



Office of the Director



Kate Brown, Governor

500 Summer St NE
Salem, OR 97301

February 28, 2022

Anna Williams, Chair, House Human Services Committee
Sara Gelsler-Blouin, Chair, Senate Human Services, Mental Health and Recovery
Rob Nosse, Human Services Co-Chair, Joint Committee on Ways and Means
Kate Lieber, Human Services Co-Chair, Joint Committee on Ways and Means
Oregon State Capitol
900 Court St NE, Room H-178
Salem, OR 97301

Dear Chairs:

SB5529 (2021) directed the Oregon Department of Human Services (ODHS) and the Oregon Health Authority (OHA) to identify barriers that individuals served by Aging and People with Disabilities (APD) and the Office of Developmental Disabilities Services (ODDS) experience accessing and receiving mental health treatment services through Medicaid and develop strategies to address these barriers.

To identify the barriers and to solicit feedback, each program area (APD, ODDS, and OHA) met with community partners. This report contains those partners' feedback and ideas and from that joint action steps and recommendations.

This report is intended to meet the requirement to report to the 2022 Interim Joint Subcommittee on Human Services on the implementation of these programs.

Sincerely,

A handwritten signature in blue ink that reads "Fariborz Pakseresht".

Fariborz Pakseresht
ODHS Director

A handwritten signature in black ink that reads "Kristine M. Kautz".

Kristine M. Kautz
OHA Deputy Director

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Executive Summary

In 2021, via SB5229, the Oregon legislature directed that:

The Oregon Department of Human Services and the Oregon Health Authority shall:

(1) Identify barriers that individuals served by Aging and People with Disabilities and the Office of Developmental Disabilities experience accessing and receiving mental health treatment services through Medicaid, and develop strategies to address these barriers; and

(2) Assess and develop strategies to remove barriers that prevent individuals with mental illness from accessing long term services and supports.

The Departments shall report the results of this work to the human services committees of the Legislative Assembly no later than February 28, 2022.

To gather information for this report, the Oregon Department of Human Services (ODHS) and the Oregon Health Authority (OHA) worked in partnership with broad range of partners. The information included in this report is the outcome of those conversations.

From those conversations, the Departments have identified significant areas for improvement and collaboration. More work is needed to address the issues, and via this report, the Departments are committing to continuing to work together to develop more person-centered and more collaborative approaches to solving these issues. ODHS and OHA propose the following actions.

1. Immediately issue a specific policy from ODHS and OHA, and improve enforcement of existing policies, to prevent discrimination in all treatment provider systems to ensure full inclusion of individuals with IDD, older adults, and people with disabilities. Determine processes for ensuring compliance.
2. Work to develop stronger communication pathways between APD, ODDS, OHA, and Community Mental Health Programs.
3. Develop processes and procedures to ensure mental health services are delivered in a person-centered manner and are culturally and linguistically appropriate, including appropriate accommodations,

- interpreter services, and Activities of Daily Living supports, and provided where individuals are comfortable in receiving the services.
4. Support existing efforts to address the ongoing workforce shortage.
 5. Develop methods to coordinate services for people with complex needs and facilitate local dialogue on coordination and integration.
 6. With community partners, explore strategies to coordinate different Medicaid authorities to ensure all individuals receive appropriate services and support through a person-centered plan that meets all their needs, and present those strategies for consideration by the legislature in 2023.
 7. Request an ongoing discussion with the legislature and community partners about the prioritization in state statute for mental health services and the restrictions on APD to serving individuals with mental illness.

Background

In 2021, via SB5229, the Oregon legislature directed that:

The Oregon Department of Human Services and the Oregon Health Authority shall:

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Aging and People with Disabilities

The mission of ODHS Aging and People with Disabilities (APD) is to ensure that Oregon's older adults, people with disabilities, and their families experience person-centered services, supports and early interventions that are innovative and help maintain independence, promote safety, wellbeing, honor choice, respect cultural preferences and uphold dignity.

APD Eligibility Background

APD traditionally serves individuals who are age 65 and older or younger individuals with disabilities, including traumatic brain injuries. Since the inception of Oregon's Home and Community Based Services Waiver in the 1980s, APD has not served individuals who are under the age 65 whose primary driver of need is a mental illness or substance use disorder. This lasting policy was driven by the federal governments prohibition on using Medicaid to fund psychiatric care at state hospitals. Since the state could not "waive" the services provided in a state

hospital, individuals with a psychiatric condition were excluded from the APD waiver.

Some things have changed over the succeeding years with the availability of new federal state plan options that allow states to serve individuals with psychiatric conditions in HCBS settings such as the 1915(K) and the 1915(i). However, the direction from the Legislature has not changed. APD does not serve individuals under the age of 65 whose primary driver of need is a psychiatric condition.

There are other good reasons why APD does not serve individuals whose needs are driven by a mental illness. First and foremost, since many of the licensed care settings provide care to older adults who are physically frail and likely have some level of cognitive impairment, it would be difficult to co-locate younger individuals with significantly different needs. Secondly, APD providers are not trained nor skilled at serving individuals who need ongoing mental health treatment and supports. Lastly, APD is not funded to serve these individuals in our case management systems or in our provider systems.

To determine the eligibility of individuals APD has had a process in to assess the primary driver of need. Currently, this process uses contracted mental health consultants to assess that primary driver of need and make a recommendation on eligibility. APD issues a final decision on eligibility.

Services are designed around supports for activities of daily living, such as mobility, eating, cognition and elimination and instrumental activities of daily living such as housekeeping and shopping. APD service settings include in-home services and supports, as well as care outside the home, including adult foster homes, residential care facilities, assisted living facilities, memory care facilities and nursing facilities.

APD services are voluntary in nature. The individual, their authorized representative, or their guardian must be willing to apply for Medicaid and participate in the eligibility determination and service planning process. APD does not have legal authority to civilly commit individuals nor the authority to make decisions on individuals' behalf. Not only is the application process voluntary but so are services. Individuals get to choose which services and where their services are provided.

Examples of APD home and community-based settings include:

- In-home supports: A person lives on their own or with family, is supported in everyday activities like mobility, eating, elimination, bathing, dressing and cognitive supports.
- Community-based care settings: For when a person does not want to stay at home and requires support for everyday activities. These settings are adult foster homes, residential care facilities, assisted living facilities and memory care.
- Nursing facility care: For when a person does not want to stay at home and requires support for everyday activities and chooses to live in a more institutional setting.

Office of Developmental Disabilities Services

The Intellectual and Developmental Disabilities (IDD) program in the Office of Developmental Disabilities (ODDS) strives to support the choices of individuals with IDD and their families within communities by promoting and providing services that are person-centered, self-directed, flexible, community inclusive, and supportive of the discovery and development of each individual's unique gifts, talents and abilities. We are committed to working toward service options that ensure people with IDD have fulfilling and meaningful lives, allowing them to contribute to and enjoy their communities.

ODDS currently helps more than 32,000 children, adults and their families to have the best quality of life possible through all stages of life. Many individuals with IDD are eligible for Medicaid-funded home and community-based services. This includes opportunities to seek employment, work in competitive and integrated settings, engage in community life, control personal resources, and receive services in the community, all to the same degree as people who do not have disabilities.

Examples of home and community-based settings include:

- In-home supports: A person lives on their own or with family, is supported in everyday activities like bathing, dressing and making meals, and receives help with behavior or communication challenges.

- 24-hour settings: For when a person is unable to stay at home on their own or with their family and requires support for everyday activities. These settings are either group homes or foster homes.
- Community living supports: These promote a person's integration, independence, and participation in the community.

Definitions of Disability for Intellectual and Developmental Disabilities

Intellectual Disability (ID) means significantly sub-average intellectual functioning with an intelligence quotient (IQ) of 75 and under as measured by a qualified professional, along with significant impairments in of daily living skills (adaptive behavior) such as, but not limited to, communicating, grooming, dressing, safety, and social skills, that show up prior to 18 years of age.

Developmental Disability (DD) is a neurological condition that:

- Begins before an individual is 22 years of age or 18 years of age for an intellectual disability
- Begins in and directly affects the brain and has continued, or is expected to continue, indefinitely
- Causes significant impairment of daily living skills (adaptive behavior) such as, but not limited to, communicating, grooming, dressing, safety, and social skills
- Includes other developmental disabilities such as autism, cerebral palsy, epilepsy, or other neurological disabling conditions

Together, these are commonly referred to as Intellectual and Developmental Disabilities, or IDD.

Medicaid, Oregon Health Plan, and Behavioral Health Services

In Oregon, Medicaid health services are provided via the Oregon Health Plan (OHP). Through managed care entities called Coordinated Care Organizations, its fee-for-service program, and value-based care, OHP provides a wide variety of healthcare, including behavioral, physical, and oral health services. OHP is overseen by OHA's Health Systems Division (HSD).

This division also contains the Behavioral Health Program. Behavioral Health is defined to include mental health, substance use disorders, and gambling disorders. This section of HSD contains many service programs, including but not

limited to Children's Intensive Services and Youth Suicide Prevention, Peer-Delivered Services and Problem Gambling Services, substance use disorder residential treatment, mental health residential treatment services, and home and community-based services for individuals with severe and persistent mental illness.

Some Behavioral Health services are paid for through Medicaid while others are not. Behavioral health services and programs have been organized within HSD alongside Medicaid/OHP in order to better integrate behavioral health, oral health, and physical health services for Oregonians.

Partner Engagement Process

ODHS and OHA recognize the importance of understanding the mental health and long-term services and supports systems for older adults and people with disabilities from multiple perspectives, especially from the perspective of individuals receiving services and their family members and support systems. Therefore, the agencies began by gathering ideas and viewpoints from a variety of partners. Outreach methods included small focus groups, virtual meetings, one-on-one interviews, and written input.

