

# Advancing Consumer Experience

Recommendations of the Medicaid Advisory Committee (MAC) Consumer Voice Subcommittee

November 2021



# Contents

- Executive Summary: ..... 3
- Recommendations to improve consumer experience ..... 4
- Proposed next steps for consumer concerns with greater complexity ..... 8
- Appendices ..... 11
- Appendix A: Subcommittee roster ..... 11
- Appendix B: Summary of recommendations ..... 12
- Appendix C: Opportunities to improve CX through the 1115 Waiver Renewal..... 13
- Appendix D: Detailed list of consumer concerns shared with subcommittee ..... 14
- Appendix E: Provider search tool example..... 22
- Appendix F. Examples of variation in care coordination descriptions and access..... 29



## Executive Summary:

The Medicaid Advisory Committee (MAC) advises the Oregon Health Authority (OHA) and the Oregon Health Policy Board (OHPB) on Oregon Health Plan (OHP) operation and policies from a consumer and community perspective. In January 2021, the MAC convened a subcommittee of OHP consumers and health care advocates to understand common challenges and identify opportunities for improving consumer experience (CX).

This report details initial findings, limitations and recommendations. MAC and subcommittee members are grateful for OHA's commitment to improve health care for all Oregonians and eliminate health inequities by 2030 and appreciate the opportunity to contribute to OHA's health system transformation efforts.

There are more than one million people enrolled in OHP. Each person is unique and has different needs and experiences. However, many consumer challenges were similar, and four areas to make meaningful improvements to consumer experience became evident. Several other areas were identified that are equally important but need more work to fully understand and develop recommendations. The focus areas outlined below apply to OHP members enrolled in fee-for-service (FFS) Medicaid and coordinated care organizations (CCOs) unless otherwise noted.



**Communication:** Challenges in communication were a factor in almost all experiences shared. Information is often designed to meet regulatory requirements, with regulatory references and legal language that is difficult to interpret. Developing plain language materials for consumers is a critical step toward improving CX. Specific recommendations related to communication begin on page 4.



**Care coordination (CC):** Many challenges consumers face could be addressed through CC. However, consumers don't always know what CC is or how to ask for these services. Consumers report variation in access to CC services across CCOs and within the same CCO. Recommendations related to CC start on page 5.



**Transitions of care (ToC):** A major stressor for consumers are care transitions that expose a fragmented system built around reimbursement policies and benefits that are siloed between physical health and behavioral health. Consumers shared extensive challenges in the following transitions (recommendations related to ToC start on page 6):

- OHP to Medicare or dual coverage
- Pediatric to adult care
- One CCO to another CCO
- One specialized care home to another



**Consumer voice:** Visibility into consumer experience and unfiltered consumer voice is essential to transforming the health system into one that is coordinated, equitable, and culturally appropriate for all. There are many community engagement activities across OHA, the Oregon Department of Human Services (ODHS) and CCOs. However, they are fragmented with limited opportunity to engage on terms the consumer defines. The subcommittee recommends that OHA prioritize consumer experience using a framework that ensures visibility into CX by race, ethnicity, preferred language, and disability status. More details are on page 9.



**Limitations:** This report is based primarily on input from a small workgroup of OHP consumers and consumer advocates who work with OHP enrollees. As noted above, an initial observation of the group was that there is limited visibility into consumer experience. The subcommittee worked with the information available. However, there are likely many consumer challenges that are not included in this report.





The term “consumer” throughout this report is intentional. The term is used to differentiate CX from patient experience (in which a person is receiving clinical care). It is also worth acknowledging that CX and community engagement are both important, but different. This report focuses on understanding and improving OHP consumer experience.

The group recognizes OHP consumers as the primary stakeholders in Oregon’s Medicaid program and the perceptions and experiences of those who receive OHP benefits as the basis to understand and improve service delivery, achieve equity and improve outcomes.






A full list of concerns shared during the first six months of the subcommittee work is in [Appendix D](#).

## Recommendations to improve consumer experience

Category	Consumer Challenge	Recommendations	Consumer Comments
	Finding relevant information that is easy to understand is difficult for many consumers; there are many sources with important information organized in different and often inconsistent ways.	<ul style="list-style-type: none"> <li>Standardize select consumer communication with room for CCO-specific details where appropriate</li> <li>Involve consumers in the work to identify information priorities, co-create in multiple languages and ensure consistent messages statewide.</li> </ul>	<i>“I am receiving information from ODHS, APD, OHP, Medicare and Social Security in the mail and via phone and most of the information contradicts each agency.”</i>
	Provider search tools are not always consumer-friendly, which creates an access barrier to needed care. One provider search tool includes a list of more than 200 different options for provider type. Still, seven different searches for a pediatrician in Portland returned 0 results.  <a href="#">Detailed examples in Appendix E</a>	<ul style="list-style-type: none"> <li>Develop common standards for provider search tools, including: <ul style="list-style-type: none"> <li>Consistent provider type categories</li> <li>Consistent functionality</li> </ul> </li> <li>Include consumers and CCOs in the work to develop standards.</li> <li>Research examples of similar projects and industry best practices.</li> </ul>	<i>“There is no list of “in-network” providers to choose from; hit or miss if a provider will take the card or not Parents just have to call and call and call ...”</i>

