Oregon Office of Developmental Disabilities

BluePrint Workgroup Recommendations

Transforming Case Management for Oregonians with Intellectual and Developmental Disabilities

April 2022

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Executive Summary (Plain Language)

The Case Management* BluePrint Group was created by the Oregon Office on Developmental Disabilities Services (ODDS) in 2019 to make recommendations on how to improve case management. It included people with disabilities, family members, people who work in case management, advocates and providers.

The BluePrint workgroup spent a lot of time looking at data and information, including a report on how Oregonians who receive supports and families see case management. They met ten times in 2019, talking about what works and does not work in case management for people with intellectual and developmental disabilities. They put together a long list of ideas for improvements. They agreed that the state needed big changes to help make case management better, called “transformational” reform.

The workgroup came up with seven goals to make case management better. They also made recommendations on what kinds of changes would help meet those goals, called “objectives,” and ideas for actions, called “strategies.” Some of these ideas would have to be completed by ODDS across the whole state, and other ideas could happen at the local level. The recommendations include both big ideas that will take more time, and some easier ideas that could happen right away.

Because of the COVID-19 pandemic, there was a delay in getting input from other people after the workgroup finished their first draft in early 2020. In 2021, there was a public online survey, and some local groups of families and people with disabilities also met to talk about the recommendations and give their feedback. Most of the people who offered feedback agreed with the recommendations from the workgroup. However, not enough people with disabilities gave their input on the recommendations.

It is important to note that these ideas are workgroup recommendations, not decisions. Any actions the state decides to make will need more feedback from people with disabilities and other stakeholders.

In February and March 2022, the BluePrint Group met to finalize the recommendations. In the pages that follow, there are many detailed recommendations that the BluePrint Group hopes can turn into action in Oregon.

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*Case Managers in Oregon are called “Service Coordinators” and “Personal Agents.” To keep things simple, this report uses the words “case management entity” for the organizations where case managers work and “case manager” to represent the people who serve in that role.

BluePrint Recommendations Summary: Plain Language

GOAL #1, Capacity and Quality: All case managers have both the time and capacity to focus on relationship aspects of supporting people with I/DD and their families; case managers are available, knowledgeable and responsive.

What does this mean?

  - All case managers have enough time and tools to focus on knowing and understanding the people they support.
  - All case managers are available, know things that are important to do the job well, and get back to people quickly when they hear from their customers or families.

- *What kinds of ideas are in the recommendations?*
  - Make sure that state rules and policies for case managers focus on the relationship between case managers and people with I/DD.
  - Make it clear to everyone what case managers are supposed to do (what their role is.)
  - Help case managers spend more time helping the people they support and less on paperwork.
  - Allow case managers and customers decide how they want to work together.
  - Make sure case managers have the tools and help they need to do a good job.
  - Take some things out of the case manager role and turn them into services.
  - Offer better training for case managers to do a good job. Have them show their skills to the state.
  - Make sure case managers have a good understanding of the vision and values of the Oregon I/DD system, including self-determination and choice.
  - Limit the number of people each case manager supports.
  - Make sure people have back-up plans in case of problems.

BluePrint Recommendations Summary: Plain Language

GOAL #2, Choice and Access: All people receiving I/DD supports (including children and people choosing residential settings) have meaningful choices in selecting a quality case management entity and accessing case managers knowledgeable about, and aligned with, their needs and preferences (regardless of age, service type, geography – factors that currently limit case management choices).

- *What does this mean?*
    - All people with I/DD (including children and people who live in provider settings like group homes, foster homes and supportive living programs) have real choices in case managers and case management entities that work well for them, no matter where they live or what services they get.

- *What kinds of ideas are in the recommendations?*
    - Make sure that every person has at least two choices of case management providers, no matter where they live or what services they receive.
    - Make sure people can choose a case management entity that people with disabilities and families run.
    - Working with stakeholders, look at how many people are getting services and supports every year, and make changes to the number of case management entities based on this information and feedback.
    - Make sure people understand how to pick a new case manager.
    - Create a friendly "front door" system that makes it easy for people to find and access supports. Make sure this system is "neutral" in helping people access the case management the need and want.

BluePrint Recommendations Summary: Plain Language

GOAL #3, Equity: All people with I/DD, including children and their families, and people from diverse communities and identities, receive equitable case management services that are culturally and linguistically responsive and respectful.

- *What does this mean?*
    - All people with I/DD (and their families) work with case managers who understand, support and respect their identities including their race, culture, gender, sexuality, language, age, life stage and family situation.

- *What kinds of ideas are in the recommendations?*
    - Set up a stakeholder group to look at whether is it a good idea to have different case management options and rules for children, to be more focused on working with families and children's issues.
    - Make sure children and their families have supports coordinated with schools and other children's systems.
    - Make sure case managers have the tools to work with all people, including state and local information in different languages, and training to address differences.
    - Set up an organization that hires people with different lived experiences who can help the case managers do a better job, including people with different disability, culture, race, language, gender and sexual identities.

BluePrint Recommendations Summary: Plain Language

GOAL #4, Person-Centeredness: All people with I/DD and their families are able to access person-centered supports that truly reflect their needs, wants and choices, with assistance from case management entities well-versed in person-centered thinking and planning.

- *What does this mean?*
  - All people with I/DD work with a case manager who really understands what is important to them and what is important for them.
  - Case managers are trained in, and really know, person-centered thinking, including how to make sure the person receiving supports is driving the process and their plan.

- *What kinds of ideas are in the recommendations?*
  - Change the Individual Support Plan (ISP) process to make it more focused on the person with less focus on the paperwork and forms.
  - Change the ISP process to make sure people with I/DD "own" their process and their plan, and it is driven by the person with I/DD.
  - Train case managers in person-centered thinking and planning
  - Build in more flexibility so case managers can work with people when, where and how it works for people with I/DD (including outside of 9-5.)
  - Look at ways to reduce paperwork.

GOAL #5, Information and Communication: People with I/DD and their families are able to easily find and understand the information they seek, and have access to flexible and efficient communication options that meet their needs.

- *What does this mean?*
    - All people with I/DD (and their families) can easily find and understand the information they need about supports.
    - All people can communicate with their case manager in ways that meet their unique needs.

- *What kinds of ideas are in the recommendations?*
    - Create an easy to read “Road Map” about Oregon I/DD supports.
    - Make information about what case managers do, and don’t do, available to everyone.
    - Find other places and ways to share information with people – not just through the case manager.
    - Make a “one-stop” website of provider information (instead of many different sites) where people with I/DD, families, and case managers can search for service providers (both agencies and PSWs.)
    - Buy an accessible electronic system that lets people with I/DD and families access their ISPs, communicate with case managers, and share information across their teams in ways that work for the person and their family.
    - Change the words in state I/DD policies and communications to reflect our values. (For example, get rid of “attendant care” and focus more on “community inclusion.”)

BluePrint Recommendations Summary: Plain Language

GOAL #6, Engagement: Quality and accountability of community stakeholder participation in state system change and decision-making processes is supported consistently.

- *What does this mean?*
    - The state makes sure that people with I/DD, families and other stakeholders have a fair chance and are supported to be involved in policy decisions that affect them.

- *What kinds of ideas are in the recommendations?*
    - Set up rules and requirements for stakeholder workgroups to make sure people know what is happening.
    - Make sure people are supported to participate.
    - Make sure people with I/DD whose voices are not always heard have a chance to participate, including people with I/DD and different lived experiences like homelessness, mental health disabilities, multi-cultural backgrounds and more.

GOAL #7, Performance, Quality and Resources: Case management performance and payment aligns with the goals of person-centeredness.

- *What does this mean?*
    - The state pays for case management services in a way that is fair and addresses different needs.
    - The state looks at how case management entities are doing based more on how the people they support are doing.

- *What kinds of ideas are in the recommendations?*
    - Make sure all case management entities contract directly with the state.
    - Change how the state looks at quality in case management and decides who is doing a good job – make sure it looks at how people with I/DD are doing.
    - Make sure funding for case management is fair and addresses different needs.
    - Stop judging case managers based on counting how many times they talk to a person and pay more attention to whether case management is helping the person with I/DD achieve their goals.

Oregon Case Management: Brief History and Background

The core values of inclusion, self-determination, choice, and person-centeredness have been the bedrock foundation in Oregon's community system of supports for people with intellectual and developmental disabilities (I/DD) for over two decades, since the *Staley* lawsuit settlement.[1] In 2001, the current case management structure of Community Developmental Disabilities Programs (CDDPs) and Support Services Brokerages was established to offer distinct supports to different populations receiving different kinds of services in different settings.

Case management is a lynchpin component of the Oregon I/DD system, and the first place those core values need to be articulated, understood and supported. Whether delivered by a Service Coordinator working for a CDDP or the state Children's Intensive In-Home Services program, or by a Personal Agent working for a Brokerage, case managers provide access, information, coordination, navigation, oversight and advocacy on behalf of the people they support.

In 2013, the Oregon service delivery system changed significantly. Two important shifts occurred:

- The addition of the Community First Choice Option (the "K Plan") that expanded access to services for eligible adults through the Medicaid state plan (instead of waivers) and established an "agency with choice" structure that eliminated full self-directed budget authority previously available in the Supports Waiver, and
- The establishment of an eligibility pathway for children with I/DD who met institutional level of care to disregard parental income (beyond the small number of slots on the model waivers for children with very high support needs), opening the door to a significant increase in enrollment of children from families of all income levels.

These service system shifts created dramatic growth and big changes in the Oregon I/DD system.

On top of this, additional regulatory and program changes occurred at both the state and federal level, including changes to ODDS functional assessment, new employment requirements under the federal Fair Labor Standards Act, new collective bargaining agreements within the HCBS delivery system, implementation of a new state payment system (eXPRS), an employment-related *Olmstead* settlement for people with I/DD, and new federal home and community-based services regulations from the Center for Medicare & Medicaid Services (CMS). The number of complex changes that occurred in a relatively short period of time left little opportunity for rethinking case management. In response, people and systems adapted. Case management evolved incrementally, without a strong focus on ensuring the core values were consistently reflected in the delivery of case management, as the number of people supported nearly doubled and a very different direct service delivery structure emerged.

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[1] Staley v. Kitzhaber, No. 00-cv-78 (D.Or. Oct. 30, 2000). https://static1.squarespace.com/static/5d645da3cf8e4c000158e55a/t/60d27660ee5b884c564f218c/1624405601036/PB-OR-0002-0003.pdf

In 2018, the Oregon Office of Developmental Disabilities Services (ODDS) Strategic Plan acknowledged the need for improvement and change in case management, with an action item to "Develop and implement a strategy to reform the case management system to be effective, easy for people and families to understand, access, and navigate; and ensure that every case management entity consistently follows the expectation to operate in a fully person-centered approach."

To support this goal, ODDS contracted with Health Management Associates (HMA) to work with a representative group of stakeholders, the Case Management BluePrint Group, to develop recommendations for case management reform. In addition, HMA completed an analysis, *Oregon's Case Management System for People with Intellectual/Developmental Disabilities October 2020*, (Appendix F) in partnership with staff from the National Association of State Directors of Developmental Disabilities Services (NASDDDS). This document was made available to the BluePrint Group in February 2022; however, due to timing, it was not considered in the development of the final workgroup recommendations.

Case Management BluePrint Group: Approach

From December 2018 through March 2019, HMA conducted an extensive stakeholder outreach and engagement process to learn from people all over the state about what is, and what is not, working for people with I/DD, families, providers and case managers. The results were compiled into a report in May 2019 (Appendix E), and were also shared at the 2019 Oregon SC/PA conference in June 2019.

Also in early 2019, ODDS contacted stakeholder organizations to help identify people to participate in a dedicated workgroup on case management reform, to represent different perspectives: people with I/DD who receive supports, family members, case management and providers. Groups selected representatives for the "Oregon Case Management Blueprint Group" and ODDS invited some individual family members and people with I/DD, as well. (See Appendix A for a full list of Blueprint Group Members.)

The Blueprint Group first met in March 2019, facilitated by staff from HMA and Supports Development Associates (SDA). Over the course of 2019, the full group met nine times, with one additional meeting involving just the workgroup members with disabilities and family members. Throughout the process, the Blueprint Group worked collaboratively to consider and discuss the stakeholder feedback from the outreach report, while also bringing the knowledge and expertise from their organizations, as well as their own experiences and perspectives into the discussion.

The group created an extensive list of ideas, action items, and implementation strategies, always considering "what will have the greatest positive impact" in people's lives, and seeking transformational change, not just transitional change.[2] The group refined extensive lists of ideas,

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[2] Meissner, H., & O'Brien, J. O. (2014). *Creating Blue Space* (Illustrated ed.). Inclusion Press.

prioritizing and paring down the lists. The members were asked to focus on goals (what is the vision), objectives (what will we do to achieve the vision), and key strategies (how we could do it). The ideas were ultimately organized into high-level goals, with systems change objectives and strategies to support each of the goals.

Further, the group determined whether the state or the case management entity (or, in some cases, the individual case manager) should be responsible for strategies and actions. At the same time, there was acknowledgement that all pieces of the I/DD system are interdependent, and members of the group often agreed that in order to be successful, everyone (state, local and individual stakeholders) would have some role in each part of the work.

Finally, the Blueprint Group worked through the most difficult objectives and strategies, related to addressing some of the structural and entrenched issues in the system. The conversations centered around how to address equity, honor choice, create accountability and meet capacity needs across the state, while allowing case managers to “get back to person-centeredness instead of paperwork and compliance.” These discussions were challenging, with spirited debates about the status quo, transformational change, what is possible, and what matters most.

As a result of this hard work, the BluePrint Group identified 7 major goals, 20 objectives, 47 state agency strategies and 21 case management entity strategies, completed in draft form in January 2020.

After delays caused by the COVID-19 pandemic, in spring of 2021 ODDS designed and implemented an online survey (Appendix B) asking about seventeen of the most significant recommendations from the BluePrint workgroup. The survey was open February 2021-December 2021, with nearly all responses received February-May 2021. (Appendix C) To gather additional perspectives in the fall of 2021, ODDS invited community organizations to engage and meet with under-represented families and people with I/DD to gather more feedback on the recommendations. (Appendix D)

In February and March 2022, the BluePrint Group met two more times to discuss the public feedback and make final revisions and adjustments. The workgroup discussed the limitations of the public input, due to several concerns:

- Survey was implemented during the pandemic without supporting webinars or meetings for stakeholders to understand it
- Online survey was difficult to follow and understand, especially for people with I/DD and families, and people with disabilities were not supported to take the survey
- Survey asked questions about objectives and strategies outside of the context of the goals, and without enough information to explain the ideas
- Some stakeholders felt that the survey questions were leading and had limited response options
- The community groups who met to discuss the recommendations in 2021 were primarily families of children
- Community group participants may not have understood the system enough to comprehend the intent of some of the recommendations and the substance
- Very little feedback was gathered from adults who receive supports

While the public input process had some important limitations that are critical to recognize, the feedback gathered did support the recommendations presented, with little dissent. Importantly, many of the qualitative comments from families (both in the community groups and online) were very similar to the comments and responses gathered at the beginning of the BluePrint process in early 2019.

Additionally, the workgroup acknowledged that over the two years since the development of the original draft recommendations, there has been significant change as a result of the pandemic and other events. Importantly, the BluePrint Group discussed recent intentional efforts at both the state and local levels to address equity, inclusion and communication concerns for people with non-dominant racial, cultural, sexual and gender identities. In particular, the group wanted to ensure clarity that the equity issues are important throughout the recommendations, not just the equity-focused recommendation, and changes should consider the needs and preferences of different people and communities including: people from tribal nations; racial, ethnic, and culturally-based communities; women; individuals who identify as LGBTQIA+; people with disabilities (including people with behavioral health/mental health disabilities); religious minorities; veterans; individuals with limited English proficiency; immigrants; refugees; people experiencing houselessness; and people with trauma. Some updates to recommendations were made in response, and ***the group hopes readers of this report understand their intent that "all means ALL" in each and every recommendation.***

The attached final recommendations are a result of the substantial hours, contributions and hard work of the group members. The BluePrint workgroup sought to reach consensus on as many ideas as possible, and often were able to agree, negotiating language and concepts to address concerns from others. At the same time, compromises were made on some issues, and the workgroup members prioritized among conflicting options, allowing the majority of the group to determine direction when there was disagreement. As one member of the group commented upon seeing the final draft, there were many complex conversations captured, and "I may not agree with all of the outcomes, but I agree that they are reflective of the group's input."

It is important to note that these ideas and concepts are recommendations, not decisions. The recommendations were developed to offer guidance, priorities and feedback to the state agency and external stakeholders, as a starting place for case management reform. The recommendations are intended to reflect what people with I/DD and families want and need from case management to help them have good lives as contributing and participating members of Oregon communities, and what case management and providers want and need in order to do their best work in supporting people with I/DD and families.

Structure of the BluePrint Recommendations

The BluePrint workgroup recommended seven priority goals for case management reform, listed below. Each goal seeks to improve the bold concept listed below. For details about the objectives and strategies that support the goal and provide further context, please see content starting on page 16.

