

Oregon On-site Review Summary Report

I. Executive Summary

The Health and Welfare Special Reviews Team (H&W SRT) conducted a 5-day intensive on-site review of Oregon's home and community-based services (HCBS) Medicaid waiver programs from September 9 through September 13, 2019. This on-site review was conducted to focus on recently renewed waivers and potential promising practices. The on-site review focused on the Aged and Physically Disabled (APD) Waiver operated by Department of Human Services, Aging and People with Disabilities (DHS/APD) as well as the Children's HCBS Waiver and Adults' HCBS Waiver operated by Department of Human Services, Office of Developmental Disabilities Services (DHS/ODDS).

The on-site review included multiple meetings with state directors and staff responsible for the administration and operation of all six Oregon 1915(c) waivers, including staff from the Oregon Health Authority (OHA), DHS/APD, and DHS/ODDS. The H&W SRT also held a joint meeting with representatives from the respective licensing entity, protective services entities, protection and advocacy entity, and HCBS ombudsman.

In addition, the H&W SRT met with case managers, investigators, providers, and participants. The focus of these meetings was to obtain a sense of how the process for reporting, investigating, and resolving critical incidents operates in practice and how health and welfare are ensured for HCBS participants in Oregon through the lens of these stakeholders. The H&W SRT split into two groups: Team A focused on the APD Waiver operated by DHS/APD, and Team B focused on the Children's HCBS Waiver and Adults' HCBS Waiver operated by DHS/ODDS. State staff members were not present during interviews with participants and providers.

During the on-site review, the H&W SRT identified a number of strengths and promising practices for ensuring health and welfare along with some challenges, which are listed here and described more fully later in the summary report.

Strengths and Promising Practices for Ensuring Health and Welfare

- A. A commitment to the safety and autonomy of the individual was voiced throughout all levels of state staff
- B. A culture of quality and system improvement across all agencies, examples include implementing the Centralized Abuse Management (CAM) system and expanding the definition of critical incidents
- C. State regulation for multidisciplinary teams promote collaboration around critical incident prevention, investigation, and response at the state and local levels
- D. Streamlined interactions between operating agencies via a single point of contact
- E. Ongoing waiver health and welfare/quality review by the state Medicaid agency supported by an interagency agreement
- F. Specific, comprehensive licensing information made public and easily accessible via a facility licensure violation website
- G. Developmental disabilities (DD) stakeholder engagement via various modes of communication
- H. Notification and reminder of mandatory reporting status at least annually to employees

- I. Cross-reporting statute requiring law enforcement and child welfare to cross-report child abuse allegations
- J. Two waiver services utilizing long-term care community nurses and positive behavioral support services that may be used to identify, address, and prevent instances of abuse, neglect, exploitation, and unexplained death

Challenges

- A. Data systems operate independently and are not integrated
- B. Ensuring health and welfare for participants who self-direct their services due to a dramatic increase in participants that self-direct
- C. Limited operating hours of the statewide abuse reporting line toll-free phone number
- D. The potential for underreporting of incidents due to providers’ discretion
- E. A critical incident process that lacks a uniform practice for requiring follow-up with the individual
- F. Inadequate critical incident education, training, and materials per feedback from providers and participants
- G. Missed opportunities for incident investigation follow-up since the only prescribed follow-up timeline is for the final report at 60 business days
- H. Impact of quality monitoring issues on health and welfare performance measure compliance rates

Recommendations

- A. Improve outreach and education to providers and participants
- B. Implement process improvements to support the success of the Centralized Abuse Management (CAM) system
- C. Make accessible an abuse registry as documented in the APD Waiver
- D. Consider implementing a DD centralized comprehensive case management system
- E. Increase the number of deaths reviewed during the mortality review process
- F. Increase stakeholder communication and engagement for the APD population

II. Background

Before the on-site review, the H&W SRT reviewed waiver program documents and other materials from the public domain related to the health and welfare assurance of individuals receiving HCBS in Oregon. Table 1 lists all six Oregon waiver programs that were reviewed prior to the visit, along with the waiver’s expiration date, operating agency, and target population.