Questions and topics discussed by partners varied depending on the forum and interests, but broadly addressed:

- Fundamental eligibility criteria
- Access to and availability of services
- Roles and responsibilities among various systems
- Barriers experienced when referring individuals for service to another delivery system, or when individuals need services from multiple service delivery systems
- Case management and care coordination between service delivery systems
- Communication between agencies, units, programs, and offices
- Choice advising and person-centered service planning
- Provider capacity, training, accessibility, and specialization
- Discriminatory practices

In each case, partners were invited to share both their experiences and suggested solutions regarding barriers to care.

Partners

The partners who provided input for this report include:

- Individuals served by APD, ODDS, and HSD
- Parents, family members, and caregivers of these individuals
- Case Management Entities, including Area Agencies on Aging, Community Developmental Disabilities Programs (CDDPs), Brokerages and providers serving these individuals. I/DD Providers included representatives from Oregon Resource Association (ORA), Community Provider Association of Oregon (CPAO), and Oregon Association of Provider Agencies (OAPA).

- Official advisory committees including the Oregon Home Care Commission, Oregon Disabilities Commission, and Disability Services Advisory Committees
- Other community organizations:
 - Comagine
 - Latino Emotional Health Collaborative
 - Northwest Habilitation Services
 - Older Adult Behavioral Health Initiative
 - Oregon Association of Area Agencies on Aging
 - Oregon Association of the Deaf
 - Oregon Family Support Network
 - Oregon Health Care Association
 - A Time for Families
- Local government entities:
 - Deschutes County Juvenile Department
 - Gilliam County Juvenile Director
 - Jackson County Juvenile Director
 - Lane County System of Care
 - Linn County Juvenile Director
 - Malheur County Juvenile Director
 - Multnomah County Aging, Disability and Veterans Services
 - Washington County Aging, Disability and Veterans Services
 - Washington County Juvenile Director
- State government entities:
 - ODHS Aging and People with Disabilities Local Offices
 - ODDS Stabilization and Crisis Unit
 - ODHS Children’s Intensive In-Home Services
 - OHA Behavioral Health Intensive Services Team
 - OHA Child and Family Behavioral Health Unit
 - OHA Ombuds Program
 - Oregon Office of Juvenile Justice and Delinquency Prevention
 - Oregon State Hospital
 - Oregon Youth Authority

ODHS and OHA appreciate the detailed and frank insights shared by all of these partners.

Partner Concerns and Suggestions

All partners who shared their thoughts with ODHS and OHA reported experiencing significant systemic barriers in accessing or supporting people with disabilities in accessing mental health services. It was noted there are systemic barriers for everyone, not just people with disabilities; however, those barriers are exacerbated for people who face additional challenges such as disability or language access needs.

Below is a summary of the concerns about these barriers, and suggestions for addressing them, raised by partners. Though they have been summarized and paraphrased by ODHS and OHA staff, the ideas in this section arise from the partners themselves. They are not listed in any priority order.

The partner input is organized under the following themes:

- Knowledge and Communication about Services
- Case Management and Service Coordination
- People with Complex Needs and Integration of Health Services
- Access to and Availability of Needed Services
- Roles, Referrals, and Responsibility for Providing Services
- Equity and Culturally and Linguistically Appropriate Services
- Provider Adequacy and Capacity
- Provider Reluctance, Discriminatory Practices, and Accommodations
- Resources
- Workforce

Most of these themes overlap. Some concerns and suggestions could easily have been placed under more than one theme. As just one example among many, issues related to the ability to access services often relate to the capacity of providers, which in turn is affected by workforce issues. It is hoped that the identification of themes and the sorting of concerns and suggestions under those themes will not distract from the goal of addressing the mental health system and the needs of people with disabilities as holistically as possible.

Knowledge and Communication About Services

Multiple parents and consumers say they do not know the array of services available. Many reported that, even if they had insurance coverage for needed treatment, they were unaware of ways to access services or what to ask for. They

also say they cannot always get or understand information about diagnoses and agency decisions. For those with complex or cross-system needs, this difficulty was exacerbated.

Likewise, when speaking with care providers, they were often confused about what was available, due to inconsistency across Oregon in the type and availability of care. Hospitals, emergency responders, and other partners may be unaware of who each program can serve.

Suggestions related to knowledge and communication about services include:

- Create an information hub or website of resources for individuals and families to access services and providers, with keywords and other methods to search for what they need.
- Create a single point of contact for individuals seeking care.
- Create a centralized online directory or web portal of services to support providers and case workers with an ability to filter by type of service needed, hours of availability, and age of the individual seeking treatment.
- Create step by step booklets with flow charts explaining how the systems function.
- Provide trainings and resources to case managers on mental health services and supports.
- Provide training on the range of therapeutic mental health interventions that are billable services under Medicaid and are appropriate to IDD clients in mental health, with particular focus on family training/therapy, case management, skills training, activity therapy, and consultation, to expand the range of interventions offered.
- Provide ongoing training for hospitals and other partners on program specifics.
- Provide training for residential providers in all systems of care on mental health and on aging issues.

Case Management and Service Coordination

Many people seek case management services to assist them in obtaining services, housing, work, income support, health insurance, and other basic supports. There seems to be a dearth of case management services offered to people with mental health needs. People may be offered individual and group counseling which they may not want or be ready for upon accessing support. If they do not receive the services they need, they often do not come back for services. Also, different

partners may have different understanding of what case management is or should be.

Many system partners reported a lack of coordination between state systems (OHA, ODHS, OYA) which created a complex set of rules, meetings, and expectations for people receiving services. In many cases, people are forced to attend multiple meetings per week with different providers because they do not coordinate care, and they experience a confusing lack of understanding of providers' roles.

In many cases, partners reported that staff working in one system had no awareness or knowledge of the workings of another system, so people seeking services were left to navigate on their own. Providers reported this lack of system integration often led to inadequate care, as providers were forced to obtain information solely from individuals seeking care in times of extreme crisis, leading to gaps in treatment information and awareness.

Partners noted that coordination of services at the local level through multidisciplinary teams is an effective strategy for individuals with complex needs and services that span more than one service delivery system. However, multidisciplinary team (MDT) structures are not currently supported by system design or funding structures.

Suggestions related to case management and service coordination include:

- Ensure access to robust and continuous case management services that support individuals in navigating the system, accessing services, and addressing the social determinants of health (housing, food, transportation, employment, education, income support, and health care) for children, families, and adults with mental health and substance abuse conditions.
- Develop policy, funding structures and resources to ensure cross-system coordination of services for individuals served by multiple systems at the local level.
- Create coordination and collaboration structures centrally and at the local level on long term supports across systems.
- Develop an interdisciplinary team approach to support individuals with complex needs who are impacted by multiple service systems, to ensure coordination of care. Create funding models and rate structures that

incentivize interdisciplinary team approaches to holistically address behaviors, mental health challenges, and other needs.

- Increase coordination between IDD, mental health, school, and other services for a more holistic approach.
- Create integration of systems at age 18 when people in services move between the child system and the adult systems. Ensure the system provides an array of services and supports across all ages and ensures smooth transition from childhood to adulthood with continuity of supports.
- Coordinate and collaborate on supported vocational and teen transition services.
- Provide cross-system trainings, such as the National Association for Developmental Disabilities, to obtain certification for providers in multi-systemic treatments, as well as training in family and consumer perspectives.
- Create models which provide hybrid case managers or consultants who can be trained in cross-system navigation.
- Create a single statewide Health Information Exchange to be utilized by all system partners, to allow for sharing of information without asking individuals to repeat their history over and over to providers.
- Complete a gap analysis of Oregon's Medicaid waivers and language to determine areas of exclusion or inequities.
- Develop agreements between OHA and ODHS clearly stating the conditions for enhanced coordination including, but not limited to, information sharing, staff time, and complex care consultation processes.
- Provide flexible funding for those involved in multiple systems to address the perception of being bounced back and forth due to funding.
- Look at adapting the Children's Wraparound model for adults and older adults which will ensure fidelity to an evidence-based coordination process.
- Create integrated regional teams across agencies that work collaboratively conducting case consultation and provider technical support.
- Jointly create a discharge pathway and a set of criteria for discharge to send a person to the right resource. Train each program area, partners and providers on the pathway and criteria.
- Create, with sufficient resources, a joint discharge assistance team to allow for coordinated approaches to discharge.

People with Complex Needs and Integration of Health Services

There needs to be an integrated approach to both physical and mental health needs. Recipients of mental health services cited their physical health condition as a barrier to functioning almost as frequently as their mental health condition.

Respondents reported that for people with “complex” needs (e.g., co-occurring developmental delays, physical disabilities, mental health, or substance abuse concerns), their providers often did not understand how to support them. In many cases, this was evidenced by providers who seemed to have little information or direction because the care was considered difficult, giving those seeking care to have little faith in their providers’ ability to meet their needs.

In more extreme cases, a lack of understanding of complex conditions led to denial of care as “inappropriate” to the setting, or referral to high levels of care such as the state hospital to manage treatment, when lower levels of care could have been more appropriate. Additionally, the complex or co-occurring conditions often results in individuals being “pushed” to one program or another rather than developing individual supports that allow for continuity of care.

Suggestions related to people with complex needs and integration of health services include:

- Integrate behavioral health and physical health in delivery of clinical and prevention services. Work closely on mental behavioral and public health preventive and supplemental services and interventions for individuals receiving psychiatric medications that negatively impact physical health.
- Improve integration of behavioral health, physical health and counseling around medication management, and provide necessary training.
- Develop training for APD providers on serving individuals who are eligible but have co-occurring substance use disorder.
- For dually diagnosed individuals (intellectual or developmental disability and mental health), develop strategies and funding mechanisms for behavior specialists and behavioral health clinicians to work together with long term services and supports providers on how to manage the mental illness. This approach can also work well in crisis to prevent or reduce emergency department usage.
- Develop capacity in the addiction treatment system to serve older adults and people with disabilities including those with traumatic brain injury.