- **Capacity and Quality:** All case managers have both the time and capacity to focus on relationship aspects of supporting people with I/DD and their families; case managers are available, knowledgeable and responsive.
- **Choice and Access:** All people receiving I/DD supports (including children and people choosing residential settings) have meaningful choices in selecting a quality case management entity and accessing case managers knowledgeable about, and aligned with, their needs and preferences (regardless of age, service type, geography – factors that currently limit case management choices).
- **Equity:** All people with I/DD, including children and their families, and people from diverse communities and identities, receive equitable case management services that are culturally and linguistically responsive and respectful.
- **Person-Centeredness:** All people with I/DD and their families are able to access person-centered supports that truly reflect their needs, wants and choices, with assistance from case management entities well-versed in person-centered thinking and planning.
- **Information and Communication:** People with I/DD and their families are able to easily find and understand the information they seek, and have access to flexible and efficient communication options that meet their needs.
- **Engagement:** Quality and accountability of community stakeholder participation in state system change and decision-making processes is supported consistently.
- **Performance, Quality and Resources:** Case management performance and payment aligns with the goals of person-centeredness.

These goals are not presented in any particular order and nothing should be construed from the sequence of the seven goals. ***The BluePrint Group did develop the recommendations for objectives and strategies to be considered holistically in the context of each of the goals, not independently.***

The structure of the recommendations follow this outline:

Goals: Important changes for the Case Management system to make it better

a. **Objectives:** What will support the changes stated in the goals

    i. ***State Strategies:*** Actions that need to be driven at a statewide or state agency level to achieve the objectives and meet the goal

    ii. ***Case Management Entities (CME) Strategies:*** Actions that local entities can take to achieve the objectives and meet the goal

It is the view of the BluePrint workgroup that any individual objectives and strategies considered for implementation outside of the overarching goal (the reason for the objective or strategy) may not align with the intent of the recommendation. ***The "why" behind each element is very important and contributes to the transformational change that the workgroup envisioned.***

The timelines necessary for the implementation of the recommendations range from multi-year processes to activities which could occur quickly and without significant resources. Some are far-reaching, requiring structural and statutory changes; others are administrative or related to communication and information.

Implementing Transformational Change in Case Management

The BluePrint workgroup acknowledged the complexity and challenges of transformational systems change; however, there was great optimism within the group that Oregon could achieve important and necessary reform with direct and robust engagement from the broader I/DD stakeholder community. In the final meeting of the group in March 2022, there was extensive conversation about the need for implementation and training guidance from the BluePrint group, to see that these recommendations move forward consistent with intent and values, and that people with I/DD are the "drivers" of implementation efforts. The core concept of "Nothing About Us Without Us" was repeated and voiced as a reminder. One suggestion from the group was to create opportunities for people to learn more about the recommendations through formal presentations or learning opportunities.

The group also acknowledged lessons learned throughout the BluePrint process, and the importance of implementing better stakeholder engagement consistent with recommendations under Goal #6 of this report (page 24, below). The BluePrint group would like to see the state establish an implementation body led by adults who receive supports and families of people with I/DD, with state staff and case management staff in the minority. The group acknowledged the complexity of ensuring that all people statewide have enough accessible information and knowledge about systems and policy to level power imbalances between professionals who work in case management or state policy and those who participate in services, but agreed this is possible when time and resources are made available, and committed workgroups, focus groups and engagement are supported at both the local and state level. Workgroup members hope that state agencies, case management entities and policymakers will move these transformational changes forward.

The Case Management BluePrint Group is pleased to present the following recommendations for reform of the Oregon intellectual and developmental disabilities case management system.

RECOMMENDATIONS: GOALS, OBJECTIVES AND STRATEGIES

GOAL #1, CAPACITY AND QUALITY: All case managers have both the time and capacity to focus on relationship aspects of supporting people with I/DD and their families; case managers are available, knowledgeable and responsive.

a. **Define the role and responsibilities of case managers in state policy, creating a reasonable level of complexity for the individual case manager. Focus should be on relationships with the people receiving supports and their families.**

   State Strategies:

   - Clarify and communicate a well-defined role for case managers, what they do and don't do, alignment to values, and provide training and information on core responsibilities to case managers, families, and people receiving supports.

   Case Management Entities Strategies:

   - Create a more manageable job for case managers, with room to be available and responsive, so they can communicate with people receiving supports and families, be an expert on less information, and have time to share information with people in ways that ensure understanding and comprehension by all team members.
   - Improve case manager job satisfaction and reduce turnover through implementation of best practices in case management, reduced caseloads, and aligning case management responsibilities with the people doing the work (eg, "let social workers be social workers, and find other ways to get the administrative paperwork done.")
   - Create a clear expectation and space in the job to be local community experts. Take clerical and non-meaningful work out of case managers' responsibilities.

b. **Improve the ability of case management entities to efficiently and effectively help people receive quality services and supports, while also reducing health and safety risks.**

   State Strategies:

   - Clarify, articulate through policy and create clear expectations and authority for monitoring across service settings (including in-home and integrated community). Hold CMEs accountable to monitoring requirements and face-to-face meetings.
   - Allow more flexibility in the requirements for contact methods and frequency of contact, based upon individual needs and preferences, while still adhering to federal minimum standards and ensuring health and safety.
   - Standardize the collaboration process across Medicaid Coordinated Care Organizations and case management entities to improve responsiveness and coordination.
   - Improve process and establish specific timelines for approval of ancillary services and any service/rate exceptions that must be approved by state staff. Consider lower

thresholds for what can be authorized/approved at the CME level in order to increase responsiveness, timeliness and reduce the time spent by case managers seeking state approval.

Case Management Entities Strategies:

- Share local expertise and assistance for case managers seeking state approval for authorizations and exceptions.

c. Improve the knowledge and skills of case management staff statewide.

State Strategies:

- Further standardize case management training and qualifications across all case management entities. Build real-world understanding of person-centered thinking in life situations. Create competency-based qualifications requiring demonstration of skills and knowledge in I/DD supports, not just process and compliance, including vision and values, understanding self-determination, choice, person-centered thinking, to be demonstrated by all CMs on an ongoing basis (beyond current initial orientation requirements.)

Case Management Entities Strategies:

- Offer comprehensive education and training on vision and values, self-determination, choice, person-centeredness, etc. for case managers, families, and people receiving supports.

d. Expand case management capacity by making additional resources available to assist case management entities.

State Strategies:

- Establish shared regional “subject matter experts” with deep knowledge on certain subjects (eg housing, CCOs, education) to work across multiple CMEs in support of all case managers who can then access this specialty technical assistance as needed.
- Create capacity in the system for professional experts in person-centered thinking and planning (not the case managers) to facilitate large or important planning meetings (eg, especially at key transition points) instead of relying upon the case manager to both facilitate and participate.

Case Management Entities Strategies:

- Build in time for systems navigation, opportunities for case managers to seek assistance on behalf of individual customers.

e. Expand capacity by moving some functions to support services, instead of being provided by case managers.

State Strategies:

- Establish a new service offering self-direction counseling and training, assistance with personal support worker (PSW) identification/recruitment and management, support for individuals as employer of record, and other supports brokering functions, as a distinct service separate from case management (and distinct from current responsibilities of the statewide fiscal intermediary). Make accessible and require participation in training for individuals and families working with PSWs. When families are paid providers, require training about accountability, self-determination, values, conflict-of-interest.
- Establish a new service offering "community guide" or "community connections" as a distinct service outside of case managers, providing individualized community resource development, assistance with accommodations in integrated community participation, peer-to-peer navigation support, facilitation in establishing personal circles of support, and/or assistance in engaging with local non-disability organizations. (For example, a "community developer" role that is similar to the idea of the "job developer.")
- In order to address the day-to-day details and coordination needs of individuals receiving in-home and/or non-residential day/employment services, especially those who are working with support team members from multiple organizations and/or multiple PSWs, service definitions should be revised to incorporate the expectation that all team members collaborate and communicate about day-to-day coordination, scheduling and issues of importance to the person as needed. DSPs and PSWs should be paid for this time. The frequency and process should be determined by the person and their team, and may require engagement on a frequent (weekly, biweekly or monthly) basis.

f. Establish statewide consistency in caseloads to improve responsiveness and quality of case management services delivered.

State Strategies:

- The state should set maximum caseload size(s) per individual case manager as state policy for all CMEs, based upon an analysis of differences in population needs (eg children vs adults, urban vs rural, residential vs in-home) and geographic differences.
- Explore the establishment of clear guidelines in CME contracts to ensure that case management entities have consistent policies and procedures to support 24/7 responsiveness for urgent needs that do not rise to the level of crisis or emergency, as well as meetings and engagement outside of "business hours." The state needs to consider this expectation when determining funding and resources available to support this level of responsiveness.
- As part of ISP development, ensure that every individual has a meaningful back-up plan when primary supports and/or services may not be available.

Case Management Entities Strategies:

- Make CME caseload policy decisions transparent for stakeholders, with annual public reporting on per case manager caseloads for all CMEs, disaggregated by county and population served (including demographic information, adults vs children, in-home vs residential, etc.)

GOAL #2, CHOICE AND ACCESS: All people receiving I/DD supports (including children and people choosing residential settings) have meaningful choices in selecting a quality case management entity and accessing case managers knowledgeable about, and aligned with, their needs and preferences (regardless of age, service type, geography – factors that currently limit case management choice).

g. Change the case management structure to ensure multiple choices for case management organizations are available to each person in all areas of the state.

State Strategies:

- Establish real choice by developing opportunities for additional entities to provide case management services (on a local/regional basis, not necessarily tied to county geography), and for existing CMEs to expand the populations they serve, so that every person has a choice of at least two quality CMEs regardless of the type of services a person receives.
- Eliminate the current restriction on case management choice based on the type of services a person receives, so that people do not have to change case management entities unless they choose to do so. Ensure that this occurs with thoughtful planning, stakeholder engagement and adequate transition and change management efforts.
- Create a routine state-led stakeholder process to annually evaluate CME size, geographic catchment area, and population growth patterns, with the possibility of recommending CME structure refinements. Evaluate the CME landscape and make transparent adjustments, with full stakeholder involvement.
- In support of self-determination and choice/control, ensure that every person receiving supports has the choice of at least one CME that maintains a governance structure comprised of a majority of people receiving supports and family members, providing opportunity to engage in monitoring quality and performance of the CME and helping to direct policy and program decisions.

h. Establish clear requirements regarding choice of case manager and create processes to support this choice for every person.

State Strategies:

- Require case management entities to offer meaningful and informed choice among available case managers and ensure adequate capacity within the system for people to exercise these options. Require case management entities to offer meaningful and informed choice among available case managers.

Case Management Entities Strategies:

- Provide written information, website bios and/or “matching” events allowing people and families to learn about individual case managers and make informed choices.
- Establish and preserve long-term relationships between case managers and customers/families by allowing adequate time for relationship-building as part of case management, supporting choice among case managers, and prioritizing maintenance of existing relationships in policy and practice.

i. Establish a neutral enrollment process for choosing case management entity.

State Strategies:

- Create a separate, neutral, unbiased front door entity or structure responsible for supporting intake, eligibility and enrollment in case management that could be either a local regional entity or state agency staff.
- Create clear guidance and definition for choice advising, education and support related to case management, and what makes a person or entity qualified to render choice counseling to select from service and CME options, and among case managers within the CME.

Case Management Entities Strategies:

- Provide a venue and/or process across local CMEs for prospective customers to engage in informed choice prior to referral for enrollment.
- ODDS to send annual written notification of CME options to individuals and their designated representatives, including contact information for each CME and a description of the process for requesting changes to CM or CME, including timelines people should expect to encounter.

GOAL #3, EQUITY: All people with I/DD, including children and their families, and people from diverse communities and identities, receive equitable case management services that are culturally and linguistically responsive and respectful.

j. Ensure that case managers working with families of children have different skills and tools than those who work with adults.

State Strategies:

- Establish a comprehensive statewide planning process to design and establish a unique and knowledgeable case management infrastructure for all children with I/DD, age birth to 21 (to align with timing related to educational services and Medicaid Early Periodic Screening Diagnosis and Treatment/EPSDT requirements, and to avoid transition of case management at age 18) which may include consideration of incorporating Children's Intensive In-Home Services (CIIS) case management. The planning process should consider all options.

- Establish unique qualifications, caseloads, and training requirements for children's case management staff.
- Expand state requirements of children's case management to more explicitly address the planning, coordination and delivery of I/DD services to children in collaboration with other children's systems (early childhood, K-12 education, child care, pediatric care, etc.) in order to improve consistency, reduce redundancy, align service plans and address support needs and preferences in the context of the family.

k. **Ensure the I/DD system addresses non-dominant culture, identity and language needs as a mainstream function**.

State Strategies:

- Resource a statewide or regional technical assistance and training structure to enhance the capacities of the CMEs without reducing the expectations or responsibilities of CMEs to ensure service equity and knowledgeable case managers, and partnerships with communities. The technical assistance should be led and staffed by people from different cultures and lived experiences, including people who can provide content-knowledgeable and timely interpretation, translation services, and people with diverse sexual and gender identities.
- Make all important statewide information and materials available in multiple languages (not just upon request).
- Require both CMEs and contracted entities (eg financial management services) to meet cultural and language needs as part of contracts. Include measures related to meeting these needs as part of oversight and monitoring.

Case Management Entities Strategies:

- Develop additional capacity within the case management entities to be more culturally responsive to customers.
- Make all important local information and materials available in multiple languages (not just upon request).
- Work to develop local resources, partnerships and capacities to support people with I/DD, reflective of diverse communities.

GOAL #4, PERSON-CENTEREDNESS:* All people with I/DD and their families are able to access person-centered supports that truly reflect their needs, wants and choices, with assistance from case management entities well-versed in person-centered thinking and planning.

l. Redesign the Individual Support Plan (ISP) process with a systemwide re-set on person-centered plan development, participation and engagement.

State Strategies:

- Reconsider the structure, steps and sequencing of the elements of the ISP process (and supporting materials and forms) in order to re-focus on the person. Develop a process where teams understand that the person-centered plan belongs to, and should be driven by, the person receiving supports.
- Ensure adequate time and capacity to engage in the actual person-centered planning and meeting processes. Make it about the person, not the paperwork and forms.

m. Improve training and integration of person-centered practices.

State Strategies:

- Case managers should have flexible schedules and team processes that allow for non-business hour availability and a more customer-service oriented responsiveness (without expecting each case manager to work excessive hours.)

Case Management Entities Strategies:

- Prioritize person-centered thinking and planning training for case management entity staff, and implement person-centered thinking as a priority across the CME.

n. Align policy and rules to support person-centered practices.

State Strategies:

- Review federal and state requirements for case management functions to reduce administrative burden and ensure that the focus is on the person and providing true person-centered supports.

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*The workgroup discussed at length and agreed upon the importance of improving consistency and knowledge in person-centered thinking, re-establishing best practices in person-centered planning, and the need to re-think and re-sequence the ISP process to focus more on strengths and goals and less on formal assessment. However, because the state had a separate concurrent initiative dedicated to the ISP process redesign, the BluePrint Group did not develop extensive objectives and strategies for this goal.

GOAL #5, INFORMATION/COMMUNICATION: People with I/DD and their families are able to easily find and understand the information they seek about I/DD supports, and have access to flexible and efficient communication options that meet their needs.

o. Increase easy access to information about services, supports, and community resources.

State Strategies:

- Create an easy-to-read "Road Map and Guide to Understanding DD Supports" (including Case Management) targeted for people seeking supports and their families, available in multiple languages.
- Make available comprehensive information, accessible in multiple languages and formats, that describes the expectations for case managers, offers upfront information and systems mapping, and helps people and families understand the roles and responsibilities of CMEs.
- Develop tools to provide consistent information about case management and supports, regardless of CME. Strategies include website(s), videos, handouts, required text/information to be provided when people and families are making choices about CMEs.
- Create ODDS-maintained agency provider list (searchable by service, geography and capacity including language and culture) to complement existing employment services website, residential provider capacity list, and homecare worker registry. Cross-link all provider capacity websites. Use geo-mapping to assess statewide provider capacities using enrolled provider lists to identify needs and gaps, make this information public.

Case Management Entities Strategies:

- Offer training to individuals and families to learn to advocate for themselves and learn about what case management does (and does not do), including support for diverse family participation.
- Increase access to information resources for individuals, families, providers and case managers through multiple venues and processes.
- Diversify access points to information – strategically and planfully, to get information to people in many ways (not just reliant on the case manager.)

p. Improve quality, efficiency and flexibility in communication processes, records sharing and information flow across teams including people receiving supports and families.

State Strategies:

- Invest in a centralized case management and communications system that is person-centered, user-friendly and accessible, with state staff, case management, person/family, and provider permissions and portals. System should allow for privacy controls driven by the person receiving supports, and include access to records such as assessment data, person-centered plans and service authorizations; offer secure communications and HIPAA-compliant information-sharing across combinations of team members as needed and consented by person; create efficiencies in clerical and communications processes.

- Untangle policy and privacy issues around people's preferred communication methods to increase flexibility and efficiency, providing for better email, texting, calling options. Identify tools and processes that will more allow for more fluid and accessible ways to communicate and share information while still maintaining privacy and confidentiality.
- Reset outward-facing language to reflect our values, and move away from traditional medical/institutional terminology. Get rid of terms like "Attendant Care" in our everyday system vocabulary. Recommit to words like "Community Inclusion" and "Community Living," and create new terms that accurately and simply describe what people are asking for from the services, and what we intend to deliver.