Category	Consumer challenge	Recommendations	Consumer comments
	<p>The denial process is a frequent cause of consumer frustration due in part to:</p> <ul style="list-style-type: none"> <li>• Unclear notices with industry-specific terminology.</li> <li>• Denial reasons in numeric code.</li> <li>• Late denial notices (example: the day before a procedure scheduled months in advance). *</li> </ul>	<ul style="list-style-type: none"> <li>• Develop plain language for denial notices.</li> <li>• Develop standards for timely prior authorization.</li> <li>• Involve consumers in this work.</li> </ul>	<p><i>“How can I participate in an appeal process if I don’t even know why the procedure was denied?”</i></p> <p><i>“I have two college degrees but had to get help from an attorney to understand the notices I received.”</i></p>
	<p>Consumers do not have adequate information about the process to request health-related services (HRS) or flexible services (FS). Extensive <a href="#">guidance</a> is available for CCOs and providers, but similar resources do not exist for consumers to enable active participation in self-advocacy and care decisions.</p>	<ul style="list-style-type: none"> <li>• Create a consumer-facing plain language guide to HRS and FS, including information about: <ul style="list-style-type: none"> <li>○ What they are.</li> <li>○ How to access them.</li> </ul> </li> <li>• Include standard language in CCO handbooks.</li> <li>• Include consumers in this work.</li> </ul>	<p><i>“Can I request HRS or does my doctor have to submit the request?”</i></p> <p><i>“Can I appeal a decision regarding flexible services?”</i></p>
 	<p>Members who try to request CC often face roadblocks to getting the help they need; other consumers don’t know about CC services.</p> <p>Members are unclear about who qualifies for intensive care coordination (ICC) (as opposed to “regular” CC – and both lack standard definitions)</p> <p><a href="#">Examples are in Appendix F.</a></p>	<ul style="list-style-type: none"> <li>• Create materials for consumers that describe (in the language that consumers use): <ul style="list-style-type: none"> <li>○ What care coordination is.</li> <li>○ How these services help.</li> <li>○ How to request services.</li> </ul> </li> <li>• Develop standard processes for how all OHP consumers can initiate CC and for how CC services are offered.</li> <li>• Develop standard language to explain the difference between CC and ICC.</li> </ul>	<p><i>“In trying to develop a safety plan for discharging a pediatric patient with complex needs and safety concerns - it took 10 calls and an OHA senior administrator to get access to a complex care coordinator. Why was this so difficult?”</i></p>

\* OHA is currently working on revising the Notice of Adverse Benefit Determination (NOABD) language. The committee discussed this topic and the recommendation to include consumers in the work during the Feb. 24, 2021 MAC meeting.

Category	Consumer challenge	Recommendations	Consumer comments
	<p>It is difficult to find providers who are willing and able to treat consumers with complex needs or history (e.g., parole monitoring, substance use disorder, disability, or behavioral needs).</p>	<ul style="list-style-type: none"> <li>• Include this in the list of challenges CC can help address.</li> <li>• Develop a method to track wait times by service and provider specialty.</li> <li>• Engage MAC in monitoring wait times.</li> <li>• Based on reporting, develop the right standards and an escalation policy to ensure access.</li> </ul>	<p><i>“My doctor retired, and it took me 18 months to get another doctor.”</i></p>
 	<p>Families and youth experience challenges in the transition from childhood to adult service providers; this is especially challenging for children and youth with special needs or complex conditions who also lose services (for example, wraparound care).*</p>	<ul style="list-style-type: none"> <li>• Adopt standard transition planning policies for OHP consumers as they approach age 18, especially those who require multiple providers for special health needs.</li> <li>• Leverage existing evidence-based tools from the Health Resources and Services Administration (HRSA)-funded National Alliance to Advance Adolescent Health (Gottransition.org)</li> </ul>	<p><i>“Families are left to start from scratch to find adult providers willing to treat young adults with disabilities.”</i></p> <p><i>“Need more cross-system care-coordination ... during any transition from one service delivery system to another.”</i></p>
	<p>Consumers experience disjointed, fragmented transitions when new physical or behavioral health (BH) conditions develop.</p> <p>See consumer story below.</p>	<ul style="list-style-type: none"> <li>• Use CC to find services and supports to meet consumer needs; avoid or minimize disruption to the consumer when possible.</li> <li>• Address reimbursement issues to make sure that care providers are paid adequately for consumers with complex needs.</li> </ul>	<p><i>“We often see consumers who are required to move out of a home because of a new comorbid condition (for example, someone develops diabetes in a facility designed for mental health needs).”</i></p>
	<p>Options available to OHP consumers for sharing challenges, successes, and preferences about health care experiences are limited.</p> <p><a href="#">Click here for more details.</a></p>	<ul style="list-style-type: none"> <li>• Prioritize consumer experience (CX) and voice as a body of work across OHA and ODHS.</li> <li>• Include OHP consumers in the work.</li> </ul>	

\* Related research findings can be found [here](#).

### *Consumer experience*

A person who lived in an adult foster home (AFH) for **12 years** developed a behavioral health condition; because the AFH was not equipped to support BH needs the consumer had to move. This scenario is inefficient and unnecessarily inconvenient for consumers.

## Proposed next steps for consumer concerns with greater complexity

Many of the concerns that consumers shared are complex and require more input from OHP consumers, OHA staff and policy experts to fully understand the root causes and identify opportunities to improve the consumer experience. Proposed next steps for these areas are below.