- Increase the capacity of providers who have experience and skills supporting people with IDD. Mental health professionals need to be trained on working with people with IDD, better communication strategies, treating people with IDD with dignity and respect, and trusting they are the expert on their own needs.
- Develop crisis teams to support individuals who are living in their own home but for whom substance use or mental illness is causing problems with caregiving and housing stability.
- OHA and APD should partner to develop training and possible credentialing processes similar to memory care for providers who are willing to serve individuals with co-occurring mental illness or substance use issues.
- Develop a wraparound rate to facilitate recruitment of gero-psychiatry professionals.
- Clarify to ACT providers that they can, and should, serve APD eligible individuals regardless of setting.
- Direct OHA to routinely report on the Medicaid services that APD and ODDS consumers receive through their Behavioral Health benefit.
- Provide training on identifying and addressing trauma and attachment issues in children and unique presentations in IDD such as medical trauma, to offer appropriate interventions for children and families.
- Provide training on behavior therapy and behavioral health as part of mental health therapy for both IDD and mental health providers, to provide an array of appropriate interventions.
- Provide training on the provision of mental health services to the IDD population for existing providers and also as part of the academic training and internships for new clinicians entering the field, to increase the comfort level of providers and expand the provider pool. New mental health interns should have time in programs serving IDD clients with mental health issues.
- Provide training on appropriate treatment interventions for people with autism, whether they qualify for IDD services or not.

Access to and Availability of Needed Services

Many individuals with mental health needs and their families seem to have difficulty finding the front door of the mental health system. They often end up at the front door of the APD or IDD system for which they are not eligible for services. This difficulty is compounded because ODHS, APD conducts Medicaid eligibility determinations for all Oregonians, regardless of service needs.

Likewise, people with mental or physical health conditions who need assistance accessing basic supports (SSI, OHP, housing assistance, OVRs, etc.) often don't know where to go. The system requires that people self-diagnose or self-categorize in order to access basic supports. Outreach is needed to people who would be eligible for OHP and/or long-term services and supports but need help accessing the supports for which they qualify.

Also, the mental health "system" is a collection of programs, rather than a system. These separate programs provide intensive services for small, targeted groups of people but not a spectrum or continuum.

Partners were concerned that the behavioral health system, particularly for adults, in Oregon is heavily reliant on institutional settings and underutilizes more cost-effective home and community-based services that are more desirable and produce better outcomes for individuals. It often requires individuals to enter a crisis state before services are provided. Existing community-based services are very limited, difficult to access, do not provide continuity over time and settings, and lack in case management supports to navigate a very disjointed and complex system.

The system over-relies on medication and therapies and lacks supports that are required for individuals experiencing mental health challenges to live successfully in the community, such as case management, long term services and supports, housing and employment supports.

Suggestions related to access to, and availability of, needed services include:

- Expand OHP benefits to cover all Oregonians.
- Expand Citizen Waived Medical (CWM) to cover mental health services and treatment.
- Provide a single point of contact within OHA for individuals seeking insurance coverage.
- Make wraparound services available to all Oregonians regardless of insurance.
- Require OHP/CCOs to pay for services provided by independent contractors to expand provider capacity at the local level. This will also increase access to specialty providers who have expertise in certain areas, such as older adults, individuals with traumatic brain injuries and individuals with intellectual or developmental disabilities.

- Develop and provide a broad range of mental health services, and de-institutionalize the mental health system. Provide, and shift the priority and budget to, a home and community-based continuum of supports that is long-term based and is provided at equal scope and scale as within APD and ODDS systems.
- Ensure that mental health and substance abuse services are provided where an individual lives including residential settings.
- Use flexible Medicaid authorities, such as 1915(i), to provide housing and employment supports, and other community supports.
- Consider using the 1915(k) to support access to long term services and supports for individuals with a mental illness.
- Create a more welcoming entry into services to improve access and utilization of services for people from all backgrounds and geographic areas of the state.
- Identify clinical “champions” in each Community Mental Health Program for specific populations who have been hard to serve.
- Identify a “point person” for behavioral health in ODHS local offices.
- Provide cross-sector training for CMHP, APD and ODDS staff to better identify, assess and refer their consumers to appropriate behavioral services.
- Ensure that receiving entities understand their requirement to serve the populations who are being referred.
- Provide access to technology for people to access services virtually when that is a good fit.
- Improve access to suicide prevention resources and training for case managers.
- Require and fund mental health providers to offer onsite mental health supports to individuals in APD residential programs
- Ensure that habilitation services are available to APD and ODDS consumers.
- Consider Substance Use (SU) Disorder Enhanced Care Services, based on the mental health Enhanced Care Services model, where APD pays for the long-term services and supports and OHA pays for on-site SU treatment.
- Hold CCOs accountable for ensuring that APD eligible individuals with a mental illness have their treatment needs affectively addressed.
- Review CCO-APD MOU requirements and expand those. Consider including IDD in the MOU expectation.

- Increase access to early intervention supports funded by APD.
- Increase the use of older adults and people with disabilities as peer supports.
- Increase the availability of interpreter services to ensure Deaf individuals can access services.
- Move eligibility for mental health State Plan Personal Care and Residential to APD but require OHA to partner with delivering services.
- Provide funding and staffing to APD to serve individuals under age 65 with a mental illness who meet APD eligibility criteria.
- Require OHA to use their contracted case management entity to be solely responsible for eligibility, removing the CMHPs from the process.

Roles, Referrals, and Responsibility for Providing Services

Partners emphasized that various parties in the system do not always understand each other's roles (distinct from knowing what services are available elsewhere in the system). This is an issue at all levels of the system, including at the agency level and local level. Different parties struggle to understand the role of therapists, what the IDD case management role is, etc. There is a strong need for interagency collaboration to educate both systems about the services available and various roles within each service delivery structure.

There is a lack of communication on decisions. When one program area denies services for an individual, there is no feedback to the other program area that likely referred the individual. Additionally, when one program denies, there is no expectation that the referring program area serve the individual. This means that individuals often fall through the crack with no supports which causes confusion among external referring entities such as hospitals.

There sometimes is a refusal of behavioral health providers to provide personal care. Due to a common misperception or perhaps an intentional refusal, OHA contracted providers do not want to provide hands-on personal care for individuals who have both a psychiatric condition and physical needs. This causes a constant referral-denial-referral cycle that ends with the individual not receiving the supports they need.

Suggestions related to roles, referrals, and responsibility for providing services include:

- Provide education and information on the roles and responsibilities of different parties in supporting people with IDD and mental health issues.
- Clarify funding sources and how they work together to support individuals holistically. Mental health providers and CCOs are more familiar with county services and Community Developmental Disabilities Programs, and they need education about Brokerages and Personal Agents.
- Require state agencies to notify another agency that referred a person to it on the disposition of that person's eligibility.
- When a program denies an individual referred by another program, require case staffing to ensure the individual does not fall through the cracks.
- Direct OHA to clarify in administrative rule that mental health providers should provide needed supports and accommodations for people who have Activities of Daily Living needs to access mental health services.
- Conversely, fund APD to provide personal care and residential services for individuals with behavioral health needs. There would need to be training and resources to ensure providers can effectively support this new population.
- Increase personal care attendants and in-home supports, like APD's and ODDS' systems, to ensure that individuals can receive in home supports rather than relying on residential providers.
- Allow APD and ODDS to enroll mental health providers so individuals can quickly access their chosen provider.
- Allow APD to serve individuals while mental health determines eligibility. In general, APD's eligibility process is more defined and better known. APD already does this for people with intellectual and developmental disabilities.

Equity and Culturally and Linguistically Appropriate Services

People with IDD who experience communication challenges, who have limited language proficiency, or who come from diverse cultures and backgrounds experience additional barriers accessing behavioral health services. For example, a recent [report by the Coalition of Communities of Color](#) highlights the challenges experienced by diverse communities across Oregon in accessing the mental health system.

Multiple family and caregiver groups reported a lack of available translation or interpretation into languages other than English, as well as a lack of

understanding of different cultural values in treatment (such as the importance of family treatment in Latinx families).

There is a lack of culturally relevant services, and of bilingual and bicultural providers. Case managers and service providers often are not prepared to interact with the cultural and linguistic needs of the family. Interpreters are insufficient to address the cultural or emotional needs of the family members, and peer delivered services are rarely provided along with the interpreters.

Some families reported a fear of accessing care for their complex needs, related to stigma, traumatic interactions with the system, or a fear of being reported due to undocumented status.

Partners also noted the behavioral health system generally struggles in serving transgender people, as well as individuals who use ways other than language to communicate.

Suggestions related to equity and culturally and linguistically appropriate services include:

- Promote equity by expanding the workforce to be more representative of Oregon's diverse communities, and by ensuring appropriate accommodations are provided to individuals and families accessing all mental health services in all settings.
- Develop culturally specific and bilingual providers. Ensure robust language access supports and accommodation including, but not limited to, access to information in variety of languages and modalities in a culturally sensitive way, translation and interpretation services, and assistive technologies, based on person's needs. Information about accommodations needs to be available and providers need to be trained on providing them.
- Ensure accountability within the county and CCO contracts for culturally specific care, including easily accessible interpreters for health services, and specially trained interpreters for behavioral health services.
- Provide funding for providers to obtain translated clinical documentation.
- Require reporting of REAL-D and SOGI data for all clients in order to obtain better data on health equity needs across Oregon.
- Provide additional training for providers in cultural humility and culturally appropriate care within mental health training programs and as free post-graduate education programs.