Case Management Entities Strategies:

- Improve communication between case managers and providers regarding access to resources, meeting needs, honoring preferences, addressing ISP goals and implementing supports to meet those goals.
- With permission from the person or guardian, communicate with family members of people living in provider-controlled residential settings (group homes, foster care) about monitoring, follow up, update activities. Make this the default (opt-out) so families are "in the loop."

GOAL #6, ENGAGEMENT: Quality and accountability of community stakeholder participation, including for individuals and families with barriers to engagement, in state system change and decision-making processes is supported consistently.

q. Establish clear expectations and standards for state workgroups to increase effective stakeholder engagement.

State Strategies:

- Address barriers and create equitable opportunity for all people, including people with disabilities and people from multicultural backgrounds, to participate and contribute to workgroups, including underserved and under-represented communities such as people from tribal nations; racial, ethnic, and culturally-based communities; women; individuals who identify as LGBTQIA+; people with disabilities (including people with behavioral health/mental health disabilities); religious minorities; veterans; individuals with limited English proficiency; immigrants; refugees; and people experiencing homelessness, addiction, multi-generational poverty and trauma.
- Increase use of technology to better cover all parts of the state and improve access.

- Create consistent standards for stakeholder workgroups established by ODDS (or their contractors) that articulate requirements related to scheduling with participants, provide publicly-available minutes or other forms of documentation of discussion and agreement points, and publicly communicate the final decisions, products and/or results of the workgroup effort.
- Establish guidelines and expectations for state stakeholder workgroups to make it clear what is needed for each member, and from each member, to fully engage them and their representative groups and to tap their expertise.

GOAL #7, PERFORMANCE, QUALITY AND RESOURCES: Case management performance and payment aligns with the goals of person-centeredness.

r. Increase accountability and consistency statewide.

State Strategies:

- Require that all CMEs hold direct contracts with the state; end subcontracting option for counties.

s. Develop quality assurance and performance measurement processes that incentivize quality person-centered outcomes.

State Strategies:

- Measure person-centeredness and self-determination as part of performance and quality metrics. Find balance in the approach to measuring person-centeredness – "The more one has to document how person-centered a plan is, the less person-centered that plan inherently becomes."
- Track more data and information at the state level, including case management choices made by individuals, and individual movements to ensure timely completion of choice implementation.
- Improve review process – reviews are often conducted by a team or outside party unfamiliar with the person and their family, without validating information through interviews or experience surveys.

Case Management Entities Strategies:

- Ensure that the person (and individuals important to the person) have a critical role in defining and ensuring quality as the person/family sees it.

t. Ensure funding incentivizes person-centered, quality case management in an equitable manner for all people receiving supports.

State Strategies:

- Revisit how case management services are paid for by the state, with rates and a payment structure to support capacity, equity, quality and differences among people’s needs.

Case Management Entities Strategies:

- Support a change in performance expectations of case managers, moving away from meeting targets based on number of encounters, towards outcomes as a more person-centered approach.

APPENDIX A: Members of the BluePrint Group (2019-2022)

- Pat Allen-Sleeman, *Oregon Resource Association*
- Arlen Bynem, *Brokerage Personal Agent*
- Justin Connelly, *Self-Advocate*
- Jaime Daignault/Leslie Sutton, *Oregon Council on Developmental Disabilities*
- Jill Fummerton, *Oregon Family Networks*
- Tom Giles, *Parent*
- Gabrielle Guedon, *Oregon Self-Advocacy Coalition*
- Anna Keenan-Mudrick, *Community Providers Association of Oregon*
- Paulina Laurenas, *Parent*
- Jordan Lawson, *Self-Advocate*
- Linda Lund, *AFSCME and CDDP Service Coordinator*
- Corissa Neufelt, *Association of Community Mental Health Providers/CDDP Directors*
- Susana Ramirez, *Parent*
- Katie Rose, *Oregon Support Services Association*
- Ross Ryan, *Oregon Self-Advocacy Coalition*
- Craig Santiago, *SEIU and CIIS Service Coordinator*
- Jen Wheelon, *Oregon Coalition of Small Provider Organizations*
- Stephanie Widler, *Oregon Family Networks*

State Agency Sponsors:

- Anna Lansky, Deputy Director, Oregon Office of Developmental Disabilities Services
- Lilia Teninty, Director, Oregon Office of Developmental Disabilities Services

Workgroup Facilitation and Reports:

- Sharon Lewis, Health Management Associates
- Sherrie Anderson, Support Development Associates
- Sarah Bain, independent contractor
- Elizabeth Tenney, Health Management Associates

APPENDIX B: Results from Online Survey, 2021

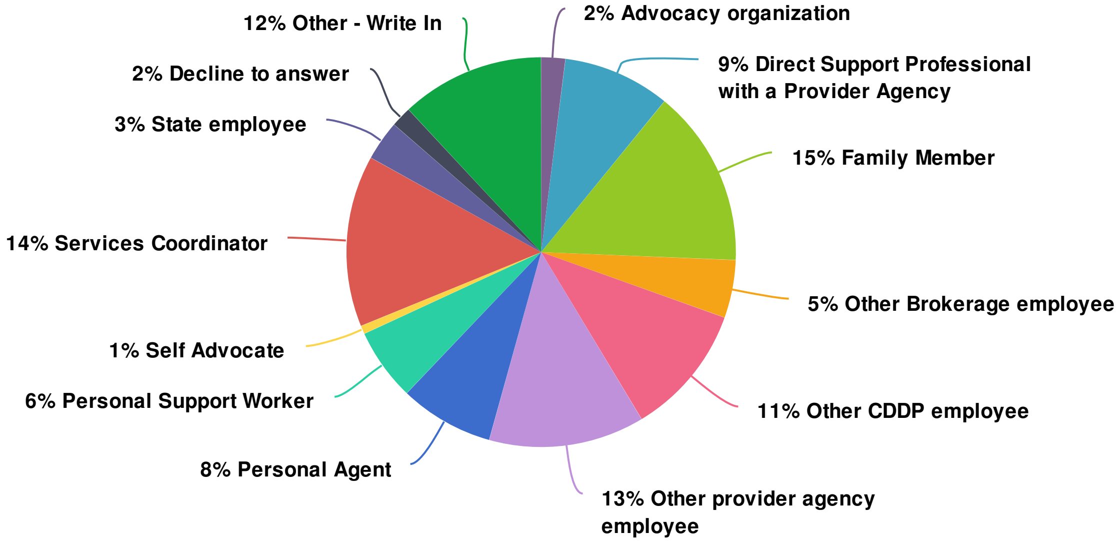
Summary Report for Office of Developmental Disabilities Services Case Management Blueprint Recommendations Survey

Response Counts

Completion Rate:	**100%**	
	Complete	688

Totals: 688

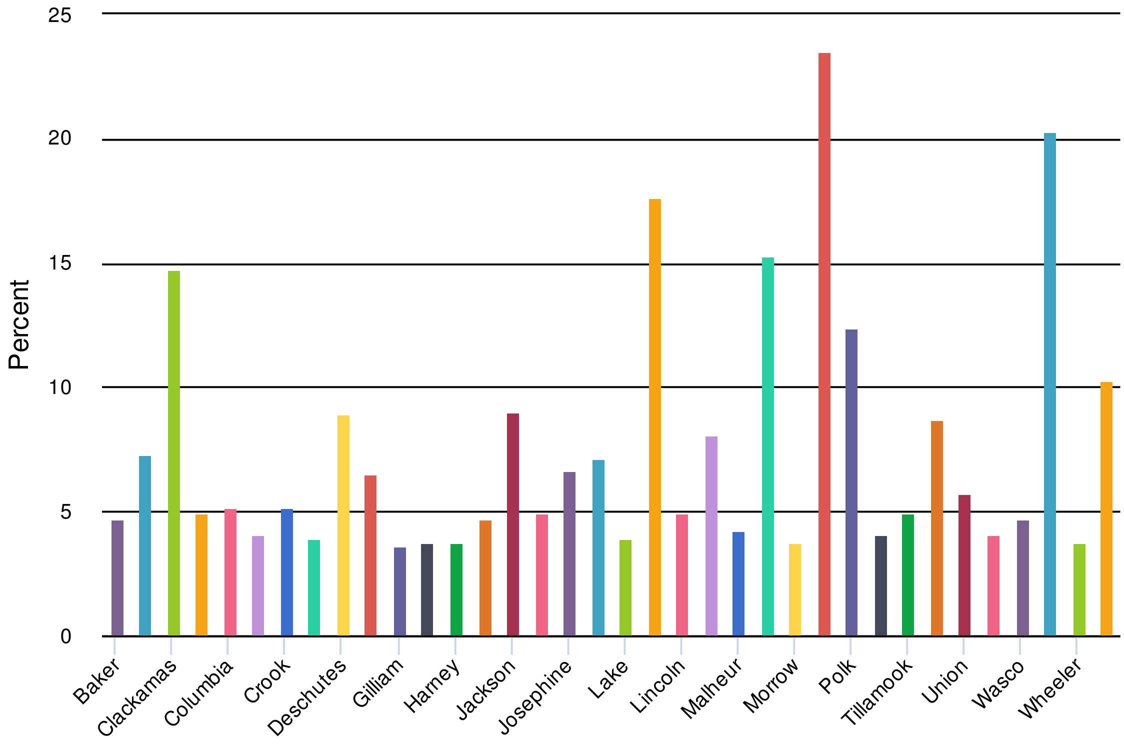
1. Please tell us your role as a ODDS Community Partner



Value	Percent	Responses
Advocacy organization	2.0%	14
Direct Support Professional with a Provider Agency	8.9%	61
Family Member	14.7%	101
Other Brokerage employee	4.8%	33
Other CDDP employee	10.9%	75
Other provider agency employee	12.9%	89
Personal Agent	7.8%	54
Personal Support Worker	6.0%	41
Self Advocate	0.7%	5
Services Coordinator	14.2%	98
State employee	3.3%	23
Decline to answer	1.7%	12
Other - Write In	11.9%	82
		Totals: 688

Statistics	
Total Responses	769

2. In which Oregon County(s) do you receive or provide services? (select all that apply)



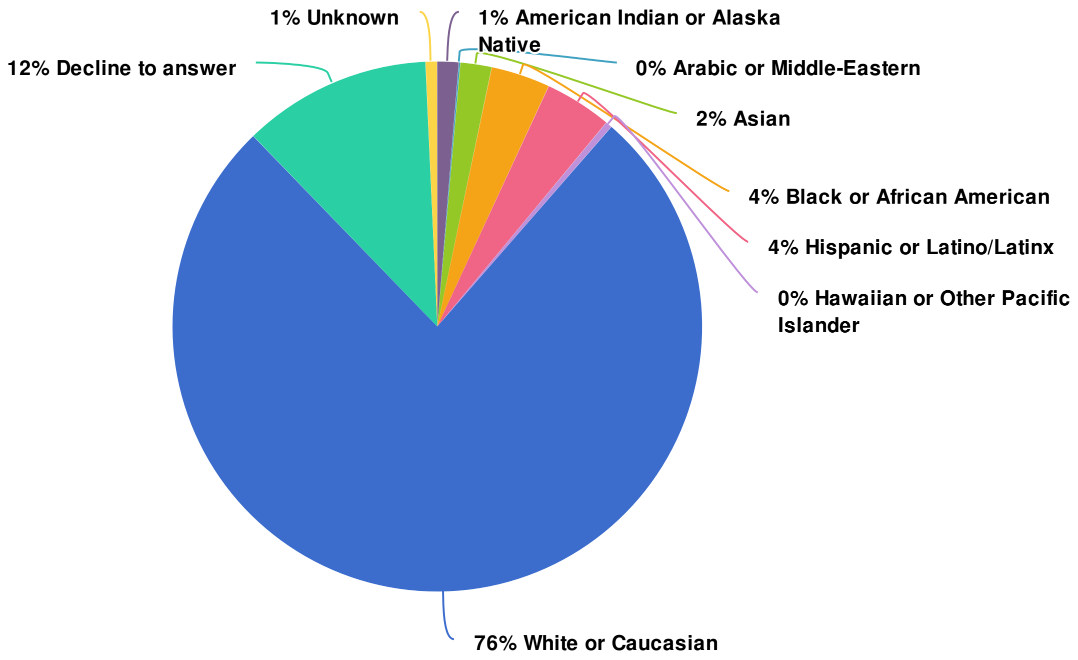
Value	Percent	Responses
Baker	4.7%	32
Benton	7.3%	50
Clackamas	14.7%	101
Clatsop	4.9%	34
Columbia	5.2%	36
Coos	4.1%	28
Crook	5.2%	36
Curry	3.9%	27
Deschutes	8.9%	61
Douglas	6.5%	45
Gilliam	3.6%	25
Grant	3.8%	26
Harney	3.8%	26

Value	Percent	Responses
Hood River	4.7%	32
Jackson	9.0%	62
Jefferson	4.9%	34
Josephine	6.7%	46
Klamath	7.1%	49
Lake	3.9%	27
Lane	17.6%	121
Lincoln	4.9%	34
Linn	8.1%	56
Malheur	4.2%	29
Marion	15.3%	105
Morrow	3.8%	26
Multnomah	23.5%	162
Polk	12.4%	85
Sherman	4.1%	28
Tillamook	4.9%	34
Umatilla	8.7%	60
Union	5.7%	39
Wallowa	4.1%	28
Wasco	4.7%	32
Washington	20.3%	140
Wheeler	3.8%	26
Yamhill	10.3%	71

Statistics

Total Responses	688

3. Please select the primary racial/ethnic group you most closely identify with: (please select one)



Value	Percent	Responses
American Indian or Alaska Native	1.3%	9
Arabic or Middle-Eastern	0.1%	1
Asian	1.9%	13
Black or African American	3.6%	25
Hispanic or Latino/Latinx	4.1%	28
Hawaiian or Other Pacific Islander	0.4%	3
White or Caucasian	76.2%	522
Decline to answer	11.5%	79
Unknown	0.7%	5
		Totals: 685

Statistics	
Total Responses	685

4. Need to clearly define and communicate the role and expectations of case managers in statewide policy. (A1)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	16 2.3%	21 3.1%	86 12.6%	305 44.7%	254 37.2%	682
Totals Total Responses						682

5. Need to clearly define and communicate the role and expectations of case managers in statewide policy. (A1) - comments

6. Improve the knowledge and skills of case management staff, including state competency-based qualifications and demonstration of person-centered thinking skills and knowledge. (A8)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	20 2.9%	25 3.7%	118 17.4%	288 42.4%	228 33.6%	679
Totals Total Responses						679

7. Improve the knowledge and skills of case management staff, including state competency-based qualifications and demonstration of person-centered thinking skills and knowledge. (A8) - comments

8. Develop access to technical assistance to support case managers with knowledge and resources that are challenging to develop within each individual case management entity. (A9)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	12 1.8%	14 2.1%	98 14.5%	312 46.0%	242 35.7%	678
Totals Total Responses						678

9. Develop access to technical assistance to support case managers with knowledge and resources that are challenging to develop within each individual case management entity. (A9) - comments

10. Develop a new service providing self-direction assistance, counseling, training, employer-of-record supports and related assistance for people working with personal support workers. (A10)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	24 3.6%	31 4.6%	154 22.8%	261 38.7%	204 30.3%	674
Totals Total Responses						674

11. Develop a new service providing self-direction assistance, counseling, training, employer-of-record supports and related assistance for people working with personal support workers. (A10) - comments

12. Develop a new service providing individualized community resource development, assistance with accommodations in integrated community participation, peer-to-peer navigation support, facilitation in establishing personal circles of support, and/or assistance in engaging with local non-disability organizations. (A10)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	24 3.6%	32 4.8%	168 25.0%	274 40.7%	175 26.0%	673
Totals Total Responses						673

13. Develop a new service providing individualized community resource development, assistance with accommodations in integrated community participation, peer-to-peer navigation support, facilitation in establishing personal circles of support, and/or assistance in engaging with local non-disability organizations. (A10) - comments

14. Establish a comprehensive statewide planning process to design and establish a unique and knowledgeable case management infrastructure for all children with I/DD, age birth to 21. (C22)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	16 2.4%	20 3.0%	172 25.5%	284 42.1%	183 27.1%	675
Totals Total Responses						675

15. Establish a comprehensive statewide planning process to design and establish a unique and knowledgeable case management infrastructure for all children with I/DD, age birth to 21. (C22) - comments

16. Create a separate, neutral, unbiased front door structure responsible for supporting intake, eligibility and enrollment in case management. (B20)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	35 5.2%	41 6.1%	183 27.0%	249 36.8%	169 25.0%	677
Totals Total Responses						677

17. Create a separate, neutral, unbiased front door structure responsible for supporting intake, eligibility and enrollment in case management. (B20) - comments

18. Eliminate the current restriction on case management choice based upon the type of services a person receives. (B15)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	29 4.3%	66 9.9%	227 33.9%	216 32.2%	132 19.7%	670
Totals Total Responses						670