Consumer challenge	Proposed next steps for the subcommittee
<p>Consumers experience coverage decisions that don't support whole person needs. Examples include:</p> <ul style="list-style-type: none"> <li>• Denials for procedures the consumer needs to stay employed.</li> <li>• Parents of children with special health needs are denied coverage for mobility devices because the devices are used by a caregiver and not the OHP member.</li> </ul>	<ul style="list-style-type: none"> <li>• Continue research to understand how consumers experience this issue.</li> <li>• Research innovative models in other states.</li> </ul>
<p>Many consumers experience challenges accessing specialty care, resulting in unmet health needs and treatment delays. Contributing factors include:</p> <ul style="list-style-type: none"> <li>• Inadequate provider capacity for certain specialties, geographies or both.</li> <li>• Providers who limit appointments for Medicaid members.</li> </ul> <p>Specific concerns were raised about neurology, psychiatry, cardiology, pain management, and treatment for eating disorders.</p>	<ul style="list-style-type: none"> <li>• Find data sources to better understand this issue.</li> <li>• Develop a method to track wait times by service and provider specialty.</li> <li>• Work with other stakeholders and committees as appropriate.</li> </ul>
<p>Transition of care often lead to service disruption and negative health consequences. Challenging transitions include:</p> <ul style="list-style-type: none"> <li>• From CCO to CCO, or CCO to a non-CCO.</li> <li>• Across care settings.</li> <li>• Payer changes (for example, from OHP to Medicare as the primary payer).*</li> </ul>	<ul style="list-style-type: none"> <li>• Research best practices for supporting consumers across various care transitions.</li> <li>• Gather consumer care transition experiences.</li> <li>• Identify ways to preserve benefits during a transition period.</li> <li>• Develop recommendations for ongoing monitoring</li> </ul>

### *Access to pain management services*

*“In the last four years, I've heard ‘OHP patient quota full,’ ‘OHP does not pay for visits beyond initial eval so we don't take OHP patients,’ and ‘we are not contracted’ (even though they are per records thru CCO).”*

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\* This challenge is a potential 1115 waiver opportunity for improving CX (preservation of benefits across care transitions).



## Consumer experience (CX):

Visibility into CX and unfiltered consumer voice are essential to developing a system of care that is person-centered and equitable. Many data sources provide some visibility into CX and there are several committees and councils supported by OHA that provide a forum for consumers to provide input. While these are all valuable, they have the following limitations:

- Lack of integration and siloed information.
- Many forums for consumer engagement are public meetings; this is a barrier for consumers who do not want to share personal health experiences in a public setting.
- Public comment can lead to anxiety instead of relief. After sharing a personal and traumatic experience, the response is essentially, 'thank you for your comment,' with no expression of support or empathy.
- Taking part in a council or other committee is not feasible for most consumers; this leads to possible bias in information used to guide program and policy development.
- Lack of a defined structure to collect and compile information so that it can be used to develop solutions.
- Discussion topics in many meetings are pre-defined without consumer input, often for good reason; this however is a barrier to unfiltered consumer voice.
- Grievances and complaints (G&C) provide a narrow view into CX.; many consumers are reluctant to file a grievance or complaint for a variety of reasons.
- Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey findings are valuable but offer a limited opportunity to understand care experiences in the words consumers use.
- The approach to community engagement is episodic, while consumer experience is individual and continuous starting with the OHP application process.

Lack of visibility into CX was noted in the first subcommittee meeting. The group discussed many possible avenues to increase visibility into CX. More work is needed to develop a strategy. There are at least two state Medical Care Advisory Committees (the equivalent of Oregon's MAC) that have separate consumer panels or subcommittees:

- Colorado
  - Has a Member Experience Council focused solely on how the Medicaid program communicates with consumers. Initially, it was limited to 15 members. However, in response to high demand it was extended to online memberships. This has become a mechanism to capture more voices through monthly online surveys.
  - Developing a video orientation about Medicaid policy to support consumers to engage in policy work.
- Pennsylvania:
  - Maintains a subcommittee comprised exclusively of Medicaid consumers in addition to its Medicaid Consumer Advisory Committee.

- **Recommendation for ongoing work:** Increasing visibility into CX is aligned with the MAC's role of advising OHA and OHPB on OHP policies and operations from a consumer viewpoint. The subcommittee recommends continuing work to develop a detailed framework based on best practices from CX in healthcare and OHP consumer input.

### Report Conclusion

Successful implementation of these recommendations requires ongoing input from consumers and collaboration across all areas of the healthcare delivery system. The MAC and consumer experience subcommittee respectfully ask that OHA leaders demonstrate a commitment to OHP consumers by providing the resources and oversight needed to implement the recommendations detailed in this report.

## Appendices







- A. [Subcommittee Roster](#)
- B. [Summary of recommendations](#)
- C. [Opportunities to improve CX through the 1115 waiver renewal](#)
- D. [Full list of consumer concerns](#)
- E. [Provider Search Example](#)
- F. [Examples of variation in care coordination descriptions and access instructions](#)

### Appendix A: Subcommittee roster

Thank you to all subcommittee members below who graciously volunteered their time and experiences to help improve CX for people enrolled in OHP.