Provider Adequacy and Capacity

All partners reported severe shortages of provider capacity across the state, especially in rural areas. Existing providers either do not take new clients or have long waiting lists. Some individuals and families reported waiting for months, some for years. Many reported having to travel long distances, primarily to Portland Metro areas, to access providers. Respondents reported a lack of providers led to inadequate care for those with complex needs, as well as insufficient access to recommended resources such as Occupational Therapy, Respite Care, or Physical Therapy.

Several individuals and families reported there is not always a behavioral health service for their need in the Oregon system. It may not be provided in Oregon or may not be covered by insurance. Some reported having to go out of state to access what they needed.

The provider shortage is also made worse by the fact that CCOs only work with a clinical model and do not contract with independent providers, limiting options ever further, especially in rural areas. When Case Management Entities look for resources for an individual, they are limited by the panel of providers contracted with by CCOs which may or may not provide resources in the local community. Open card, which offers broader choice of providers, is not as available anymore. Few Community Developmental Disabilities Programs are able to hire their own mental health clinicians now to mitigate the access issue.

Partners also reported the need to go into crisis or have an “accelerating” event, such as a suicide attempt, to be able to get services.

Suggestions related to provider adequacy and capacity include:

- Provider capacity needs to be increased in general. Regional disparities need to be addressed. Services need to be available timely, when needed, especially in crisis.
- Develop a joint needs assessment to determine needed capacity to serve older adults and people with disabilities with behavioral health, behaviors or substance use including the need to serve diverse individuals.
- Move away from a crisis driven system, to where all citizens have access to a set number of behavioral health visits per year. Ensure that from there, those who need more intensive or ongoing supports have access.

- Expand the use of the non-traditional behavioral health workforce such as Community Health Workers and Peers and Personal Support Workers to deliver some behavioral health services in an outreach model.
- Create respite option for caregivers, especially for high behavioral needs people and ensure there are qualified providers to deliver respite.
- Consultation to the caregivers or family is a billable service by clinician and is very underutilized. Promote this service.
- Create MOUs to increase cross-system partnerships and collaboration.
- Provide information on in-home supports, to help people stay at home to reduce referrals to higher levels of care
- Use of telehealth should be considered wherever appropriate to make qualified providers available in parts of the state with greater need.
- Expand Enhanced Care Services and Enhanced Care Outreach Services, joint programs between OHA and APD that provide both long term services and supports and treatment services.
- Increase APD's Specific Needs Contracts to increase access within the APD system.
- Create a crisis placement program within APD.
- Develop a system for crisis prevention and stabilization for individuals with IDD in mental crisis. Explore model programs to coordinate mental health and IDD support during crisis.

Provider Reluctance, Discriminatory Practices, and Accommodations

For individuals with IDD, the provider shortage across the state is compounded by provider reluctance to serve individuals with intellectual and developmental disabilities, and by criteria and practices that limit or deny access to mental health services by this population. As an example, some programs established and publicized criteria that deny services to individuals below a certain IQ score. Many providers refuse to serve people with IDD because they are intimidated or concerned, they can't serve this population well, or that therapies are not appropriate for individuals with IDD.

Partners expressed frustration that the mental health system has a notion that serving IDD population is an "option" – not a requirement – and felt strongly that Oregon needs to take a strong, proactive actions to eliminate discrimination and disparities within the system.

Some individuals and families reported getting denied mental health services through OHP, including counseling services, with the reason for denial being individuals with IDD would not derive mental health benefits. The same services were approved through private insurance. Alternatively, in some instances it would be opposite: individuals were able to access services only through OHP and not private insurance.

The mental health service delivery system is required to make reasonable accommodations for people with disabilities to be able to access appropriate services. Unfortunately, many partners are reporting that people with IDD do not receive needed accommodations to access mental services and are denied access due to lack of needed accommodations.

Suggestions related to provider reluctance, discriminatory practices, and accommodations include:

- Eliminate discriminatory practices where people with IDD are denied access to mental health and other behavioral services due to their disability. Implement strong compliance measures.
- Provide training on responsibilities of provider agencies under the ADA to provide reasonable accommodations to access appropriate services, to ensure equal access on equal terms to residential and acute care services to all eligible individuals.
- Mandate accommodations to be provided for people with IDD to access mental health services and supports based on their needs in all settings. Ensure rate and funding structures support these efforts. Accommodations must include adaptations in how services are delivered, including corresponding funding models to allow for those adaptations.

In APD's experience, mental health providers do not think they can provide hands-on-care. This often results in referrals to the APD system for "personal care" once the individual needs assistance with mobility, bathing, dressing or elimination. This refusal to provide personal care often means that individuals are left without critical mental health supports and fall between the cracks in the two systems, one denying the individual due to primary driver of need criteria and one denying because of the need for personal care.

Resources

Partners discussed their concerns that IDD referrals take a "very long time" to get approved (up to a year at times), and that mental health assessments can be waitlisted 2- 6 months due to lack of staffing to complete referrals.

They also relayed concerns that new initiatives or changes from the state or federal level often do not consider the resource demands on the system. Given the current workforce shortages and limited resources of time, funding, and physical space, this leads to delays in service provision for the most complex client needs.

Suggestions related to resources include:

- Implement compatible funding mechanisms for long term supports between mental health services, APD, and ODDS so there can be greater access to and coordination of individual supports and funding. The same provider should not need different billing mechanisms to provide the same type of support to different individuals. Streamline billing processes for providers across similar services funded by different systems.
- Increase flex funding for children and families across systems.
- Provide funding for model programs for intensive day treatment for children with autism.
- When determining timelines and funding, build in appropriate project management and support resources for providers.
- Fund the cost of mental health assessments for individuals who are incarcerated or in detention, especially in rural and frontier counties.

Workforce

Feedback was received from many groups about the workforce shortage being experienced across the health care and human service systems. A qualified and well-trained direct care workforce is a great asset in providing support to individuals who have mental health challenges. High turnover of staff makes it difficult to train and build experience with workers supporting people with mental health needs. With the current workforce crisis, finding and keeping quality caregivers is extremely challenging.

As noted earlier, respondents reported a lack of providers led to inadequate care for those with complex needs, as well as insufficient access to recommended resources. Families of children with complex needs reported they often have good

service plans with direction on how to manage their children's needs, but the recommended services are almost impossible to obtain.

Partners also reported the frequent change in their providers made them feel as if they needed to 'teach' young clinicians about not only themselves but also about the system, and they needed to repeat their story over and over to get their needs met because the system does not work collaboratively to share information across providers.

Suggestions related to workforce include:

- Use a multi-pronged approach to build the capacity of our current behavioral workforce to better identify, assess and treat individuals who are consumers of APD and ODDS. This would include Project ECHO case-based learning, webinars, community of practices and learning collaboratives to build a qualified workforce. Some of this is already happening through the Older Adult Behavioral Health Initiative that OHA funds.
- Shift focus away from high level discussions to providing training and skills building to Direct Support Professionals (DSPs), Personal Support Workers (PSWs) and other caregivers, and providing training and supports to actual case managers for proactive planning. Trained professionals providing direct care make the most difference.
- Create cross-system partnerships to streamline workforce efforts connected to recent legislation on living wages for providers and recruitment and retention efforts.
- Invest in Medicaid rates offering a differential for individuals with training specific to older adults with mental health and substance use concerns.

ODHS and OHA Next Steps

Drawing on the wealth of information shared by partners, ODHS and OHA propose the following actions.

8. Immediately issue a specific policy from ODHS and OHA, and improve enforcement of existing policies, to prevent discrimination in all treatment provider systems to ensure full inclusion of individuals with IDD, older adults, and people with disabilities. Determine processes for ensuring compliance.
9. Work to develop stronger communication pathways between APD, ODDS, OHA, and Community Mental Health Programs.
10. Develop processes and procedures to ensure mental health services are delivered in a person-centered manner and are culturally and linguistically appropriate, including appropriate accommodations, interpreter services, and Activities of Daily Living supports, and provided where individuals are comfortable in receiving the services.
11. Support existing efforts to address the ongoing workforce shortage.
12. Develop methods to coordinate services for people with complex needs and facilitate local dialogue on coordination and integration.
13. With community partners, explore strategies to coordinate different Medicaid authorities to ensure all individuals receive appropriate services and support through a person-centered plan that meets all their needs, and present those strategies for consideration by the legislature in 2023.
14. Request an ongoing discussion with the legislature and community partners about the prioritization in state statute for mental health services and the restrictions on APD to serving individuals with mental illness.

Appendix 1: Detailed Partner Feedback

Below is the more detailed, though still paraphrased, feedback received from partners about their concerns and their suggested solutions regarding barriers to care. It is included here to provide the full spectrum of their perspectives, and to ensure that their ideas were captured even if not specified in the summaries in this report. The feedback is sorted by the same themes as the report.

Knowledge and Communication About Services

- Parents and consumers may confuse the different names of these services, because neurodivergence and behavioral health systems sometimes refer to similar services by a different title or name.
- Case managers need to know their job and be able to explain services. They need to know their own programs and how to maneuver the system and explain it to families.
- There is a lack of training about benefits and services that exist in general, and the process to request benefits.
- Oftentimes juvenile staff are not aware that the youth is qualified for IDD (instead, they rely on self/family report). It would be helpful to know who to reach out to in order to find out if a youth has DD eligibility and receiving services.
- Lots of acronyms can be very confusing.
- Diagnoses that disqualify youth for services do not seem to be straightforward.
- Hospitals, police, EMTs and partners are often unaware of who each program can serve, especially the voluntary nature of the Medicaid program, especially APD programs who do not have the authority to civilly commit individuals.
- APD case managers do not have adequate knowledge about mental and community resources.
- Often case managers only know resources or services relating to the primary diagnosis of their own department or program and cannot or do not assist the family to learn about, apply for, and use other services or community-based resources. Few case managers know about assistance that is not paid for by government funding.
- The system is slow moving and when we don't understand how to navigate the other systems it becomes frustrating. We would like more

communication about the efforts being made by the other systems on shared cases.