19. Eliminate the current restriction on case management choice based upon the type of services a person receives. (B15) - comments

20. Ensure that every person has at least two choices of case management entities, including the ability to choose one CME with a customer-led governance structure. (B15)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	19 2.8%	46 6.8%	203 30.1%	267 39.6%	140 20.7%	675
Totals Total Responses						675

21. Ensure that every person has at least two choices of case management entities, including the ability to choose one CME with a customer-led governance structure. (B15) - comments

22. Set a consistent maximum caseload size for individual case managers, for all CMEs statewide. (B12)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	15 2.2%	23 3.4%	50 7.4%	251 37.0%	340 50.1%	679
Totals Total Responses						679

23. Set a consistent maximum caseload size for individual case managers, for all CMEs statewide. (B12) - comments

24. Provide cultural support and language access through a statewide/regional technical assistance structure, led and staffed by people of different cultural and ethnic communities, including interpretation and translation services. (C25)

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**	**Responses**
Scale Count Row %	9 1.3%	16 2.4%	104 15.4%	281 41.6%	266 39.3%	676
Totals Total Responses						676

25. Provide cultural support and language access through a statewide/regional technical assistance structure, led and staffed by people of different cultural and ethnic communities, including interpretation and translation services. (C25) - comments

26. Redesign the ISP process with a system-wide focus on person-centered plan development, participation and engagement. (D28)

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**	**Responses**
Scale Count Row %	24 3.5%	65 9.6%	162 23.9%	234 34.5%	193 28.5%	678
Totals Total Responses						678

27. Redesign the ISP process with a system-wide focus on person-centered plan development, participation and engagement. (D28) - comments

28. Invest in a centralized case management and communications platform that is person-centered, user-friendly and accessible to people receiving services, families (as applicable), case management, providers and state staff to share information and records securely and efficiently. (E36)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	13 1.9%	17 2.5%	97 14.3%	278 41.1%	272 40.2%	677
Totals Total Responses						677

29. Invest in a centralized case management and communications platform that is person-centered, user-friendly and accessible to people receiving services, families (as applicable), case management, providers and state staff to share information and records securely and efficiently. (E36) - comments

30. Establish and implement clear expectations, guidelines and standards for operating state stakeholder work groups. (F39)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	4 0.6%	10 1.5%	227 33.4%	297 43.7%	141 20.8%	679
Totals Total Responses						679

31. Establish and implement clear expectations, guidelines and standards for operating state stakeholder work groups. (F39) - comments

32. Require all case management entities to hold direct contracts with the state, without subcontracts through counties, to improve accountability and consistency. (G42)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	28 4.1%	38 5.6%	275 40.5%	181 26.7%	157 23.1%	679
Totals Total Responses						679

33. Require all case management entities to hold direct contracts with the state, without subcontracts through counties, to improve accountability and consistency. (G42) - comments

34. Develop quality assurance and performance measurement processes that incentivize person-centered outcomes and self-determination. (G43)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	18 2.7%	34 5.1%	192 28.5%	289 42.9%	140 20.8%	673
Totals Total Responses						673

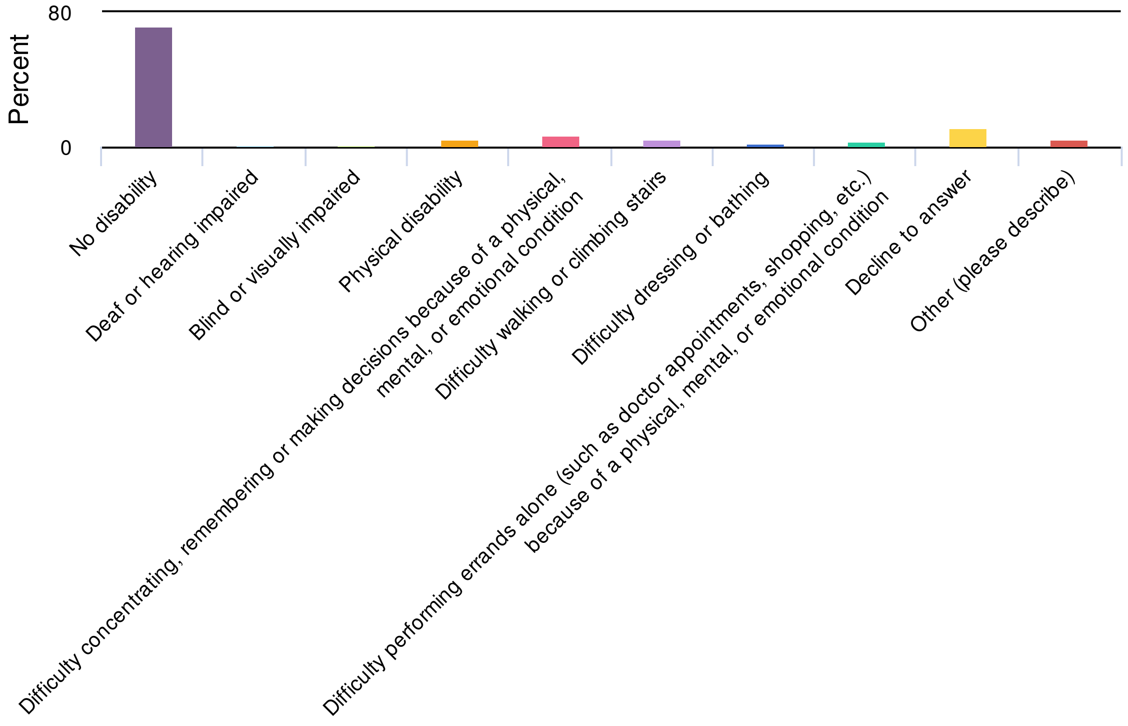
35. Develop quality assurance and performance measurement processes that incentivize person-centered outcomes and self-determination. (G43) - comments

36. Revisit how case management services are paid for by the state, with rates and a payment structure to support capacity, equity, quality and differences among people's needs. (G46)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Responses
Scale Count Row %	15 2.2%	14 2.1%	185 27.2%	282 41.5%	183 27.0%	679
Totals Total Responses						679

37. Revisit how case management services are paid for by the state, with rates and a payment structure to support capacity, equity, quality and differences among people's needs. (G46) - comments

38. Based on the definition above, please tell us whether you have a disability (select all that apply):



Value	Percent	Responses
No disability	72.2%	483
Deaf or hearing impaired	1.6%	11
Blind or visually impaired	1.2%	8
Physical disability	4.6%	31
Difficulty concentrating, remembering or making decisions because of a physical, mental, or emotional condition	7.2%	48
Difficulty walking or climbing stairs	4.2%	28
Difficulty dressing or bathing	1.9%	13
Difficulty performing errands alone (such as doctor appointments, shopping, etc.) because of a physical, mental, or emotional condition	4.0%	27
Decline to answer	11.5%	77
Other (please describe)	4.5%	30

Statistics	
Total Responses	669

39. Do you have any additional comments or feedback about the proposed ODDS Case Management Blueprint Recommendations to provide at this time?

APPENDIX C: Community groups feedback, 2021

Summary: ODDS Focus Groups (Fall 2021)

Family members of children: 55
Family members (unknown age of participant): 21
Family members of adults: 11
Self-advocates: 4

Overall, the focus groups expressed general agreement with the BluePrint recommendations. Participants were asked to discuss simplified versions of similar questions from the survey, reflected below. The majority of the narrative comments (see attachment) align with the information gathered in the 2018 surveys, meetings and focus groups.

There were no comments attributed to self-advocates in the feedback provided.

Themes from focus group comments

- Concerns about responsiveness and lack of communication, inconsistency
- Need for coordination with education and educational services
- Equitable access and treatment of people/families from various cultures
- Choice as an important value
- Interest in electronic communication and information platforms accessible to families
- Comments related to services, not case management

There were several questions where a significant number of participants did not agree or disagree.

Question	Agree	Disagree
Make sure that state policies are written so that case managers understand exactly what's expected.	100%	0%
Make sure case management staff have better training to do a good job, and they can show their skills to the state.	87.1%	0%
Invest in additional support that helps to make sure that case managers are doing good work for everybody, including help with housing, education, healthcare and more.	95.7%	0%
Create other organizations that can offer more support and training for people who choose to pick and hire their own personal support workers.	55.7%	0%
Start a new service to connect children and adults with local resources and support that fully includes them in community life.	40%	0%

Set a maximum number of people served (caseload) for all case managers so they have the time that they need to support each person.	72.9%	10%
Make sure that every person has at least two choices of case management providers, no matter where they live or what services they receive.	45.7%	4.3%
Make sure that one of these case management choices has people receiving services and families in charge of the organization.	44.3%	0%
Get rid of the rule that says some people have to work with county service coordinators while other people have to work with brokerage personal agents.	35.7%	0%
Create a friendly and welcoming “front door” system that makes it easy for people to find and access I/DD services.	100%	0%
Consider a new case management option designed just for children.	92.9%	5.7%
Provide resources to case managers to better support people from diverse backgrounds, making sure this effort is led and staffed by people from different cultural and ethnic communities.	100%	0%
Change the person-centered planning process to make it easier and more focused on the person and their goals.	100%	0%
Build an information-sharing and communication system that is easy to use and keeps private information safe, including access for people receiving services.	100%	0%
Set up standards and expectations around state workgroups to make sure all voices can be heard when there are big changes.	52.9%	0%
Make all case management organizations work with and report to the state, not just counties, to make sure they are doing a good job.	100%	0%
The state should decide whether a case management organization is doing a good job based on how the well the people they support are doing.	90%	0%
Change how case management services are paid for by the state - Funding should be fair and enough for case managers to do a good job with all people who all have different needs	42.9%	0%

Appendix: Comments from ODDS Focus Groups

- With the time it takes to communicate with them we lose continuity and there is no follow-up with problems
- My child's needs change, but they are so slow to react the needs change by the time you hear back anything.
- I don't want to answer case manager's phone calls. They only do renewal communications, and give no support during the year.
- I don't want the case manager to get paid for helping us anymore, when they don't. I received a call for renewal only, never calls to see how the child is, only the review.
- The type of work that they do is very bad. As a mom, I disagree with what they do. Just reviewing our kids every year is not helping.
- I get no communication. When I call, they don't return calls and we don't get any follow up with services. Why are they paying them for nothing good for our families
- I am not sure how many children they have under their care, and that would make a difference. They could be busy - but it would be nice it the state would employ people who are capable. Do we all go to the one Spanish speaking case manager? Is it too many kids for one case manager?
- I have heard a lot about the case managers complaining about the paperwork they have to fill out. They apologize about all of the paperwork, but that is takes too much of their time. Can they find a better way to process the paperwork faster so the case manager is available to help more?
- I like the idea that someone would work with only children, but that person needs to be trained properly.
- Services aren't provided in Spanish, and we are unable to communicate with them directly.
- It took me six years to get my child something we needed, with someone who spoke very little Spanish.
- Maybe I am ignored because I am Latina? We know they listen to you better if you are Caucasian. We are just ignored. What I see is if you are Caucasian your problems are solved quickly.*This was echoed by the group.
- We need people willing to work and support their community.

- They need to feel empathy for our kids.
- It is a joke what they do.
- Maybe they aren’t capable of serving their community.
- Us Latinas have to struggle and fight for our children’s benefits
- My son has received services for seven years and hasn’t advanced at all. What benefits does your child have a right to? What could benefit you and your child? What is missing? Where can you go? Right now my child is waiting to see if he can work somewhere but we have been waiting and waiting and never heard anything. His brother gave him a job and he is now 27 years old and working without the support of DDS. We never knew he had a disability. He always had an IEP but no one ever told us why. Susana Ramirez helped us get a diagnosis. Where are the other people that are supposed to help? Where is the equity employing someone that just speaks Spanish if they don’t know the services or respect us? It is our kids right to receive the same services as white kids. I knew a white lady who knew her rights and she always got services for her child. When my son graduated from high school (a year before) they told me we should only speak one language at home (when he was a senior). He ended up with a modified diploma which hasn’t helped him with his career. I never received information about transitioning from high school. School never referred him to DDS or mentioned anything other than his speech. The Doctor only asked if there was an IEP and assumed that was good enough. He speaks Spanish at home and he gets compensatory education after being connected with Susana. Where was DDS to help figure any of this out?”
- “I also have had very bad experience with a Service Coordinator. It took them over nine years to help my son. Susana Ramirez came out of nowhere and helped me.”
- “During the fires we needed support and they didn’t offer us anything. Why does my child have a case worker if they cannot do anything?”
- “I asked for help finding good swimming lessons for my child, and we didn’t receive any help. I want my child to socialize and be safe, but the swim lessons I sent my other kids to don’t work for my child with a disability and I don’t know where else to go. Why can’t they help us with this?”
- “I am asking myself why am I in this program? I do get calls regularly, some raffle information and something about someone giving away cards with

stipulations. We never qualify, so I don’t trust the case manager knows how to help us correctly and I don’t want to ask them for help with anything anymore.”

- “In my case, I disagree from the start. If we don’t know a person from the beginning, and someone just picked them for us, then they explain some services but they don’t know us good enough to know what we need, and they can’t really tell us how they can help, how can they help us with anything?”
- “I feel like I have no one helping me. My case manager does nothing for my child.”
- “Why do they offer a plan to help and then not implement any of the help
- “What is this service? How do they help people? I haven’t received anything. No support. What do they give?”
- “Let me know what to do, and I will do it myself. But I need to know what to do.”
- “Service Coordinators should specify what supports can be given to us, so we know what to ask for. Workers need to give us a better idea of what they’re there for so we don’t waste time asking for help with things they cannot help with. They seem useless.”
- “We have communication troubles. Everything is by phone, including our one-year plan. They just asked me to send a picture to see if my child has grown, they haven’t seen my child in person. How can they know the kids needs if they don’t know them? I need to communicate in person.”
- “They need to better explain what their program is about. They don’t provide information to understand what it is for. We need detailed information explaining specifically what is available for our children.”
- “So far, for me, I can’t get my son eligible or approved for DD Services. I have been working on that for nine years. I was recently recommended to take him to a local psychologist to get more testing. If I had that information a long time ago, he would have had services a long time ago. He was always just rejected, but we were not offered any reasons or additional steps to take to try again. It has need nine years since my first application and I disagree with how they managed that because I always knew my son had a disability and he always had an IEP at school. If they would have told me when he was seven that they needed certain specific things to get approved, I could have gotten them. But now that I hear everyone’s complaints, I see that there is no support for them so maybe it wouldn’t have made a difference. I have always paid for everything out of pocket. Some of the classes we thought he needed in the

past, he didn’t take because the teacher said it would be too difficult for my child. I would like more structured academic support at home, but it sounds like DD Services doesn’t offer educational support. I can imagine at some point you can get some benefits, but if you don’t know what they are then you’re completely blind. I want information to be very specific with advice to appeal because I think we have the right to do those things. They say we can appeal, but don’t tell us how to appeal.”

- “An app would be nice to see what we can use, communicate with our service coordinator, and there be a record that we contacted them and they didn’t respond.”
- “No more promises, we want actions!”
- “Someone should be monitoring them so that we know the work that they are doing is worth it.”
- “It would be a good idea to take into account if the case manager is doing a quality job.”
- “They need a check or checkup. Supervision is needed to make sure case managers are doing their job.”
- “When you don’t have a case manager that returns your calls or requests, is there someone you can call and ask how long you should wait to hear back? Who can you complain to when they don’t return your calls?”
- “Do they know each other? We don’t hear anything and if we complain do they tell each other?”
- “The Service Coordinator’s need to have an inspector, someone that is checking on them to see if they’re meeting their short term and long term goals with our kids.”
- “It would be a good idea to ask parents to review or vote on decisions before they set rules and laws.”
- “My child was not learning due to COVID and they needed support with school work at home because I don’t know how to help. A little help can make a big difference, but we didn’t get any.”
- “In order for me to help my child with their homework, it takes me an hour or two to just write it down. I need to translate everything in order to be able to understand. So I start working on her homework and then after we finish, we have to translate everything into English so she can turn it in. Her patience is

limited due to her disability. I would love for the education system and DD services to come together and work together. As parents we are speaking up and saying that is what we need."

- "Our case worker speaks Spanish so that wasn't the problem. We asked about education problems and the case manager sent us a phone number to call, but it didn't help and he never offered anything else. If he calls again, why should I respond?"
- "My child needs education help. Our Service Coordinator doesn't help. They can't fund anything at home that has to do with learning, but that is what we need help with because I do not know how to help with school work and they are behind because of their disability. My child was referred to tutors and it's not affordable."
- "Education support at home needs to be included." *The group echoed this sentiment.
- I strongly believe that choice advising, whether it is about choice of CME or out of home placement, should be done by a neutral 3rd party.
- Case management proportions are not good. I'm not getting anything out of CM except hours they must meet. They should direct and help and I'm not feeling that at all from CM.
- Communication in the end needs to be enhanced (hopefully with future technology ex. using same-system software) .
- I barely hear from DD Services except for when they need their common paperwork. It wasn't until we hit "crisis" mode in our family that we heard about Family Networks and other resources. CM needs to centralize communication and step up on resource recommendations
- Instead of CM supporting me, it has been more parents supporting parents, not getting information from the people that should be supporting us.
- "Will there be a waitlist if there is a cap on caseloads?"
- "Great goal but it's not happening. It's a loaded statement. Too many things in one thing. How can they implement that?"
- "Horrible if there would be a waitlist like other states."
- "We haven't been able to meet with a caseworker because of COVID, but they are very responsive over the phone and email. Because of them not meeting

in person, it doesn't feel like the caseworker knows my child." *This is echoed by several other parents.