Table 1. Waiver Programs Reviewed by the H&W SRT

Waiver Name and Number	Expiration Date	Operating Agency	Target Population
Aged and Physically Disabled Waiver (0185)	December 2026	Oregon Department of Human Services, Aging and People with Disabilities	Participants who are older adults or are 18 years and older with physical disabilities
Medically Involved Children’s Waiver (0565)	June 2024	Oregon Department of Human Services, Office of Developmental Disabilities Services	Children aged 0–17 years with physical disabilities

Waiver Name and Number	Expiration Date	Operating Agency	Target Population
Medically Fragile Model Waiver (40193)	June 2024	Oregon Department of Human Services, Office of Developmental Disabilities Services	Children aged 0–17 years who are medically fragile
Behavioral (ICF/IDD) Model Waiver (40194)	June 2024	Oregon Department of Human Services, Office of Developmental Disabilities Services	Children age 0–17 years with an intellectual or developmental disability
Children’s HCBS Waiver (0117)	June 2023	Oregon Department of Human Services, Office of Developmental Disabilities Services	Children age 0–17 years with an intellectual or developmental disability
Adults’ HCBS Waiver (0375)	June 2024	Oregon Department of Human Services, Office of Developmental Disabilities Services	Participants age 18 years and older with an intellectual or developmental disability

Through review of preliminary information, the H&W SRT determined it was best to focus on the Aging and Physically Disabled (APD) Waiver, the Children’s HCBS Waiver, and the Adults’ HCBS Waiver. The APD Waiver was selected as the only active 1915(c) waiver program serving the aging and physically disabled population. The Children’s HCBS Waiver and Adults’ HCBS Waiver were selected (1) to include waiver programs designed to serve either children or adults with intellectual disabilities and developmental disabilities and (2) because they have a considerable number of participants. Below are descriptions of the three waivers.

The **Aging and Physical Disabilities (APD) Waiver** provides case management and community transition services to participants who are older adults or are 18 years and older with physical disabilities. These individuals receive other HCBS services through the state’s 1915(k) state plan program. The APD Waiver supports approximately 35,000 waiver participants and is operated by the Department of Human Services (DHS), Aging and People with Disabilities (APD). All critical incidents should be reported within one business day through the Adult Protective Services (APS) System. APS investigators initiate their investigation either the same day, the next day, or within five days of receipt. Investigations must be completed within 60 business days for residential settings and within 120 business days for participants receiving services in their own home.

The **Adults’ HCBS Waiver** provides services to participants who are age 18 years and older with an intellectual or developmental disability. The Adults’ HCBS Waiver supports approximately 7,800 waiver participants and is operated by the Department of Human Services (DHS), Office of Developmental Disabilities Services (ODDS). Providers must submit critical incidents to the case manager within five business days. Incidents are screened at the county level within three days to determine whether an investigation is warranted.

Most incidents are investigated at the county level; however, those meeting a specified threshold are referred to the state for investigation by the Oregon Office of Training, Investigation and Safety. The timeframe to complete the investigation is 60 days.

The **Children’s HCBS Waiver** provides services to participants who are age 0–17 years with an intellectual or developmental disability. The Children’s HCBS Waiver supports approximately 14,600 waiver participants and is operated by DHS/ODDS. The critical incident process is the same as it is for the Adults’ HCBS Waiver.

III. Oregon On-site Review

The H&W SRT conducted the on-site visit over a five-day period and met with various state staff, stakeholders, advocates, providers and participants. The following topics were covered in addition to reviewing a sample of critical incident reports.