- Our local provider does a good job of attending meetings and talking about their programs, but in the same breath says there no homes, long waitlists, etc. It doesn't make the program sound like it is an option.
- Lots of youth with IDD default into the criminal system because they are not getting services they need in the community. It is an uphill battle to explain they behave like they do because of their disability; they are not criminal, and the criminal system is not what they need.
- I would love to have more information on what agencies serve my rural area and what they can offer families I work with. But who is the contact person?
- Information for parents needs to be provided in a straightforward manner: expected typical physical, emotional, neurological development with another column for how to address diversity.
- Survey mental health providers to create a map of services with filters (what services they provide, age groups, hours).
- Provide regular communication to providers and families who would be interacting with both agencies.
- Have all workers and community partners do a poverty simulation, IDD focused. Workers need to understand why they need to explain things, why people get frustrated with the runaround/pass-off, etc.
- Create a training and resource manual for staff and community partners.
- Review licensed mental health providers in Oregon with a survey that gets at whether each accepts Medicaid and each accepts private insurance.
- Hold provider listening sessions to gather improved understanding of barriers and opportunities.
- Create a menu of health and home benefits online that OHP members can look up themselves to apply online for.
- OHA needs to gain better cultural understanding of mental health consumers and their individual needs.
- Families and individuals who qualify for in home services and supports should be offered training in their rights and responsibilities and support in making the connections.
- Provide a single point entry to obtain benefits.

- Provide central Health Information Sharing so everyone involved knows what's happening without relying on client/family report.

Case Management and Service Coordination

- Mental health case management is time limited, and there is an important and distinct difference between mental health and IDD systems. Mental health case management is crisis oriented; once the crisis is perceived to be over and service is over, then the person is discharged from that service. When next crisis happens, the individual must re-enter the system and reinitiate that process. IDD case management is a continuous long-term relationship and can be immediately engaged, but mental health takes time to re-engage during the crisis situation.
- There is a big difference between on-going case management and point in time case management.
- Case managers are not informed and do not have knowledge or information to refer people to mental health resources, services, wrap around services for kids, or providers. Families must find out the information about the mental health system and services from other families, school, or other sources.
- There is a high turnover among case managers. Case managers are overwhelmed with caseloads and are unable to adequately support individuals.
- In some cases, there are several providers assigned to similar tasks, and in other cases large portions of the work feel unassigned.
- Parents often do not have the time to attend multiple team meetings and need them to be consolidated and coordinated on a regular basis. Parents are frustrated with being case managers for the multiple agencies' case managers.
- At times ODDS is the case management system and the main point of contact. If there are other case management services, there is rarely collaboration/communication.
- For children and families, there is often a lack of coordination with schools, creating even more confusion about resources and supports
- Multiple respondents reported a "drop off" in services when young people turn 18 and have to learn to navigate an entirely new and confusing adult system.

- Families may be referred, but not receive support in getting connected to these services. Families give up after trying multiple times and learn that there really isn't help out there for them.
- The child serving systems are not well coordinated and integrated. This differs across communities across the state.
- Families continue to hear that they need to go to a mental health provider to receive mental health services.
- Case management from mental health and case management from DHS/ODDS do not understand how the application process of the other works. Case management from both sides don't know how to support the needs of the other. Neither side is a magic bullet for the barriers of the client, and often handing off a client to the other side of the barrier leaves the client open-ended in their service needs.
- There is a lack of transparency for each system to see the other, for example, how the money pots work. Currently, a client can't receive funding from both mental health (non-OHP) and ODHS services at same time.
- There is a lack of understanding from OHA, DHS, CCOs, and community partners about the difference, purpose, and function of "case management," "care coordination," and "benefit administration."
- There is a lack of compliance regulated care coordination between Medicaid and Medicare.
- There is a lack of ability for a person moving from one system to another to have a means of communication, such as a phone number or cell phone. Communication is impacted by houselessness, service interruption while at the state hospital or in incarceration, lack of access to email, etc.
- There is a lack of IDT team follow through after discharge from anywhere. Does a billing mechanism for this exist?
- Arguably more than any other system of care, folks in need of help with mental health need support as they try to access the care they need. Immediate intervention and care coordination can make a difference
- There is a lack of transitional case management independent of a single agency.
- There are difficulties from the CCO prior authorization structure, redetermination processes, and review.
- Often there are conflicting and overlapping treatment plans from provider to provider.

- There is a lack of uniform expectation from county to county regarding service delivery and approach.
- There is a lack of strong partnerships and collaboration with APD and mental health at the local level.
- There is a need to refer individuals to multiple systems to meet needs. The systems don't know how the other systems work, and every area functions differently.
- At times the barrier is the diagnosis of an IDD. Other agencies are not as willing to partner due to the hands off approach for someone with an IDD.
- There is a lack of coordination between programs, lack of coordination with schools, and a lack of role clarity.
- Communication seems to vary depending on the location, community, and situation. For youth that are in process of getting approved for services at the time of interaction with juvenile system, seems to lead to more challenges in determining next steps. For youth turning 18, there are varying experiences and lack of consistency; some transition very smoothly and others have significant challenges accessing services.
- Unfortunately, there are many intersections between ODHS and the behavioral health system where the systems do not have the same understanding of who and how people should be served. Many case managers on both programs are not trained on how to access supports and what supports they (the APD staff) can provide.
- There are agency silos of process, instead of universal process.
- Communication between units, programs, and offices needs to be improved and streamlined.
- How can we bolster training to ensure case management services are aware of OHA/ODHS benefit packages as a service option?
- Clients go to their APD office to be screened for LTCSS. If the driver of the need for LTCSS is physical health, the pathway is clear. If there is ambivalence about whether mental or physical health is the driver, a consultant is brought in to do an evaluation. If mental health is identified as the driver, the client is referred for a different evaluation. Clients, information, and access are lost in that unnecessary hand off.
- It is not clear what services are available to what youth. There seems to be a breakdown when youth turn 18.

- At times it seems that the caseworker is just a broker of services, but it is not clear which entity oversees what for the youth and family, which can be confusing for the Juvenile Department as well as families.
- At times it seems that caseworkers are not aware of options that are available to the youth.
- Even when services are available, providers will often rely on the Juvenile Department for direction on managing significant conduct issues. Providers don't always understand the role of the Juvenile Department workers.
- For OYA, it would be very helpful if the original workers could follow the youth as they move. Youth can get lost in the shuffle as they move around.
- Make care coordination work as it can and is intended for all OHP clients in need, regardless of whether the driving issue is physical, mental, or dental driven, and regardless of whether the issue is long term and lifelong or simply a need for temporary support.
- Case managers need to understand problems, know resources, and be able to access services to address both intellectual/developmental and emotional health needs whether or not they are funded by the government.
- The various treatment/services teams need to agree on a facilitator or lead planner amongst the multiple services participants in OHA, ODHS, ODE, OYA and CW. A long-term "Fidelity Wraparound" model may be applicable.
- Examine and desegregate mental health disability from APD services, by adding them back to APD services.
- Clarification is not needed as much as collaboration. Once an individual is identified as IDD, it falls on IDD services to resolve the issues. Other partner agencies need to take an active role in providing services that that the IDD system cannot facilitate such as mental health services, housing, etc.
- Support a smaller caseload size and trainings for case management.
- Provide a hybrid case management system or consultant (like APD Diversion/Transition) trained on all the systems, and who can spend 90 days with people so they can know resources and help people apply. Remain involved until the client is settled. The APD model saves money by keeping people out of institutions, avoiding the emergency department, etc.
- Screen in instead of screen out. Need to switch from "physical versus mental" or "what can we exclude you from?" to "what support are you eligible for?"

- Provide wraparound services for all, with a single point of contact, and an MOU between agencies, in both the adult and child system (OHA, APD, ODDS, ODHS, OYA).
- Provide realistic training that shows the actual SWOT of moving a client willy-nilly from service set to service set hoping to find a magic bullet for difficult caseloads.
- Offer online Medicaid state certification training courses.
- Exact all needed contract language.
- Create and follow through with compliance requirements.
- Ensure planners are aware of benefit options to meet the needs of the whole person.
- Do not require separate processes and evaluations for whole benefit assessments.
- Use portable mental health/substance use disorder treatment plans to reduce retraumatizing members through the requirement of multiple treatments plans by simultaneous providers.
- OHA should lead in training for all CCOs, CMHPS, and mental health providers about mental health services and programs that are available for all clients, how to access them and where to turn if access does not seem to be happening.
- OHA should document concerns from providers, CCOS and other contractors, along with clients, so the agency is better able to respond.
- All mental health providers who serve clients should be able to connect with Comagine directly. This would help reduce trauma by reducing the need for the over-assessment of our members.
- OHA should reaffirm ties to APD offices where many people with disabilities go to get other services and which have a very effective and uniformly understand process for screening clients in need of LTCSS because of physical disabilities. Clients in need of LTCSS because of mental health should be able to use that door as well. There should be no difference in ability to access these services based on type of disability.
- Providers need to be cross trained and understand the process for IDD services from beginning to end.
- There needs to be more training and explanation around services for youth who are turning 18 and how that affects service availability.

