports that elevates the to the "very high" service tier. The same is true for medical support needs.

Meghan Robledo: So basically if my son is non speaking, level 3 autistic, cognitively 21 months at age 7, and requires a substantial amount of support he may not qualify if he isn't level 5 on his ONA?
The ONA is not a developmental assessment, but rather an assessment of the need for supports to accomplish ADLs and IADLs (scaled for age), the need for medical supports and the need for behavior supports. The same assessment will yield different results at different age levels because, in general, as parents we must provide more supports to our 5 year olds to get through the day than our 12 year olds. The ONA accounts for that.

For instance, for a seven year old, there are not five service tiers. There are only 3— very low/low support needs, moderate support needs and high/very high support needs.

It's also important to point out that the qualification is for the eligibility to pay a parent—not eligibility for services at all.

Jennifer Murphy: Is the 2:1 a different pay rate if they are capped at 60 hours and caring for 2 eligible children?

The 60 hour cap is per household, regardless of the number of parents or the number of children. The rate model includes a different rate of pay for staffing more than one individual vs. 1:1 staffing. Through an agency, these rates will be determined through the agency. For PSWs, this is a rate negotiated in the collective bargaining contract.

Jenn Whitten: Why would Oregon not want to keep the funding in Oregon instead of driving families out of state?
I'm not sure which state families would go to in order to access paid parent services. If they are not eligible here to be paid as parents under the proposed program, they would be very unlikely to be eligible in another state. In addition, they would need to calculate the impact of the other associated benefits with ODDS services eligibility here in Oregon vs. participating in a waiver in another state.

The other states do operate their programs through a waiver, and not as part of their state Medicaid plan. I addition, Oregon is one of very few states that offers any in home support hours for children with ID/DD that are not also medically fragile.

Romi Ross: CA's system is not nearly as limiting as this proposed bill, and the ONA
We will see if we can get staff to develop a comparison table to show the difference in the services.

John (Merrick) Russell (Self): Personally Exploratory Phase, Do we have to worry about the 2030 something SSI?SSDI and Medicate Fed Conversation if this state law becomes law?
No. This would be done under a waiver and this would not result in increased income to the individual child.

Theresa Jahangir (she/her): Will there be an opportunity to continue this conversation for example, in a work group, on this bill?
Both of these bills will be part of the 2023 legislative session. Public hearings will be held as with all other bills introduced into the session.

Jenn Whitten: Yes. Non-parent DSP's are not filling 70% of all assigned hours now. That limitation does nothing to secure support for our kids, who we, respectfully, prioritize over adult workers.
The 70% is across the entire DD system for in home supports for children and adults. Currently, paid parents of minor children make up only a fraction of the people compensated for those hours.

Adults with ID/DD in the ODDS system often have no other supports available to them. We must protect the workforce and grow the workforce of non-parent caregivers or else there will be nothing left for adults with ID/DD who have far less access to natural supports than children.

Lisa Tschudi: There is absolutely no reason to prefer or privilege the non-family workforce, though. What about choice?

Public benefits always come with restrictions because the “pie” must be spread out to all people. As drafted, this concept will allow a significant number of hours each week to be provided by the parents of minor children while also working to protect and expand the nonfamily workforce that is needed by the majority of individuals who utilize ID/DD services across the lifespan.

Jenn Whitten: Will there be a requirement on agencies to hire parents?
I have not heard of an agency turning away a qualified provider.

K. Rotella: Punishing the agencies isn’t the way. They’re responsible for ensuring the DSPs are trained, supported, etc. regardless of if they’re parents or not.
This is not a punishment. This is a safeguard in the system to protect public funds and to align with the overall requirements of agencies designed to expand and stabilize the workforce.

Lisa Tschudi: if parents are the chosen providers?
I don’t understand this question. However, parents can be the chosen provider for up to 60 hours a week. Under the new service tier system, for many children this will be the majority of their hours—if not all of their hours—unless they are eligible for an exception.

Chris Wilcox: Parents can be harmed by that, there needs to be another way to encourage recruiting without holding hours hostage
The hours are not held hostage. This is an expansion from what is currently available. The 70% requirement is on the agency across ALL of their in home services for people with ID/DD. It is not applied to each individual family. In this system, some minor children may have 100% of their hours provided by their parents. However, the agency as a whole will have a variety of adult and child clients that will employ a majority of providers that are not providing services directly to a minor child. Keep in mind that any hour assigned for a person over the age of 18 counts towards the 70%.

Gabriel Triplett (Parent Advocate): In some areas there is only a handful or even 1 agency.
The number of agencies has recently grown and ODDS is doing good work to better regulate and equip these agencies.