- State’s handling of allegations of abuse, neglect, exploitation, and unexplained death
- State’s mortality review process
- Licensure/contract oversight process and how it intersects with incident reporting and investigations
- Critical incident reporting process from both the provider and participant perspectives

During the on-site visit, the state provided additional documents, such as reporting forms, notification of rights, organizational chart, memos, brochures for participants, and training manuals for providers. Additionally, providers shared training materials and reporting forms, among other items. Oregon also noted that claims payments are made if a service was provided, even if a service was provided poorly, but will be recouped if a service was found to not have been provided. Case managers serving participants receiving DD waiver services indicated that any time there is an incident involving a personal service worker, the case manager can make a recommendation to the provider unit to temporarily inactivate the provider number or suspend the provider’s ability to be paid. After the investigation is complete, the provider unit conducts its own review process to determine whether further sanctions are required.

IV. State Strengths and Promising Practices for Ensuring Health and Welfare

The following is an overview of the state’s strengths identified by the H&W SRT through both the preliminary review and the on-site visit regarding the design or practice of ensuring the health and welfare of HCBS participants in Oregon.

A. A commitment to the safety and autonomy of the individual throughout all levels of state staff

In all conversations with state personnel and with providers during the on-site visit, there was evidence of the state having a commitment to both the safety and autonomy of the individual. The recognition of the importance of a meaningful life including acceptance of a level of risk was voiced in multiple settings.

B. A culture of quality and system improvement across all agencies

In multiple conversations, it was clear that there is a commitment for improvement within OHA and DHS. This commitment to develop a better system to address, track, trend, and analyze critical incidents was also recognized by stakeholders, and recent improvements were evident. For example, the state has made strides toward rectifying data integration issues through its recent efforts to implement the Centralized Abuse Management (CAM)

system and recently expanded its definition of *critical incidents*, which should result in more comprehensive data from which to draw. The state also recently improved its process for conducting background checks. These are among several improvements on which the state is working.

C. Multidisciplinary collaboration around critical incident prevention, investigation, and response at the state and local levels

Approximately 6 years ago, Oregon implemented a regulation for multidisciplinary teams statewide supported by the local District Attorney's office. As a result, state staff meet regularly and collaborate with law enforcement, the Attorney General's office, hospitals, and more around critical incident prevention, investigation, and response. This approach seems to be more effective in the larger counties because the smaller ones are reportedly having some difficulty instituting it. Stakeholders seemed to have a solid understanding of the critical incident process.

D. Streamlined interactions between operating agencies via a single point of contact

A designated liaison works with both DHS/APD and DHS/ODDS to provide seamless communications, planning, and operations. The contact works closely with OHA, DHS/APD, and DHS/ODDS leadership to streamline interactions.

E. Ongoing waiver health and welfare quality review by the state Medicaid agency

OHA conducts quality assurance reviews of 10 percent of providers that DHS/APD and DHS/ODDS have reviewed. This is a look behind to review how the operating agencies have monitored health and welfare. OHA and DHS have an interagency agreement that includes a process on how to resolve disputes. It begins at the front line and works up to the OHA/DHS director level, with OHA having the final decision.

F. Specific, comprehensive licensing information made public and easily accessible via a facility licensure violation website

DHS/APD has a website with very specific, comprehensive detail about licensure violations and inspection results.

G. DD stakeholder engagement

The DD stakeholders reported a significant level of engagement with the state operating agency. ODDS uses various modes of communication, including email blasts, quarterly provider meetings, town halls, and social media.

H. Notification and reminder of mandatory reporting status

According to the approved Adults' HCBS Waiver application, DHS requires notification of mandatory reporting status at least annually to all employees of case management entities or provider organizations. All employees must be provided with a DHS-produced card regarding abuse reporting status.

I. Cross-reporting statute requiring law enforcement and child welfare to cross-report child abuse allegations

Oregon's Behavioral (ICF/IDD) Model Waiver describes the state's cross-reporting statute (ORS419B.015) for suspected child abuse that applies to DHS and law

enforcement entities. The statute requires DHS child welfare and law enforcement to report to each other within specified timeframes based on assessed level of risk.

J. Two waiver services that may be used to identify, address, and prevent instances of abuse, neglect, exploitation, and unexplained death

Oregon uses an innovative approach to staffing/services by offering the following two services under its 1915(k) Community First Choice program. These services may be used to identify, address, and prevent instances of abuse, neglect, exploitation, and unexplained death (health and welfare sub-assurance #1).