Tamara Bakewell	MAC member and Family Involvement Manager, Oregon Center for Children and Youth with Special Health Needs
Heather Gately	Consumer
Lavinia Goto	MAC member and subcommittee chair, Project Manager of LTC Innovation and SDOH, Northwest Senior and Disability Services, and Operations Manager, Oregon Wellness Network
Miguel Angel-Herrada	MAC member and Health Equity Strategist, PacificSource
Janet Holboke	Older adult behavioral health specialist
Ruth McEwen	Consumer and chair of Oregon Homecare Commission and NWSDS senior advisory council
Ellen Pinney	OHA Principal Ombudsperson
Judith Richards	Consumer
Terese Rummell	Services Manager, Northwest Senior and Disability Services
Karun Virtue	Consumer, MAC member, Intercommunity Health Network (IHN) board member and IHN CAC member

## Appendix B: Summary of recommendations

Category	Recommendations
	<p>Priority areas for improving communication include:</p> <ol style="list-style-type: none"> <li>1. Provider search tools - develop common standards, consistent provider type categories, and functionality</li> <li>2. Denial notices - develop standardized, plain language notice text, and standards for timely prior authorization</li> <li>3. Health-related services/flexible services - create a consumer-facing guide including what HRS/FS are and how to request or access service</li> <li>4. Care coordination information</li> </ol> <ul style="list-style-type: none"> <li>• Standardize consumer-facing materials for the areas above, with room for CCO-specific details where appropriate</li> <li>• Involve consumers in the work to identify needs, co-create in multiple languages and ensure consistent messages statewide.</li> </ul>
	<p>To improve CX related to care coordination services:</p> <ul style="list-style-type: none"> <li>• Create materials for consumers that describe (in terms that consumers use) what care coordination is, how these services can help, and how to request services.</li> <li>• Develop standard processes for how all OHP consumers can initiate CC and for how CC services are offered.</li> <li>• Develop standard language that clarifies the differences between CC and ICC.</li> </ul>
	<p>Improve access to care using CC to find providers who are available and willing to treat consumers with complex needs.</p> <ul style="list-style-type: none"> <li>• Promote care coordination services to support in situations where consumers cannot find a provider who is available and willing to meet member needs</li> <li>• Develop a method to track wait times by service and provider specialty, and engage the MAC in monitoring wait time</li> <li>• Based on reporting, develop appropriate standards and escalation policy to ensure access</li> </ul>
	<ul style="list-style-type: none"> <li>• For children and youth with special health needs, adopt standard transition planning policies that are offered to OHP consumers as they approach 18.</li> <li>• Leverage existing evidence-based tools from the HRSA-funded National Alliance to Advance Adolescent Health (Gottransition.org)</li> </ul>
	<ul style="list-style-type: none"> <li>• Use care coordination to find services and supports to meet consumer needs; avoid disruptive relocation when possible</li> <li>• Coordinate benefits and reimbursement to ensure that care providers are compensated appropriately for consumers with complex needs</li> </ul>
	<ul style="list-style-type: none"> <li>• Prioritize consumer experience (CX) and voice as a body of work across OHA, including services that are delivery through ODHS</li> <li>• Include OHP consumers in the work to design a comprehensive CX strategy</li> </ul>

## Appendix C: Opportunities to improve CX through the 1115 waiver renewal

The MAC is taking part in the 1115 waiver renewal by reviewing the waiver application from a consumer perspective and by serving as one of the public comment forums. The subcommittee shared the following areas with the MAC and the waiver team during the May 2021 MAC meeting to elevate consumer voice and inform waiver policy development. The subcommittee will revisit any of the issues outlined below which the 1115 Waiver does not address.

Consumer challenges	Alignment with waiver goals and example(s)
<p>There are inequitable services for consumers in fee-for-service (FFS) Medicaid (OHP). (FFS is also known as “open card.”) FFS enrollees do not have access to health-related services (HRS) or flexible services (FS). This creates gaps in member supports. Many FFS consumers have complex health needs and roughly half of tribal enrollees are in FFS OHP.</p>	<p>Ensure access to coverage; create an equity-centered system of health.</p> <p><i>“One of our families with an open card has a classic use case for flex funds ... if they were in a CCO, I know they could get help.”</i></p>
<p>Consumers experience benefit loss and access challenges when they transition to Medicare or to dual (Medicaid and Medicare) coverage. Proposed options for improving this transition include:</p> <ul style="list-style-type: none"> <li>• Early planning for predictable changes (for example, age-based benefit changes).</li> <li>• Benefit preservation during a defined transition period.</li> <li>• Change the limit for dual coverage to 138% of the federal poverty level (FPL).</li> <li>• Preserve non-emergency medical transportation (NEMT) benefits in the transition to Medicare NEMT loss is particularly harmful in this transition.</li> <li>• Move to income-based eligibility to simplify the process. The current criteria are very confusing, and many consumers do not receive all services for which they qualify.</li> </ul> <p>An operational change which may not require a waiver but supports waiver goals is to screen OHP members for eligibility for other programs and services <b>before</b> they lose any OHP benefits.</p>	<p>OHP coverage is preserved as patients transition across systems.</p> <p><i>“The so-called “transition” was non-existent; my providers who don’t take Medicare dropped me or asked for cash pay.”</i></p>
<p>Lack of transitional housing is an underlying cause of many other problems for consumers and a critical barrier to improving outcomes. Without transitional housing, APD assessments don’t happen and hospital discharge results in an ongoing cycle of emergency department (ED) use.</p>	<p>Encouraging smart, flexible spending. Reinvesting savings across systems.</p>
<p>Consumers are increasingly screened for social needs, but social service providers have limited capacity for the increase in demand. Platforms that connect providers, consumers, and community agencies (examples: Aunt Bertha, Unite Us) have streamlined the referral process, but significant gaps in funding remain to increase capacity of social services.</p>	<p>Reinvesting savings across systems.</p>

