Oregon Department of Human Services
Office of Developmental Disabilities Services
July 22, 2022

ODDS Response to Caregiver Issue

1. **If a youth does not want their parent to provide personal care, how would that youth be protected to express that/terminate the parent?**

   Answer: There is not currently a clearly defined process for protecting a youth's choice in the situation described in this question. OAR 411-415-0070 requires case management entities to assure person-centered choices throughout the planning process. OAR 411-320, 411-415, and 411-318 reference the role of parents in consenting to services and making decisions on behalf of their children.

2. **Would Medicaid allow a parent being paid as a caregiver to multitask during caregiver hours? For instance, would that parent, while providing line of sight supervision while a medically fragile child is sleeping, be permitted to care for other children in the home, work on an at-home business, do general housework, cook dinner for family, etc.?**

   Answer: CMS does not have regulations that explicitly prohibit providers from "multi-tasking"; however, all services must be provided according to the child's ISP. The expectation is that attendant care is a 1:1 service, with the provider's time dedicated to meeting the support needs of the person/child. Tasks that are unrelated to providing direct care and may put a child at risk or impede service delivery are not permitted.

3. **Have the families that use parents as paid caregivers for minor children maintained the hours of outside caregiver usage from prior to the policy being implemented?**

   Answer: 92 children had hours worked decrease for the non-parent providers;
   184 children had hours worked increase for the non-parent providers.

Time Periods	Total average monthly hours provided **per non-parent** caregivers	Total average monthly hours provided **per parent** caregivers
3/1/2019-2/29/2020 Pre COVID	31,392	0
3/1/2020-12/31/2020 Pre Parents as Providers	37,672	0
1/1/2021-12/31/2021 Post Parents as Providers	38,801 avg monthly hours	24,186 avg monthly hours

4. **Among families that are using parents as paid caregivers for minor children, in how many cases is more than one parent being paid as the caregiver?**

   Answer:
   We have received information from the CMEs stating there are 3 individuals who have more than one parent being paid as the caregiver; however, we are not confident that the number is correct and do not have a way to accurately pull this information. For example, parents or legal guardians may have different last names from each other or from their children. Also, paid family members with similar last names may live in the same home but not be the child's parent.

5. **Among families that are using parents as paid caregivers, how many are working as PSWs and how many are working through an agency?**

   Answer: 65% of parents of minors paid as providers for their own children are working as DSPs and 35% are working as PSWs.

6. **What are the lowest and highest number of hours claimed per week for parental caregivers by families that are using parents as paid caregivers for minor children? What is the largest?**

   1/1/2021 to 6/13/2022

Type of Parent Provider	DSP	PSW
Lowest Weekly Hours	.20 hours	.30 hours
Highest Weekly Hours	167.90 hours	120.30 hours

7. **How much overtime (OT) is being claimed by parents paid as caregivers for minor children?**

   1/1/2021 – 6/13/2022

Type of Parent Provider	DSP	PSW
Total OT hours for the period 1/1/2021 - 6/13/2022	91,612	11,904

   Answer:
   The overtime hours above represent 31% of total hours billed for this time period.

8. **Among families that are using parents as paid caregivers for minor children, how many are claiming more than 40 hours a week for parent caregivers? More than 60 hours a week? More than 80 hours a week?**

   Answer: The table below shows the number of children with providers billing within various ranges of hours per week

   1/1/2021 to 6/13/2022

Hours per week	DSP	PSW
40 to 59 Hrs in a Week	128	59
60 to 79 Hrs in a Week	91	28
80 or More Hrs in a week	50	10

9. **Is there any benchmark through ODDS, Child Welfare, or any other program in the nation, that identifies the base number of hours that are normal parental responsibility (i.e., parent is responsible for either directly providing care and supervision or finding someone else to provide care or supervision) for children based on age?**

   Answer: There is no benchmark through ODDS, Child Welfare or any other known program that identifies a base number of hours a parent is responsible for the care and supervision of their child.

10. **How does the ONA determine what is a general support need based on disability and what is an extraordinary need that extends beyond parental responsibility?**

    Answer: Both the Children's Needs Assessment (CNA) and the ONA assess a child's support needs, regardless of the nature of the disability and/or who provides the support. With each assessment, a child's age is considered and skills that a child usually has at various ages are assessed. Skills a child would not be expected to have are not assessed.