- Long-term care community nurses assist in providing safe and appropriate community care supports, as well as collaborate with person-centered plan coordinators, care providers, and others to maintain a healthy and safe living situation and promote autonomy and choice.
- Positive behavioral support services to support participants with behavioral challenges that prevent them from accomplishing activities of daily living, instrumental activities of daily living, and health-related tasks, including consult with other providers to mitigate behaviors that place the participant's health and safety at risk or that risk the participant's institutionalization.

V. State Challenges

The following is an overview of the challenges identified by the H&W SRT regarding the design or practice of ensuring the health and welfare of HCBS participants in Oregon.

A. Data systems that operate independently and are not integrated

The H&W SRT learned about numerous DHS/APD systems that are not integrated into a centralized system. As a result, DHS/APD staff described a significant number of manual actions and entries. There is a lot of information that is not automatically pulled, requiring one staff person to research and manually enter it elsewhere. For example, when a name is entered into the CAM system, CAM is not able to pull in any information from any other state database. One central office staff person researches in other databases and then enters the following information into CAM: the individual's Medicaid ID number, whether the individual is in a waiver program, whether the individual has had other incidents, and the individual's assigned case manager.

B. Ensuring health and welfare for participants who self-direct their services

OHA and DODD raised an issue related to safely serving an increased number of Children's HCBS Waiver participants with complex needs. Because of the implementation of Oregon's 1915(k) program (the K Plan), many more children with DD are able to receive HCBS services in their own home. Prior to Oregon implementing the K Plan, the state served 600 children in Children's HCBS Waiver receiving services in their home, using a limited budget of \$20,000 a year. Children's HCBS Waiver is no longer limited by a budget cap because many of the services are paid through the K Plan. This allows waiver participants to receive more costly services, making it possible for children with more complex needs to receive services in their own home rather than other more regulated settings. The number of Children's HCBS Waiver children receiving HCBS services in their own home has grown from 600 to 4,000. With this increase in

high-risk participants using self-direction, Oregon finds it challenging to balance the risk factors against personal choice and preventing the population from being taken advantage of or abused. In response to learning this, the H&W SRT informed Oregon about the “Balancing Risk and Choice” training posted on Medicaid.gov, which may assist the state in its efforts to safely serve these individuals.

C. Limited operating hours of the statewide abuse reporting line toll-free phone number

Critical incidents can be reported only Monday through Friday from 8 am to 5 pm. The H&W SRT also heard from DHS/APD stakeholders that case managers are also available only Monday through Friday from 8 am to 5 pm. With these limited hours, incidents that occur in the evening or on a weekend cannot be reported in a timely manner, which increases risk to the health and welfare of waiver participants.

D. The potential for underreporting of incidents

- Providers have discretion to decide whether something should be reported. The H&W SRT heard examples of incidents that providers decided should not be reported. Because all incidents are reported through APS, DHS/APD stakeholders indicated that they believe only the most egregious incidents would warrant reporting. There was a lack of reporting noted from personal support workers who provide services to DD waiver participants, due to lack of training and education at the direct services provider level. The case managers also indicated that many personal support workers do not communicate well using the English language, which creates a barrier for both education and reporting of incidents.
- Incidents that are not reported to the state may or may not be tracked by the provider. There is no requirement for providers to maintain an on-site incident log of all incidents (those reported and those not) for state monitoring and oversight or for other follow-up. Some providers choose to maintain incident records despite there not being a requirement.

E. A critical incident process that lacks a uniform practice for requiring follow-up with the individual

The critical incident investigation and report includes limited details about what needs to be done for the individual. There is no requirement or uniform practice for including case managers in consideration of the follow-up and implementation. The H&W SRT observed differences in the extent to which providers and case managers were able to work together. It was reported that brokerages may be less collaborative than county-based case managers.