## Appendix D: Detailed list of consumer concerns shared with subcommittee

Consumer challenges	Opportunity for improvement				
	Access	Equity	Communication	Care coordination	Alignment with waiver
The FFS provider search tool is not consumer-friendly; it is hard to find and not branded as an OHP tool. The “Terms of service” place financial responsibility and reliability of the search tool on members. Sample search produced zero providers, but a message "Kepro's Find a Clinician Locator System is an online directory of Kepro's mental health and substance abuse practitioners. Use this convenient service to locate a practitioner of your choice near your office or home. "	x		x	x	
Families cannot get the same services on “open card” OHP that they can from a CCO.		x			
Services between CCOs are not the same. Moving from one CCO to another disrupts the continuity of care. Families generally cannot keep the same treatment providers from one CCO to another. This is <b>very</b> disruptive for children and youth.		x			
Lack of specialists who accept Open Card (the access is even more difficult outside of primary care).	x	x			
OHP Care Coordination eligibility: The burden is on the member to navigate to this service and the descriptions vary by CCO and FFS. What members experience and what is described as 'standard' CC are very different.	x	x		x	
The terms we use are not intuitive or meaningful for OHP members. For example, how does a member know if they are enrolled in Open Card or CCO at any given point in time?			x	x	

Consumer challenges	Access	Equity	Communication	Care coordination	Alignment with waiver
"My only frustration with our open card is with the pharmacy benefits. It is necessary to fill the prescription exactly one month from the previous filling, making it impossible to create an emergency surplus. There also have been instances when my son's meds were filled at a different pharmacy and his Medicaid did not cover it. It is usually a small amount that I pay but it adds up. Time is a precious commodity to any family raising a child who experiences a disability and this system has some pieces which take time to understand. "	x	x			
"When I search for Open Card online, I am always sent to CCO information and I am not sure how much it applies."	x		x		
For open card, there is no list of "in-network" providers to choose from, hit or miss if a provider will take the card or not. Parents just have to call and call and call'	x				
Training for HRS is for CCOs; members deserve to know what qualifies and how to request services; similarly, community agencies need to know what the rules are to advocate for member needs in an effective way.	x	x	x	x	
Not all providers involved in "authorized" procedures are contracted with OHP for FFS; this leaves members and providers in very complex processes. Members are caught in the middle.	x	x		x	
Many committees and councils include OHP consumers. However, opportunities for consumers to take part are limited. This is because meetings are often structured around the needs of providers and representatives of health care organizations.				x	
Information related to health care is confusing. Consumers receive multiple messages that often conflict with each other; health care seems like it requires learning a whole new language.			x		

Consumer challenges	Access	Equity	Communication	Care coordination	Alignment with waiver
Lack of compensation to consumers for take part in care transformation activities is a barrier to: <ul style="list-style-type: none"> <li>Engagement</li> <li>Equity.</li> </ul>		x			
The categories for tracking consumer complaints and grievances are inconsistent, making it difficult to interpret and use data to improve consumer experience.			x		
There are lots of challenges with out of state billing.					
Lack of capacity for behavioral health needs is a challenge for many consumers.	x				
People with unmet MH needs end up incarcerated or in the ED; neither setting is equipped to deliver whole person coordinated care, and both are terrible consumer experiences and costly.	x	x		x	x
Lack of housing is an underlying cause of multiple other problems for consumers.	x	x			x
Cross agency communication is lacking, leaving members with fragmented, piecemeal care. This is confusing and frustrating.			x	x	x
"The grievance process is not helpful."			x		
"Customer service process lacks continuity (no notes for each interaction)."			x		
"The OHA appeals process requires an attorney; I have two college degrees and could not discern the meaning of the letters I received."			x		
Siblings in the same family can be assigned to different CCOs and dental care organizations (DCOs). This makes coordination of appointments tricky for parents.				x	
Parents don't realize they have Open Card. This creates limitations on services that CCOs can cover under HRS/FS.		x	x		x
Access to MH and SA services for older adults is challenging due to limited MH benefits for Medicare and stigma related to MHSA services.	x				



Consumer Challenges	Access	Equity	Communication	Care coordination	Aligns with waiver
"Current opioid guidance for treating older adults with chronic pain issues is confusing and few providers are willing or trained to address."	x				
There are drastic changes in benefits for teenagers aging out of childhood services. There is a need for more cross-systems care-coordination during transitions, especially for predictable transitions at age 18 and age 65, or any transition from one service delivery system to another.	x		x	x	x
There are challenges in transitions of care and benefit changes for adults who receive Medicaid and become eligible for Medicare (which becomes the primary payer).				x	x
Language access is a huge barrier. Network adequacy standards are out of sync with actual needs. There are lots of reasons for this. However, one is that underlying data are not adequate to draw conclusions about needs.	x	x	x	x	
Lack of plain language documentation is a problem that affects all members. For example, notices sent in the first quarter of 2021 about the Integrated Eligibility system included statements about which benefits a member qualifies for; these notices caused a lot of anxiety for members, who thought they were losing benefits.			x		
Some benefits change based on the primary driver of disability (i.e., physical or behavioral); this is not conducive to whole-person care and is very disruptive.	x	x		x	x
"(My) mental health CCO is different than my regular medical plan CCO; communication between the two CCOs the provider has been a problem with nobody knowing how certain services are categorized and who to get prior authorization from, etc.)"			x	x	
"Pain management providers who are contracted with OHP turn folks away for various reasons. In the last four years, I've heard 'OHP patient quota full,' 'OHP does not pay for visits beyond initial eval so we don't take OHP patients,' 'we are not contracted,' (even though they are per records thru the CCO) and the one that was already mentioned: current opioid guidance issues confusing to specialists and primary care providers so refuse to treat chronic pain patients."	x			x	