Jenn Whitten: Why do you keep excluding step parents?
It is my understanding that step parents are not currently included as individuals that **can’t** be paid under the federal law. I will double check that. However, by excluding the step parents, that means that their hours do not count as paid parent hours. Therefore, the child’s dad could provide 60 hours and the child’s step mom could provide the balance of the hours because the step parent is not excluded as an eligible paid provider. As part of the hearing process we will seek clarification on this point. The intention is to have language that does allow step parents to be paid.

Rachel Bowman-Cryer: why is the recruiting of strangers to do a job that is better and more safely done by the parents or family important?

ODDS services are intended to supplement rather than supplant natural supports. In addition, it is critical to ensure that the workforce is expanded and stabilized as the majority of individuals that need and use ID/DD services across the lifespan do not have family members that can provide this support, or do not wish to have family members provide this support.

Lisa Ledson: why would parents be treated different than non-family DSPs?
They would not. There are very few non-family DSPs that are authorized to work more than 40 hours a week.

Jenn Whitten: Step parents cannot be paid caregivers for their step children currently. Would that change?
My understand is that step parents can currently be paid caregivers. I will double check on that as I may be mistaken. If they are not currently able to be paid, I will fix that to ensure they are included in the definition of parent.

Mmastalski: Why not just make it so an agency can't only have paid parents?
That is difficult to enforce. Law needs to be much more explicity. For instance, an agency could get around this by having one DSP that works 40 hours a week and then 60 paid parent providers. That would comply with a prohibition on not having "only" paid parents but would not meet the goal of ensuring a robust workforce.

Valentina: Where is this list for 5?
It probably does not make sense to refer to this as level 5 because the ONA service tiers are a little different. The service tiers can be found here: https://www.oregon.gov/dhs/Compass-Project/Pages/Service-Groups.aspx

There is a great deal of information also available throughout the links on this page.

paige hall: A question I have is, how will agencies train their employees better? Most are not qualified to handle children with the amount of behavioral and or medical needs they have. Could it be written in for them to have collaborative problem solving training and trauma informed trainings?
With the passage of SB 1548 last February, ODDS recently developed new rules for agencies related to training for staff and services required to be provided--- including more robust recruitment, training, coverage for absences, scheduling, etc. Those changes are in the process of being implemented right now.

Theresa Jahangir (she/her): what about children that have BOTH medical and behavioral needs; are the two scores combined?
I don't completely understand the question. However, in the ODDS modeling regarding eligibility there were children identified as qualifying under both the very high behavior support needs AND the very high medical support needs.

K. Rotella: It sounds like this could take a long duration to establish, configure and vote on. Is there a plan in place to continue the current emergency plan past April while this is sorted out so parents aren't on pins and needles every time the extension deadline nears?
This is the regular process for considering changes in law and public programs. There currently is not a plan or funding to continue the paid parent program once the PHE ends unless and until a new program is put into place. That would require the plan to be funded entirely by general fund for an unspecified period of time.

This is frustrating and scary for families. It is also true for many individuals across the state who benefited from crucial supports provided on a temporary basis during the public health emergency. Many of those services were possible only because of enhanced funding provided to the state by the federal government. Over the course of the session, legislators will need to prioritize among very important programs and make some very difficult choices.

K. Rotella: The hours that were given out should have already been budgeted for each year. Therefore there's no increase or decrease in budget cost. Clearly the state has thrown attendant hours out to families that were never indented to actually be filled by existing DSPs or PSWs.
The hours are not given out as an entitlement or benefit. The hours are the result of an assessment to determine the number of hours that an individual needs supports to accomplish ADLs and IADLs. The assessment does not distinguish between paid supports and natural supports. All in home programs (kids, adults, seniors, etc) are budgeted based on hours used rather than hours assessed.

Shasta Kearns Moore: Ages 0-3 would not qualify at all
Attendant care services are intended to provide needed supports for ADLs and IADLs. The current tool does not do a good job of distinguishing across age groups. All birth to three year olds require near total care from adults to complete their activities of daily living—none of us would be able to leave a 3 year old to their own devices for eating, toileting, safety, dressing, bathing, etc. The service tier levels recognize this and better distinguish the enhanced need relative to age and what would be needed for a typically developing child.

Please keep in mind that we are talking about ***attendant care hours***. These are NOT nursing hours.

Also, please note, that children under three may still qualify for some attendant care hours—just a far lower number of hours than older children. Those decisions have not been part of the paid parent caregiver process, but are part of a long process over multiple years that involved a great deal of study, validation, stakeholder involvement, consultation with CMS, consultants, etc. It is still unclear when the new model will be implemented. It is also important to note that there will be the ability to seek exceptions if the assessed hours through the tool do not meet a specific child's needs.