F. Inadequate critical incident education, training, and materials

Across both delivery systems, there were concerns raised about providers and participants not having enough understanding about critical incident prevention, reporting, and investigation. Training materials offered by the state are reported to be confusing and written at too high a reading level. The training seems to vary on the basis of the provider’s choice of what to offer and when, according to the providers with whom we spoke. There also appears to be inconsistency in understanding of training requirements.

It should be noted that OHA had taken immediate action on the reading level issue when the issue was brought to its attention by the H&W SRT.

G. Missed opportunities for incident investigation follow-up

The APS investigation timeframes, as explained to the H&W SRT, are disparate. Timeframes are outlined in the Oregon Administrative Rule (411-020-0080 *Triage*) for when an investigator must initiate an investigation to eligible referrals—immediately, the end of the same or next business day, or within five working days, depending on the severity of the risk to individuals. There are no timeframes outlined for completing follow-up action and intervention on behalf of the individual except for the final written report. Final written reports must be completed within 60 business days for facilities or 120 business days for in-home cases. As providers are waiting, issues are getting stale and correction may be moot by the time the report comes back.

H. Impact of quality monitoring issues on compliance rates

In recent years, Oregon experienced significant issues with quality monitoring across its HCBS waivers at a systemic level, which resulted in noncompliance for the health and welfare assurance. Across a sample of waiver programs, including the state’s Medically Fragile Waiver, the Behavioral Model Waiver, and the Adults’ HCBS Waiver, the state reported deficiencies with regard to incident report monitoring, poor compliance rates for health and welfare performance measures, failure to review representative samples, and need for revision of some health and welfare performance measures.

VI. H&W SRT Recommendations and Next Steps for Follow-up Technical Assistance

A. Improve outreach and education to providers and participants

Educational documents and trainings could be more accessible and written at an acceptable reading level.

B. Implement process improvements to support the success of the CAM system

Both operating agencies use CAM and will continue to benefit from cross-collaboration and expansion of the system. The H&W SRT identified the following strategies to improve CAM:

- Educate participants and providers about identifying and reporting all critical incidents
- Enhance data integration from external data sources
- Standardize processes, timeframes, and expectations around training, reporting, investigating, and correcting critical incidents
- Adopt a proactive, standardized approach to monitoring and oversight

C. Make accessible an abuse registry as documented in the APD Waiver

Although an abuse registry is not required, the Aging and Physical Disabilities 1915(c) waiver application indicates that the state has an abuse registry. The H&W SRT did not find (and no stakeholders confirmed) the existence of an abuse registry. The H&W SRT recommends that the state make accessible an abuse registry to align with the approved APD Waiver or amend this waiver to reflect that there is no registry.

D. Consider implementing a DD centralized comprehensive case management system

The DHS/ODDS system does not have a centralized case management system. The DD state staff and stakeholders articulated that the absence of a centralized case management system is a challenge for many reasons; this creates critical incident management challenges because the operating agency has no oversight or monitoring ability from its central location and can only review paper and electronic files while conducting reviews in the field. State staff indicated that having a DD centralized case management system would help them assure the health and welfare of participants.

E. Increase the number of deaths reviewed during the mortality review process

The mortality review process includes the review of only four cases per year. The selection of cases is based on the provider types, and the outcome is intended to improve the provider delivery of services. We recommend that the state review a larger number of deaths annually to gather additional data.

F. Increase stakeholder communication and engagement

- **APD stakeholder engagement** - The APD stakeholders reported limited interaction with the state operating agency. On the DHS/APD side, the state could be more transparent, more connected to the providers, and more known to the providers. The providers we saw did not know who the APD Director was. One provider sent the email from the APD Director related to scheduling the on-site review to her corporate office because she thought it was a scam.
- **Communication gaps** - There appears to be a gap in communication between the state and providers. APD providers may benefit from a more systematic, modernized approach to information sharing. The smaller, individual DD providers indicated that they felt disconnected from the process. All DD providers noted difficulty keeping up with policy changes and their implications.

As the state considers next steps to the challenges and recommendations outlined above, please note that CMS may be able to provide additional technical assistance if requested by the state.