- "Sounds great in theory, but what are the negative implications?"
- "Some of the logistical issues seem like they'd cancel out the good parts of the goal."
- "I would love to have options in Curry County, there aren't any currently
- "There aren't any other options in Jackson County. We would hate to lose our current case manager, so choice is very important. She's incredible and I'd hate to lose her. *This is echoed by several other parents who all love their current case manager. Turned out three children whose parents are participating in the focus group have the same case manager and were all assigned to her before COVID.
- "Loved the idea of choosing a case manager. We had a good one, but she moved on. Then we had a temporary one and now another new one, all within a year and a half. My child has never met his case manager and it doesn't feel like there's as much of a connection. Would love to have more options so there is some healthy competition."
- "There are little resources in Curry County, so there is nowhere to send my child." *This parent is having to create resources for her child with the help of the service coordinator because of lack of services. They mentioned several times how stressful the lack of resources is for their family.
- "Within the DD system, it would be nice to have choice. I'm assigned to the case manager for foster families and she doesn't have knowledge of special needs services. I know much more than she does because I have experience. I would love to have someone helping me who is knowledgeable."
- "Adult vs kid's coordinators are different, but sometimes they do both and they don't seem to know much about the kid's services when they are split."
- "Having to address lack of communication from SC's with them is awkward. Can we know who else to talk to when we are unhappy with our SC?"
- "Depends on the case manager as to what you can get. This is very frustrating."
- "I really love the children only portion. Early intervention is so important and I hear from my son's case manager that she was not allowed to refer him to EI.

She has to go through a whole process and it made it hard to easily help my family."

- "Strange goal. Seems like common sense and something that should already be in practice."
- "Should be doing it already, but I say its fine."
- "Some kids with the same diagnosis are getting different care and supports, even though they are experiencing the same thing. This is because of different case managers interpreting rules different ways, and having different levels of communication with different parents. Doesn't seem very equitable." *This was echoed by the group.
- Person Centered: "This one should have already been done."
- "What does making it easier to access services mean? For the service coordinator or for the parents or disabled person?"
- "When I think of them saying an "front" door policy, it's not ok to be in a tiny little office doing the DD Services paperwork with your child."
- "I feel like all the goals are good, but they all need to be more detailed with an action plan" *This sentiment was echoed by the group several times.
- "They need to think more about it being like a community center if it's going to be a front door system. What does this goal mean? What does that entail?"
- "There are many issues with retaining DSP's because of the restrictive rules and lack of things like pay when the client is sick. There are many barriers as to getting DSP's. There was also no action plan communicated to families when COVID hit. Should we have DSP's in our home? Should we pause?"
- "This needs to be treated like a legitimate career so we have access to quality DSP's."
- "If we have the hours from DD Services that they give us, what's the point if we can't find DSP's? Also, there isn't much help finding a DSP. Can service coordinators do better at this part?"
- "Having a drop in daycare or afterschool program that you can use your DSP hours. Most of these are not accessible to our kids. They could get social interaction and have one on one time with the DSP's to work on those social skills."

- “I have a friend who is seeking help but she’s just given the run around and long waits and she can’t get help. Why was my child easily approved and hers isn’t since our kids are similar?”
- “There is a real lack of consistency or basic knowledge on what people are eligible for. We’ve asked about funds for equipment and the case manager never seems to have an answer, and when we do get an answer its very “maybe”. Some other families I know get things I cannot, and vice versa. It makes no sense and isn’t person centered.” *This was echoed by the group several times again.
- “DD Services should be like an insurance policy - you know up front what you can use towards something.”
- “Write state policy that case managers have to know what funds are available at times.” *This is echoed by the group and several parents mention the COVID funds that some case managers knew about and some didn’t. Parents that needed help are frustrated that they didn’t know they could ask for it.
- “It’s going to be hard to do anything person centered when the case manager doesn’t know my family or my child.”
- “Special family dynamics and circumstances need to be evaluated for care. Not everyone fits in the same box of 2 parents or more or less siblings.”
- “There’s no consistency from one case manager to another”
- “It’s frustrating when you know that if you just had a different case manager you might get something you need.”
- “My son needs a stroller but I can’t get him one. I have a bad back and he’s 5 and I have to carry him everywhere, and a judge even overruled me getting help so I still don’t have one. I wouldn’t have wasted time and energy fighting the system it if I hadn’t had a friend that was approved for a stroller with a child that is more mobile than mine.’’ *Two other parents said they did get strollers through DD Services and this further frustrated the group due to the inconsistencies.
- “Anytime there are extra funds they need a universal way of telling people. Many people didn’t know about the extra COVID funds. Anytime there is a big announcement it needs to be centrally located for families and easily understandable.”
- “A DD Services app that would ping us with big announcements or information would be nice.”

- “It will be great to find out what they do with something that is centralized. I have to go on the Oregon.gov site and dig for forms because I don’t understand what they are asking me and I end up answering wrong on the spot. When I go back to speak with them they said I answered wrong to get more hours for PSW support or I’m already getting the max, but the form I found said something different. Again, why should I find something different than the case manager?”
- “Will it be a MyChart sort of thing?” *The group really liked this idea.
- “Communication network for supportive services for different specialists to communicate effectively as well as who is available for services. A database of this information is so needed. Things like making referrals easier. Centralized system for DSP’s with reviews from families.” *The group REALLY liked the idea of an app that DDS kept updated with vetted DSP’s, their specialties, and their availability with reviews from other families.
- “There was a lack of communication and our service coordinator thought Rever Grand was telling us about an hour increase and Rever Grand thought our service coordinator was, so we missed out on 5 months of over double extra hours a month because no one ever notified us. Who should have told us our hours increased?”
- “If you move county to county they don’t have a good way to talk to each other, and you have to start all over. This is really frustrating and silly.”
- “How are they currently measuring this? How would it change?”
- “What does the funding part mean?”
- “Like the idea of reporting to the state. They should be reporting to someone!”
- “Like that idea coming from a rural county because there’s a lot of nepotism currently.”
- “Better funding for caseworkers might mean less turnover.”
- “I am concerned that measuring performance would mean “fixing” our kids. Or providing more/less so the case managers could look like they are doing a good job. How would this be measured?” *The group all agreed with this thought and are very concerned on how a “good job” could be defined.
- “I personally think the goal of engagement is great, and the better the family interaction the better the systems will be.” *This was echoed by the group.

- “I feel like they don’t want parents to contribute as much as they want other caregivers, such as siblings.”
- “Excited to have representation of parents in leadership.”
- The state and CDDPs should keep staff retention rates high by providing enough training rather than having staff train on the job due to low staff numbers, offering job flexibility, and having strong leadership that will inspire and motivate staff to do a good job providing services.
- Staff should be trained in all cross sectors systems that involve people diagnosed with IDD, for example, the Supplemental Security Income benefits. Many families get letters in English of overpayments or other concerns, and families need assistance navigating that system. As well as getting familiar with school systems that write IEP’s and what is included in an IEP.
- New service coordinators should have in-depth training to understand what is included in each service plan, how much a family can spend, and what items.
- It is recommended that the state and local CDDPs establish a mentoring program between service coordinators. Service coordinators with more experience and a high satisfaction rate can mentor a new service coordinator for six months.
- Caseworkers should understand other cultures to best serve families based on their culture.
- Caseworkers should clearly understand the many barriers cultural families face, from immigration, low literacy, low income, lack of transportation, etc.
- It is recommended that Bilingual (Spanish) caseworkers only take Spanish-speaking families/clients; this helps them better focus on the population they serve.
- Even if cultural families do not ask questions, they like to be informed of any changes to prepare better rather than end in a crisis because their service plan changed.
- “create a uniform system county to county; we have PSWs/DSPs working in multiple counties and that should be a streamline”
- “… that too much advocacy, follow up, and work is left up to the family/individual. “I agree......the individual, their parents or

- advocates should not have to do all the work (strategy + paperwork) ---we have NEVER successfully been able to get all the BIDS necessary for adaptive equipment, home renovations, ramps, etc.”
- “families/individuals having to be ‘employers’ with little support for recruiting is difficult to impossible. It’s hard on case managers to do this. Create a PSW/DSP county roles to alleviate this burden”
- “Zoom’s increased accessibility, families/individuals need tech support”
- “You cannot make choice or know you have it, if you don’t know what’s out there, it is not coming from case management”
- “Everyone receives different information and is at the mercy of a case manager’s time, willingness, and ability”
- “Improve the language, “Case Manager” wrong terminology, clients are not looked at as people.”
- “expressed a lack of access to services. Case management could be more knowledgeable. There is so much that we are all missing out on.”
- “We have excellent communication. Don’t want more regulation because more paperwork takes away time from my daughter”
- “Case management leaves everything up to the parent. ONLY authorizing services, NOT helping through system”
- “high turnover creates many layers of problems”
- “standard of practice county to county should match”
- “…feels that she has no choice over case management. High turnover with case managers and they have lack of knowledge and are not as helpful as they could be. She is doing most of their work herself and frequently purchases her own needed supports instead of going through the long process that they require to grant her the needed items.”
- “DD Advisory groups could play bigger accountability role, and should”
- “ABSOLUTELY, the STATE needs to make the brokerages accountable, especially about protection & advocacy issues. Counties on the coast are too close to the people involved and DD issues are statewide rather than county specific. I have a 22 daughter with I/DD issues who has NOT received her

services through the brokerage who is being PAID to help her ---why should they be paid more just because she managed to survive from 18-22 without their help. This is where ACCOUNTABILITY should be inserted into these Goals."

- "Families with children in case management are more dissatisfied than adults… or…are adults less informed?"

- The participating families stressed the importance of structure for both communication with CM and information about the services that CM's provide and that their children are eligible for. They would have been happy to receive a list of services they are eligible for once they were assigned a CM. Right now most of the information that has been useful for them has come from other parents and social media groups.

- Even the family that has started working with a CM does not know exactly what CM's can and can not help them with, what CM's job description is, and how to find the list of services that their child is eligible for. So far the CM told them only about the K-plan, the Behavior specialist, and the money that is available to spend on items their child needs. However, out of these 3 services, the family only started using the K-plan (and that required information they had to get from other parents to set up), they have not yet met with a Behavioral specialist (scheduling and paperwork requires a lot of time), the things they need for their child have not been met with understanding from the CM—the CM has offered things the child does not need (like a communication device) but did not provide information about other things that can be obtained for the child that the child actually needs. The family does not know if they and their child are eligible for other services and they don't know how to find this information. They would like regularly scheduled meetings with the CM to learn about new services/events for their child, ask questions, etc. They also don't know if they can change their CM and how that process would work. The family that has not yet been assigned a CM reported that they got stuck in the application process and don't know who to contact for support and where they are in the process.

APPENDIX D: Case Management Stakeholder Engagement Report, 2019

HEALTH MANAGEMENT ASSOCIATES

Stakeholder Perspectives on Oregon Case Management Services

PREPARED FOR
OREGON OFFICE OF DEVELOPMENTAL DISABILITIES SERVICES

BY
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MAY 2019

Research and Consulting in the Fields of Health and Human Services Policy, Health Economics and Finance, Program Evaluation, Data Analysis, and Health System Restructuring

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Appendices

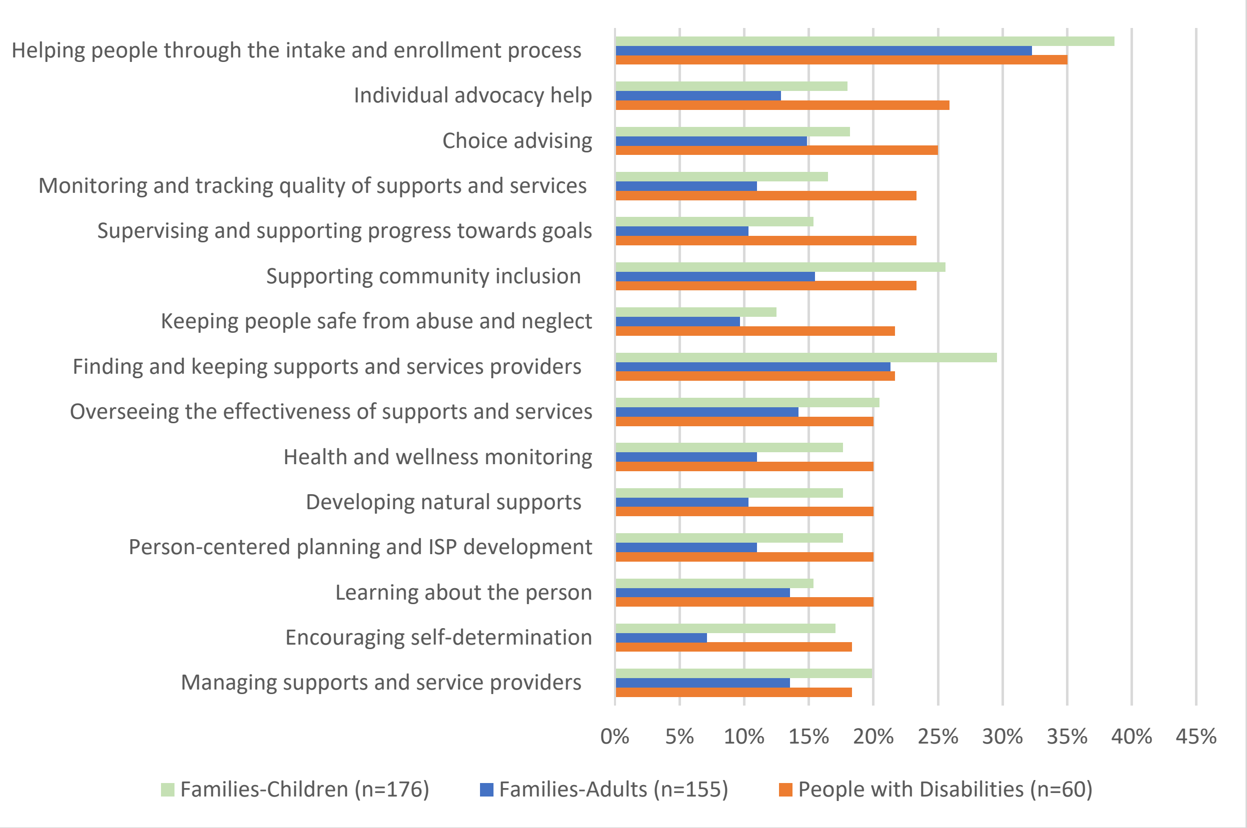
Appendix A: First Person Survey

Appendix B: Written Questions to Case Management Entities

Background

In fall of 2018, the Oregon Office of Developmental Disabilities Services (ODDS) contracted with Health Management Associates (HMA), in collaboration with the National Association of State Directors of Developmental Disabilities Services and Support Development Associates, to assess the Oregon Case Management System for people with intellectual and developmental disabilities (I/DD), and to develop recommendations based upon policy and program analysis and stakeholder feedback.

As one component of this effort, HMA sought to gather the perspectives of many stakeholders across the state through interviews, focus groups, meetings and surveys/questionnaires, focusing primarily on the various functions of case management as experienced by the people who rely upon supports. This process included a comprehensive statewide survey, which formed the basis of much of the quantitative data. For example, people receiving supports, and their families, were asked which case management activities they would like to see improved, expanded or enhanced:



Much more detailed and nuanced feedback is summarized in the following pages, collected from over 1,000 stakeholders through multiple processes supporting both qualitative and quantitative responses.

The information contained in this report is currently (as of May 2019) being reviewed and considered by the Oregon Case Management Blueprint Workgroup to inform the development of priority recommendations. A final report representing all of the elements of the project, including this stakeholder report, a policy gap analysis, and recommendations from the Blueprint Workgroup, is scheduled to be completed later this year.

Stakeholder Engagement: Approach and Methodology

The stakeholder engagement process sought to explore what is working well, and what could be better, in the Oregon case management system for people with intellectual/developmental disabilities (I/DD). There were six key components to this stakeholder engagement process:

A. Review of prior stakeholder input documents (2015-2018);[1]
B. Interviews with key informants;
C. Meetings with advocacy and association groups;
D. Oregon 2019 Survey on I/DD Case Management Roles and Responsibilities;
E. Focus groups; and
F. Written questions to case management entities (CMEs).

Prior stakeholder feedback reviewed for this process included documents sharing viewpoints from people with I/DD, families, associations, the Oregon Developmental Disabilities Coalition, and prior state stakeholder meetings. The processes for other information gathering from stakeholders is described, below. Stakeholder engagement prioritized statewide regional representation, diversity across types of case management, varied experiences with the system (including cultural perspectives, service settings and length of time receiving services), as well as efforts to create multiple opportunities for a wide range of perspectives to be shared.