Jenn Whitten: It feels paradoxical that this program would be limited to the kids with the highest levels of need, but also requires our children be in school from 8-3 and only makes exceptions for traveling for things like 'school trips' and 'team activities.' Are we talking about children with the most complex care needs in Oregon or are we talking about travel team soccer students with perfect school attendance?
State and federal law require that every school district provide a free and appropriate public education to every child, regardless of disability or medical need. This includes the right to the same number of hours and same number of days as all other students in the district. If the district makes an alternate placement, they remain responsible during school hours.

Meghan Robledo: So if a child is homeschooled they would not qualify?
They would qualify for attendant care hours, but under federal rules attendant care hours cannot be provided to a school aged child during school hours (including for home schooled children) regardless of who the provider is. This is not specific to paid providers. There was some flexibility with this under during the public health emergency but this will go away once the PHE ends.

Joey Razzano: who provides the fiscal impact statement for the ways and means committee for this?
Oregon DHS will provide information, materials and estimates to the non-partisan Legislative Fiscal Office. They have analysts that will dig into the information, ask questions and probe the data. Ultimately, it is the LFO that writes the fiscal impact statement that goes to Ways and Means.

Jenn Whitten: Correct, Meghan. It also sounds like public charter school and online schools are not valid choices.
Public charter schools and online schools remain valid education choices. However, federal rules preclude Medicaid paying for services that another party is responsible for. In this case, school districts are responsible during school hours. When parents make a choice about where to enroll their children, the number of hours of service is one of the elements they will want to consider.

Michael Paruch: What about those who are home bound or remote learning?
Federal rules preclude Medicaid paying for services that another party is responsible for. In this case, school districts are responsible during school hours even when a student is home bound or remote learning. Those children have a right to the same number of hours and days as all other students. In addition, IDEA requires the district to provide the supports and related services necessary to access school—including nursing, 1:1 support, etc.

Susan Hight: Yes, my child was not allowed to go to school because he had an NGtube because they didn't have staffing etc. it is so outrageous what the schools are doing.
I agree, This is completely illegal. I would really like to talk with you about this. My top priority for this legislative session is addressing this issue.

Priscila Gomora: Wow! Children who are homeschooled won't qualify?! Have you asked why most children are homeschooled? Most of them were failed by the Education System!
Children who are homeschooled are eligible for in home services and paid parent services (under this bill). However, like all other students, attendant care hours can't be funded by Medicaid during school hours. This is true for all students and is a federal rule.

I agree that our education system is failing our kids with disabilities and contributing to all of the issues we are discussing here. The consequences of the failure to provide quality education (and in some cases ANY education) to students with disabilities are far reaching beyond even the daily crisis. Addressing this issue is my top priority for the 2023 session.

Jenn Whitten: Not every alternative school choice is a negative one.
Agreed. The issue here isn't about the validity of school choices. It is simply that federal rules prohibit using Medicaid funds for attendant care services ***during*** school hours.

Meghan Robledo: That is pretty unfair. My district won't give my son a 1:1 he's a flight/fall risk, gets sick super easy. brother brings home something (older son has missed 17 days of school due to rsv, Covid, flu) and I literally have to quarantine him away. so we chose to homeschool.
Please contact me offline. I'd love to try to talk through this. These are exactly the kinds of examples we need to share to better explain how severe the problem is with our schools failing to comply with their obligations under state and federal law.

Also, it is not this concept that creates the prohibition on attendant care hours during school hours. That is a federal rule for which there was some flexibility during the public health emergency. I am very worried that people do not realize that is going away.

Tobi Rates, ASO (she/her): Thank you for hosting this session, although it's been a bit frustrating to try to participate. I would appreciate more opportunity to have input and discuss concerns with this bill. How can we create more opportunities for constructive discussion of things we can change (ie, not CMS requirements)?
I apologize for the technology issues and also that I was not at the top of my game due to a migraine. However, I did not want to cancel as I had committed to this long ago!

The legislative session begins on January 9. Both of these bills will be heard in that session and there will be opportunities for public testimony.

Your best strategy is to identify your legislative champions to draft proposed amendments to the bills and to identify what your bottom line is for support of any measure. Amendments have to be drafted through the Legislative Counsel and can only be requested by a member. Once the amendment is received, the member can submit that amendment to the committee. It takes a majority vote of the committee to adopt an amendment. It also takes a majority vote of the committee to move the bill forward. Keep in mind that all bills must pass out of their policy committee by early April in order to "stay alive" in this session.