Consumer challenges	Access	Equity	Communication	Care coordination	Alignment with waiver
“Vaccine access for DHS and OHP folks and the messaging not being clear as to who is currently eligible or in the near future.”			x		
“Lack of coordinated referrals to adult-focused providers when youth, especially those with special health needs, transition at age 18. Families are left to start from scratch to find adult providers willing to treat young adults with disabilities.”	x			x	
Denials are communicated late (e.g., the day before a scheduled procedure), after consumers have done the emotional and logistical work to prepare.			x	x	
Benefit decisions are described in terms of codes and not plain language - which actively prevents consumers from participating in the discussion and the appeal process.	x		x	x	
Benefit decisions that do not include impact on independence (e.g., impact on ability to work)	x			x	
Hospitals discharging consumers who are homeless and who have barriers to housing (e.g., active substance abuse). These consumers frequently cycle back through ED. Lack of transitional care housing in our communities (including options for individuals with substance abuse).	x			x	
“Consumers experiencing homelessness or inconsistent housing options needing to be assessed for APD services. Due to their lack of stable housing, assessing consumers experiencing homelessness for services is difficult. There is a lack of transitional housing or affordable housing in general in our communities.”	x			x	
“We work with individuals who have been taken to the ED by a provider, who then refuse to take the consumer back when the hospital is ready to discharge (per hospital). “	x			x	

Consumer Challenges	Access	Equity	Communication	Care Coordination	Alignment w/Waiver
Consumers with MH diagnoses, active substance abuse, and/or challenging behaviors are often unable to find providers willing to take consumer due to consumer's past care setting history.	x	x		x	
Consumers recently released from the prison system and eligible for APD services have access challenges due to a lack of providers willing to admit consumers with ongoing parole monitoring or consumers' history.	x	x			
Consumer under 65 years with significant MH diagnosis and/or active substance abuse seeking Aging and People with Disabilities (APD) services who are at risk of losing housing and/or frequent users of community and emergency services and do not meet APD service criteria but are still at risk. Lack of Adult Behavioral Health (ABH) resources available for these consumers and/or the consumer is unwilling to seek ABH services.	x			X	
Lacking providers that have experience/training working with older adults with substance abuse and/or challenging behaviors (due to physical disability or MH diagnosis).	x				
Lack of clarity regarding the process for requesting (and receiving) flex funds ("Is it only providers who can request or can patients request for themselves? Is the policy universal between CCOs? Is there a role of the ICM?")		x	x		
In trying to develop a safety plan for discharging a child with complex needs - it took 10 steps and assistance from an administrator at OHA to get in touch with a complex care coordinator. This is a family who was actively asking for support.			x	X	
Sometimes vendors have products families need but will not contract with the state because the rate is too low." This has happened with some DME, and more recently to incontinence supplies.	x				

Consumer challenges	Access	Equity	Communication	Care Coordination	Alignment with waiver
"I have a visual impairment; I recently received information in the mail. The cover letter was in 16-point font - so OHA accurately reflects my visual need, but there were an additional 10 pages in tiny print that I could not read."			x		
Flex fund process variation across CCOs, so consumers experience unequal levels of service and support for health-related social needs.	x	x	x		x
Consumer shared reports of HIPAA violations in clinic wait areas (due to COVID requirements for social distancing between patients and staff) and that social distancing among patients was not always possible.					
The transition from one CCO to another is a struggle; consumers are left without access to any providers for some period of time and the process is cumbersome; one example - CCO was 'backed up on all fronts' and difficult for me to navigate. "I had someone that needed to leave (the hospital) with a vent that the hospital couldn't get established with a PCP before d/c because pt wasn't IN that county yet...would not enroll in CCO until the consumer entered the county; after the address is updated, that is the system 'trigger' to make the update...it was weeks before the new CCO became effective. There is a period where the consumer just has to hope that the previous PCP will continue to treat until the assignment/selection of the new PCP is established.	x		x	x	
Multiple consumers shared challenges with NEMT: when requesting NEMT reimbursement, questions are not trauma-informed and require sharing protected health information.	x			x	
Members are required to get a letter from a BH provider in order to be approved for gender affirming surgery, and it isn't clear how to bill for this (BH or physical health)	x	x			
Members with eating disorders who are receiving outpatient or residential treatment are billed on the BH side, but if the patient receives hospital inpatient treatment, the benefit and billing switch to the medical benefit - which interrupts continuity of care				x	
Transgender members experience variation in information, access, and support across CCOs when seeking gender affirming care	x	x		x	

Consumer Challenges	Access	Equity	Communication	Care Coordination	Alignment w/Waiver
<p>"I've recently received two calls from parents of 18-year-old OHP members who receive developmental disability funds...who have not been adequately transitioned to APD services. ...neither of them knew anything about what it meant to leave the child system and end up in the adult system. The way these services are offered is very different and families have no idea of the changes."</p>	x		x	x	

## Appendix E: Provider search tool example

The screenshots below are from the provider search tool for consumers enrolled in fee-for-service (FFS) Medicaid. The red text is added by reviewers.