    For example, with a two-year-old, we do not assess bathroom or cooking skills because we don't expect a child of that age to have those skills. We expect the child gets support for those needs from others, but we don't specify in the assessment process who might be providing age-appropriate support. Another example would be that we assess laundry skills for older teens, because we consider that an activity a typical teen is able to complete.

    The CNA was developed quickly, over a matter of months, when Oregon first adopted the K Plan. It has not been tested for validity or reliability and ODDS has made clear over the years that we do not consider it or the Adult Needs Assessment (ANA) to be valid assessment tools. That is why we initiated the effort to develop the Oregon Needs Assessment (ONA). Unfortunately, even after many years and various project stops and starts, we still use the CNA and ANA to determine in-home hour authorizations. In the

future (after the ARPA funding MOE requirements end), we plan to transition to the ONA for in-home hour authorizations and end use of the CNA and the ANA completely.

The ONA was developed by Mission Analytics with input from ODDS and the broader DD community. It was tested for validity by Mission Analytics and independently by OHSU. We've gone through an extensive planning effort to use the ONA to assign individuals a "service group" based on the results of the assessment, and eventually will have both service rates and in-home hour authorizations tied to a person's service group.

11. Of the families that are using parents as paid caregivers for minor children, what percentage are families who meet eligibility criteria for each of the waivers (Medically Involved, Medically Fragile, Behavior)

Waiver	**% of Children**
Behavior Waiver	9.21%
Medically Fragile Waiver	11.51%
Medically Involved Waiver	22.04%
Children's In-Home Services	77.24%
Grand Total	100.00%

12. What number of hours are being claimed during school hours for parents being paid as caregivers? For all children receiving ODDS in-home hours?

Time Period Not including the summer months of June, July, August	Parents as Providers	Non Parent Providers	Total Hours
3/1/2019-2/29/2020 Pre COVID (12 months)	N/A	523,067	523,067
3/1/2020-12/31/2020 COVID (10 months)	N/A	1,031,510	1,031,510
1/1/2021-6/11/2022 Parents and Agency Providers (17.33 months)	45,579	1,869,806	1,915,385

13. What percentage of the families that are using parents as paid caregivers for minor children are using Rever Grand as their agency?

Answer: During a survey Rever Grand reported they are serving 102 Children via parents as DSPs which is 35% of all parent paid caregivers.

14. **If the public emergency ended, what would the monthly GF cost be to freeze the program at its current capacity?**

    Answer: $1.7M monthly.

15. **Is there any state or federal policy barrier to creating a GF program to "bridge" the end of the public health emergency and the beginning of a new program, if that "bridge" program was limited only to the children currently receiving services from paid parent caregivers and with those hours capped at their present usage?**

    Answer: There is no known federal policy barrier to creating a GF only "bridge" program.

16. **If such a bridge program was created, would it establish a sort of maintenance of effort requirement that would preclude the state from establishing a clearer framework for the use of parents as paid caregivers (such as limiting overtime/weekly number of parent compensated hours, narrowing eligibility criteria for use of paid parent caregivers, eliminating approval of paid hours regardless of provider during school hours, etc.)**

    Answer: The MOE requirement related to ARPA is specific to Medicaid funded services, we do not think it would apply to a GF-only program. It would be difficult to see how a state-funded "bridge" program would preclude the state from creating a new program with different requirements through legislation in the future.

17. **Please describe how hours are allocated within the CIIS program. Are parents able to convert hours allocated as "nursing" hours to "attendant care" hours? If so, is there a way to determine what percentage of hours claimed during the public health emergency for paid parent caregivers were technically nursing hours and which were attendant care hours?**

    Answer: There are three CIIS Waiver programs – Intensive Behavior, Medically Involved, and Medically Fragile. Children in each of these programs have a Child Needs Assessment (CNA) completed to determine the number of attendant care hours they are eligible for each month. Children who are eligible for the Medically Fragile waiver also have a PDN clinical criteria assessment to determine the number of private duty nursing hours they are eligible for each month. When nurses are not available to provide the private duty nursing supports, an exception may be approved to increase the attendant care hour authorization. Because private duty nursing is paid out of MMIS and attendant care is paid out of the eXPRS payment system, we are unable to determine what percentage of hours claimed during the public health emergency were technically "nursing hours" and which were assessed attendant care hours.