Interviews with Key Informants

Health Management Associates (HMA) worked with ODDS to develop a list of over fifty individuals and organizations representing various experiences

A WORD ABOUT WORDS

When talking or writing about people, we believe in using respectful language that honors their preferences, and we understand that each person may have a different view on what constitutes culturally sensitive and respectful language.

For purposes of this report, we have chosen the following terms and approaches for consistency and simplicity. We do not intend these choices to infer any particular bias.

- **Customers:** People with I/DD who receive supports and services, as well as their family members and guardians, are referred to as "customers" when we are discussing this combined group of stakeholders as a whole.
- **Families and guardians:** In order to maximize readability, we have incorporated the survey data from "guardians of adults" into "families of adults" and "guardians of children" into "families of children," unless otherwise noted.
- **Professionals:** The survey required respondents to identify their "role," including direct service providers, case managers/CME staff, and advocates. To keep it simple, we have combined these roles under the umbrella of "professionals" when we are referring to all of the "non-customer" respondents.
- **Case Managers:** In Oregon, professionals who implement case management responsibilities are called "Service Coordinators" and "Personal Agents" but to simplify, we often refer to all as case managers throughout this document.

When there is a distinct difference in the perspectives and/or the data, we are careful to acknowledge the unique feedback from these different groups explicitly.

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[1] Documents provided by ODDS and other stakeholders included notes from stakeholder meetings, AOCMHP DD Options for Case Management Models (2016), Oregon Support Services Association Vision (2016), DD Coalition recommendations on Case Management, (2016), family and self-advocate focus groups summaries (2016), Features of Family-Friendly Case Management paper (2018).

with the Oregon I/DD case management system, including self-advocates, parents, service providers, case managers, educators, clinicians and representatives from advocacy organizations and community resources. The key informants came from multiple regions of the state, and included perspectives from people who are often underrepresented, such as those from the immigrant/refugee community. HMA conducted twelve 1:1 interviews, assuring the confidentiality of the discussions in order to encourage candor. Summary feedback from these interviews has been incorporated in this report, without attribution.

Meetings with advocacy groups and associations

HMA attended meetings with multiple organizations to discuss the Case Management Assessment project and gather input on both the project process and outreach, as well as hearing from stakeholders about case management for people with I/DD in Oregon in an open-ended discussion. Approximately 95 people participated in these meetings. Groups included the Oregon Self Advocacy Coalition, the Sustaining Families Committee of the Oregon DD Coalition, the Oregon Support Services Association, the Association of Oregon Community Mental Health Programs Developmental Disabilities group, and the Oregon Resource Association. Additionally, the Oregon DD Coalition provided feedback from recent discussions specific to case management.

Oregon 2019 Survey on I/DD Case Management Roles and Responsibilities

HMA designed and conducted a statewide survey in collaboration with the Oregon Office of Developmental Disabilities Services (ODDS). The National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Supports Development Associates (SDA) also reviewed the draft survey and provided input. Questions were designed to elicit feedback about the experiences of people who rely upon case managers, and to understand how people perceive the activities and functions performed by case managers. HMA used Qualtrics, an online survey tool, to create and disseminate the survey. A paper version of the survey in English and Spanish was also made available upon request and distributed at a small number of events.

Surveys were developed with the respondent in mind, as shown in Table 1. If the survey was being answered by an adult with I/DD, questions were designed in the first person. If the survey was being answered by a family member/guardian of a person with I/DD, questions referenced their family member with I/DD or themselves. For professionals, questions were designed so that they responded more broadly regarding the experiences of people with I/DD and their families.

The second customization that occurred in the survey design was the reference to the case management type. For example, if a survey respondent said they worked with a personal agent, all questions were customized so it asked about their personal agent. (see Appendix A for Survey Questionnaire). See following examples in Table 1.

Table 1: Example Customization of the Survey per Respondent Type

Respondent Type	Survey Question
Adults with I/DD	• I picked my case manager. • I get the help I need from my case manager to navigate the system.
Family members/guardians of adults with I/DD	• My family member with I/DD picked their case manager. • My family member with I/DD gets the help they need from the case manager to navigate the system.
Family members/guardians of children with I/DD	• My family picked my family member's case manager. • Our family gets the help we need from the case manager to navigate the system.
Professionals (Case Management Staff, Service Provider Staff, Advocacy Organizations)	• Adults with I/DD usually pick their case manager. • People with I/DD and their families get the help they need from case management to navigate the system.

Upon launch, ODDS distributed the link to the survey electronically through the state's email list, with a message from the Director. The survey was also promoted through email and social media platforms by the Oregon Council on Developmental Disabilities, case management entities, family networks, advocacy groups, and service providers, along with information explaining the survey's intended audience and purpose. Additionally, ODDS mailed an invitation to participate in the survey to the homes of a representative demographic sample of over 2600 recipients of I/DD case management services across the state. Representation in the state sample of mailer recipients considered age, race/ethnicity, language, geographic location, and type of case management.

The survey was open for seven weeks from January 29, 2019 to March 15, 2019. As shown in Table 2, a total of 981 individuals answered at least one question, of which 73% (n=712) completed the full survey. Of those who completed the full survey, 65% (n=460) were customers and 35% (n=252) were professionals.

Table 2: ODDS Case Management Survey Demographic Data for Respondents

	Completed Surveys	Proportion (Completed)	Partial Surveys	Total Responses
SUBTOTAL: CUSTOMERS	**460**	**65%**	**185**	**645**
People with I/DD	71	10%	16	87
Families/Guardians - Adults	194	27%	65	259
Families/Guardians - Children	195	27%	104	299
SUBTOTAL: PROFESSIONALS	**252**	**35%**	**84**	**336**
CDDP Staff	65	9%	11	76
Brokerage Staff	60	8%	8	68
Service Providers	91	13%	32	123
Other	36	5%	33	69
TOTAL SURVEY PARTICIPANTS	**712**	**100%**	**269**	**981**

Demographics of Customer Respondents

Case Management Type

Of those who completed the survey, there was approximately an even split between adults who work with CDDP service coordinators and those who work with Brokerage personal agents. Specifically, among adults with I/DD:

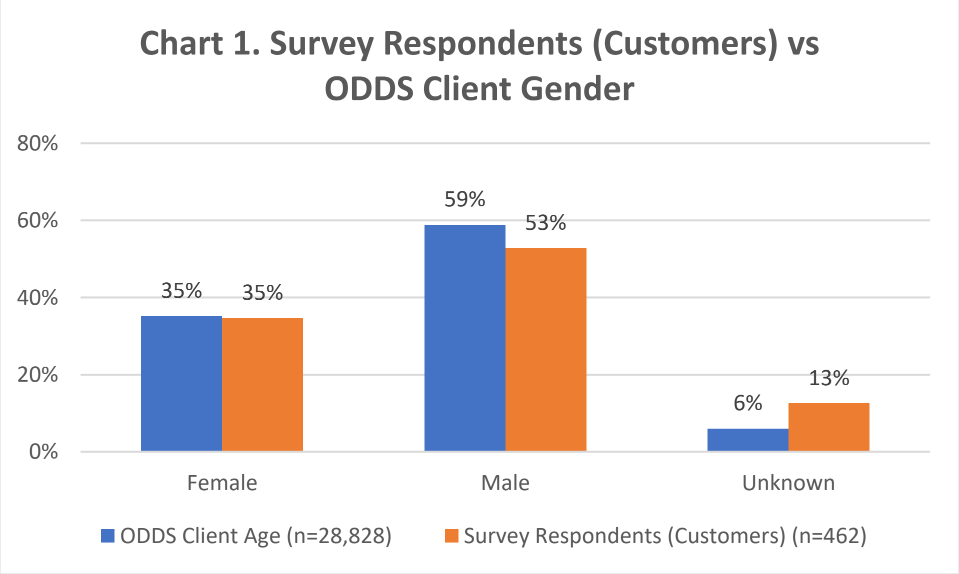
- 44% (n=31) work with CDDP service coordinators;
- 39% (n=28) work with Brokerage personal agents; and
- 17% (n=12) do not know what kind of case manager they have.

Among families/guardians of adults with I/DD:

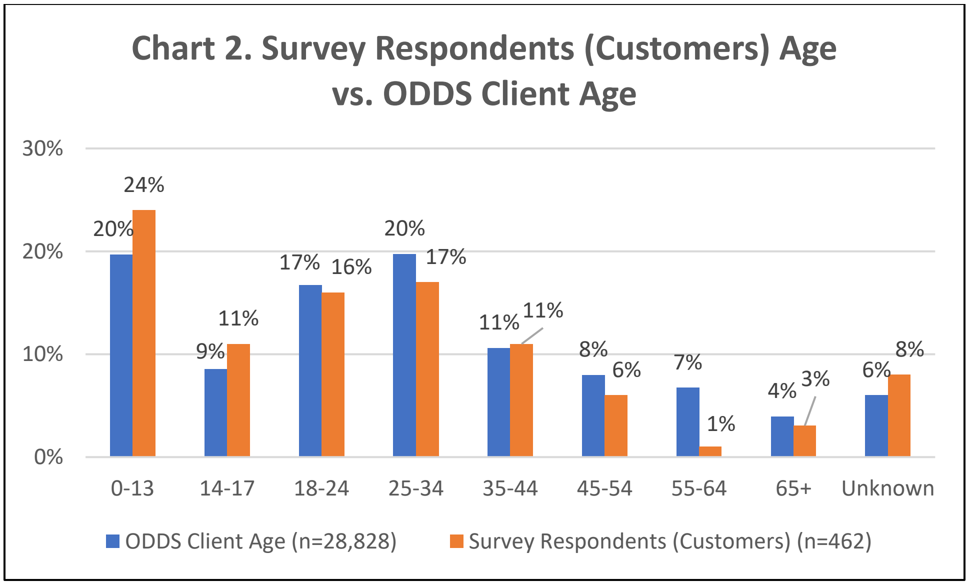
- 46% (n=90) work with CDDP service coordinators;
- 49% (n=96) work with Brokerage personal agents; and
- 4% (n=8) do not know what kind of case manager they have.

Age and Gender of People with I/DD

Survey participants were asked to report the age and gender of the person with I/DD. As shown in Chart 1, more than half (57% or 244) of the survey participants responded male, with another 37% (n=160) responding female. Six percent (n=24) preferred not to report their gender. There are similar proportions of gender type between survey respondents and ODDS clientele, but survey results may slightly under represent males.

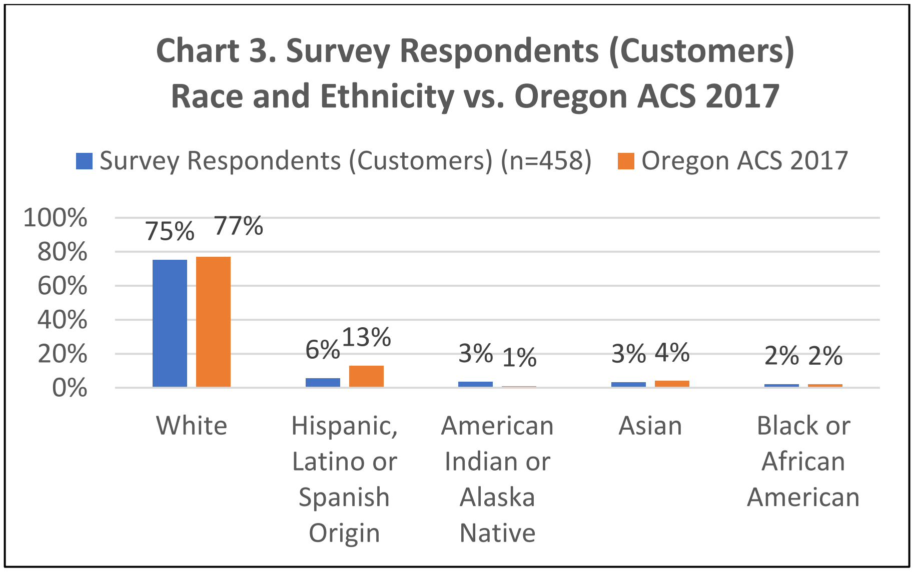


As shown in Chart 2, more than one third (38% or 159) of people with I/DD represented in the survey (usually by family members) were age 17 or younger. People with I/DD who are young adults (age 18 to 24) represented 18% (n=76) of the survey respondents, with 19% (n=80) representing ages 25 to 34 and 12% (n=51) representing ages 35 to 44. Ten percent (n=43) of respondents represented people with I/DD who were 45 years or older. There are similar proportions of age groups between survey respondents and ODDS clientele. However, survey results may over-represent customers ages 17 and younger, while under representing those older than 18 years of age.



Race and Ethnicity

Survey participants were asked to report the race and ethnicity of the person with I/DD they were representing, as shown in Chart 3, compared to Oregon's population in 2017. Three quarters of people (n=343) selected white. Thirteen percent (n=66) of respondents identified some other race and ethnicity, including Hispanic, Latino or Spanish (5% or 25), American Indian or Alaska Native (3% or 16), Asian (3% or 15) or Black or African American (2% or 10). There are similar proportions of race and ethnic groups between survey respondents and Oregon American Community Survey (ACS) in 2017. However, survey results may under-represent customers of Hispanic, Latino, or Spanish origin.



Main Language Spoken at Home

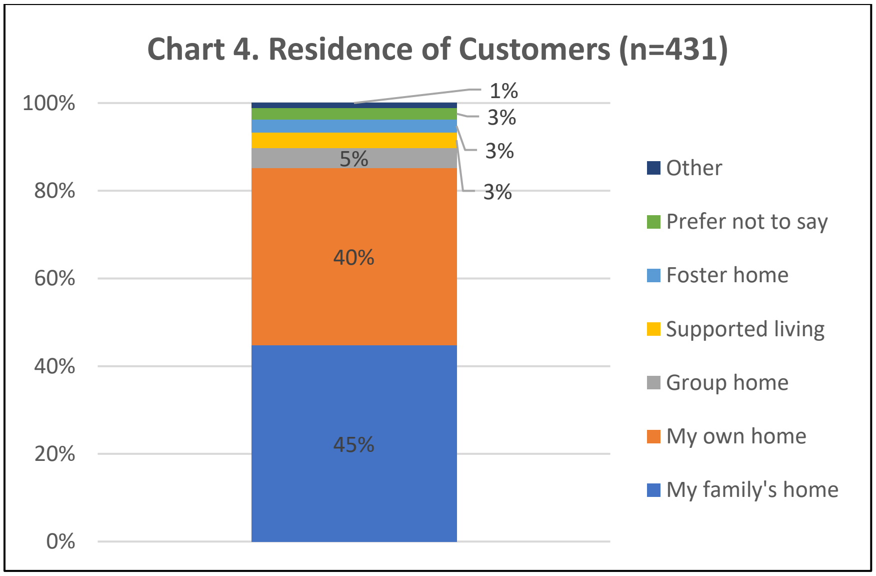
Seven percent (n=36) of survey participants reported they mainly spoke a language other than English at home. Specifically, 2% (n=9) use sign language and another 1% (n=4) each speak Spanish, Vietnamese, Arabic, or Cantonese. Two percent (n=9) of respondents who reported "other" indicated the person with IDD was "nonverbal" or "does not speak."

Length of Time with Oregon DD Services

Of those who provided the information, 20% (n=84) of customers started services before 2001 and 31% (n=132) of customers started receiving services between 2001 and 2013. Another 29% (n=126) of customers enrolled sometime after July 2013, when Oregon implemented the Community First Choice Option (the "K plan") and opened services to more children under age 18. Fifteen percent of customers reported that they did not know when they started receiving services, with another 5% (n=20) preferring not to say.

Residence

Of respondents who provided the information, nearly all (95% or 367) indicated that the person with I/DD they represented lived in their own home or in their family's home, as shown in Chart 4. Another 5% (n=20) indicated they lived in group home, followed by 3.5% (n=15) in each in supported living or 2.6% (n=11) in a foster home. Four percent (n=16) of customers responded "other" or preferred not to say. People receiving residential services are under-represented in the survey responses.



Geography

Survey participants were asked to provide a zip code of where the person with I/DD lives, as reflected in the table below, compared to the proportion of state residents in that county.