**DISCLAIMER AND PRIVACY POLICY**

**Provider Search**  
Kepro provides this listing as a service, offering you the ability to search for a provider to best fit your needs. Kepro offers this tool to assist you in your provider selection, including location, hours, specialties, and languages. Kepro routinely updates listings to correctly identify providers who accept Medicaid Fee For Service (OHPCC) members and have contracts with the state. Please confirm provider status at the time of service. Please read the disclaimer below for further details.

**Member Disclaimer:**

- ~ I understand searching the provider network is not an endorsement of any healthcare professional or their ability to care for my needs.
- ~ I understand the selection of a provider is not a guarantee of payment and the services I receive must be covered under the terms of my health benefits plan.
- ~ I understand I must check my benefit information on which services require prior authorization. Failure to do so may result in non-payment for services or a reduction in the benefits available to me.
- ~ I release KEPRO from any claims and liability arising from any questionable service or advice that I receive from a network provider.

- Clicking on the Accept button indicates that you understand and agree to the above information and takes you directly to Provider Search Screen.
- Clicking on Decline will take you back to the log in screen.

[accept](#) [decline](#) [print](#)

See Terms of Service below.

The Disclaimer and Privacy Policy place all responsibility for information accuracy on the member – including potential financial liability; the whole “look” of the site doesn’t seem to have the quality or look of other OHA or CCO branded sites.

This site

Cardiologist  
Cardiovascular Surgery  
Case Management  
CCOB - Physical  
CCOE - Mental  
Certified Registered Nurse Anesthetist (CRNA)  
Child & Adolescent Psychiatry  
Child Welfare Targeted Case Management  
Chiropractor  
Chore  
Clearinghouse  
Clinic  
Common Carrier (Non-ambulatory)  
Community Mental Health Center, Adult  
Community Mental Health Program  
Community MH Center, Adolescent/Children  
Community/Behavioral  
Contract RNs  
Copy Services  
Counselor - Addition / Substance Abuse Disorder  
Critical Access  
DCO Capitated Provider  
Delegating Nsg (CIIS) RN  
Dental Clinic  
Dental Hygienist (LAP)  
Dentist (Default Spec)  
Denturist  
Dermatologist  
Diagnostic Radiology  
DME/Medical Supply Dealer  
E.I. Case Mgmt  
Education Agency  
Emergency Med Practitioner  
Emergency Response (Lifeline)  
Endodontist  
Enteral / Parenteral Nutrition  
Family Nurse Practitioner  
Family Planning Clinic  
Family Practitioner  
Family Training  
Federal Qualified Health Cntr. (FQHC) (Default)  
Foster Care - Adult APD  
Foster Care - Adult Commercial Independent  
Foster Care - Adult DD  
FQHC - Adolescent & Children Mental Health  
FQHC - Clinic/Center  
FQHC - Community Health  
FQHC - Dental Clinic  
FQHC - Primary Care  
FQHC School Based  
Free Standing Birthing Center  
Free-standing Renal Dialysis Clinic  
Gastroenterologist  
Gen. Dentistry Practitioner  
General Surgeon  
Geriatric Psychiatry

The list of provider types is overwhelmingly long.

“DCO Capitated Provider”

“Copy Services”

“Polygrapher”

“Delegating NSC (CIIS) RN”

Are there any consumers who are looking specifically for these provider types?

The search for “Specialty” is much better.

Neurologist  
Neonatal - Perinatal  
Non Billing Contractor  
Nsg Facility Other  
Nsg Facility Pediatric  
Nsg Facility Swing - Hospital  
Nsg Facility Swing - LTCF  
Nsg Facility- out of state  
Nurse Practitioner (default Spec)  
Nurse Practitioner Clinic  
Nursing Facility  
Obstetrics & Gynecology  
Occupational Therapist  
Oncologist  
Ophthalmology  
Opioid Treatment Program  
Optician  
Optometrist  
Oregon State Hospital  
Orthopedic Surgeon  
Osteopathic Physician  
Other  
Other Billing Entity  
Otologist, Laryngologist  
Outpatient Mental Health Clinic  
Oxygen Supplies  
PACE All Inclusive  
PCO Capitated Provider  
Pediatric Clinic  
Pediatric Dentist  
Pediatric Nurse Practitioner  
Pediatrics  
Pharmacist  
Pharmacy  
Physical Therapist  
Physician (Default Spec)  
Physician Assistants  
Plastic Surgeon  
Podiatrist  
Polygrapher  
Private Duty Nsg Agency  
Prosthesis  
Psychiatric Mental Health Nurse Practitioner  
Psychiatric Res Treatment Facility  
Psychiatric Res Treatment Svcs, Child/Adolescent  
Psychiatric Residential Treatment Facility  
Psychiatrist  
Psychologist - Neuropsychologist  
Psychologist Admin Eval  
Public Clinic  
Recovery assistant  
Registered Dietician  
Residential Care APD  
Residential Care Contract Rates  
Respite Services  
Rheumatology  
RN 1st Assistant  
Rural Health (default spec)  
Rural Health - Clinic/Center





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## Providers - Search

### Direct Provider Search

Please **select one or more** of the following:

Last Name:

Provider Type:

Specialty:

State:

City:

Zip Code:

Display the first  
search criteria.