18. Disregarding families that are using parents as paid caregivers for minor children, how does usage of allocated hours by children with ID/DD compare to the usage of allocated hours prior to the pandemic? Is this similar to the adult system? Is there a difference between nursing hours and attendant hours in this calculation?

	Utilization to Authorization Ratio		
	Calendar Year 2019	**Calendar Year 2020**	**Calendar Year 2021**
Adults (18 and older)	74.5%	75.5%	74.7%
Children	66.9%	68.1%	68.2%

19. When do the new nursing rates go into effect for CIIS?

Answer: July 1, 2022

20. If the ODDS budget was reconfigured to be based on all hours allocated for individuals with ID/DD through their assessments, instead of based on the history of hours used, what would the difference in cost be for the last two biennia? In other words, what is the difference between the current funds budgeted for ODDS services and the amount that would be required to pay for 100% of the hours for 100% of the individuals allocated hours through ODDS in-home services? Please break this estimate into GF and TF.

Answer: Based on the chart below, an additional $112.5 million GF would have been required for fund-authorized in-home hours in the 19-21 biennium. For 21-23, that estimate increases to $156.5 million GF.

	19/21 Actual Authorized - Attendant Care Only			19/21 Actual Billed - Attendant Care Only			19/21 Authorized Over Billed		
	GF	FF	TF	GF	FF	TF	GF	FF	TF
Children's Intensive In-Home Services	$ 14,506,761	$ 36,965,983	$ 51,472,744	$ 9,135,946	$23,280,126	$ 32,416,072	$ 5,370,815	$ 13,685,857	$ 19,056,672
Children's In-Home Services	$ 84,671,266	$ 221,980,083	$ 306,651,349	$ 52,014,482	$ 136,364,785	$ 188,379,267	$ 32,656,784	$ 85,615,298	$ 118,272,082
Adult In-Home Services	$ 271,568,058	$ 740,434,827	$ 1,012,002,885	$ 197,085,846	$ 537,357,838	$ 734,443,684	$ 74,482,212	$ 203,076,989	$ 277,559,201
Total	**$ 370,746,085**	**$ 999,380,893**	**$ 1,370,126,978**	**$ 258,236,274**	**$ 697,002,749**	**$ 955,239,023**	**$ 112,509,811**	**$ 302,378,144**	**$ 414,887,955**

	21/23 Budget if Based of Authorized Hours			21/23 Budget			21/23 Authorized Over Budget		
	GF	FF	TF	GF	FF	TF	GF	FF	TF
Children's Intensive In-Home Services	$ 20,585,966	$ 56,825,910	$ 77,411,876	$ 12,964,457	$35,787,344	$ 48,751,801	$ 7,621,509	$ 21,038,566	$ 28,660,075
Children's In-Home Services	$ 121,775,309	$ 321,892,970	$ 443,668,279	$ 74,807,900	$ 197,742,361	$ 272,550,261	$ 46,967,409	$ 124,150,609	$ 171,118,018
Adult In-Home Services	$ 371,899,147	$ 982,514,987	$ 1,354,414,134	$ 269,899,408	$ 713,043,349	$ 982,942,757	$ 101,999,739	$ 269,471,638	$ 371,471,377
Total	**$ 514,260,422**	**$ 1,361,233,867**	**$ 1,875,494,289**	**$ 357,671,765**	**$ 946,573,054**	**$ 1,304,244,819**	**$ 156,588,657**	**$ 414,660,813**	**$ 571,249,470**