People with Complex Needs and Integration of Health Services

- There is a lack of integrated health services.
- ABA programs are not coordinated with behavioral health programs and are often experienced as traumatic to both the recipient and the recipient's family. Supplementing and coordinating the approach with Parent Child Interactive Therapy, Parent Management Training Oregon and Collaborative Problem Solving would likely bring better trauma informed outcomes.
- Some providers have dually credentialed professionals who are both behaviorists and mental health clinician, but billing and tracking becomes complex. Providers have to separate the roles on paper but not at the person's level.
- There are very limited numbers of behavioral health clinicians who are competent in providing treatment (verbal and/or non-verbal) for children/youth who have dual diagnoses (neurodivergence and mental health). There are even fewer prepared to treat youth with neurodivergence and neurodivergence and addiction or neurodivergence and behavioral health concerns.
- Often the recipient must participate in a confusing and often duplicative consumer-centered or consumer directed plans of care.
- There is a lack of age-specific mental health residential programs that address both ADL needs and mental health needs, often due to siloed funding streams.
- Both systems lack complex care competencies, causing individuals with cross-sector complex care needs to fall through the cracks.
- There is a general lack of understanding among IDD staff about how to address mental when there is a cognitive disability.
- IDD workers or group home providers have more expertise in working with IDD issues and challenges. They struggle to understand mental issues and how they are acted out among the youth they are caring for. Just as it is a best practice to integrate co-occurring treatment strategies between mental health and substance use disorders, the same would apply to work in the IDD and mental health systems. We desperately need clinicians, caseworkers and skills trainers who understand both agencies and needs related to the youth they are serving.
- Family and youth peer delivered services (PDS) are not reimbursable under OHP with a simple neurodivergent related diagnosis service and are

available only if paired with a mental health diagnosis; however, parents need PDS to address the complications associated with parental stress, navigation through multiple clinicians/treatment plan and adaptive parenting skills to meet the neurodivergence and other physical/behavioral/developmental issues. Parents often need individual assistance to negotiate for and implement medically necessary activity recommended for those dual complex conditions.

- There is a lack of understanding among IDD and mental health staff of how to work with dually diagnosed children. Clients are referred to Secure IP because programs don't know how to manage clients at lower levels.
- There is a lack of competencies in co-occurring dementia, leading to frequent emergency department visits for "challenging behaviors."
- Public health prevention programs are often disconnected from mental health treatment programs and IDD programs.
- Youth that have IDD and end up in detention often stay for a longer time due to lack of placement/support options. Detention is often seen as a "safe place" for them, but detention is not a treatment program. Also, it becomes an issue when OHP is suspended while in detention. Providers are then not able to get payment for services. The numbers of youth with IDD in the juvenile justice system have been small but have been increasing yearly.
- Funding for the coordinated services/treatment plan needs to be braided rather than siloed by the child's diagnoses or the government unit that is handling that service/treatment.
- There is a need for hybrid case management, someone who can understand and meet the needs and the objectives of the clients' care based on physical, mental, and developmental criteria. ODDS is currently the best at this. At a minimum, there must be transparency between departments so that case managers from both sides can see what the impact is of handing clients over to the other side.
- One integrated neurodivergence and behavioral health service/treatment plan would be more efficient for case managers, family members and recipients.
- Provide NADD trainings, and empathy workshops for a family perspective.
- Reintegrate mental health disability into APD services.
- Collaborate between OHA and DHS on rule definitions review and clean-up to remove inconsistencies in rule language that is prohibiting people with

mental diagnoses from accessing in-home support services. Examples of the words or phrasing that should be considered include: the lack of the words “mental health disability”; chronic mental health illness; chronic mental disorder; individual with serious mental illness (SPMI). Think through the ADA implications of the use of diagnoses for defining support eligibility.

- Building provider confidence in providing services to dually diagnosed folks, with less siloed systems, will help providers to think less about criteria/eligibility and more about client needs. Blended funding and doing away with fee for service payment always seems like a possible solution.
- Mental health needs to have a full spectrum system of care in place so that individuals receive an appropriate level of care.
- Behavior consultation expertise is not blended with mental health therapy. There are skills training components of therapy that are lacking in mental health and there are mental health therapy interventions that are lacking in IDD. There needs to be integration of both approaches, based on person’s need.
- Wraparound approaches being employed successfully in children’s mental health and IDD and they are appropriate and applicable to adult mental health services, but not used for adult population.
- The transition from services for children to adult services is perilous. There needs to be a smooth transition with the same array of supports in both systems. Transition age youth with mental issues who do not have Child Welfare or IDD involvement and lack family support, are left with few options and supports in the MH system.
- Medication is overused as a solution to mental health issues.
- Many individuals are receiving psychiatric medications that have serious deleterious effects on their physical health. There needs to be better mitigation of these effects through supplemental therapy and comprehensive alternative interventions short of medication or at least in addition to medication.
- Mental health is frequently disconnected with medication prescribing, which may be more connected to primary care or physical health. Training and coordination is needed in this area.

Access to and Availability of Needed Services

- There is gatekeeping of access to behavioral health related State Plan Personal Care and Residential services. Community Mental Health

Programs are the gatekeeper to Medicaid long term services and supports for individuals with behavioral health issues. This complicates access because it presupposes that individuals are enrolled in CMHP services. One APD stakeholder specifically said that the CMHPs are the problem in the system. Many individuals are not willing to engage in treatment or have not yet engaged in treatment with the CMHP. Requiring individuals to enroll with CMHPs to access Medicaid services creates a barrier to timely access to supports. From an APD perspective, there is also a conflict of interest in allowing CMHPs to serve in this function since they are Medicaid providers. This forces Medicaid eligible individuals to receive services from a closed system in which they many do not want to engage. Recently, due to CMHP staffing shortages and demand outstripping resources, individuals who have an entitlement to behavioral health LTSS have been refused access to the services in which they qualify.

- The mental health system in Oregon needs to provide equivalent HCBS continuum of services at the scope and scale equivalent to DD/APD systems and needs to do so in coordination with other systems for individuals who are dually diagnosed or require multiple systems to support them based on their needs.
- A long term care mentality is needed in the mental health system to serve people in their communities holistically. Wrap around support/holistic support, creating multidisciplinary team approach instead of passing the baton back and forth between systems.
- Too many resources are tied up in institutional settings and residential care facilities in the mental health system that are not producing cost effective outcomes. Better outcomes are achieved in community-based support settings such as supported housing and supported employment. There needs to be a shift of resources from institutional/residential care to community-based care.
- Supported vocational services are an evidence-based practice that needs greater implementation to encourage a culture of work and self-efficacy. There is a need for consistent/compatible funding mechanisms for vocational services across DD and MH system to encourage providers to serve both populations and increase capacity.
- Many people in the mental health system will need long term supports to be successful in the community. The mental health system has not

developed a workable spectrum of long term supports for people with mental health needs.

- Therapeutic foster care options (not proctor care) for children not involved in Child Welfare or IDD do not exist.
- Adult foster care options and supported living options are inadequate for the need.
- There needs to be an increased focus on family therapy and family training especially for young children but also with care providers (foster care and group home staff). Working with family and paid care givers can produce better outcomes.
- Attachment and trauma issues are inadequately assessed and addressed in many children and in both children and adults with developmental disabilities who may have experienced trauma in many ways including medical interventions.
- Preventive approaches and flexible funding for children and families needs to be extended and not just for children who already rise to a high level of need and intervention. Small amounts of funds properly expended at the proper time can prevent expensive high intensity expenditures with worse outcomes later.
- Peer delivered services are a powerful modality and needs to be broadly implemented.
- There are long wait lists for diagnostic services: developmental pediatricians or psychologist for autism spectrum, neuropsychologists, prescribers knowledgeable in neurodivergence and behavioral health disorders.
- There is insufficient capacity for identified needs of occupational therapy, physical therapy, respite providers that will come to the home, and home care providers for ADL and support for the parents who need to work or sleep.
- Home care or personal service workers are generally not approved for issues related to behavioral health, and yet parents need the in-home support for the child while they work and sleep. The lack of paid staff in the home often results in the child's emotional health deteriorating and requiring a higher level and/or out-of-home placement. In-home support and respite would be more cost effective for the system of care and less trauma inducing for the child, the siblings in the home and the parents.

- Treatment plans are written well, but it is hard to actually access the recommended services.
- Mental health providers usually require that individuals attend in-person clinical sessions, which adds an additional burden for older adults and people with physical disabilities. Additionally, the delivery system does not know how to access mental treatment for individuals who could benefit.
- Addiction treatment programs are not able to meet the needs of APD eligible individuals due to the need for personal care or supports for co-occurring cognitive impairments. There are no onsite addiction programs that could provide substance use treatment in APD licensed care settings.
- APD providers are not trained nor equipped to address current substance use or mental illness.
- Prioritization denies access. When APD consumers do get seen, it is often only psychiatry. The wait times often mean an individual is no longer willing or able to participate. One provider said, “We have people with Schizophrenia, Bipolar Disorder, etc. and we hear they are not the priority, so they don’t get services.”
- Medicare and Medicaid rates are not sufficient to help build capacity and ensure access.
- For most APD eligible individuals with a mental illness, their only treatment is prescription drugs prescribed by a primary care physician.
- In 2012, the Oregon State Hospital changed admission criteria, denying access to many consumers traditionally served at the State Hospital. This change pushed patients with intensive behavioral issues including those with personality disorders or those with violent behaviors caused by brain injury or disease (e.g., Huntington’s Disease) to limited community resources without the resources or training to meet the needs of these individuals.
- Though it appears that APD eligible individuals should be able to access Assertive Community Treatment to meet their needs, there is a lack of access for individuals.
- There is no access to local providers in some communities for assessments. People have to travel or do telehealth. There is concern that they are not seeking input from local providers that are involved.
- Wait times are too long across the board.
- Wrap around care is not available to youth that have private insurance or OHP Open Card. Two vulnerable populations impacted by this are youth

adopted through ODHS and youth receiving IDD services. These same youth are overrepresented in special education and juvenile justice systems and their behavioral health needs can be very complex. Parents have resorted to relinquishing custody to Child Welfare in order for their child to access system of care through the CCO and BRS services through ODHS. There are concerns that youth needs must escalate to the level of a safety threat before they are eligible for services, at which time they then become involved in juvenile justice, child welfare, or both.