County	2017 Population	Proportion State Pop	Customer Responses	Proportion Respondents
Baker County	15,980	0.40%	2	**0.48%**
Benton County	88,249	2.19%	10	**2.41%**
Clackamas County	399,962	9.94%	67	**16.14%**
Clatsop County	38,021	0.94%	9	**2.17%**
Columbia County	50,207	1.25%	8	**1.93%**
Coos County	62,921	1.56%	4	**0.96%**
Crook County	21,717	0.54%	0	**0.00%**
Curry County	22,377	0.56%	0	**0.00%**
Deschutes County	175,321	4.36%	35	**8.43%**

County	2017 Population	Proportion State Pop	Customer Responses	Proportion Respondents
Douglas County	107,576	2.67%	12	**2.89%**
Gilliam County	1,910	0.05%	0	**0.00%**
Grant County	7,209	0.18%	0	**0.00%**
Harney County	7,195	0.18%	0	**0.00%**
Hood River County	22,938	0.57%	2	**0.48%**
Jackson County	212,070	5.27%	27	**6.51%**
Jefferson County	22,707	0.56%	3	**0.72%**
Josephine County	84,514	2.10%	12	**2.89%**
Klamath County	66,018	1.64%	3	**0.72%**
Lake County	7,807	0.19%	0	**0.00%**
Lane County	363,471	9.03%	20	**4.82%**
Lincoln County	47,307	1.18%	0	**0.00%**
Linn County	121,074	3.01%	7	**1.69%**
Malheur County	30,421	0.76%	1	**0.24%**
Marion County	330,453	8.21%	25	**6.02%**
Morrow County	11,153	0.28%	0	**0.00%**
Multnomah County	788,459	19.59%	76	**18.31%**
Polk County	79,666	1.98%	8	**1.93%**
Sherman County	1,635	0.04%	0	**0.00%**
Tillamook County	25,840	0.64%	4	**0.96%**
Umatilla County	76,736	1.91%	13	**3.13%**
Union County	25,810	0.64%	3	**0.72%**
Wallowa County	6,864	0.17%	0	**0.00%**
Wasco County	25,687	0.64%	0	**0.00%**
Washington County	572,071	14.21%	54	**13.01%**
Wheeler County	1,415	0.04%	0	**0.00%**
Yamhill County	102,366	2.54%	10	**2.41%**
TOTAL	4,025,127	100.00%	415	**100.00%**

Demographics of Professional Respondents

Length of experience

Nearly two thirds (64% or 217) of professionals who responded to the survey reported they started working in DD services after 2001, of which about half (n=108) started after July 2013. One quarter of professionals who responded have been working in the field since at least 2001.

Language Spoken with Clients

All professionals who responded to the survey speak English with their clients. Of these professionals, 8% (n=26) reported that they also spoke Spanish, followed by 7% (n=22) who also used sign language. Approximately 3% (n=6) of professionals reported speaking another language, including Mandarin, Russian, or French with their clients (as well as English).

Geography

Professionals were asked where they provide services, based upon zip code, as reflected in the table below, compared to the proportion of state residents in that county.

County	2017 Population	Proportion State Pop	Professional Responses	Proportion Respondents
Baker County	15,980	0.40%	1	**0.33%**
Benton County	88,249	2.19%	6	**1.99%**
Clackamas County	399,962	9.94%	16	**5.30%**
Clatsop County	38,021	0.94%	4	**1.32%**
Columbia County	50,207	1.25%	7	**2.32%**
Coos County	62,921	1.56%	2	**0.66%**
Crook County	21,717	0.54%	3	**0.99%**
Curry County	22,377	0.56%	0	**0.00%**
Deschutes County	175,321	4.36%	26	**8.61%**
Douglas County	107,576	2.67%	5	**1.66%**
Gilliam County	1,910	0.05%	0	**0.00%**
Grant County	7,209	0.18%	2	**0.66%**
Harney County	7,195	0.18%	0	**0.00%**
Hood River County	22,938	0.57%	3	**0.99%**
Jackson County	212,070	5.27%	11	**3.64%**
Jefferson County	22,707	0.56%	1	**0.33%**
Josephine County	84,514	2.10%	6	**1.99%**
Klamath County	66,018	1.64%	2	**0.66%**
Lake County	7,807	0.19%	1	**0.33%**
Lane County	363,471	9.03%	19	**6.29%**
Lincoln County	47,307	1.18%	2	**0.66%**
Linn County	121,074	3.01%	5	**1.66%**
Malheur County	30,421	0.76%	1	**0.33%**
Marion County	330,453	8.21%	32	**10.60%**
Morrow County	11,153	0.28%	0	**0.00%**
Multnomah County	788,459	19.59%	57	**18.87%**
Polk County	79,666	1.98%	10	**3.31%**
Sherman County	1,635	0.04%	0	**0.00%**
Tillamook County	25,840	0.64%	3	**0.99%**
Umatilla County	76,736	1.91%	21	**6.95%**
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Wallowa County	6,864	0.17%	2	**0.66%**
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Yamhill County	102,366	2.54%	7	**2.32%**
	4,025,127	100.00%	302	**100.00%**

Focus Group Discussions

HMA worked collaboratively with case management entities, service providers, family organizations, and educators to identify people to participate in a series of focus groups across the state. Outreach was conducted through known relationships (eg, case managers and service providers helped invite clients, school staff helped invite families, advocates invited people receiving supports). Organizations were asked to help recruit and support people who are less often involved in advocacy or stakeholder engagement efforts, and people new to providing systems feedback, to try to include others beyond the people who frequently speak up from the advocacy community. Focus groups were loosely organized by common experiences, such as adults living in 24/7 residential settings, families of preschool age children, adolescents/young adults with I/DD, Spanish-speaking families, or families who included a member with I/DD who has received services for decades.

HMA, with assistance from NASDDDS and SDA, developed an outline and approach to the focus group discussions to encourage engagement from all participants, drawing upon person-centered planning facilitation. Groups were asked to offer ideas on the ideal or “dream” life for Oregonians with I/DD and their families, and then to talk about how to navigate to that vision, and who/what helps along the way. After identifying these expectations, participants offered their opinions about what is -- and is not -- working in the case management system, and their ideas for improvements and priorities.

A total of 15 focus groups were conducted with 104 participants from many parts of the state, with eleven different counties represented. Of these participants, 51% (n=53) were people with I/DD and 49% (n=51) were family members of people with I/DD. The groups included multiple generations of families (the age of the person receiving supports ranged from 11 months to 63 years), with parents, siblings, and grandparents all sharing their thoughts. People with I/DD, ranging in age from 15 to 79, contributed important perspectives about their experiences.

Written Questions to Case Management Entities

Upon completion of the focus groups, HMA drafted a set of written questions for the CMEs, which were emailed to program leadership in each organization. There were 10 questions, covering case management practices and processes at the local level, with several questions derived from issues arising in the initial feedback from the survey and the focus groups. The CMEs were also given the opportunity to share their best practices, and to describe barriers and challenges. Fourteen entities (out of 42) responded to the request. (The questions are included in Appendix B).

Combined Findings

Taken together, the findings from the survey, focus groups, advocacy and association group discussions, and case management entities responses begin to tell a collective story of case management services in Oregon. Specifically, the information included in stakeholder engagement data analysis focused on understanding the experience of several case management functions by both people with I/DD and their family members. The information has been organized into the following groups of functions, acknowledging that the activities are interdependent and related, and not easily separated.

A. Enrollment and Choice
B. Accessible assistance, communication, reliability and trust
C. Person-centered thinking and planning; Self-determination
D. Systems and Resource Navigation; Community Capacity Development and Connections
E. Oversight and Monitoring; Follow Up Activities

The key findings are presented as complimentary to one another. The survey provides quantitative and qualitative data points on the experiences of people, while the interviews, focus groups, meetings with advocacy and association groups, and responses from case management entities created an opportunity for context and deeper understanding.

Limitations

There are some limitations to the stakeholder engagement feedback. Participation in all aspects of the process was voluntary for all respondents, including case management entities. Therefore, those who chose to participate were self-selecting, resulting in the potential for findings that may differ from the group of people who chose not to participate, and demographics that do not completely align with those of the 28,000 Oregonians who receive I/DD services. Another limitation was the heavy reliance on an electronic survey tool, which may have influenced the participation. ODDS does not have the means to communicate with all participants in case management services electronically (e.g. limitation of accurate email addresses). To try to overcome this limitation, a postal mailing was distributed to over 2600 recipients of I/DD case management services across the state, inviting a representative sample to participate in the survey. Additionally, difficulty in soliciting full participation in focus groups during hazardous winter weather on relatively short timeframes resulted in smaller turnout in some groups. Finally, the volume of responses and information received did not allow for all feedback to be included, but comments from a wide range of sources were selected as representative perspectives for inclusion in this summary.

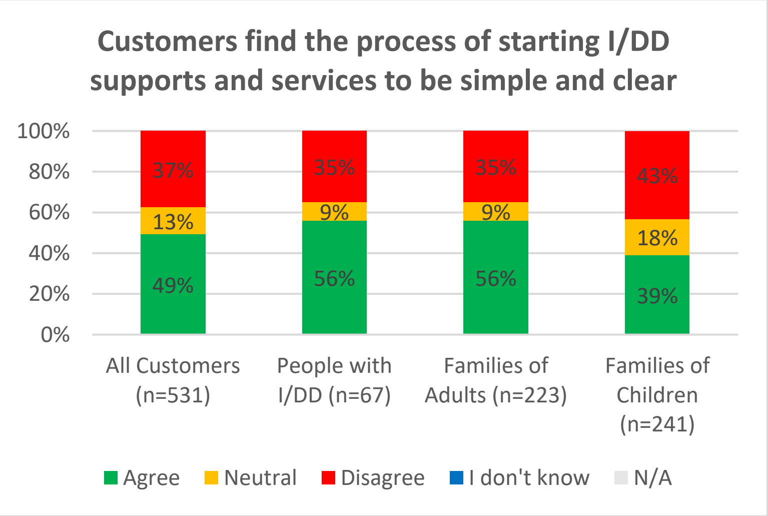
A. Enrollment and Choice

Summary

- Enrolling in services is not easy and clear for many people
- People would appreciate online information about both case management and services
- Many people do not understand their case management choices
- People are often unable to exercise individual choice among case managers
- Unrequested changes in case managers are disruptive
- While both are important, having a longer relationship with a case manager is more valued than specialized knowledge
- When people have a good relationship with their case manager, they want to keep them, especially through periods of change and transition
- Many people do not feel that case managers help them understand their service and support options, especially among families of children
- People would like more information about service providers and service options

Getting started with services

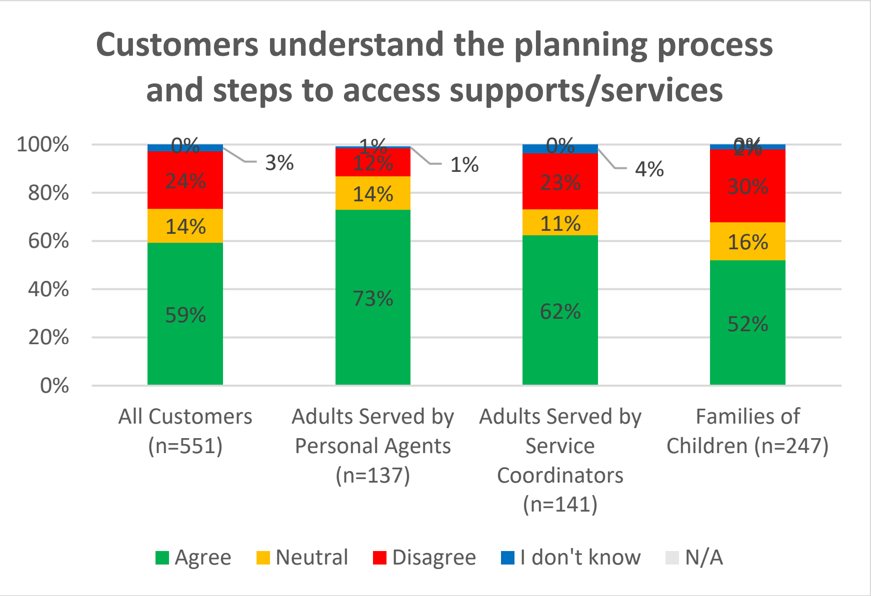
Overall, survey results show that approximately one in two customers found the process of starting I/DD supports and services to be simple and clear. This increases slightly for people with I/DD and for families of adults with I/DD. However, families of children were least likely to agree that the process was simple and clear. Of the remaining customers, over one-third of people reported that they did not find the intake and enrollment process to be simple and clear, as did over half (55%) of the professionals who responded.



Through comments provided in the survey and in focus groups, many talked about the process taking far longer than anticipated to get to the point that services start. Families would appreciate access to straightforward, understandable information -- preferably available online -- and the opportunity to understand what to expect. “No one explained things to us,” one parent indicated, going on to say, “My child was assessed for services months ago, and I am not even sure who to contact or where we are in the process, as my calls do not get returned.”

People in the focus groups frequently expressed frustration, feeling that no one within the system helped them navigate during the initial enrollment process, and they did not have clarity around system deadlines, or when to expect the process to be completed. One survey respondent wrote about the lack of clear information, “The biggest problem we had in the beginning was just getting into the system and getting supports. Everyone told us something different. Even now everyone thinks it works different.” One focus group participant had recently moved to Oregon from another state where their child had received Medicaid-funded home and community services, and described shock at the complexity and time involved in the enrollment process, as well as surprise with the level of fragmentation across health care, early intervention and in-home services compared to their prior experience.

Families who have relationships with other families said these peers are an important source of support and information, with one commenter saying “Make sure every family knows about the Family Networks right away!” Families often spoke of other families as the most important “navigators” of the system available to help them, including through the eligibility and enrollment process.



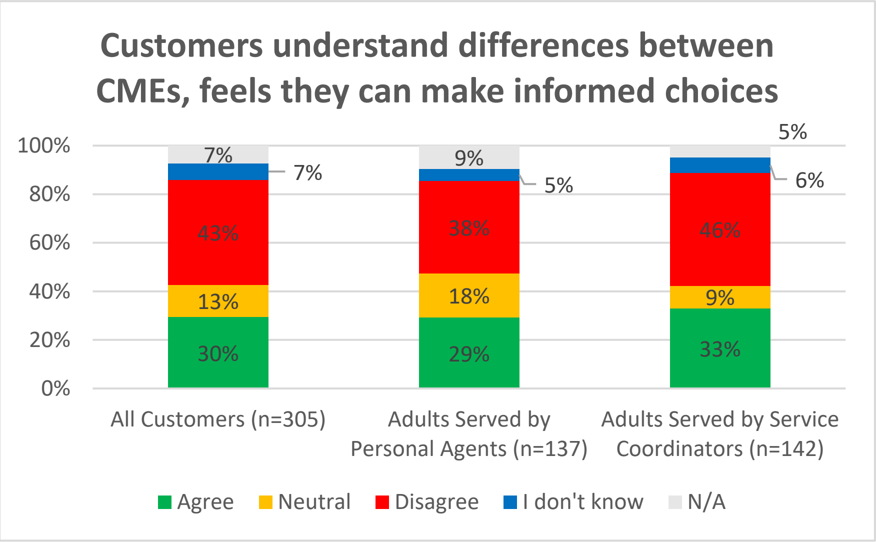
Survey results indicate that only 59% of customers understand the planning process and the steps involved to access supports and services. Among families of children, this number drops to 52%. Many people mentioned the need for better website(s) and electronic information, and wanting to be able to access more understandable written information. One family member commented, “The original intake procedure could be A LOT better. Say a "Parents Guide to DD For Dummies" type of thing.” Others talked about the friction involved in the assessments, and the feeling of invasiveness and negativity during the initial meetings. “Why can’t they use more of the information from Early Intervention and my pediatrician? Duplicating this information collection does not seem like a good use of resources.” Families also conveyed other concerns about the process, “Assessment and ISP process is far too complex and stressful on families and always feels like it’s shoved into one long meeting, versus breaking it up and being thoughtful about answers and developing solid supports and plans.” “

Understanding Case Management Options

Among adults and family members of adults (as families of children do not have choice of case management entities), 30% of survey respondents indicated that they understand the differences between the case management entities and that they can make informed choices, whereas 43% do not. Among professionals, that number was even lower, with only 25% agreeing that people understand the differences.

Adults served by service coordinators (and their families) were more likely to have an opinion on this matter than those served by personal agents. Families and adults served by service coordinators were more likely to agree that they understand the differences between case management entities and can make informed choices, while they are also more likely to disagree that they have an understanding and can make informed choices, as compared to those served by personal agents.

Interviews, group discussions and responses from case management entities also raised concerns about choice advising and ensuring people understand their options. Lack of access to information, uncertainty in the process, seeking an unbiased or neutral third party to help explain choices (eg, other families, service providers, teachers) were all mentioned by various stakeholders. Additionally, some families of young adults and people with I/DD reported not knowing about the existence of the Brokerages or understanding that they had a choice in CMEs. One focus group family indicated that their choice advising consisted of the service coordinator telling them, “Brokerages are the same as us – why would you want to change?” A survey respondent wrote, “My family member started receiving services when he was under two and he is 24 now. As he was going through school, I was discouraged by the lack of info that the transition program within the schools had. Staff appeared to not know what services were available other than you could obtain some services through the CDDP. No mention of specific options.”



Generally, findings from stakeholder engagement suggests choice advising approaches and effectiveness vary tremendously, and seem to be very dependent upon the approach of the local CMEs and their leadership. Some CDDPs and Brokerages have established collaborative approaches to implement meaningful choice advising about case management (eg, service coordinators and personal agents jointly meeting with people, shared local events to help provide information at the same time, agreements with high school transition coordinators to work collaboratively), yet cooperation does not seem to be a consistent practice. One Brokerage said “We have offered to be present at any, initial or otherwise, choice advising meeting we are invited to. Not all counties have taken us up on the offer.” When asked about collaboration across CMEs, one CDDP indicated "Our experience has been that this won’t change unless it is mandated.”

Additionally, annual choice advising as described by the CMEs may not always present options to people in a meaningful way, (eg simply providing a form once a year that asks if someone wants a change), without much discussion nor opportunity to explore choices. As such, truly informed choice may not be available to all Oregonians with I/DD, even when options exist.