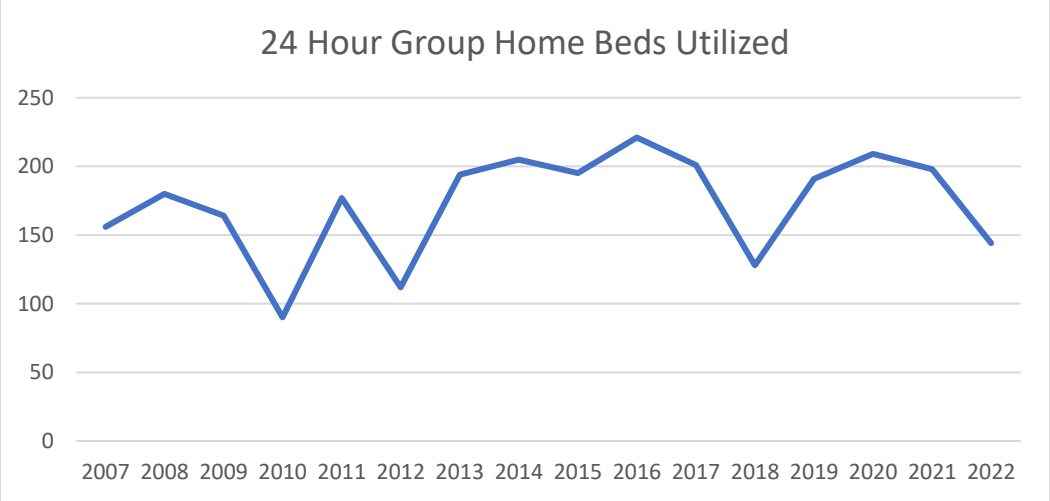
21. What percentage of children receiving ODDS services would be ineligible for services if the policy of ignoring parental income was ended?

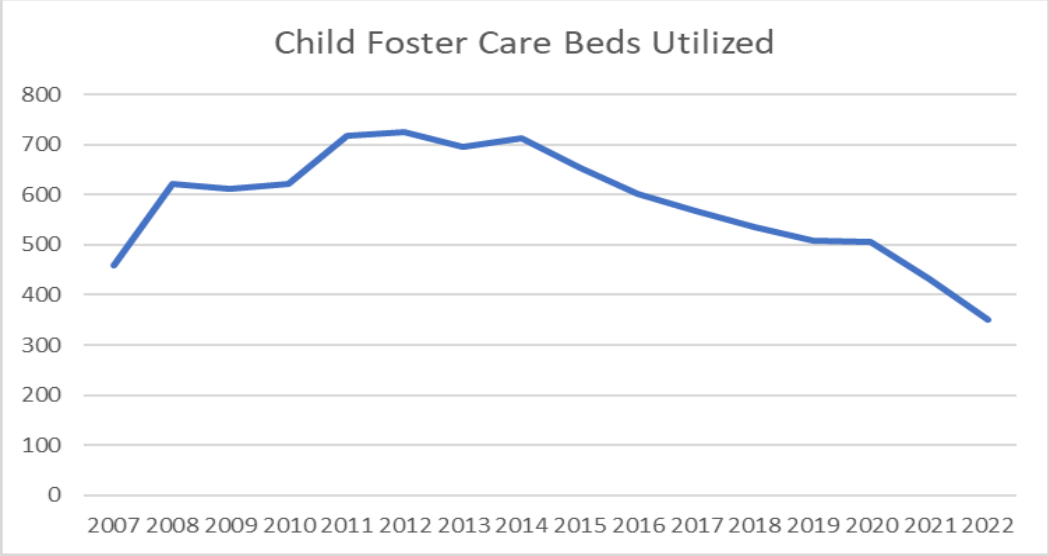
Answer: ODDS estimates that 27% of children would lose services if the policy of disregarding parental income was ended.

22. What is the formula for determining extraordinary need? How do you determine what is normal parental responsibility and what is extra?

Answer: There is no current definition or formula for "extraordinary need". The CNA and ONA assess the support needs of children as described in the response to question 10 above.

23. Over the last 10 – 15 years, has there been an increase or decrease in out-of-home placements?





24. What happens with things that happen at home when a parent is a caregiver, things like sibling care? Do we have to consider these?

Answer: Same answer as for question 2 above. CMS does not have regulations that explicitly prohibit providers from "multi-tasking". However, all services must be provided according to the child's ISP. The expectation is that attendant care is a 1:1 service, with the provider's time dedicated to meeting the support needs of the person/child. Tasks that are unrelated to providing direct care and may put a child at risk or impede service delivery are not permitted.

25. How is "parental responsibility" defined? Different by age?

Answer: "Parental responsibility" is not defined. The specific ADLs and IADLs the CNA and ONA assesses are different based on a child's age.

26. What is the level of care required for paid providers, and does it change if the provider is a parent? Do parents have to complete the same training?

Answer: Currently, the same standards and provider qualifications apply regardless of other relationships between an individual and the chosen provider.

27. What accountability measures are in place for this? What is the capacity for agency for oversight? What liability does the state hold when there are changes to this?

Answer: ODDS credentialing, oversight, and monitoring responsibilities are the same for parent providers as other providers.