- When youth do not get treatment needed, it can lead to significant impacts including remaining in ODHS substitute care longer, and risk of further engagement with juvenile justice.
- Referrals take forever to get processed, up to 1 year. Also, there are no programs so extensive wait lists, with kids in limbo and not getting services needed. It often takes major pushing, but families don't always know how to advocate and push for what is needed.
- There is no clear direction about, and lack of awareness related to, the very, very narrow door that must be opened for providers and their clients who clearly qualify for LTCSS because of mental health issues to be evaluated for and have access to those services.
- Children who are identified as IDD have limited bed space within a PRTF system that relies heavily upon a talk-therapy group/milieu setting.
- Some families are struggling to get into services because of insurance. This is particularly true for those youth on open card. Parents talk about long periods of time where they are having to wait regarding eligibility for services when commercial insurance is in play.
- The state and OHA should view the fact that the mental health access crisis and jails are functioning as the default mental health system as a public health epidemic. They should work across all systems, Medicaid, licensing, education, and private insurance to increase the workforce, raise starting pay, and expand access to every type of mental health support, including peers.
- Provide funding and staffing to APD to serve individuals under age 65 with a mental illness who meet APD eligibility criteria.
- Require OHA to use their contracted case management entity to be solely responsible for eligibility removing the CMHPs from the process.
- Youth and families need access to community based mental health services at lower levels of care.

- LTCSS should be understood as part of the continuum of services to which people in need of support for mental health issues should have access.
- More flexibility is needed for location of services. Many individuals and families are impacted by significant barriers to office-based treatment including transportation, traffic, time, and expenses. Individuals with an IDD can have sensory overload and struggle with transitions making office-based treatment less accessible and effective.

Roles, Referrals, and Responsibility for Providing Services

- APD often sees requests to serve individuals who have a behaviorally health diagnosis. When the individual is denied, the diagnosis is changed to have the individual determined eligible for APD services.
- The current mental health system prioritizes individuals who are in crisis, or civilly committed and being referred to the Oregon State Hospital. This prioritization means that many people who need ongoing supports are left without critical supports.
- On challenges such as multisystem services, transportation to various appointments, and overloaded plates, some have a mindset that it is someone else's problem.
- There is a lack of compliance regulated follow through to make known and request the benefit.
- There is a lack of general education (OHA, DHS, CCO, and Community partners) about Traditional Health Workers (PSS, PWS, FSS, YSS) and Home Care Commission (PSW) roles, their difference, and the necessity that each exists independent of one another.
- There is a lack of clarity around roles and expectations as well as the process for seeking services. Wait times can be very lengthy including wait times for assessments to even determine eligibility as well as assessments to determine need. Wait lists can be very confusing in terms of who is prioritized, i.e., we can be told that a youth is at the top of the list but then they are not the first one to admit when there is an opening.
- It is difficult to know who is responsible for what in general. Local areas and each CCO do things differently, including authorization processes.
- There is confusion around personal support workers. Who selects that person, and what is their role?
- There is a limited understanding of OYA's role and responsibility for youth when working with the various systems, i.e., advocating for a youth with

unmet IDD needs. Parents are seen as an option for IDD, but not a viable solution/option for the court mandates related to safety due to other safety concerns at the home. IDD folks have seen this as they have taken care of their responsibility, yet OYA still has a youth with unmet IDD needs and without an acceptable placement to support the IDD needs.

- Referrals for youth who are close to turning 18 into IDD services is difficult because of the rate differences between adults and children (especially residential). There seems to be a lot of grey area, with each system thinking another system is responsible rather than really partnering.
- For OYA, youth can be seen as just OYA responsibility rather than being able to access the more appropriate services, i.e., screened out due to their adjudicated offense, despite the fact that their unmet IDD or mental health need is what led to their charges in the first place.
- Several participants reported a perception that systems "pawn off" clients from one system to another due to a lack of resources, because complex clients who are involved in several areas of treatment require intensive staffing and treatment needs. This feedback was especially strong for those with any criminal involvement, due to the stigma involved.
- Separate agencies are so busy putting out their own fires that the buck gets passed around.
- Youth in the juvenile justice system sometimes get the short end as they have committed a criminal offense and seem to get pushed into that system further due to the lack of appropriate DD placements.
- A barrier to accessing for IDD is that practitioners will say that the individual does not fit their milieu due to cognitive impairments. Although this may be the case for some, there can be more collaborative and creative ways of assessing a person for possible behavioral health needs and treatment, which may look different than the current model and would require training of practitioners and financial support through insurance.
- From the behavioral health side, the main barrier to accessing IDD services is the individual needs to be found eligible before services can start: lots of paperwork, assessments, etc. The eligibility determination process is very ingrained in statute and OARs so easing any of it would require significant system change.
- The way youth in OYA get capitated to CCOs is unique and can be confusing for those involved, which can lead to additional questions around who is responsible for what. There are just so many points of contact, with ever

changing faces, it becomes really difficult to track. Written resources can be helpful when they are maintained and kept up to date

- People who do not qualify for IDD cannot access HCBS 1915i services through mental health system. This program is very underutilized. There is not a good system in place to access it, and it is not administered at the local level. There is one contractor KEPRO that does assessment for it, so access is privatized and is very limited.
- Package of services in 1915i is not helpful and there is no real case management available, even though it is required under the program.
- Include all potential benefits as a part of the ONE system application process, so that it flags a need for “care coordination,” “case management,” and possible disability benefit assessment.
- There needs to be clarification on roles and responsibilities related to the difference between skills support/habilitation and caregiving.
- Provide flexible/blended funding, and better integration of systems to avoid "drop off" of service providers at age 18.
- Write rule and contract language updates that define OHA, DHS, CCO, and Community partner roles.
- Workforce collaboration between OHA & DHS the workforce delineation between (DHS - PWS HCW – Oregon Home Care Commission for ADL and IADL supports under Personal Care Plan 20) with the (OHA OEI – PSS and PSW – for HB, BH and PSG supports under 1915i) needs clear reinforcement and support so that available certified workers can be identified and provided program/role education.

Equity and Culturally and Linguistically Appropriate Services

- Language access is a huge barrier for people with limited English proficiency or communication challenges across the entire system. No accommodations are provided to individuals to access mental health services.
- For individuals who use ways other than language to communicate, assistive technologies and use of apps has helped, but efforts need to continue to increase accessibility.
- The mental health system generally struggles in serving transgender people and addressing other gender issues.

- Mental health is based on diagnosis of individual's pathology, and it does not address social pathologies, like racism, sexism, etc. The system tends to individualize the problems that are societal, including trauma.
- Very few clinicians and PDS are people of color or multilingual.
- Youth miss opportunities to engage with more culturally matching services. This disproportionately impacts students of color. There is significant stigma around mental health in the black community, when combined with historical experiences, leads to extreme reluctance to engage in services.
- There is a lack of culturally responsive services, translation, Spanish-language services, and of understanding that family involvement is essential for Latinx families.
- There is a lack of culturally specific intensive outpatient programs and SPMI culturally specific programs.
- Provide equitable opportunities for non-English speaking communities to learn about the services, and to receive communication and supports in the language of their preference.

Provider Adequacy and Capacity

- Families have to sort through many providers (sometimes more than 100) to find someone who is willing and available to provide services. Rural areas are particularly short of providers.
- Lack of provider capacity is also exacerbated by confusion, lack of transparency and consistency across different coverage options, like OHP/Medicaid and private insurances. Families and individuals struggle to understand what services are covered by which source. Many providers accept one form of coverage, but not the other. Many providers do not take clients covered by Medicare/Medicaid, or those individuals experience longer waiting time.
- Community health workers are underutilized, there are no billing codes for them so they cannot be used and billed for to provide that extra work that is needed. CCOs only contract with providers who deliver clinical model, but not with independent providers, that removes valuable resource from options available to the individuals.
- There is a general lack of understanding about what a child's behavior may be the result of. This becomes more challenging when the youth's behavior is aggressive or as they become teens and young adults.

- Overall provider capacity needs to be improved for everyone to make services more accessible and reduce or eliminate wait times. However, concerted effort needs to be made to increase capacity to serve populations that experience additional challenges in accessing the system, such as people with disabilities, people with limited English proficiency, and people experiencing other barriers or who need accommodations.
- There seems to be a general lack of Trauma Informed Care.
- There are not enough providers for the 1915i services, so even if one gets through the hoops to enroll, it is difficult to find providers.
- There are not enough mental health providers in Oregon and, additionally, insufficient numbers of mental health providers willing to accept Medicaid. CCOs returned money provided for intensive in-home behavioral health services and supports because, two CCOs reported, there were not sufficient qualified staff available for the 24-7 care the program requires.
- There is a lack of ability to continue seeing a mental health provider with whom clients have become comfortable. Clients report that their 'providers' are interns, only there for the degree, then they move on, forcing clients to have to reestablish care and understanding with a brand-new provider who then moves on.
- The lack of sufficient mental health providers results in visits much less frequently than a treatment plan identifies as necessary, and in a reliance on very short visits and medication when perhaps counseling would be most appropriate.
- In some cases, the lack of providers has meant that proactive services are not obtained when needed, and so complex clients are referred to higher (and more expensive) levels of care to meet their needs.
- Residential treatment programs for children and adults are insufficient with long wait times. Thus, children and adults in crisis are locked in the emergency department or, in the case of adults, released to the streets.
- Emergency departments have become a revolving door for folks in severe mental health crisis. Instead of admitting and evaluation, patients are held and released back to the street.
- There are not respite providers and placement providers that specialize in IDD care.
- There is lack of community engagement opportunities for youth (e.g., Special Olympics, etc.).
- There is a lack of appropriate care and of appropriately trained providers.

- Parents want access to PDS in order to discuss their understanding with another parent with community-based Family Support Specialists and as expansion of the Parent/Family WarmLine, and coordination with FACT and Family-to-Family
- Peer services are only billable when paired with a mental health diagnosis.
- Alternative treatment (non-Western or non-clinical) are rarely discussed.
- There is a requirement that accessing Traditional Health Workers (PSS, PWS, FSS, YSS) requires the service to be part of a medical model mental health treatment plan.
- Community health workers not recognized in Medicaid system. Related concerns include: some billing codes limit desired interventions; flexible engagement code does not exist; can only bill for family or individual therapy service on the same day; can only bill for more 1-hour group therapy; cannot bill for services by CHWs; only people registered in mental health services receive treatment, others are not welcomed.
- Behavioral health services are unavailable in most APD licensed residential settings.
- Resident-providers know little about mental health and how to interact with their clients with mental issues.
- There is a younger sub-group of individuals in APD residential settings with substance use disorder and/or traumatic brain injury with difficulty accessing appropriate services.
- Service providers often have not parented children, and specifically children with neurodiversity and behavioral health issues. They need more information and consultation about the issues, problems, and possible remedies, including best practices.
- Family members are unable to support adult family members due to HIPAA.
- The gap between the time of discharge from detention to getting a mental health assessment to get services sets up children for potential failure.
- There are huge issues with provider capacity within the DD system and residential services across the state are collapsing. Residential homes are closing due to lack of workforce and crisis units are not accepting new referrals. Kids are returning to their home county to families that are not ready to provide care. At times children are being housed in hotel rooms.
- Youth and families experience long wait times to receive services, and things are not always clear which leads to confusion and frustration. Some

IDD caseworkers report lag in seeing youth/families due to workload, leading to less frequent contact with those youth and families.

- There is a lack of acute mental health care services (crisis services and suicide prevention).
- Access to the crisis mental health team and suicide prevention hotline is a big issue. Typically, this is due to lack of staff and capacity resulting in long wait times.
- A combination of psychoeducation that is specific to this population of children and youth may be one of the most helpful strategies.
- Some children and youth who experience co-occurring IDD and mental health can benefit from cognitive coaching around the behaviors they have. Strategies around cognitive coaching or therapy need to be more individualized to meet the child's needs.
- All providers who work with this population need to engage in professional development/training that focuses on both DD and MH treatment modalities.
- Allow billing for Traditional Health Worker and peers, and train providers on use of peers
- Provide workforce collaboration between systems
- Provide families with information on how to obtain in-home supports
- Provide general fund dollars to cover the cost of mental health assessments for individuals who are incarcerated or in detention, especially in rural and frontier counties.
- It would be helpful if we received copies of the PCSP for each client to align goals within the mental health system.
- Providers should be trained about the availability of peers and how to open the door for their patients to understand how to access peer support.
- All CCOS should be required to contract with all residential treatment programs.
- All CCO's should be required to contract with all ITS programs (acute mental health care services).

Provider Reluctance, Discriminatory Practices, and Accommodations

- About 40% of individuals receiving IDD services also have an axis 1 mental health diagnosis. These individuals benefit greatly from mental health therapy. There is ample evidence to show that cognitive behavioral and other approaches can be used successfully in the IDD population. The IDD

system provides case management and community-based services but cannot pay for or provide mental health therapy.

- There is no correlation between IQ scores and behavior problems. There is a correlation between various mental health diagnoses and inappropriate behavior. If behavioral issues are present, it is clinically indicated to look at mental and physical health issues rather than IQ.
- Many mental therapists lack a comfort level serving the IDD population. There is a belief that specialized training is needed. If it is a specialty, it is based upon experience and willingness, not specialty skills and training. Communication issues are significant and challenging. Therapy in the IDD population may be longer term and more intensive and require patience and a more gradual pace.
- There is a persistent belief that the general population has mental health issues and the IDD population has behavioral issues. This distinction is not supported by evidence. IQ has little if any correlation to mental illness. Both interventions can be employed by mental professionals for all populations.
- People with developmental disabilities have difficulty accessing acute care when needed. If granted access, often it is with a request for a one-on-one assistant regardless of need.
- Many residential treatment facilities for addictions have IQ score requirements that exclude individuals with IQ scores below 70. This does not appear to have any basis in evidence-based practice. These institutions are required to make reasonable accommodations for people with disabilities to be able to access appropriate services. If a person has a physical or sensory disability, they would need to be accommodated by the institution. It should not be different for a person with a developmental disability.
- There are growing numbers of children diagnosed with autism spectrum disorders. Many of these children have attachment and trauma issues that are not appropriately addressed when an autism diagnosis is given. Many children with autism diagnoses do not meet eligibility criteria for IDD services.
- The state needs to take strong stance in eliminating discriminatory practices and stigma that keep people with IDD from accessing mental health and substance use services and ensure that individuals can receive necessary accommodations to access services based on their needs.

- A partnership between IDD and mental health allows for a proven effective evidence-based approach combining case management, community-based supports, and mental health therapy.
- A high level of coordination between IDD and mental health services greatly improves treatment outcomes and provider satisfaction. With any mental client, service needs to be individualized and clinical judgment used. This is true with an IDD client seeking mental health services as well.
- Remove IQ eligibility for services.
- There needs to be a resource within the mental health system to serve individuals on the autism spectrum. Most autism spectrum disorders have features of ADHD, OCD, anxiety, mood disorders, social impairments, or other mental health diagnoses. These children could benefit from appropriate day treatment programs for autism. Autism is a billable mental health diagnosis now for OHP.
- Appropriate mental health therapy often includes skills training whether the individual has a developmental disability or not.
- Some people with IDD need more time to complete various assessments or to engage with the service. Time accommodations may be needed for some people with IDD to receive mental health services.
- Mental health provides brief therapy instead of long-term relationship, which is critical for people with IDD. It is a problem generated by the policy and billing system of mental health. Stakeholders emphasized strong need for relationship and trust building for successful mental health services for people with IDD, but there are currently systemic barriers for that to occur.
- Standard approaches may not be accessible or working for people with IDD. Counseling is typically based on verbal communication and it can be challenging for someone with communication disorder. Accommodations must be made based on individual needs, trauma, etc.
- Technology can be both a resource and a barrier, especially during COVID. Many adults and middle-aged individuals don't know how to use computer or don't have a computer or other technology at home.
- Telehealth can be very helpful for many individuals in accessing services, including individuals with ASD, significant mobility or medical needs. However, this is not a tool that works universally. For many individuals with IDD use of technology or access to technology can be a barrier. During COVID, telehealth became "better than nothing" for many individuals.

- Flexibilities can be introduced and incentivized within the system to make mental services more accessible and optimally effective for people with IDD. These flexibilities need to be supported by policy and the rate and funding structures.
- Allow for services to occur in a space that is comfortable for the individual. Alternative space for counseling or therapy should be possible for individual to engage with treatment more productively.
- Some assistive technology and apps have been successful as teaching or service facilitation tools and need to be explored more.

Resources

- There is a lack of adequate funding, and adequate guardianship resources.
- There are very limited resources in rural communities.
- Particularly in the Juvenile Justice system, this gap between the time of discharge from detention and obtaining a mental health assessment to get services sets up children for potential failure.
- Provide appropriate project management resources when determining timelines. Prevent positions granted from being shifted to other priorities.

Workforce

- The mental health system faces a chronic shortage of providers, especially providers who are trained to serve older adults with mental health and substance use concerns. Additionally, due the limited nature of the OHA-Behavioral Health in-home program, there is a lack of personal care attendants, causing another “push” to the APD system that has a more robust provider network for both in-home and residential providers.
- Home care, personal service workers, peer delivered services, and respite needs to be paid at a sustainable living wage or actual cost. The workforce is not paid competitive salaries.
- Services require people. Unless you are ready to employ robots in the provision of mental health services, we can’t afford to lose strong candidates to other industry fields.
- There is a lack of a behavioral workforce in geriatric behavioral health.
- Training is needed for the workforce in both IDD and mental health: DMID 2, TTT, Summit, Developmental adaptations.

- While families in the IDD system have access to brokerage services, they are not always able to access them either because of the current issues surrounding workforce shortage.
- Provide a living wage for providers for stability, and conduct workforce retention effort.
- Support telehealth.

Appendix 2: Partner Feedback Related to Schools

Some partners expressed concerns and suggestions related to schools and the education system. Schools are not overseen by ODHS and OHA, though OHA does provide some in-school services. These agencies are not providing suggestions on school issues at this time, but still feel it is important to note the concerns and suggestions by partners:

- Grievances and appeals of §504 often are not acted upon by school districts. Then no remedial action happens, and IEP grievances and appeals take often more than one school year to resolve.
- FACT assists parents with FAPE related information and processing but has insufficient capacity to assist during the IEP meetings or discussions with the school personnel, parent and students. FACT has less expertise with dual diagnosis issues and behavioral health related issues than intellectual/developmental or physical disability problems.
- FACT staff and their website are very helpful but need more capacity.
- Parents don't know what programs and services are available, because since each school or school district may have different services (in-house, contracted or in partnership with other organizations).
- Testing is often done without observation in classroom or other settings, and therefore does not capture the behavioral difficulties.
- Schools tend to push out or reduce the school day when behavioral difficulties cannot be contained.
- Schools often do not allow behavioral health agencies' "skills trainers" and peer delivered services into the school or classroom.
- Behavioral health and I/DD-ODHS "skills trainers" often do not coordinate with schools so that the services are complementary.
- Students of color tend to receive fewer services. Their atypical behavior tends to be handled through disciplinary means rather than adding special tutoring or skills training.
- There is a general lack of understanding across the education system about how to address mental health when there is a cognitive disability.
- Some schools are very responsive to students with dual diagnoses need e.g., Parkrose School District. However, most schools did not have partnerships or contracts with community-based staff to handle behavioral health needs.