- ✓ Not Selected
- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Pennsylvania
- Rhode Island

For Oregon members – it seems like the options might be Oregon, Washington, Idaho and California; the complete list creates uncertainty that this is the correct tool to find a provider who accepts OHP members.

If a member needs out of state support beyond states that border Oregon, there should be a separate process to help the member find a provider and proactively prevent the out-of-state billing issues that are a common source of member frustration.

  
HELP

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**PROVIDER LIST (RESULT SCREEN)**

**Active Providers - Eligible providers:** These providers have met the credentialing requirements and are considered active participants of the Kepro provider network.

Active Providers   Providers Being Credentialed   Inactive Providers



This site is best viewed at 800x600 or 1024x768 resolution  
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A search that included a broad provider type (physician) and specialty (family practice) in the largest metro area (Portland) in state returned zero results.

Provider Type:

Specialty:  Not Selected

State:

City:

Zip Code:

Display the first search criteria.

A&D Residential Treatment Program - H

A&D Residential Treatment Program - R

Accupuncturist

Acute Care

Addiction Medicine - Family Practice

Addiction Medicine - Psychiatry

Addiction Medicine, Neurology

Adult Day Services APD

Adult Res Treatment State Operated

Adult Residential Treatment Facility / Ho

Adult Residential Treatment Facility/Hor

Advance Practice Nurse

Air Ambulance

Alcohol/Drug Provider

Allergy & Immunology

Ambulance

Ambulatory Surgical Center (ASC)

AMH - Personal Care Services 20

**AMH-A&D County Referring Provider**

Anesthesiologist

Assisted Living Facility APD

Assistive Technology

Audiologist

Behavioral Consultant

After selecting "Dentist" the list of specialties is not filtered accordingly

Even some simple guidance to help people successfully find what they need would help.

The search for "Dentist" in "Portland" returned zero results.

"Pediatician" does not show up on the drop down for Provider Type, which seems odd. Pediatician does show up under Specialty. Are the differences between provider type and specialty clear to members?

Seven different combinations of searching for a pediatician in the Portland metro area all returned zero results. It is difficult to know if this was because of:

- A glitch
- User error
- A real lack of pediaticians in Portland who accept OHP



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## PROVIDER LIST (RESULT SCREEN)

**Active Providers - *Eligible providers:*** These providers have met the credentialing requirements and are considered active participants of the Kepro provider network.

Active Providers

Providers Being Credentialed

Inactive Providers



This site is best

## Appendix F. Examples of variation in care coordination descriptions and access

Below are examples of how care coordination is described in member handbooks for three CCOs. Highlighted text indicates access instructions for members.

### Example 1:

[CCO] coordinates the care you receive. Instead of just treating you when you get sick, we work with you to help keep you healthy.

- We can work with you to prevent unnecessary trips to the hospital or ER.
- You will get the tools and support you need to help you stay healthy.
- We offer advice about your care that will be easy to understand and follow.
- We will coordinate the care we provide by making it easy for all of your providers to share information that will help to get you healthy and help keep you healthy.
- All of your providers will work together, and with you, to improve your health and make sure all of your medical, dental, and mental health needs are met.
- We will offer prevention programs to help keep you and your family from getting sick.

We want you to get the best care possible. Sometimes we provide health-related services (formerly called flexible services) that OHP doesn't cover. These are non-medical services that CCO's may pay for in special situations. Health-related services can be for one person, or for a community, to benefit the broader population. Call Member Services for more information.

Another way we coordinate your care is ask our providers to be recognized by the Oregon Health Authority (OHA) as a Patient Centered Primary Care Home (PCPCH), or other primary care team. That means they can receive extra funds to follow their patients closely, and make sure all their medical, dental, and mental health needs are met. You can ask at your clinic or provider's office if it is a PCPCH.

If you are a Full Benefit Dual Eligible (FBDE) member, and have questions or need help with navigating the coordinated health care system, please contact Member Services at the number listed above, or toll free at xxx-xxx-xxxx and someone at [CCO] will help you.

**Example #2:** Note that while there is content indicating that members may ask for a case manager for help understanding benefits or medical care, there is no instruction on how to make this request.

## Care Coordination and Other Services

[CCO] helps members find providers. Our Customer Service and Case Management Teams help members access physical, behavioral, and oral health care and connect members to local resources and supports. Members are referred to Case Management (CM) when:

- Your provider asks us to help you.
- The Health Risk Assessment (in your new member packet) may prompt us to call
- You may ask for a CM if you need help understanding benefits or your medical care.

A nurse or other staff will contact you by phone, video conferencing, or text message. CM works with you, your provider, and other local agencies to help you and remove or reduce barriers to care. We want to help you identify and meet your health goals.

**Example #3** – Note: reviewers found no information about general care coordination in the member handbook, but did find information about exceptional needs care coordination as shown below:

### Exceptional Needs Care Coordination (ENCC)

We have Registered Nurses who assist members who are aged, blind, or disabled and have complex medical or special needs. ENCC nurses help arrange your health care services, including services after you leave the hospital, and community and social services. You may request ENCC help by calling [CCO] at xxx-xxx-xxxx: