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Oregon Dual Diagnosis Research Project

Analyzing Experiences and Systems of Care: Mental and Behavioral Health Services for Individuals with I/DD in Oregon

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Executive Summary

The Oregon Dual Diagnosis Research Project resulted in a comprehensive analysis of the experiences and perspectives of individuals with intellectual and developmental disabilities (I/DD) and the stakeholders involved in or connected to their systems of support. The study examined their interactions with mental and behavioral health services in Oregon, highlighting key insights to inform system improvements. Funded by the Oregon Council on Developmental Disabilities (OCDD) in partnership with the National Association for the Dually Diagnosed (NADD), this study identified strengths and gaps in the current systems and offers recommendations to enhance service delivery and outcomes for individuals with dual diagnoses.

Key Findings

1. **Fragmentation and Integration Needs**: Oregon's mental health and I/DD systems, while in some areas robust, often operate in silos. Enhancing integration and communication between these systems presents a significant opportunity to improve care coordination and accessibility.

2. **Service Accessibility Challenges and Opportunities:** Individuals with I/DD face barriers such as long wait times, limited clinical provider availability, and group home staffing issues. Addressing these challenges will provide more equitable and efficient access to care.

3. **Workforce Development:** Providers across the I/DD and mental health sectors demonstrate a strong commitment to their work. They could benefit from targeted training in trauma-informed care, crisis management, diagnosis and assessment, adaptations to psychotherapy, and other treatment modalities specific to the needs of people with I/DD and co-occurring mental health conditions.

4. **Community and Family Dynamics:** Families and caregivers play a critical role in supporting individuals with I/DD experiencing mental health challenges and face significant stress from navigating complex systems. Expanding family support services, including respite care, and family peer-to-peer mentoring programs would be beneficial.

5. **Promising Practices with Room for Growth:** Established approaches such as Person-Centered Planning (PCP), Positive Behavior Support (PBS), Assertive Community Treatment (ACT), Trauma-Informed Care, and Supported Employment, effectively support independence and integration. Scaling these practices alongside innovative models like telehealth would amplify their benefits.

Recommendations

1. **Integrated Care Models:** Strengthen coordination between I/DD and mental health services to deliver seamless, person-centered care tailored to individuals' needs.

2. **Investing in Resources:** Increase funding and expand capacity for mental/behavioral health care in residential settings and rural supports, ensuring resources are equitably distributed and accessible.

3. **Workforce Empowerment:** Expand specialized training opportunities for professionals, enhancing their ability to address the complexities of supporting people with I/DD and co-occurring mental health conditions effectively.

4. **Data-Driven Improvements:** Utilize comprehensive data collection and analysis to evaluate service effectiveness, identify gaps, and guide resource allocation.

5. **Community-Centered Innovations:** Foster peer support networks, enhance family engagement, and promote individualized care plans to create inclusive environments where individuals can thrive.

Conclusion

Oregon's service systems for individuals with dual diagnoses (people with I/DD and co-occurring mental health conditions) hold significant potential for improvement. By addressing identified challenges and building on existing strengths, the state can deliver a more equitable, efficient, and supportive care environment. These strategic enhancements will ensure that individuals with I/DD and co-occurring mental health conditions achieve better outcomes and experience full inclusion in their communities.

Introduction

The Oregon Council on Developmental Disabilities (OCDD) partnered with the National Association for the Dually Diagnosed (NADD) to conduct a research study to investigate the experiences of individuals with intellectual and/or developmental disabilities (I/DD) accessing mental and behavioral health services in Oregon. This study aimed to inform recommendations for improving service access and delivery, focusing on both the Oregon Health Plan for mental health services and Oregon Developmental Disability Services for behavioral support services. The research explored current system strengths, barriers, and gaps, and identified promising practices for enhancing outcomes for individuals with I/DD and co-occurring mental or behavioral health challenges. This report details the study's methodology, findings, and resulting recommendations for system improvement.

Background and Literature Review

Individuals with intellectual disabilities are at an increased risk of co-occurring mental health disorders (Mazza et al., 2019). The term "dual diagnosis" specifically refers to the presence of both intellectual disability and mental health conditions (McLennan, 2018). Research indicates that young adults with intellectual/developmental disabilities often experience significant mental health disparities (Schwartz et al., 2020). Moreover, individuals with intellectual disabilities have a high prevalence of co-occurring mental health conditions, such as anxiety and depression (Schwartz & Hwang, 2022). The presence of intellectual disability can complicate the establishment of mental health diagnoses (Naveed, 2019).

Studies have shown that individuals with intellectual disabilities have a higher likelihood of having mental health disorders compared to the general population (Robertson, 2011). The co-occurrence of cognitive and behavioral impairments in individuals with intellectual disabilities can pose challenges for parents, teachers, and healthcare providers (McIntyre, 2008). Additionally, individuals with autism spectrum disorder and co-occurring intellectual disabilities face difficulties in accessing necessary support services (Karpur et al., 2021).

The intersection of intellectual disabilities and mental health disorders presents a complex challenge that requires specialized attention and support. Understanding the prevalence, impact, and unique needs of individuals with dual diagnoses is crucial for providing effective care and improving outcomes in this population.

Demographic analysis: Diagnoses, age, gender affected

To gain insights into intellectual and developmental disabilities (IDD) for individuals living in Oregon, it is essential to consider the existing literature on various aspects such as health disparities, community engagement, family support, and healthcare access. Individuals with I/DD make up approximately 2% of the population and frequently experience poorer health outcomes compared to the general population (Krahn et al., 2006). Collaborative research involving individuals with

I/DD, families, and stakeholders has been instrumental in identifying research priorities and fostering community participation (Lorito et al., 2017).

Studies have highlighted the challenges faced by parents of children with I/DD and the impact on child outcomes, emphasizing the need for targeted support services for these families (Llewellyn & Hindmarsh, 2015). Efforts to improve the quality of life and life expectancy of individuals with I/DD have shown positive trends over time, aligning with improvements seen in the general population (Coppus, 2013). However, nurses' attitudes and emotions toward caring for adults with I/DD have been identified as areas needing attention to ensure quality care and support (Desroches et al., 2021).

In Oregon, as in other regions, individuals with I/DD face barriers to accessing sexual health services, receiving adequate healthcare, and navigating healthcare systems (Frawley et al., 2022). Addressing these barriers and promoting health equity for individuals with I/DD require collaborative efforts involving healthcare providers, policymakers, and community organizations (McNeil, 2023). Additionally, supporting family caregivers of individuals with I/DD is crucial for ensuring the well-being and quality of life of both individuals with I/DD and their families (Williamson et al., 2016).

Understanding the challenges and needs of individuals with I/DD in Oregon involves considering a range of factors, including health disparities, community engagement, family support, and healthcare access. Collaborative efforts involving various stakeholders are essential for addressing these challenges and promoting the well-being of individuals with I/DD in the state.

Importance of service integration, crisis intervention, and specialized support services

The integration of services is essential to ensure individuals with dual diagnoses have access to quality treatment and support (Edward & Munro, 2009). Integrated services can bridge gaps in care, facilitate communication between service providers, and create personalized care plans that address the complex needs of individuals with dual diagnoses (Son et al., 2018; Edward & Munro, 2009).

The provision of crisis intervention and specialized support services is crucial for individuals with dual diagnoses. By implementing integrated treatment models, improving service coordination, and emphasizing early intervention, healthcare providers can better meet the complex needs of individuals with I/DD and co-occurring mental health conditions. Crisis services play a vital role in providing timely and comprehensive care to individuals experiencing acute mental health crises. Crisis intervention services are critical for preventing escalation to crisis points and promoting early intervention (Son et al., 2018). These services not only address immediate crises but also focus on prevention and early intervention to support individuals before they reach crisis points (Son et al., 2018).

Specialized crisis services have been developed to address the unique needs of individuals with dual diagnosis, emphasizing the importance of tailored care (Davis et al., 2008).

Review of Existing Policies and Service Systems

Legislation and policies relevant to dual diagnosis crisis intervention

Legislation and state policies are crucial in ensuring individuals with intellectual and developmental disabilities experiencing a mental health crisis receive appropriate support and care. Specific laws and regulations aim to safeguard the rights and well-being of this vulnerable population. In Canada, policies address emergency psychiatric services for individuals with intellectual disabilities to provide timely and effective care during crises (Lunsky et al., 2008). National surveys in Canada emphasize the importance of mental health services tailored to individuals with intellectual disabilities, highlighting the need for specialized support (Lunsky et al., 2007).

In Australia, legislation promotes inclusive policy development in mental health to better meet the needs of individuals with intellectual disabilities (Dew et al., 2018). The Rights of Persons with Disabilities Act in India supports improved programs and services for individuals with intellectual and developmental disabilities, aligning with international standards such as the UNCRPD (Mishra, 2024). Recent legislation in Italy provides specific supports for individuals with severe disabilities or autism spectrum disorder, focusing on addressing the unique needs of individuals with developmental disabilities (Bacherini, 2024).

Legislation in various countries also addresses the transition of adolescents and emerging adults with intellectual disabilities, ensuring they receive appropriate support in education, rehabilitation, and employment (Betz, 2023). Legislative advocacy programs empower parents of individuals with intellectual and developmental disabilities, stressing the importance of including their voices in disability legislation (Burke et al., 2021).

Overview of current service systems for individuals with dual diagnosis in Oregon and nationally

To provide an overview of current service systems for individuals with dual diagnoses in Oregon and nationally, it is essential to consider the existing literature on integrated treatment programs, barriers to care, and the need for specialized services. Research indicates that integrated treatment programs for individuals with dual diagnosis, particularly those involved with the criminal justice system, are considered specialty services (Hartwell et al., 2013).

Efforts to break down silos and enhance collaboration between current services for youth with dual diagnosis have been suggested, including the expansion of specialized intellectual disability/mental health services and capacity-building for service providers (Son et al., 2018).

Studies have shown that individuals with dual diagnosis often receive treatment in either mental health services or substance use treatment programs, underscoring the importance of comprehensive and integrated care (Prodromou & Koukia, 2016). Collaborative efforts and holistic, long-term social work support have been identified as crucial for successful linkage to services for individuals with dual diagnosis (Thomas et al., 2023). Families of individuals with dual diagnosis also require support and services to navigate the complexities of care (Nicholas et al., 2017).

The literature underscores the importance of integrated treatment programs, specialized crisis services, and collaborative approaches to address the needs of individuals with dual diagnosis. Efforts to enhance service coordination, improve access to care, and provide tailored support are essential for ensuring quality services for this vulnerable population.

Identification of stakeholders, partnerships, and collaborative relationships

Stakeholders, partnerships, and collaborative relationships within the intellectual and developmental disabilities community play a vital role in ensuring the well-being and inclusion of individuals with disabilities. Research has highlighted the importance of social inclusion for individuals with intellectual and developmental disabilities, emphasizing the involvement of various stakeholders such as families, service providers, policymakers, and the community (Simplican et al., 2015). Collaborative efforts involving individuals with disabilities, families, and other stakeholders have been instrumental in identifying research priorities and fostering community participation for individuals with intellectual and developmental disabilities (Bendixen et al., 2022).

Studies have emphasized the significance of self-determination and quality of life for individuals with intellectual and developmental disabilities, underscoring the need to promote self-determination to enhance their quality of life (Wehmeyer, 2020). Collaborative research initiatives involving individuals with intellectual disabilities have shown benefits for all stakeholders, provided there is adequate infrastructure to empower co-researchers (Lorito et al., 2017). Inclusive research teams have published guides and toolkits on engaging in collaborative partnerships with individuals with intellectual and developmental disabilities, emphasizing power-sharing and accessibility (Hughes & Martino, 2023).

Efforts to support individuals with intellectual and developmental disabilities extend to addressing health equity, mortality rates, and access to healthcare services. Research has highlighted the elevated health risks and systemic inequities experienced by individuals with intellectual and developmental disabilities, particularly during the COVID-19 pandemic (Johnston et al., 2022). Collaborative approaches involving multidisciplinary teams have been essential in managing mental health and behavioral issues in individuals with intellectual disabilities during challenging times (Rauf et al., 2021).

Collaborative relationships involving individuals with intellectual and developmental disabilities, families, service providers, policymakers, and the broader community are essential for promoting social inclusion, self-determination, and quality of life for individuals with disabilities. These partnerships are crucial for addressing barriers, advocating for equity, and enhancing the overall well-being of individuals with intellectual and developmental disabilities.

Implementation strategies, best practices, and barriers

To address the mental health crisis experienced by individuals with intellectual and developmental disabilities (IDD), it is crucial to implement effective strategies and best practices and overcome barriers. Research suggests that individuals with I/DD often face challenges in accessing mental health services due to multiple barriers (Lunsky et al., 2008). One strategy to enhance access is the integration of mental health treatment guidelines for prescribers, providing an interdisciplinary and culturally competent approach to care (Caoili et al., 2022). Additionally, involving peer providers in the behavioral health workforce has shown promise in improving mental health outcomes for individuals with I/DD (Gaiser et al., 2021).

Peer mentoring programs have been identified as beneficial for young adults with I/DD and co-occurring mental health conditions, offering support and coping strategies (Loeper & Schwartz, 2023). Furthermore, the utilization of mental health first aid tailored to individuals with I/DD can help address mental health crises effectively (Bond et al., 2021). It is essential to consider the perspectives of caregivers and hospital staff in emergency psychiatric services to ensure appropriate care during crises (Weiss et al., 2009; Eagleson et al., 2019).

Training pathways in intellectual and developmental disability psychiatry can enhance the clinical capacity of psychiatrists working with individuals with I/DD, improving mental health service delivery (Robertson, 2011). Moreover, the adaptation of mindfulness-based psychotherapeutic practices has shown effectiveness in managing anxiety, mood, stress, aggression, and self-injury in individuals with I/DD. Collaborative efforts involving stakeholders, policymakers, healthcare providers, and individuals with I/DD are essential to address the mental health crisis effectively.

Implementing integrated mental health treatment, peer mentoring programs, mental health first aid, and mindfulness-based practices can enhance mental health support for individuals with I/DD. Overcoming barriers through collaborative partnerships and specialized training can improve mental health outcomes and ensure individuals with I/DD receive the care they need when they need it.

Measurable outcomes of current policies and systems

To assess the measurable outcomes of current policies and systems for individuals with intellectual and developmental disabilities (IDD) facing a mental health crisis, it is crucial to review the existing literature on mental health interventions, service utilization, and policy implications. Studies have underscored the high prevalence of mental health issues in adults with I/DD and the associated factors, emphasizing the necessity for suitable interventions, public health strategies, and policy development (Cooper et al., 2007). Moreover, the positive impact of community-based employment on the health and well-being of individuals with I/DD has been acknowledged, with policies supporting this approach to enhance outcomes (Robertson et al., 2019).

Various tools for measuring mental health conditions and well-being in individuals with severe or profound intellectual disabilities have been identified, offering valuable insights into evaluating mental health outcomes in this population

(Flynn et al., 2017). However, interventions for mental health issues in children and adults with severe intellectual disabilities have not received adequate attention, highlighting the need for effective treatment options and policy backing (Vereenooghe et al., 2018). The importance of ensuring the right to information for individuals with intellectual disabilities in Australian mental health policy has been emphasized as a crucial step to addressing health outcome disparities and enhancing access to mental health services (Newman et al., 2021).

In India, the Rights of Persons with Disabilities Act has been enacted to bolster programs and services for individuals with intellectual and developmental disabilities, aligning with global standards (Mishra, 2024). Understanding the socio-emotional brain functions in individuals with intellectual disabilities can guide treatment and support strategies to promote good mental health in this vulnerable population (Sappok et al., 2022). The significance of thriving in mental health among individuals with intellectual and developmental disabilities during the COVID-19 pandemic highlights the need to address stressors and foster mental well-being (Sellitto, 2023).

Evaluating the measurable outcomes of current policies and systems for individuals with I/DD facing a mental health crisis necessitates a comprehensive understanding of mental health interventions, policy implications, and the impact of employment on health outcomes. Collaborative efforts involving stakeholders, policymakers, and healthcare providers are vital to mitigate disparities, enhance access to care, and improve mental health outcomes for individuals with I/DD.

Evidence-Based and Promising Practices

Preventative practices for crisis intervention

Preventative practices for crisis intervention in individuals with intellectual and developmental disabilities (IDD) are crucial to ensure their well-being and quality of life. Several studies offer insights into effective interventions and strategies to prevent crises and promote mental health in this population.

Aronow & Hahn (2005) discuss the feasibility of community-based preventive interventions for individuals aging with I/DD, indicating that such interventions are viable for randomized trials. This suggests that community-based preventive programs can be effective in preventing crises and promoting overall health in individuals with I/DD.

Patel et al. (2020) highlights the role of medical practitioners in providing ongoing preventive healthcare for individuals with I/DD. This highlights the critical need for regular preventive care and health monitoring to proactively address potential health issues and prevent crises.

Furthermore, Schwartz & Levin (2021) present a peer mentoring program for young adults with I/DD and co-occurring mental health conditions, focusing on coping strategies and mental health support. Peer mentoring interventions can be valuable in preventing crises by providing support and guidance to individuals with I/DD.

Implementing preventative practices such as community-based interventions, regular preventive healthcare, and peer mentoring programs can help prevent crises and promote mental health in individuals with I/DD. These strategies can contribute to improving outcomes and enhancing the overall well-being of individuals with intellectual and developmental disabilities.

Developmentally appropriate strategies for dual diagnosis populations

To develop appropriate strategies for individuals with dual diagnosis, it is essential to consider the complex needs of this population. A study by Drake & Wallach (2000) discusses different perspectives on dual diagnosis, including medical, moralistic, psychosocial risk, and phenomenological viewpoints. Understanding these perspectives can guide the development of comprehensive strategies that consider the multifaceted nature of dual diagnosis.

Another important reference is the work by Roncero et al. (2016), which explores professionals' perceptions of managing patients with dual disorders. This study highlights the significance of treatment adherence and its impact on prognostic implications, especially in dual-diagnosis populations. Strategies to enhance treatment adherence can be crucial in improving outcomes for individuals with dual diagnosis.

Additionally, Fuller & Sabatino (1998) discuss the diagnosis and treatment considerations for comorbid developmental disabilities. This reference emphasizes the importance of considering treatment plans and accessing appropriate services for individuals with dual diagnosis. Tailored interventions that address the unique needs of individuals with comorbid conditions are essential for effective care.

Developing appropriate strategies for individuals with dual diagnosis requires a comprehensive understanding of the complexities involved in treating both developmental disabilities and mental health conditions. By considering different perspectives, treatment adherence, and tailored interventions, healthcare providers can enhance the quality of care and outcomes for individuals with dual diagnosis.

Effectiveness of practices for specific demographic groups

Several effective practices for individuals with intellectual and developmental disabilities (IDD) within specific demographic groups have been identified:

- **Telehealth Interventions:** Jeste et al. (2020) suggest that telehealth interventions can provide sustainable access to educational and healthcare services for individuals with I/DD, especially during times of restrictions like the COVID-

19 pandemic. Implementing telehealth services can ensure continuity of care and support for individuals with I/DD, particularly those in rural areas and demographic groups facing challenges in accessing traditional healthcare services.

- **Tailored Interventions:** Koslowski et al. (2016) emphasize the importance of tailored interventions for individuals with mild to moderate intellectual disabilities and mental health conditions. Strategies that consider the severity of intellectual disabilities and provide appropriate treatment options can be effective in addressing mental health issues within specific demographic groups.

- **Lifestyle Change Interventions:** Willems et al. (2018) highlight the effectiveness of lifestyle change interventions for people with intellectual disabilities. Implementing lifestyle change programs tailored to specific demographic groups can promote health and well-being among individuals with I/DD.

- **Person-Centered Care:** Doody & Keenan (2021) stress the importance of a rights-based, person-centered approach to care for individuals with intellectual disabilities. By focusing on individual needs and preferences, healthcare providers can deliver more effective and personalized care to individuals within specific demographic groups.

- **Family Support and Future Planning:** Brennan et al. (2020) discuss the outcomes of future planning for family carers of adults with I/DD. Providing support and resources for family caregivers within specific demographic groups can enhance the overall well-being and quality of life of individuals with I/DD.

Implementing telehealth interventions, tailored strategies, lifestyle change programs, person-centered care, and family support can be effective practices for individuals with I/DD within specific demographic groups. These approaches can address the unique needs and challenges faced by individuals with intellectual and developmental disabilities, ultimately improving their outcomes and quality of life.

Analysis of practices related to specific diagnoses

Analyzing practices related to specific diagnoses of individuals with intellectual and developmental disabilities (IDD) involves understanding the unique challenges and needs associated with different conditions. Here are some studies that provide insights into effective practices for specific diagnoses within the I/DD population:

- **Comprehensive Evaluation:** Moeschler et al. (2014) emphasize the significance of accurate etiologic diagnosis and expert clinical evaluation in enhancing outcomes for children with intellectual disabilities. This source offers valuable insights into the comprehensive evaluation of specific diagnoses within the I/DD population.

- **Trauma-Specific Treatment:** Keesler et al. (2020) focus on trauma-specific treatment for individuals with I/DD, highlighting the increased risk of adverse experiences and posttraumatic stress disorder in this population.

Understanding trauma-specific interventions can be beneficial for addressing specific diagnoses related to trauma in individuals with I/DD.

- **Genetic Developmental Disability:** Langenfeld et al. (2021) present a case report on genetic developmental disability diagnosed in adulthood, offering insights into specific genetic conditions that may lead to intellectual and developmental disabilities. Understanding genetic diagnoses can guide tailored interventions and support for individuals with I/DD.

- **Reproductive and Pregnancy Health Care:** Ransohoff et al. (2022) explore reproductive and pregnancy health care for women with intellectual and developmental disabilities, focusing on health care equity and outcomes. This reference provides valuable information on specific diagnoses related to reproductive health within the I/DD population.

- **Risk of Re-Institutionalization:** Ouellette-Kuntz et al. (2017) examine the risk of re-institutionalization among adults with intellectual and developmental disabilities over time, highlighting factors leading to admission to long-term care facilities. Understanding specific diagnoses associated with re-institutionalization can inform preventive strategies and community living support.

By analyzing these strategies, practitioners and researchers can gain valuable insights into effective practices for specific diagnoses within the I/DD population, leading to improved care, support, and outcomes for individuals with intellectual and developmental disabilities.

Stakeholder Perspectives

Experiences and needs as reported by individuals with dual diagnosis and their families

Before, during, and after a mental health crisis event, individuals with intellectual and developmental disabilities (IDD) and their families have specific needs that should be addressed to ensure their well-being and effective support. The following studies provide insights into these needs:

- **Preventive Mental Health Services:** Srasuebkul et al. (2021) discuss the importance of preventive mental health services for individuals with intellectual disabilities to address mental health issues before they escalate into crises.

- **Accessible and Person-Centered Services:** Donner et al. (2010) emphasize the necessity of accessible and person-centered mental health services tailored to meet the specific needs of individuals with I/DD before, during, and after a mental health crisis event.

- **Recognition of Mental Health Issues:** Sutton & Kupara (2022) underscore the significance of recognizing and addressing mental health issues in individuals with I/DD before, during, and after a crisis.

- **Support and Communication:** Bond et al. (2021) highlight the importance of providing appropriate support, communication, and respect to individuals with intellectual disabilities during a mental health crisis event.

- **Emotional Impact and Support:** Ross & Dodds (2022) shed light on the emotional impact of supporting individuals with I/DD in crisis situations and the need for caregiver support and mental health services.

By addressing these needs with preventive services, accessible and person-centered care, early identification of mental health concerns, effective communication, and emotional support for individuals and their families, the well-being and outcomes of individuals with intellectual and developmental disabilities can be greatly improved at every stage: before, during, and after a mental health crisis.

Insights from service providers on challenges and resource needs

Based on previous research, service providers identify several challenges and resource needs for individuals with intellectual and developmental disabilities (IDD) experiencing a mental health challenge:

- **Access to Resources:** Amor et al. (2021) highlight the importance of ensuring that individuals with I/DD have access to resources, including information and health services, to promote their rights to health and well-being during a crisis.

- **Proactive Supports:** Cooper et al. (2007) emphasize the need for proactive supports and interventions for individuals with profound intellectual disabilities who are more susceptible to mental ill-health, underscoring the importance of early intervention and support.

- **Person-Centered Services:** Donner et al. (2010) stress the significance of accessible and person-centered mental health services for individuals with I/DD to recognize and address mental health problems effectively before, during, and after a crisis event.

- **Support for Family Carers:** James (2013) discusses the experiences of family carers of individuals with I/DD who also have challenging behavior and mental health issues, highlighting the need for support services to address the challenges faced by caregivers.

- **Staff Competence and Communication:** Kroese et al. (2012) emphasize the importance of staff competence, communication skills, and understanding the unique needs of individuals with I/DD and mental health problems to provide effective support during a crisis.

- **Emergency Department Visits:** Weiss et al. (2009) discuss the strains on the mental health system and the challenges faced by individuals with I/DD in accessing appropriate services, often leading to emergency department visits during a mental health crisis.

- **Quality of Mental Health Services:** Whittle et al. (2018) highlight the barriers preventing individuals with intellectual disabilities from accessing appropriate mental health services, underscoring the need for improved service accessibility and quality.

Service providers identify challenges and resource needs for individuals with I/DD experiencing a mental health crisis, including access to resources, proactive supports, person-centered services, support for family carers, staff competence, communication, and the quality of mental health services. Addressing these needs can enhance the well-being and outcomes of individuals with intellectual and developmental disabilities during a mental health crisis.

Education, training, and awareness among service providers

Some of the existing education, training, and awareness initiatives among service providers for persons with intellectual and developmental disabilities include:

- **Trauma-Informed Care Training:** Rich et al. (2020) discuss the importance of trauma-informed care in intellectual and developmental disability services, highlighting the perceptions of service providers in promoting healing and preventing re-traumatization.

- **Training Needs for Healthcare Professionals:** Hemm et al. (2014) identify the training needs for mainstream healthcare professionals to prepare them for working with individuals with intellectual disabilities, emphasizing the importance of providing accessible and competent healthcare services.

- **Sexuality Education Training:** Schmidt et al. (2020) explore recommendations to improve the accessibility of sexuality education for individuals with intellectual and developmental disabilities, emphasizing the need for continued education and focus on sexuality education.

- **Empowerment Training:** Flatt-Fultz & Phillips (2012) discuss empowerment training for direct support professionals, focusing on improving attitudes and practices in supporting individuals with intellectual disabilities.

- **Parent Training Programs:** Machalicek et al. (2015) highlight trends, issues, and future directions in training parents of children with intellectual disabilities, emphasizing the importance of providing support, education, and resources to address the needs of children with significant disabilities.

These initiatives aim to enhance the knowledge, skills, and awareness of service providers working with individuals with intellectual and developmental disabilities, ultimately improving the quality of care and support provided to this population.

Expertise, specialization, and the importance of multidisciplinary collaboration

Expertise, specialization, and multidisciplinary collaboration are essential for the successful treatment of individuals with intellectual and developmental disabilities (IDD). Here are some key points:

- **Shared Expertise:** Adam et al. (2020) stress the significance of a multidisciplinary approach that facilitates shared expertise among intellectual disability specialists, palliative care providers, hospital services, community teams, and general practitioners. This collaborative strategy ensures that individuals with I/DD receive comprehensive and holistic care tailored to their unique needs.

- **Integrated Models of Care:** Melville et al. (2007) underscore the importance of integrated models of care that utilize multidisciplinary and partnership working to offer accessible and relevant services for individuals with intellectual disabilities. This approach guarantees that individuals with I/DD receive coordinated care addressing their physical, mental, and social well-being.

- **Collaborative Teams:** Rauf et al. (2021) discuss the role of multidisciplinary teams in managing mental health and behavioral challenges in individuals with intellectual disabilities and autism spectrum disorder, particularly during the COVID-19 pandemic. Collaborative efforts among various professionals are crucial for addressing complex needs and ensuring effective treatment outcomes.

- **Person-Centered Planning**: Shooshtari (2021) advocates for multidisciplinary assessment involving caregivers and the documentation of preferences and wishes as vital components of person-centered planning for individuals with intellectual and developmental disabilities. This approach guarantees that care plans are individualized to meet the person’s specific needs and preferences.

Case Studies and Promising Approaches

Description of case studies illustrating successful interventions

Here are some case studies that illustrate successful interventions for individuals with intellectual and developmental disabilities experiencing a mental health challenge:

- **Case Study on Trauma-Informed Care:** Williams (2016) presents a case study on integrating early childhood mental health and trauma-informed care for homeless families with young children, demonstrating successful application of the "Incredible Years" intervention in a homeless shelter setting.

- **Case Study on Cognitive Behavioral Therapy (CBT):** Taylor et al. (2008) discuss the emerging evidence and effectiveness of CBT for individuals with intellectual disabilities, showcasing promising results in the treatment of mental health problems in this population.

- **Case Study on Dialectical Behavior Therapy (DBT):** Jones et al. (2021) present a case study on the adaptation and feasibility of dialectical behavior therapy for adults with intellectual developmental disabilities and transdiagnoses, demonstrating the potential effectiveness of DBT in this population.

- **Case Study on Mental Health Needs**: Sutton & Kupara (2022) provide a case study on meeting the mental health needs of a young person with an intellectual disability, highlighting the increased risk of mental health issues in individuals with intellectual disabilities and the importance of tailored interventions.

- **Case Study on Narrative Exposure Therapy:** Mayer et al. (2023) discuss a case study on trauma treatment using Narrative Exposure Therapy adapted to individuals with intellectual disabilities or severe chronic mental disorders, demonstrating the effectiveness of this intervention in addressing trauma-related issues.

These case studies showcase successful interventions and treatment approaches for individuals with intellectual and developmental disabilities experiencing mental health challenges, highlighting the importance of tailored and evidence-based strategies in promoting mental well-being and recovery in this population.

Promising practices in crisis management from other states

Here are some evidence-based practices for individuals with intellectual and developmental disabilities experiencing a mental health condition in the United States:

- **Integration of Mindfulness Intervention:** Hwang & Kearney (2013) conducted a systematic review that demonstrated the effectiveness of mindfulness interventions in reducing behavioral and psychological problems in individuals with developmental disabilities.

- **Improving Community Mental Health Services:** Maddox et al. (2019) used qualitative methods to identify ways to enhance community mental health services for autistic adults with co-occurring psychiatric conditions.

- **Enhancing Mental Health Services Accessibility:** Pouls et al. (2023) discussed the importance of improved mental healthcare services for adults with mild intellectual disabilities and highlighted the significance of interprofessional collaboration in enhancing mental health outcomes in this population.

- **Virtual Education Programs:** Thakur et al. (2021) presented a virtual education program designed to support providers caring for individuals with intellectual and developmental disabilities during the COVID-19 pandemic, showcasing the effectiveness of innovative approaches to deliver mental health support remotely.

- **Peer Mentoring Interventions:** Schwartz & Levin (2021) explored the feasibility of a peer mentoring program for young adults with intellectual and developmental disabilities and co-occurring mental health conditions, emphasizing the potential benefits of peer support in addressing mental health challenges.

These evidence-based practices underscore the importance of tailored and collaborative strategies in improving mental health outcomes for individuals with intellectual and developmental disabilities affected by mental health conditions in the United States.

Areas identified for resource development and capacity building

Based on the provided references, here are some areas identified for resource development and capacity building for individuals with intellectual and developmental disabilities experiencing mental health conditions:

- **Peer Mentoring Programs:** Schwartz & Levin (2021) discuss the feasibility and effectiveness of peer mentoring programs for young adults with intellectual and developmental disabilities and co-occurring mental health conditions, emphasizing the potential benefits of peer support in managing mental health challenges.

- **Subspecialty Training in Psychiatry:** Eagleson et al. (2019) explore the current status and future opportunities for subspecialty training pathways in intellectual and developmental disability psychiatry in Australia and New Zealand, highlighting the need for specialized training to address the mental health needs of individuals with intellectual and developmental disabilities.

- **Supporting Young Adults with I/DD:** Schwartz & Hwang (2022) evaluate the fidelity and resources required to support young adults with intellectual and developmental disabilities in delivering a peer mentoring intervention, underscoring the importance of resources and support for successful implementation.

- **Hospital Utilization and Health Care:** Balogh et al. (2005) examine hospital utilization among individuals with intellectual disabilities in Ontario, Canada, emphasizing the need for improved health care services and support for this population.

- **Health and Social Policies:** Wilson et al. (2018) discuss health and social policies for Australian men and boys with intellectual and developmental disabilities, stressing the importance of addressing health disparities and promoting well-being in this specific population.

These examples provide valuable insights into areas for resource development and capacity building to support individuals with intellectual and developmental disabilities experiencing mental health conditions, highlighting the need for specialized training, peer support programs, improved health care services, and targeted policies to address the unique needs of this population.

Gaps in Knowledge and Practice

Analysis of unmet needs and system failures

Areas where current policies, programs, and supports fail to meet the needs of individuals with intellectual and developmental disabilities experiencing co-occurring mental health conditions include:

- **Access to Services:** Vohra et al. (2013) highlight challenges in accessing services, quality of care, and the impact on families for children with autism, other developmental disabilities, and mental health conditions, indicating gaps in service provision and support.

- **Health Services Accessibility:** Hughes-Mccormack et al. (2017) point out difficulties faced by individuals with intellectual disabilities in accessing mainstream services, indicating a lack of accessibility and tailored support for this population.

- **Inappropriate Care:** Lin et al. (2012) discuss the inappropriate care received by individuals with intellectual and developmental disabilities, highlighting the need for more suitable and effective treatment approaches to address their mental health needs.

- **Lack of Recognition:** Dew et al. (2018) emphasize the poor recognition of mental health issues in individuals with intellectual disabilities in Australian mental health policy, indicating a lack of awareness and support for this vulnerable population.

- **Barriers to Healthcare:** Perera et al. (2019) discuss the challenges faced by individuals with intellectual disabilities in accessing appropriate healthcare, indicating barriers to receiving preventive care and necessary treatments for physical and mental health conditions.

These studies highlight the gaps and opportunities to improve current policies, programs, and supports for individuals with intellectual and developmental disabilities experiencing mental health conditions, underscoring the need for improved access to services, quality of care, recognition of mental health issues, and tailored support to meet the unique needs of this population.

Barriers to effective crisis intervention and support services

Some of the barriers experienced by persons with intellectual and developmental disabilities (IDD) and their families when seeking effective crisis management and support services in the United States include:

- **Limited Access to Services:** Individuals with I/DD and their families may face challenges in accessing appropriate crisis management and support services due to limited availability, long wait times, and inadequate resources in the mental health system.

- **Lack of Specialized Care:** The lack of specialized care and trained professionals in addressing the unique needs of individuals with I/DD during a mental health crisis can hinder effective intervention and support.

- **Communication Barriers:** Communication barriers between individuals with I/DD, their families, and service providers may impede the delivery of timely and appropriate crisis management services, leading to misunderstandings and ineffective support.

- **Stigma and Discrimination:** Stigma and discrimination against individuals with I/DD and mental health conditions can create barriers to accessing quality crisis management services and may contribute to inadequate support and treatment.

- **Fragmented Services:** Fragmented and disjointed services within the mental health system can result in gaps in care, lack of coordination, and challenges in navigating the complex healthcare landscape for individuals with I/DD and their families.

- **Limited Awareness and Education:** Limited awareness and education among service providers and the general public about the specific needs and challenges faced by individuals with I/DD during a mental health crisis can lead to inadequate support and inappropriate interventions.

Addressing these barriers requires a comprehensive approach that includes improving access to specialized care, enhancing communication and collaboration among stakeholders, reducing stigma, promoting awareness and education, and ensuring coordinated and integrated crisis management services for individuals with I/DD and their families in the United States.

Recommendations for policy improvements and service system enhancements

Here are some evidence-based recommendations for policy improvements and service system enhancements that can enhance the lives of individuals with intellectual and developmental disabilities and their families:

- **Acknowledging the Role of Family Caregivers:** Williamson et al. (2018) emphasize the importance of recognizing the role of family caregivers in Medicaid Managed Long-Term Services and Supports (MLTSS) to enhance the quality of care and support for individuals with I/DD.

- **Emphasis on Accessible and Person-Centered Services:** Donner et al. (2010) emphasize the importance of accessible, person-centered mental health services in effectively addressing the mental health needs of individuals with intellectual disabilities.

- **Inclusive Policy Development:** Dew et al. (2018) advocate for inclusive policy development involving key stakeholders, including individuals with intellectual disabilities and mental illness, their families, and caregivers, to ensure comprehensive and effective policy implementation.

- **Comprehensive Education and Support:** Belluzzo (2024) stresses the importance of comprehensive education and support for individuals with severe mental illness, intellectual disability, and Down syndrome to improve overall well-being.

- **Inclusion of Siblings in Family Support Policies:** Lee et al. (2020) recommend explicitly including siblings in family support policies to address the needs of individuals with I/DD and promote family involvement in care planning.

- **Enhanced Services and Experiences:** Hewitt et al. (2013) discuss the need for policy improvements and service enhancements to provide better support and experiences for families of individuals with intellectual and developmental disabilities.

By implementing these evidence-based recommendations, policymakers and service providers can enhance the quality of care, support, and services for individuals with intellectual and developmental disabilities, ultimately improving their overall well-being and quality of life.

In conclusion, current research highlights the opportunity to enhance mental health services for individuals with intellectual and developmental disabilities by addressing existing disparities and barriers. Studies emphasize the importance of bridging critical gaps in service provision, care quality, and policy support for this community. Key areas for improvement include expanding service access, providing specialized care, improving communication, reducing stigma, and fostering seamless coordination among services. By adopting a comprehensive strategy, we can ensure greater access to person-centered and specialized care, promote understanding, and encourage inclusive policies. Evidence-based recommendations, such as supporting family caregivers, ensuring accessible and tailored services, engaging siblings in support frameworks, and fostering inclusive policy development, provide a clear pathway to improving mental health outcomes and overall well-being for individuals with I/DD. By embracing these priorities, service providers and policymakers can create a more equitable and responsive healthcare system, significantly enhancing the quality of care and support for individuals with I/DD and their families.

Research Design and Methodology

This study employed a mixed methods design to investigate the experiences and needs of individuals with an I/DD accessing mental and behavioral health services in Oregon. This approach was chosen to provide a comprehensive understanding of the current service landscape by integrating both quantitative and qualitative data. The research design included a thorough review of relevant policies and literature, an examination of evidence-based practices, and data collection from key stakeholders through surveys, interviews, and focus groups. This multifaceted approach allowed for a robust exploration of the challenges and opportunities within the system, ultimately informing recommendations for improved service delivery and outcomes for individuals with I/DD and co-occurring mental or behavioral health conditions.

The research design incorporated several key components:

1. **Literature Review:** A comprehensive review of existing literature and policies at both the state and national levels was conducted. This review sought to identify relevant legislation, existing service systems and stakeholders, demographics of individuals impacted, effective implementation strategies and barriers, current practices, and lessons learned from both state and national perspectives. The literature review aimed to provide a foundational understanding of the current landscape of I/DD and mental/behavioral health services.

2. **Evidence-Based Practices Review:** A separate literature review focused specifically on evidence-based and promising practices for individuals with I/DD and co-occurring mental health disorders. This review examined preventative practices, developmentally appropriate practices, and effective practices for specific groups and diagnoses. This component aimed to identify best practices that could inform recommendations for improving service delivery in Oregon.

3. **Data Collection:** Using purposive sampling, data was collected from key stakeholders, including individuals with I/DD, family members, mental health professionals, I/DD professionals, healthcare providers, and service providers. Surveys were deployed to gather broad perspectives, while targeted interviews and focus groups provided in-depth insights into the experiences and needs of individuals accessing and providing services. This data collection focused on understanding service utilization, needs, experiences, and recommendations from diverse perspectives.

4. **Data Analysis:** Collected data was analyzed using several methods: **Research Synthesis:** Findings from multiple data sources, including the literature and policy reviews, were synthesized to generate generalizable knowledge and new insights. **Quantitative Analysis:** Survey data underwent quantitative analysis to evaluate existing policies, services, and outcomes. **Qualitative Analysis:** Interview and focus group data were analyzed using thematic content analysis and narrative analysis to identify common themes, patterns, and individual perspectives.

Recruitment, Selection, and Participation Logic

Using purposive sampling, the Research Team developed and deployed a survey, conducted targeted interviews, and hosted focus groups with relevant stakeholders, including people with I/DD and their families, mental health professionals, I/DD professionals, health care providers, and service providers to learn more about their experiences of looking for and using mental and behavioral health services and supports in their community. These activities focus on:

- *What persons with I/DD and their families have to tell us about their service and support utilization and needs*

- *What service providers have to tell us about their experiences and needs*

- *What systems representatives have to tell us about their experiences and recommendations*

These data collection pathways intended to evaluate the information discovered from the literature review, surveys, interviews, and focus groups related to the following:

- Education, training, and awareness
- Expertise and specialization
- Multidisciplinary collaboration
- Care coordination between medical and clinical providers
- Resources (and knowledge of them, funding, insurance payment)
- Family support and person-centered practices
- Behavioral and mental health crisis prevention services
- Community-based diversion services

Participants were required to meet specific inclusion criteria to be eligible to participate in the study:

- Must be 18 years or older;
- Must live in and/or work in Oregon;
- Must be able to speak, read, and understand English or Spanish; and
- Must be a parent, self-advocate, provider, clinician, government employee, community organization representative, or school personnel who cares for or works directly with someone with an I/DD and co-occurring mental health condition.

Summary of Findings

Demographics

The following data provides a demographic overview of the individuals who participated in this research on support and services for persons with an I/DD living in Oregon. This information will help contextualize the findings and provide insights into the characteristics of the individuals whose experiences and perspectives informed this study. By examining these demographic factors, we can better understand the generalizability of the research and identify potential disparities in access to and utilization of I/DD supports and services.

Respondent Profiles

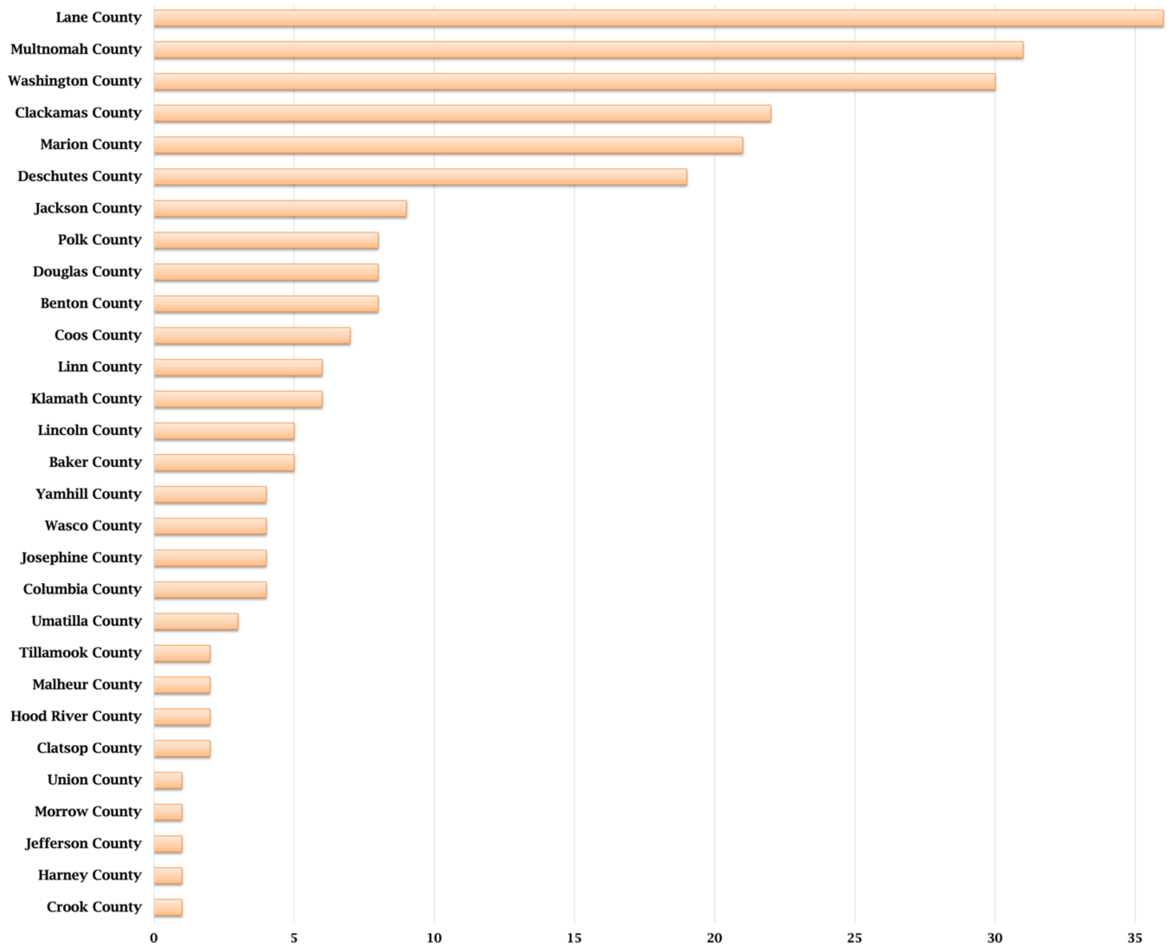
Insights and lived experiences were collected from 376 respondents for this study. Of these, 11 were interviewed virtually, 55 participated in an in-person listening session/focus group, and 310 completed the online survey. The following figures provide further details about the participants by various key categories identified.

Most participants (49.8%) identified as a family member or caregiver, with the remaining population disclosing that they were an Oregon governmental agency employee (18.2%), a self-advocate (17.4%), a medical provider (6.7%), and a clinical practitioner (6.3%). The remaining affiliations, which account for less than 1.6% of the participants, include teachers/school staff, group home providers, or brokerage representatives. More than 65% of participants identified as female.

Figure 1 shows the breakdown of participants by county, with nearly 63% of the total population residing or providing services in Deschutes, Marion, Clackamas, Washington, Multnomah, and Lane Counties.

Figure 1

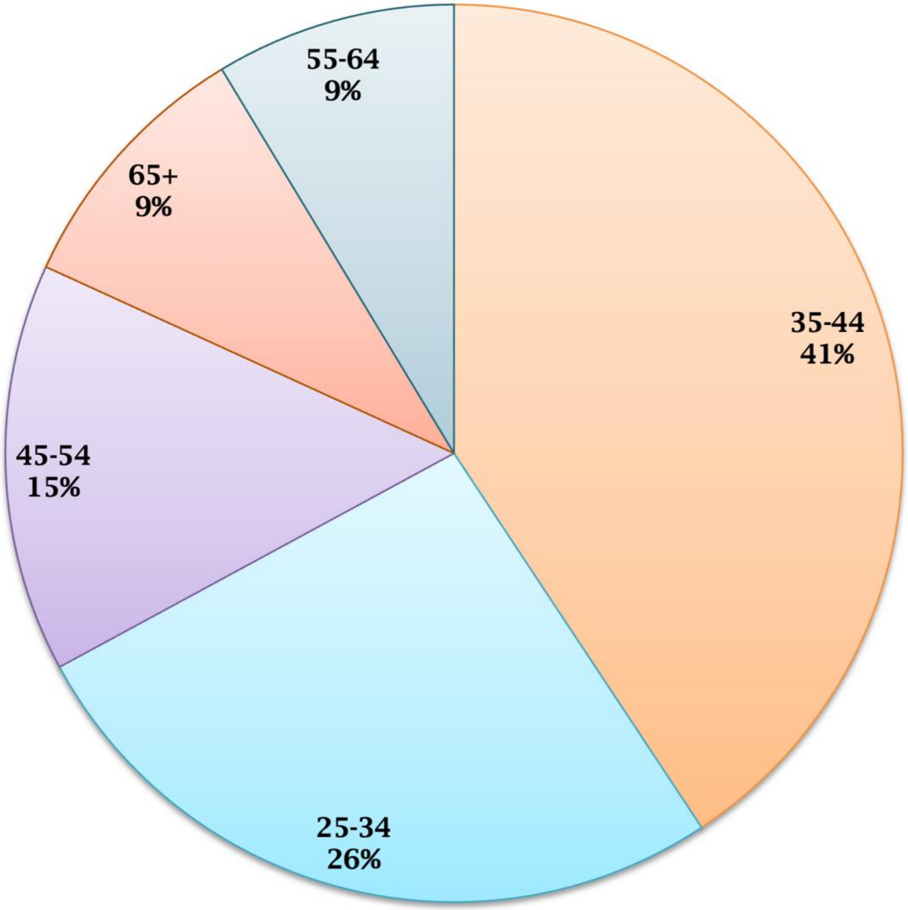
Geographic Representation by County



As shown in **Figure 2**, most (67%) of participants were aged 25-44**.**

Figure 2

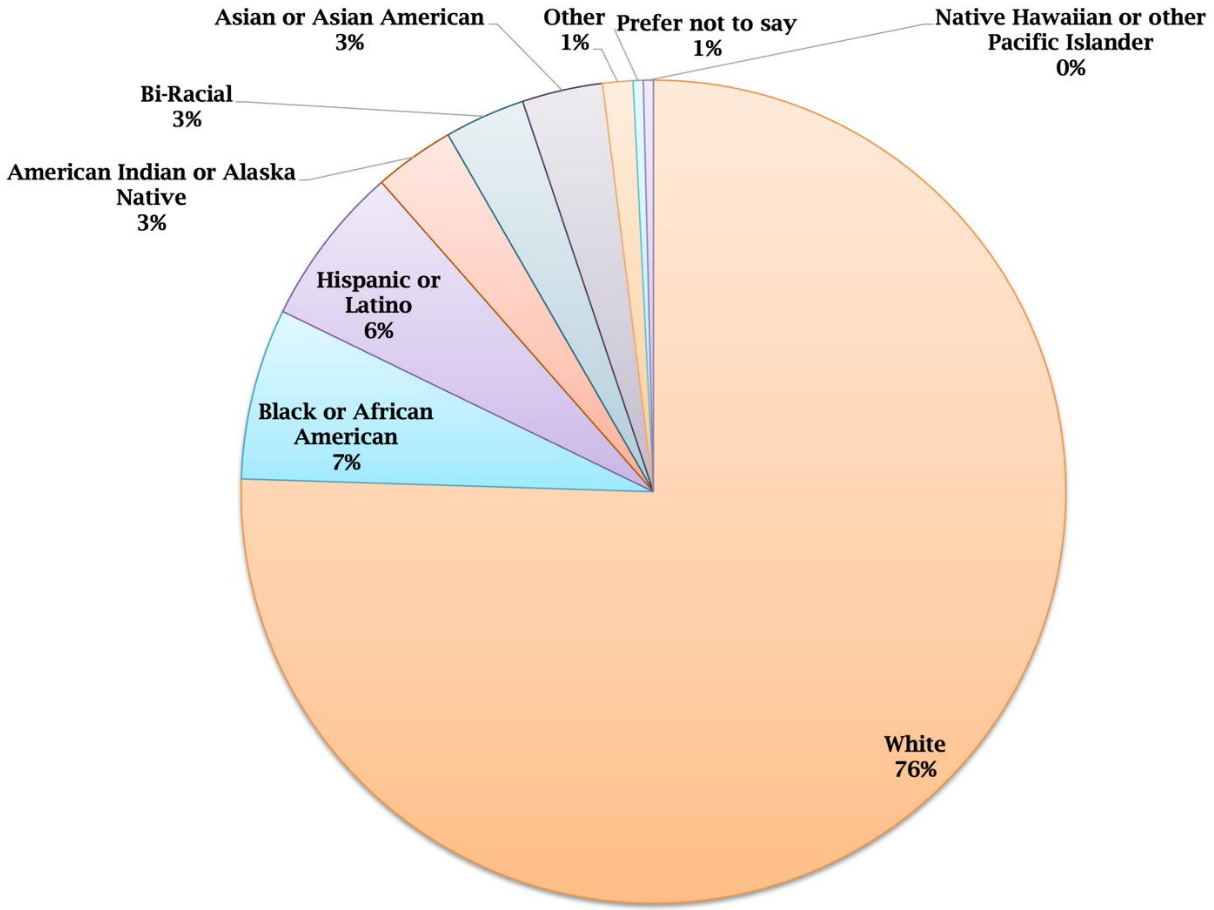
Age Range of Respondents



Although most respondents were Caucasian, there was significant representation from non-white populations across all three data collection methods, as shown in **Figure 3.**

Figure 3

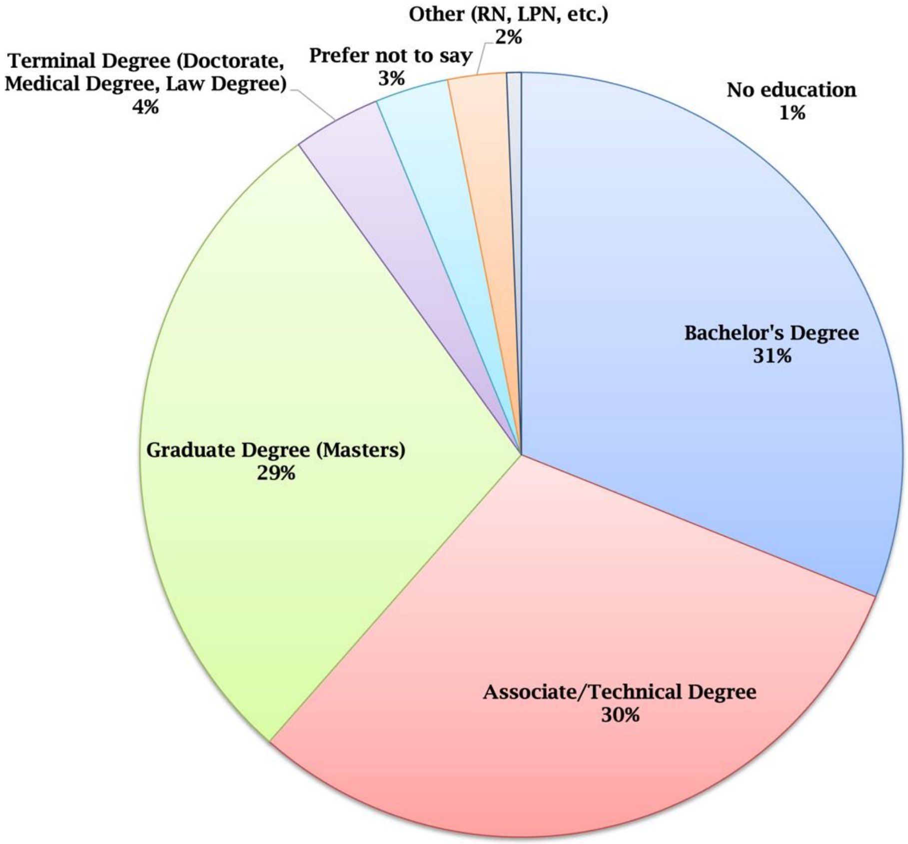
Ethnicity of Respondents



The lived experiences of participants didn't appear to be impacted by their educational level, which alludes to the fact that the process of finding, sharing, utilizing, and deploying services was similar across all educational levels. However, it is interesting to note that most respondents had at least one (1) degree beyond a high school diploma, as shown in **Figure 4**.

Figure 4

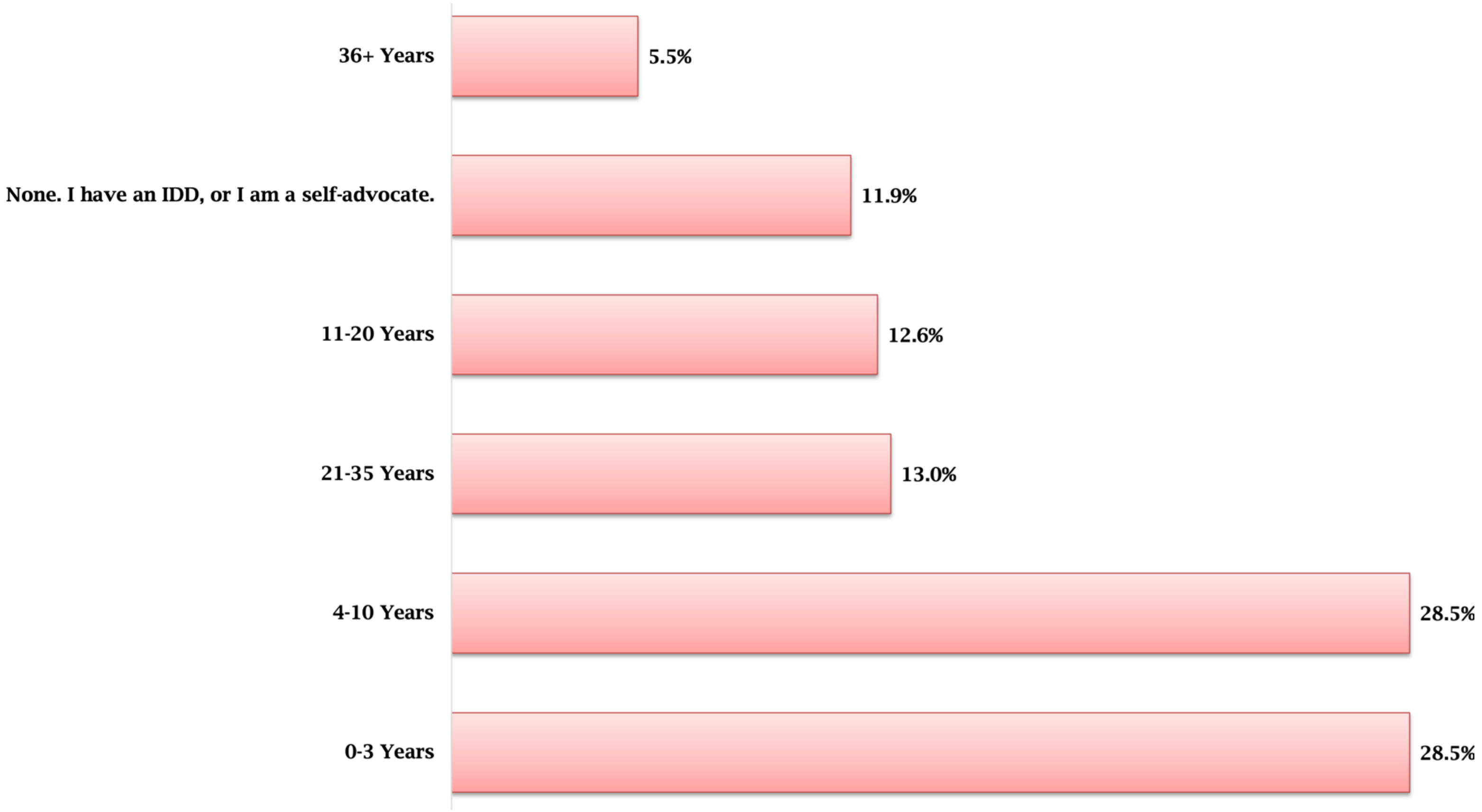
Education Level of Respondents



As shown in **Figure 5**, most participants have been working in, providing services for, caring for, or have been diagnosed with an I/DD and using behavior or mental health services for less than 10 years.

Figure 5

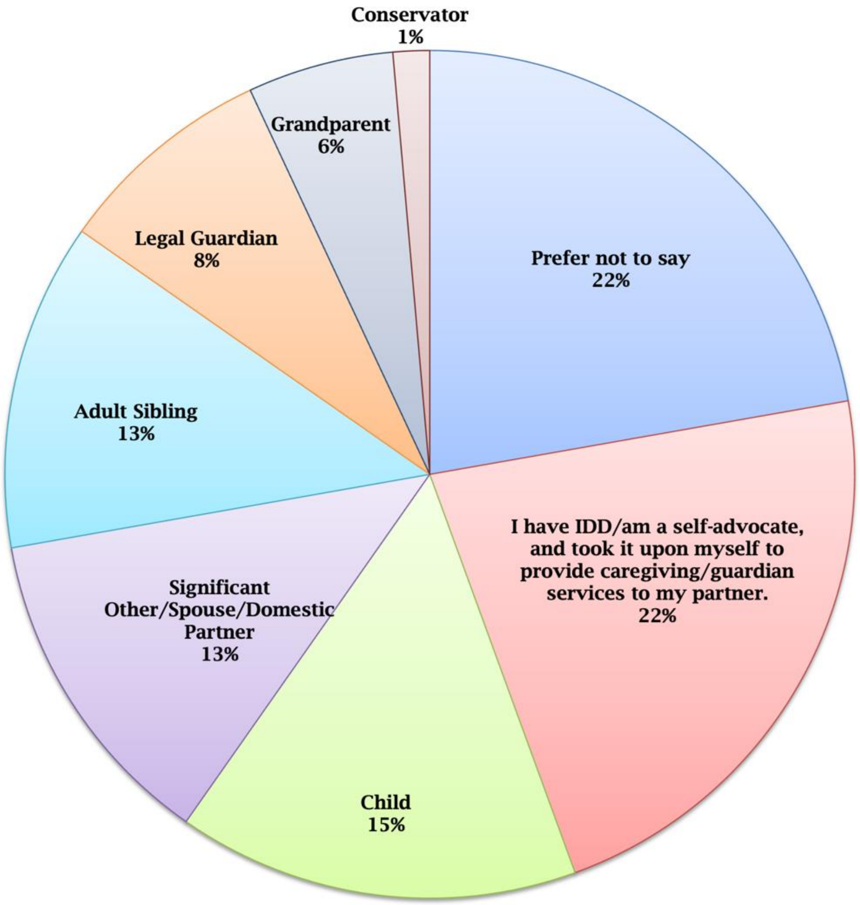
Respondent Years Working in or Using Services Within I/DD, BH, or MH Industries



Of the family members and caregivers who participated in this study, there was widespread representation across non-parental caregivers. **Figure 6** provides a detailed breakout of these roles.

Figure 6

Relation of Family Member Respondent to Person(s) with I/DD



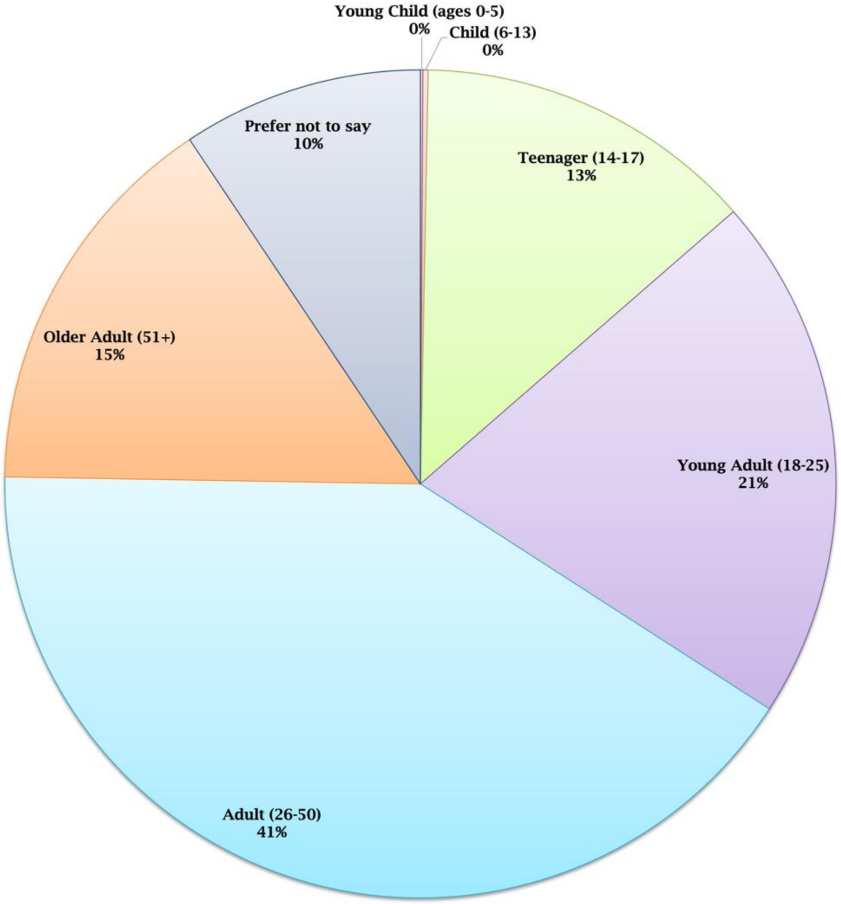
Persons with I/DD Profiles

Understanding the demographics of persons with intellectual and developmental disabilities is essential for informing policy, planning services, and ensuring equitable access to supports. The following data provides a demographic overview of individuals with I/DD in Oregon, offering insights into the characteristics and needs of this population. This information will be valuable for contextualizing the subsequent discussion of evidence-based promising practices for support and services, as outlined in this document. By examining these demographic factors, we can better tailor interventions and supports to meet the diverse needs of individuals with I/DD in Oregon and promote their full inclusion and participation in community life.

Most (51%) of participants noted that they cared for or provided services for adults aged 18-50, as **Figure *7*** depicts. However, many behavioral and mental health providers who participated in the study shared that they often provided services across all age groups due to workforce limitations or resource availability.

Figure 7

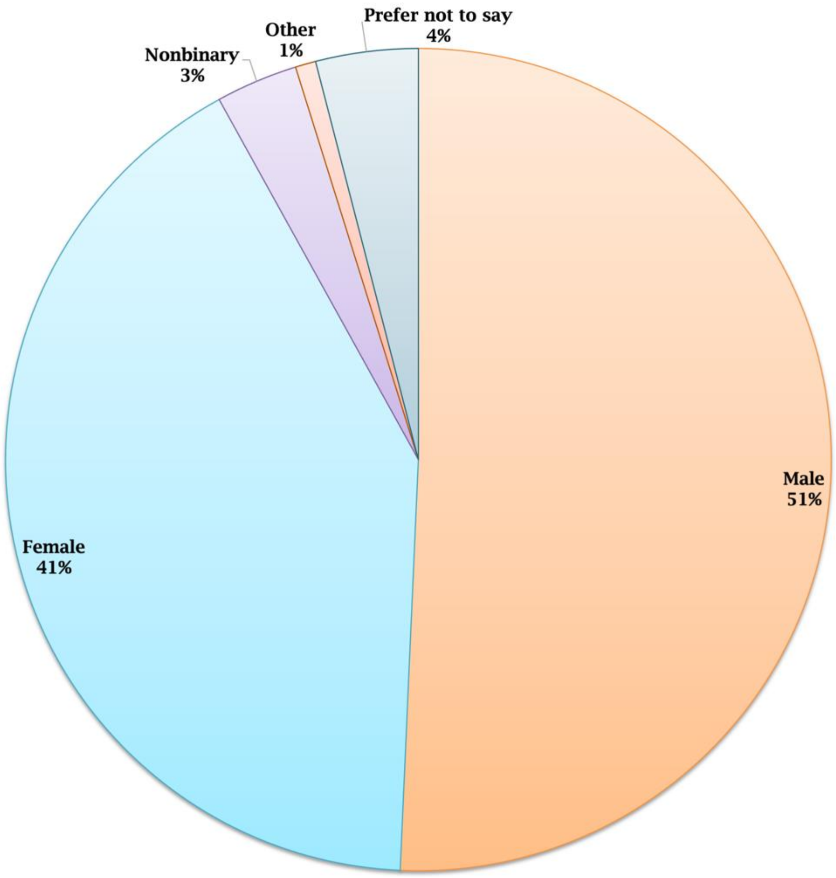
Age Range of Person(s) with I/DD



The representation of individuals diagnosed with an I/DD (**Figure 8**) aligned with studies conducted elsewhere, though the balance of male versus female within this project was much closer than previous research has shown.

Figure 8

Gender of Person(s) with I/DD



Like the participant ethnicity, most of the respondents noted that the person(s) they cared for were Caucasian (as noted in **Figure 9**, below).

Figure 9

Ethnicity of the Person(s) with I/DD

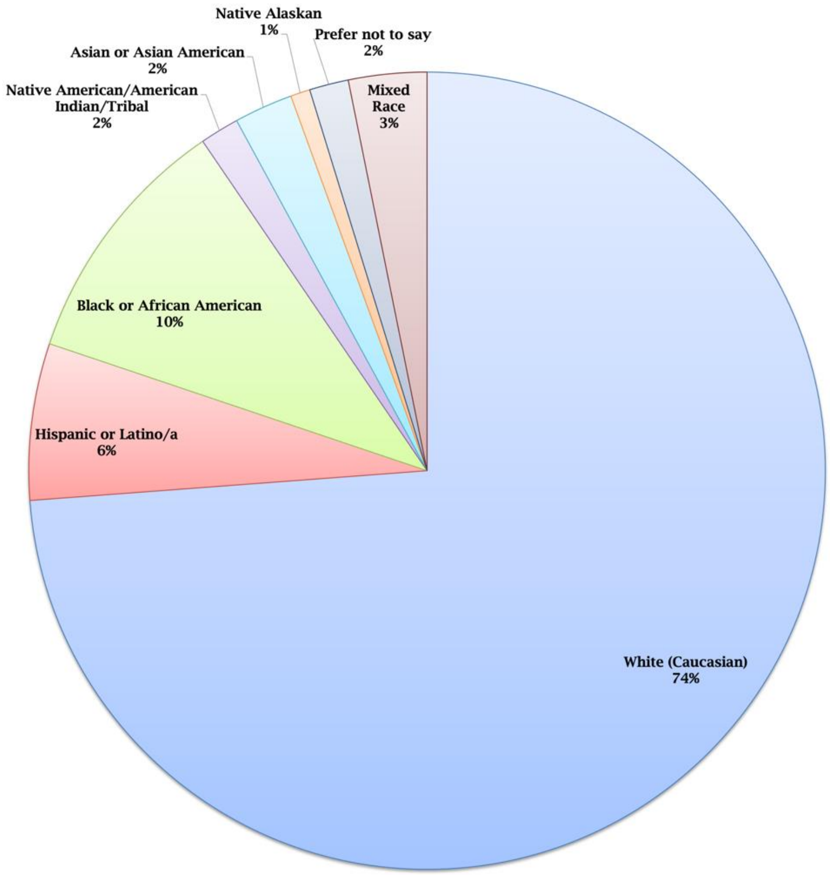
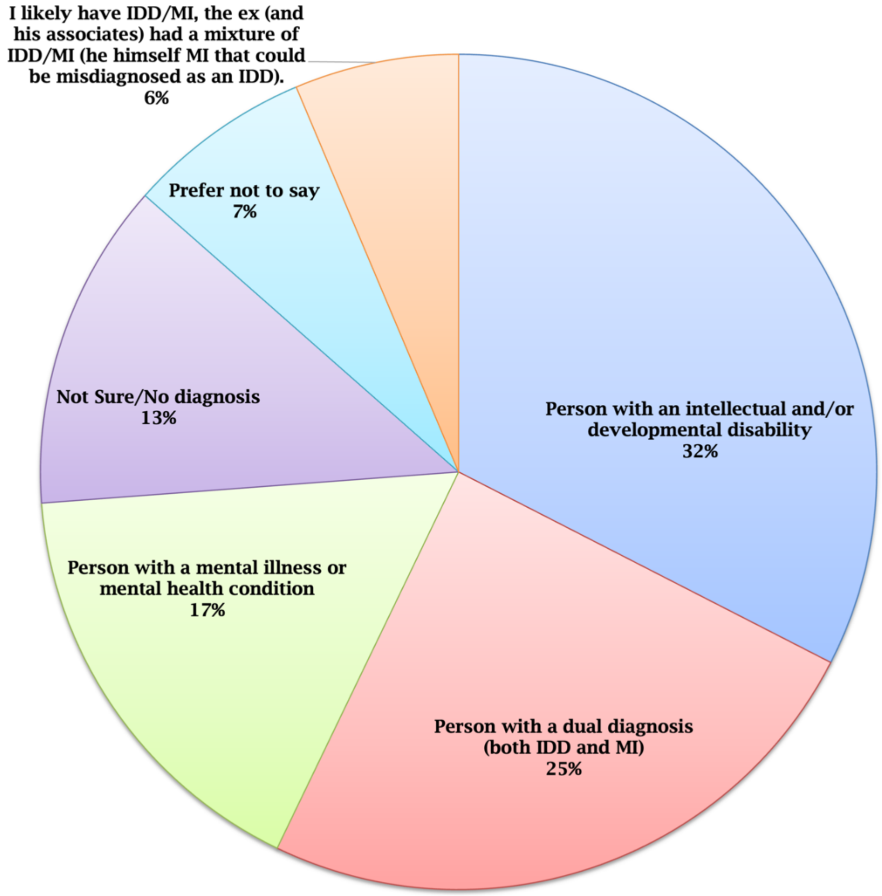


Figure 10 shows a breakdown of the general diagnosis(es) identified by the study's respondents. It should be noted that approximately 25% of participants noted that they care for or provide services for person(s) diagnosed with both an I/DD and mental health condition—a substantial representation that should signal a need for cross-collaborative care.

Figure 10

General Diagnosis(es) of Person(s) with I/DD



Systems and Services Perspectives

Gaining insight into the perspectives of individuals with lived experience is crucial for evaluating and improving systems of support and services. The following data presents the views of research participants on the existing Intellectual and Developmental Disability, behavioral, and mental health systems in Oregon. These perspectives offer valuable insights into the strengths and weaknesses of current systems and inform recommendations for enhancing service delivery and improving outcomes for persons with I/DD. By understanding the experiences and opinions of those directly affected by these systems, we can identify areas for improvement and develop more effective and person-centered approaches to support and care.

Evaluating the Effectiveness of Current Practices and Programs for Addressing the Mental Health Needs of Individuals with I/DD in Oregon

Current programs and practices in Oregon face challenges in effectively meeting the mental health needs of individuals with intellectual and developmental disabilities (IDD) due to systemic barriers, limited funding, and a lack of coordination between mental health and developmental disability services. Accessing behavioral health care can be particularly complex for individuals with I/DD, as some providers may decline to treat them, citing difficulties in active patient participation in treatments, which can be impacted by communication challenges. Additionally, long waiting lists for behavioral health and medication services further limit timely access to care.

The Oregon Health Plan, which provides health coverage for many under-resourced individuals, has limited capacity to support mental health services for this population. The state is experiencing a broader mental health crisis, which has necessitated prioritizing (triaging) support for individuals with I/DD. Adults with mental health conditions who were not diagnosed with developmental disabilities in childhood often face additional difficulties in accessing essential services as they age.

Mental health and developmental disability systems in Oregon frequently operate separately, with distinct funding and staffing challenges that further complicate coordination. While families of children with I/DD may use private insurance for medication management, state-operated systems remain the primary support for individuals with dual diagnoses, despite significant gaps. Staffing and funding constraints within group homes also impact the quality of care and support.

Enhancing communication and leveraging technology could improve the integration and coordination of care within Oregon’s mental health and I/DD systems, leading to better support for individuals with complex needs.

Areas for consideration in enhancing support for Oregonians with intellectual and developmental disabilities (I/DD) and co-occurring mental health conditions include:

- **Addressing Discrimination and Enhancing Training in Mental Health Services:** Increase awareness and provide targeted training for mental health professionals to improve their ability to support individuals with I/DD effectively.
- **Strengthening Qualifications and Training for Behavior Support Professionals (BSPs):** Enhance qualifications for BSPs to include mental health training for people with I/DD.
- **Expanding Residential Options:** Address the demand for group homes, foster homes, and other residential options to allow for more person-centered living options for people with I/DD.
- **Improving Collaboration within the I/DD System:** Enhance coordination and address financial and operational challenges to increase the system's capacity to support individuals with high needs and dual diagnoses.
- **Standardizing Crisis Systems and Services:** Strengthen crisis systems across counties through increased funding, resource allocation, and technological solutions to enhance crisis prevention, response, and coordination.
- **Expanding the Role of Stabilization and Crisis Units (SACU):** Broaden SACU's scope and integrate it into a comprehensive support framework to better serve individuals with dual diagnoses.
- **Providing Specialized, Trauma-Informed Care:** Provide training in I/DD and mental health care strategies grounded in trauma-informed approaches to deliver tailored and effective care for individuals with complex needs.
- **Engaging Stakeholders for System Improvement:** Create an opportunity for cross-sector professionals with dual-diagnosis expertise and a representative group of stakeholders to provide input into systems change initiatives.

Strategies for Improved Service System Outcomes

Our qualitative analysis examines key themes derived from interviews that specifically address the question of what is needed to improve service systems and outcomes for individuals diagnosed with intellectual and developmental disabilities (IDD). The findings are organized into thematic categories that identify the essential components for driving systemic change, aimed at enhancing the quality of care and support for those served by these systems. Each theme highlights a critical area of need—ranging from the integration of care and communication strategies to workforce training and community-centered approaches—providing a clear framework for understanding the suggested changes to optimize service delivery and improve outcomes for individuals with both I/DD and mental health conditions.

Key to systemic improvement is the integration of care and enhanced communication across service sectors, ensuring that mental health and I/DD services are well-coordinated and responsive to the complex needs of individuals. Additionally, comprehensive funding is essential to address resource gaps, sustain services, and support workforce development. The importance of investing in specialized training for support personnel also emerges as critical for improving service quality, as staff must be equipped with the skills to manage complex cases effectively. Lastly, adopting a community-centric, individualized care model that emphasizes peer support, long-term planning, and collaboration among providers and families would foster an environment where individuals with I/DD can thrive. Addressing these interconnected themes—care integration, funding, workforce development, and community-based approaches—will be foundational to advancing a more effective and supportive service system for this vulnerable population.

The theme of ***Integrated Care and Communication Enhancement*** emphasizes the need for improved communication and coordination within mental health and I/DD service systems. Participants consistently highlighted that fragmented services and poor interagency communication are major barriers to effective care. To improve outcomes, service systems must integrate care models that foster seamless communication between mental health providers, developmental disability specialists, and other relevant professionals and paraprofessionals. This theme underscores the importance of fostering collaboration and systemic change to ensure that individuals with I/DD receive timely, coordinated care across different service sectors.

Comprehensive Funding and Support for Mental Health and I/DD Services is a central theme in moving service systems toward improved outcomes. Participants stressed that inadequate funding is a significant obstacle to providing effective care for individuals with dual diagnoses. Sufficient and consistent financial support is crucial for maintaining service accessibility, expanding provider capacity, and ensuring the sustainability of essential programs. Re-evaluating current funding structures, and addressing policy barriers, such as reimbursement rates and funding for specialized services, are strategies to address existing gaps in care. This theme reinforces the need to reallocate resources and ensure that service providers receive adequate compensation and support, improving outcomes for individuals with I/DD and mental health conditions.

The theme of ***Comprehensive Training and Development for Support Personnel*** stresses the importance of ongoing education and specialized training for all personnel working with individuals with I/DD. The interviews revealed that gaps in training, particularly for staff in community-based settings, hinder the ability to provide high-quality, responsive care. Service providers, including direct support professionals, medical staff, and therapists, need opportunities for professional development to ensure that they are equipped to manage the complexities of supporting individuals who have both developmental disabilities and mental health conditions. Specialized training in areas such as behavioral health, trauma-informed care, and crisis prevention and management is essential to enhance the capacity of service providers and ensure that individuals with I/DD receive the comprehensive care they need. This theme highlights the need for targeted investments in workforce development to improve overall service quality and support for this population.

Comprehensive Community-Centric and Person-Centered Care is a theme that underscores the necessity of a holistic, community-based approach to care for individuals with dual diagnoses. The interviews indicated that a one-size-fits-all approach is insufficient for this population; instead, care models must be individualized, coordinated, and centered around that person's support needs and the natural and community supports available to them. Participants emphasized the importance of collaboration between mental health professionals, I/DD providers, family members, and peer support networks to develop personalized care plans that address the multifaceted needs of individuals. Peer support, community-based services, and long-term planning are essential support components that promote independence, inclusion, and overall well-being for individuals with I/DD and co-occurring mental health conditions. This theme emphasizes the importance of community-centric care that utilizes natural supports, is person-centered, and tailored to the unique needs of the individuals receiving services.

The theme of ***Systemic and Access Barriers in I/DD and Mental Health Services*** highlights the significant challenges individuals with I/DD face in accessing mental health services. Participants identified several systemic inadequacies that hinder service access, including lack of service integration, limited provider education, and resource gaps. Additionally, many individuals with dual diagnoses encounter difficulties in navigating both the mental health and I/DD systems, which often operate in isolation. These access barriers can delay or prevent individuals from receiving the care that they need. Understanding and addressing these systemic barriers is critical for moving service systems toward improved outcomes. This theme emphasized the importance of developing strategies for overcoming these barriers, including advocating for legislative reforms, improving service coordination, and expanding access to specialized services in underserved areas.

Discussion of Findings

Several key insights emerged from the analysis of open-ended questions within the survey. In the discussion of improving services for individuals with I/DD and mental health conditions, one central concept focuses on the integration of I/DD and mental health services, aiming to improve communication, collaboration, and service delivery across healthcare systems. Another critical insight that emerged is access inequality in mental health, particularly in rural communities, where there are significant disparities in resources compared to urban areas. These highlight the need for advanced system integration and enhanced data sharing to improve service delivery for both I/DD and mental health populations. The need to address stigma is also an important consideration, with a comprehensive approach needed to combat stereotypes, raise public awareness, and ensure accurate diagnosis and treatment of I/DD and mental health issues. Additionally, several barriers to accessing I/DD services were identified, including inadequate resources, a lack of specialized care, and challenges related to geographic location and provider accessibility.

Many individuals with I/DD also face an over-reliance on emergency rooms for crisis support, underscoring the need to address these gaps in care. Improving provider competency in I/DD care, especially through specialized training for mental health professionals, is another important focus, particularly for those working with dual diagnosis populations. Finally, the challenges of accessing qualified mental health providers for individuals with I/DD were highlighted, with systemic barriers and the limited availability of specialists being key obstacles to effective care.

Evidence-Based, Promising Practices in Place in Oregon

Several evidence-based practices (EBP) are implemented in Oregon to support individuals with an I/DD and co-occurring mental health conditions.

- **Assertive Community Treatment (ACT):** ACT provides comprehensive, community-based support through a multidisciplinary team. This model emphasizes individualized care, shared decision-making, and skills training to promote independence and community integration.
- **Integrated Dual Disorders Treatment (IDDT):** I/DDT addresses both mental health and substance use disorders concurrently. While not explicitly mentioned in the data collection or literature review, adapting EBPs for individuals with I/DD and co-occurring mental health conditions is an opportunity for service enhancement.
- **Supported Employment (SE):** SE assists individuals in finding and maintaining competitive employment and provides a rich opportunity for community engagement and social connection.
- **Family Psychoeducation:** This practice involves educating and supporting families to better understand and respond to their loved one’s condition.
- **Illness Management and Recovery:** This approach empowers individuals to manage their mental health condition through self-monitoring, coping skills development, and relapse prevention strategies.
- **Positive Behavior Support (PBS):** PBS emphasizes creating supportive environments, teaching new skills, and reinforcing positive behaviors. It emphasizes collaboration, respect for individual dignity, and the use of non-punitive strategies to enhance the quality of life for individuals while reducing the need for restrictive interventions.
- **Psychopharmacology:** Appropriate medication management is essential for stabilizing mental health conditions.
- **Person-Centered Planning (PCP):** This collaborative approach emphasizes an individual’s engagement in their own planning processes and incorporates their preferences, strengths, and goals to ensure support tailored to each person’s unique needs.

- **Supported Decision-Making:** This practice aligns with PCP and empowers individuals with disabilities to make informed decisions about their lives with support from trusted individuals.

It is important to note that effective planning processes are dependent upon an effective assessment and diagnostic process.

Existing Systems Related to Service Provision for Individuals with an I/DD

Oregon offers a network of services and supports for individuals with an I/DD, including the following:

Oregon Department of Human Services

- **Developmental Disabilities Services (DDS):** DDS is the primary agency responsible for overseeing services for individuals with I/DD in Oregon. They administer programs, allocate funding, and work with local Community Developmental Disabilities Programs.

- **Office of Aging and People with Disabilities (APD):** While DDS focuses specifically on I/DD, APD addresses the broader needs of individuals with disabilities, including older adults.

Oregon Health Authority

The Oregon Health Authority (OHA) is a state agency responsible for overseeing public health, behavioral health, and health care services in Oregon.

The OHA manages a variety of programs, including the Oregon Health Plan (Medicaid), mental health services, public health initiatives, and addiction treatment programs. It plays a pivotal role in coordinating health policy, monitoring health outcomes, and implementing statewide strategies to improve health systems.

Community Developmental Disabilities Programs (CDDP)

CDDPs are local offices that coordinate and deliver services to individuals with I/DD within their respective communities. They conduct assessments, develop Individual Support Plans, and connect individuals with appropriate services and supports.

Oregon Vocational Rehabilitation (VR) program,

This program supports individuals with disabilities, including those with I/DD, in finding and maintaining employment and achieving greater independence.

Oregon Department of Education (ODE)

ODE manages Special Education Services through the **Office of Enhancing Student Opportunities (OESO)**, which oversees services under the federal **Individuals with Disabilities Education Act (IDEA).** The ODE provides support for early intervention, K-12 special education, and transition services, ensuring equitable education and inclusion for children with disabilities from birth through age 21 in collaboration with school districts and education service districts.

Navigating these systems can be complex. Individuals with I/DD and their families typically connect with their local CDDP for guidance and support in accessing appropriate services.

Government Personnel Perspectives of Intersecting I/DD and Mental Health Systems

Based on the insights shared by the various participants in this project, the Research Team offers the following insights based on general challenges and considerations shared during the data collection process:

Cross-System Professional Perspectives

- **Siloed Systems:** Government and agency personnel acknowledge the challenges posed by fragmented service systems. Participants in this study noted difficulties in communication and collaboration between mental health and I/DD services. This can create barriers for individuals with co-occurring I/DD and mental health conditions who require integrated support.

- **Funding and Resource Allocation:** Perspectives include concerns about adequate funding and resource allocation to address the complex needs of this population. Many respondents in this study mentioned limited service flexibility and duration, suggesting resource constraints.

- **Data Collection and Needs Assessment:** Officials emphasize the importance of robust data collection and needs assessments to understand the prevalence and specific needs of individuals with I/DD and co-occurring mental health conditions.

- **Workforce Development:** Perspectives highlight the need for a skilled workforce trained to address the unique needs of this population, suggesting a broader focus on workforce development within the behavioral health system.

- **Policy and System Integration:** Government personnel advocate for policy changes and system integration to improve service coordination and access for individuals with I/DD and mental health conditions.

Providers’ Experiences and Needs

Cross-Professional Perspectives

- **Diagnostic Complexity:** Clinicians express challenges in accurately diagnosing and differentiating between I/DD, mental health conditions, and co-occurring conditions. 73% of clients seen by clinical providers in the survey had I/DD and other diagnoses, highlighting the complexity clinicians face. This can be further complicated by communication difficulties and behavioral manifestations associated with I/DD.

- **Treatment Adaptations:** Clinicians emphasize the need for adapting traditional therapies and interventions to meet the cognitive and developmental needs of individuals with I/DD. They discuss the importance of accessible *Patient-Reported Outcome Measures* for youth with I/DD, suggesting a need for adaptations across assessment and treatment modalities.

- **Collaboration and Coordination:** Clinicians highlight the importance of interdisciplinary collaboration and care coordination among various providers, including those in I/DD, mental health, and other relevant systems. Several respondents discussed the need for guidance for mental health clinicians in the context of OpenNotes, suggesting a broader need for communication and collaboration among providers.

- **Training and Resources:** Clinicians express a need for specialized training and resources to effectively address the complex needs of individuals with I/DD and/or mental health conditions. Participants addressed systems of care for individuals with ASD and serious behavioral disturbance, highlighting the need for specialized training and resources within these systems.

- **Stigma and Bias:** Clinicians acknowledge the impact of stigma and bias on access to and quality of care for individuals with I/DD and mental health conditions. Respondents noted the need for refined stakeholder perspectives on eliminating disparities in mental health service use for Latinx youth, suggesting a broader awareness of stigma and bias within mental health systems.

Self-Advocates’ and Families’ Perspectives of Resources and Supports (Utilization and Needs)

Perspectives of Self-Advocates

- **Choice and Control:** Self-advocates emphasize the importance of having choice and control over their lives, including decisions about services, supports, and living arrangements. Self-advocates in this study acknowledge supported decision-making, which empowers individuals with I/DD to make informed choices.

- **Inclusion and Community Integration:** Self-advocates express a desire for greater inclusion and integration within their communities, including opportunities for employment, social participation, and access to community resources. Respondents detailed their interest in participating in community conversations to increase employment opportunities for young adults with developmental disabilities, reflecting the importance of community integration.

- **Accessibility and Accommodation:** Self-advocates highlight the need for accessible services, supports, and environments that accommodate their diverse needs and communication styles. Participants addressed the non-usability and lack of reliability of an accessible *Patient-Reported Outcome* measure, suggesting a broader need for accessible tools and resources.

- **Respect and Dignity:** Self-advocates emphasize the importance of being treated with respect and dignity, and having their voices heard in decisions that affect their lives.

Perspectives of Families/Caregivers

- **Respite Care and Support:** Families/caregivers express a need for respite care and other supports to alleviate the challenges of providing ongoing care.

- **Service Navigation and Coordination:** Families/caregivers highlight the difficulties of navigating complex service systems and coordinating care across multiple providers.

- **Financial Assistance and Resources:** Families/caregivers express concerns about the financial burden of caring for a loved one with I/DD and the need for financial assistance and resources.

- **Future Planning and Transition:** Families/caregivers express anxieties about future planning and transitions, particularly as their loved ones age or as caregivers' own health and capacity change.

Summarized Systems Improvement Needs

Based on the perspectives of government personnel, providers, families, and self-advocates, several system improvement opportunities exist within Oregon:

Service Coordination and Integration

- **Breaking Down Silos:** Increasing communication and collaboration between I/DD, mental health, and other relevant service systems to create integrated care models that address both I/DD and mental health needs and improve outcomes for individuals with co-occurring conditions.

- **Streamlining Access:** Simplifying the process for accessing services and supports to reduce barriers for individuals and families.

- **Person-Centered Planning:** Promoting person-centered planning approaches to ensure that services and supports are tailored to individual needs and preferences.

Workforce Development

- **Specialized Training:** Investing in training for professionals across I/DD, mental health, and other relevant fields to enhance their capacity to effectively serve individuals with complex needs.

- **Interdisciplinary Collaboration:** Increasing interdisciplinary collaboration and communication to foster a team-based approach to care.

- **Cultural Competency:** Training and processes that incorporate cultural and linguistic diversity to ensure that services are responsive to the diverse needs of Oregon’s population.

Funding and Resources

- **Adequate Funding:** Securing adequate funding for I/DD and mental health services is essential to ensure access to quality supports.

- **Equitable Resource Allocation:** Allocating resources across diverse geographic regions to ensure equitability across different population groups.

- **Sustainable Funding Models:** Developing sustainable funding models to ensure long-term stability and availability of services.

Family Support

- Developing family support structures to improve access to respite care, financial assistance, service navigation, and future planning resources to better support their loved ones.

Data Collection and Evaluation

- **Comprehensive Data Collection:** Improving data collection efforts to provide a clearer understanding of the needs and outcomes of individuals with I/DD and mental health conditions.
- **Outcome Measurement:** Developing and implementing standardized outcome measures to track progress and evaluate the effectiveness of services and interventions.
- **Data Sharing and Analysis:** Promoting data sharing and analysis across agencies and organizations to facilitate system-level learning and improvement.

Addressing Stigma and Discrimination

- **Public Awareness Campaigns:** Raising public awareness about I/DD and mental health to reduce stigma and promote understanding.
- **Anti-Discrimination Policies:** Implementing and enforcing anti-discrimination policies to protect the rights of individuals with I/DD and mental health conditions.
- **Promoting Inclusive Communities:** Creating inclusive communities to create safe spaces where individuals with I/DD and mental health conditions are valued and supported.

These system improvement opportunities are a pathway for Oregon to create a more effective and equitable system of care that supports the full inclusion and participation of individuals with I/DD and mental health conditions in all aspects of community life.

Recommendations for Improving Mental and Behavioral Health Systems in Oregon

As noted throughout this research report, existing research, and the insights garnered from this project's data collection, individuals with I/DD and co-occurring mental or behavioral health care needs pose complex support needs that stress existing systems of care. Following is a set of recommendations for enhancing Oregon's mental and behavioral health systems to better serve this population.

Improving Service Access and Coordination

1. **Cross-Divisional Collaboration:** Establish clear communication channels and collaborative structures between state divisions involved in mental health, behavioral health, and behavior support services for individuals with an I/DD. This includes developing shared data systems, standardized referral processes, and joint training programs for staff.

2. **Centralized Information Hub:** Create a centralized, easily accessible online platform with information on available services, eligibility criteria, and contact information for relevant agencies. This platform should be user-friendly and cater to the diverse needs of individuals with I/DD and their families.

3. **Care Coordination Teams:** Implement care coordination teams composed of professionals from different disciplines (e.g., mental health, behavioral health, I/DD specialists) to provide integrated and person-centered care for individuals with I/DD and co-occurring mental or behavioral health challenges.

4. **Transportation Assistance:** Address transportation barriers by providing financial assistance, ride-sharing programs, or accessible transportation options to ensure individuals with I/DD can access necessary services.

5. **Culturally Competent Services:** Ensure services are culturally and linguistically appropriate for the diverse populations served, including individuals from different ethnic, racial, and cultural backgrounds.

Developing and Expanding Services

1. **Crisis Intervention Services:** Expand crisis intervention services (incorporating the three phases of crisis: pre-, during, and post-crisis) specifically designed for individuals with I/DD, including training, mobile crisis teams, crisis stabilization units, and 24/7 crisis hotlines.

2. **Community-Based Services:** Develop a comprehensive network of community-based services, such as supported housing, supported employment, and community integration programs, to promote independence and community inclusion for individuals with I/DD and mental or behavioral health needs.

3. **Peer Support Services:** Implement peer support programs that connect individuals with I/DD and their families with trained peer specialists who have lived experience with similar challenges.

4. **Respite Care:** Expand respite care services to provide temporary relief for families and caregivers of individuals with I/DD and intensive support needs.

5. **Telehealth Services:** Utilize telehealth technologies to expand access to mental and behavioral health services, particularly for individuals in rural or underserved areas.

Building Capacity within the I/DD System

1. **Workforce Development:** Invest in workforce development initiatives to increase the number of qualified professionals trained to work with individuals with I/DD and co-occurring mental or behavioral health challenges. This includes providing specialized training, continuing education opportunities, and competitive salaries to attract and retain skilled professionals.

2. **Technical Assistance:** Offer technical assistance and training to I/DD service providers on evidence-based practices for supporting individuals with mental or behavioral health needs.

3. **Data Collection and Evaluation:** Implement robust data collection and evaluation systems to track the effectiveness of services and identify areas for improvement.

4. **Family and Caregiver Support:** Provide training, resources, and support groups for families and caregivers of individuals with I/DD and mental or behavioral health challenges.

Developing an Oregon-Based Capacity Building Institute

1. **Needs Assessment:** Conduct a comprehensive needs assessment to identify the specific training and technical assistance needs of the I/DD system in Oregon.

2. **Curriculum Development:** Develop a curriculum for the Capacity Building Institute that addresses the identified needs and incorporates evidence-based practices.

3. **Stakeholder Engagement:** Engage stakeholders, including individuals with I/DD, families, service providers, and state agencies, in the design and implementation of the Capacity Building Institute.

4. **Sustainability Planning:** Develop a long-term sustainability plan for the Capacity Building Institute to ensure its continued operation and effectiveness.

These recommendations, while not exhaustive, provide a starting point for enhancing the mental and behavioral health systems in Oregon for individuals with I/DD.

Conclusion

This project highlighted actionable strategies for improving systems and supports for Oregonians with intellectual and developmental disabilities (I/DD) and co-occurring mental or behavioral health conditions with complex needs.

Key recommendations include enhancing service access through cross-divisional collaboration and culturally competent care, expanding community-based services and crisis intervention programs, investing in workforce development, and building capacity within the I/DD system. Achieving these goals requires a collaborative, resource-driven approach among stakeholders, coupled with ongoing evaluation and engagement. By implementing these forward-thinking strategies, Oregon has the opportunity to create a more inclusive, person-centered system that empowers individuals with I/DD to lead fulfilling, independent lives within their communities.

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