Choosing a Case Manager

In the focus groups and survey comments, it was made clear that many people did not know they could request a change or seek a better match with their individual case manager. Some people were excited to learn that they may have choices when it comes to selecting case managers, and “Really? I had no idea that this was even possible,” was not an uncommon type of response.

In the survey, people reported the following related to choosing their individual case manager (CM):

- 32% of people with I/DD say they **DID** choose their case manager
    - 17% of people with I/DD say that **NEITHER** they nor their family chose the CM
    - 10% of people with I/DD don't know who selected the CM
- 46% of families of adults say that **NEITHER** they nor their family member selected the CM
- 83% of families of children say they **DID NOT** select their case manager
- 51% of adults working with a service coordinator said they/their family **DID NOT** choose the CM
- 38% of adults working with a personal agent said they/their family **DID NOT** choose the CM

CDDPs frequently require that an individual utilize the case manager assigned to a particular residential setting or geographic area, or they assign case managers by client age/stage in life; most report offering some limited options for exceptions to these assignments, but few seem to actively present the opportunity for change, unless requested. As one CDDP put it, "Navigating providers and the reality of the match can be challenging." In part due to serving only adults in non-residential settings, Brokerages are more often able to honor individual preferences and many seek to "match" customers with personal agents and maximize choice, as long as caseloads remain balanced. Some Brokerages even maintain "waitlists" for certain personal agent requests.

Changes in Case Managers

In nearly every focus group, and in dozens of survey comments, people talked about disruptive changes in case manager relationships without adequate explanation, or for seemingly arbitrary reasons. Challenges with case manager turnover due to personnel departures and changes add another layer of complexity; staff turnover concerns were expressed in every stakeholder discussion, meeting and group.

Typical turnover comments from customer respondents to the survey:

- "My family member has had 10 service coordinators in 3.5 years."
- "We have had a change in personal agent every 1-3 years."
- "We had 3 service coordinators in less than a year. One we didn't even meet before we got a new one."
- "Consistency with the same Personal Agent. My daughter has had 5 or 6 in about seven years!"
- "I have also had 4 service coordinators in one year."
- "We just got a letter in the mail - this is the third change in the past year and we have never actually met any of the case managers."
- "My brother's service coordinator was switched. I was never notified, and we do not even know who it is now."
- "I would like continuity … we have had 3 different people in 5 years and they are always so new, it takes 6 months to a year for them to get the handle on things, and then they are reassigned."
- "It would be nice to have a case worker for longer than a couple of months. You just get used to them and they leave."

In the survey, 89% of all respondents (n= 842) said it was important to have the same case manager over a long period of time, while 81% of customers and 79% of professionals said that it was important to have a case manager who specializes in a certain area (eg children's services, transition to adulthood, residential). Among adults with I/DD, the difference was even greater, with only 72% prioritizing special knowledge versus 89% seeking longer relationships with case managers.

From one survey respondent, “Our service coordinator is the BEST. She has been helping all of us (we are a team family!) for years. The length of our relationship with her is part of its supportive success. Years of trust and relationship building make difficult events or conversations easier to navigate. I doubt that we are easy but she makes it look easy with her gracious professionalism and good humor. I am thankful for her help.” Another person wrote, “We have been lucky to have really good, helpful case management support with the one brokerage available in our county, with the exception of one person years ago. My son's current P.A. is wonderful, and truly cares about clients. It's hard to find good people in our rural county who will stay put long enough to get to really know them.”

Many people talked about wanting to maintain their ongoing relationship with a single case manager, especially through harder transition points in life. Contrary to this, many seem to experience a change in case management just at the point that they want continuity – as a young person is nearing adulthood, as a person decides to explore different residential options, as someone goes into crisis or has a major life disruption such as a loss of a parent – people repeatedly expressed dismay at losing good case managers during these critical moments.

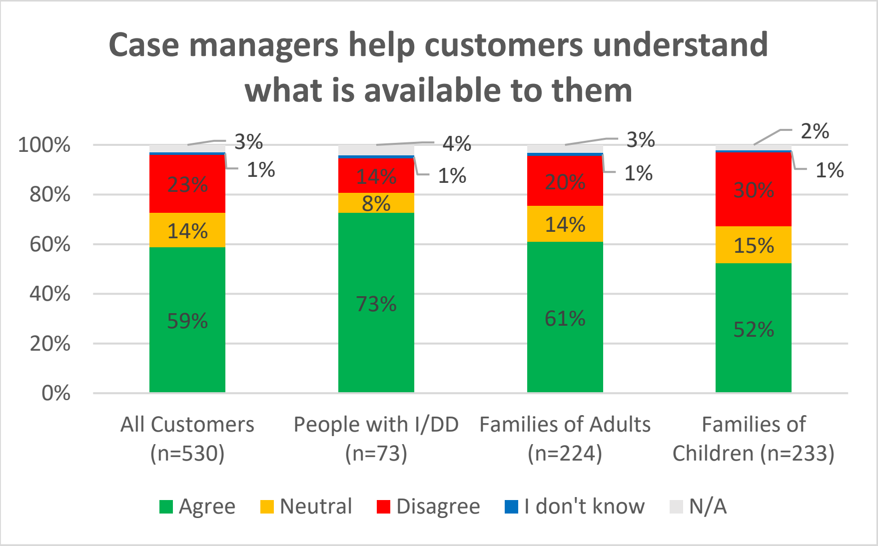
For example, “Arbitrarily pulling our established child case worker off and assigning a transition case worker while in the middle of freshman year of high school because he is approaching age 16 in 6 months was unnecessarily stressful and deprived us of an important advocate/ally in IEP meetings at his new school. With only a few weeks notice, not a great way to manage an autistic client. His new case worker still hasn't met him, and has been unavailable to attend any meetings with the school.” Or, in another situation, a young woman talked about valuing her personal agent’s support as she considered her housing options and her goal of moving out of her parents’ home, but then feeling devastated that she would lose the personal agent when she moved into an adult foster home. She talked about how hard this change in relationship made the housing decision, and how she was not sure that moving was worth the change in case management relationship. (She ultimately did move into the residential setting, and has maintained contact with her former personal agent.)

When people have a good relationship with a case manager, they do not want to lose it. Some of the most positive responses about case managers centered around a longitudinal relationship, for example, “Our case manager is very good with my family member. They have known each other for years. She is thorough and has gone out of her way to help my family member get services for things that he is interested in. She cares about his well-being. My family member has difficulty making abstract decisions, but she always presents them and lets him know that he has choices.” Another person commented, “We've been fortunate to have the same service coordinator for over 5 years now. This really does make a difference in ability for the service coordinator to help us, having been along beside us for this length of time.” Finally, another adult who receives services and supports said, “These relationships are meaningful to me. My personal agent is almost like a friend to me -- he feels like a partner versus a normal worker. We have a strong professional relationship that another worker couldn’t offer me because they turn over.”

Helping people understand available services and supports

Families and people with disabilities want to understand what kinds of options are available to them, and to be able to exercise informed choice as part of their planning process; yet they frequently believe that case managers do not share all of the relevant information about options. “It's difficult to know everything and as a family member of an adult who experiences I/DD, ‘I don't know what I don't know.’ The involvement of various agencies and personnel turnover in this whole process ensures that no one can know it all, let alone be helpful in all areas,” one survey respondent shared.

When asked whether case managers help people understand the service and support options available to them, survey respondents indicated some differences of opinion between people working with personal agents (69% positive/13% negative) and service coordinators (61% positive/22% negative). Families of children expressed the most dissatisfaction (30% negative).


Case managers help customers understand what is available to them

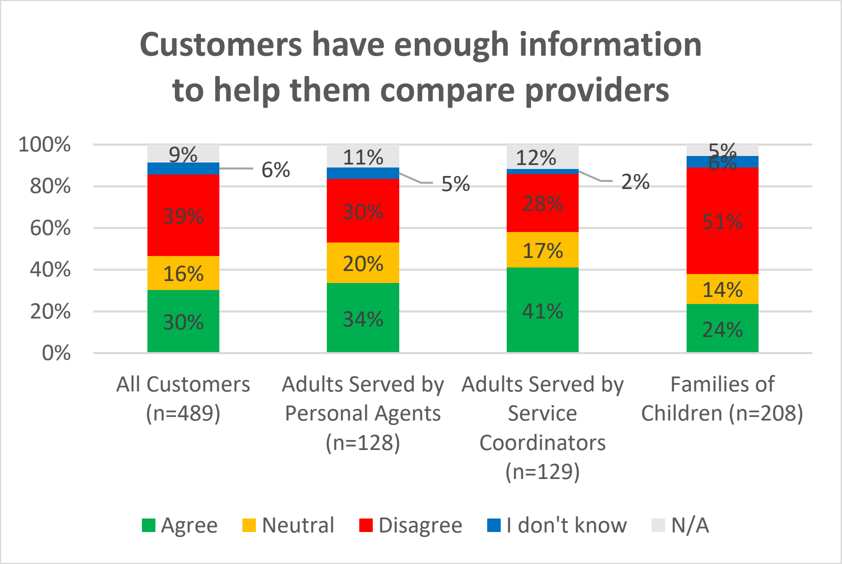
One focus group participant said they felt important information had not been provided to them, stating, “I had no idea there were any choices besides finding and hiring Personal Support Workers (PSWs). No one ever said anything about agencies or other ways to get things done. I want to learn more about that because I hate managing this stuff.” Other focus group participants concurred with this sentiment, indicating that case managers seemed to recommend hiring PSWs without presenting many other options. In another group, an adult indicated that no one had ever talked to him about the possibility of receiving services someplace besides his family home.

People often indicated that they turn to other families and self-advocates to learn about service and support options, as well as searching the internet, and they bring those resources and ideas to their case managers. “I feel like I know more than my case manager does” was not an uncommon refrain from stakeholders. In smaller, more rural communities, focus group participants pointed to local connections and relationships that seem to create more natural opportunities for people to know one another, and to know about local CMEs, providers and other community options and organizations, making it easier to identify what is available.

Information sharing about resources, supports and services

Many case management entities pride themselves on gathering and maintaining information about local community resources and nearby providers and see that as a relative strength of the local systems -- being able to match resources to people’s needs, choices and preferences through a person-centered planning process. Most CMEs reported their case managers share information they learn about local options internally within their organizations, often through staff meetings. CMEs indicate that keeping this information up to date is challenging.

Several focus group participants suggested that the state or case management entities should maintain provider and resource lists to help people understand options, and to be able to do their own research. While people seemed to be generally aware of the Home Care Commission Registry, few participants seemed to know about other resources such as the list of employment service providers on the state’s Employment Outcome website. With a few exceptions, very few case management entities post or share lists of local providers and/or community resources on their websites, leaving some people with I/DD and families to feel that the case managers are “gatekeepers” of this information. One survey respondent said, “If I don’t ask the exact right question I don’t get any information. Information is never given to me. If I ask about a service or program, he will know about it. Then why didn’t he tell me about it in the first place? …They make it so painful the families give up.”



When asked whether people have enough information about local providers to help them compare providers who can meet their needs, over a third of survey respondents indicated they do not, including more than half of families of children. More adults served by service coordinators agreed that they have enough information (41%) compared to those working with personal agents (34%).

Additionally, information sharing came up in other ways. People also report that lists of resources and events are indiscriminately sent to them by case managers without any personalization, making them “feel like a number.” Long lists of activities, events and resources seem to be sent out periodically from some case managers, and while there was some appreciation for the effort, some people also wonder why they are getting information that is not relevant to them, especially when they are seeking other help and facing challenges with responsiveness. For example, focus group participants talked about receiving these kinds of emails “loaded with disability silo activities like Special Olympics” but not able to get information and help in how to seek reasonable accommodations in mainstream parks and recreation activities (even when inclusion is a priority for the person.) Another person wrote, “She responds to requests for individual assistance with website referrals and forwarding community events.”

B. Accessible assistance, communication, reliability and trust

Summary

- People with I/DD and families generally want more contact with their case manager, and more quality engagement
- Some people with I/DD want less contact with their case manager
- Most people are able to meet with their case manager when and where they prefer
- Responsiveness is a major concern, with many people reporting they cannot reach their case manager when they need to
- People value longitudinal relationships with their case managers, and want a case manager they can trust and rely upon
- People with varying cultural needs and preferences find it hard to find information and to communicate due to language-access issues
- Language is only part of meeting cultural needs and it is challenging to get culturally-appropriate case management support

Frequency and Convenience of Case Management Contacts

The minimum required number of contacts for Oregonians receiving I/DD services and supports depends upon their individual circumstances, but generally everyone is required to have at least one face-to-face meeting per year, with at least one reciprocal contact (by phone or email) every three months. For people with more significant health and safety risks, case managers are expected to maintain monthly contact, and many individuals receiving waiver services must also receive a case management service (have at least one reciprocal contact) every month in order to maintain eligibility. Case managers supporting people in residential settings (group homes, foster care, supported living) also have obligations related to quarterly site visits, which also may create opportunities for engagement with customers, increasing the frequency of in-person visits for those individuals.

Survey respondents reported their experiences as follows:

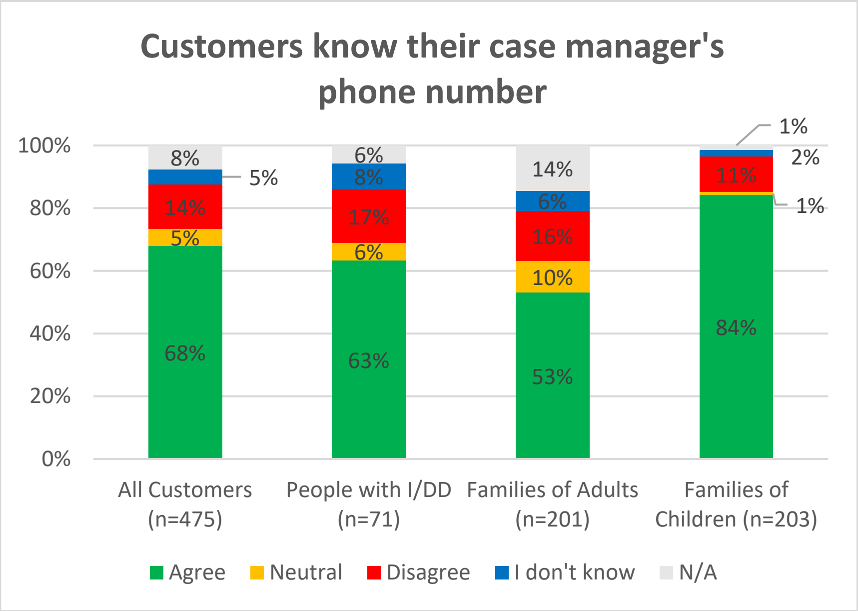
	Adult Residential Setting (n=35)	Adult Family Home (n=135)	Adult Own Home (n=80)	Children (all settings) (n=203)	Adult Personal Agent (n=126)	Adult Service Coord. (n=124)
Meet in person with Case Manager:						
Every month	43%	10%	19%	5%	10%	22%
Every 3 months	26%	28%	24%	19%	27%	27%
Every 6 months	14%	18%	21%	20%	25%	15%
Once a year	11%	37%	31%	47%	37%	30%
Have not met	6%	7%	5%	9%	2%	7%
Communicate with Case Manager (phone, email, text):						
Every month	37%	31%	45%	41%	36%	39%
Every 3 months	17%	23%	27%	15%	29%	18%
Every 6 months	0%	10%	5%	6%	10%	3%
Once a year	3%	10%	14%	6%	8%	12%
Have not communicated	43%	27%	9%	32%	16%	28%

In the survey, 35% of adults with I/DD, 16% of families of adults, and 33% of families of children reported not having enough contact with their case manager, whereas 50% of all customers overall said they have enough contact. About a quarter of professional respondents feel that customers do have enough contact with their case managers, while 33% believe customers do not have enough contact.

In the focus groups, people discussed the quality of contacts more than the quantity. Both families and people with I/DD talked about the kind of relationship they would like, one in which the case manager knows and understands them, and often tied that back to face-to-face contacts. “Our case manager rarely contacts us, missed an appointment at our home, and has barely spent time with our child. How are they supposed to provide services/advocate for our child and our family when they don’t know us?” One survey respondent put it this way, “Not much time to build a rapport. I wish that part was easier.” Another person expressed overall satisfaction but would like more contact, “I would like to hear from my service coordinator more often to check on me, I would also like the opportunity to be able to meet in the community besides home visits. But for the most part she does a great job over all!”

Interestingly, among adults with I/DD, 24% reported being contacted by their case manager too often, whereas that was not a significant concern of families, with only 9% agreeing that contact occurred too often. In the focus groups, with the exception of one family member, the complaint of “too much contact” was not observed; far more people described challenges with access, quality of engagement and preferring additional contact.

According to most survey respondents, the vast majority of case managers meet with customers at times (83%) and places (86%) of convenience to the person/their family, consistent with federal and state requirements. Families of children voiced more concerns about flexibility and convenience than adults and families of adults did, with 10% of families of children indicating that case managers do not meet on days and at times they prefer. However, focus group participants did not raise concerns about the convenience of annual meeting times or locations.

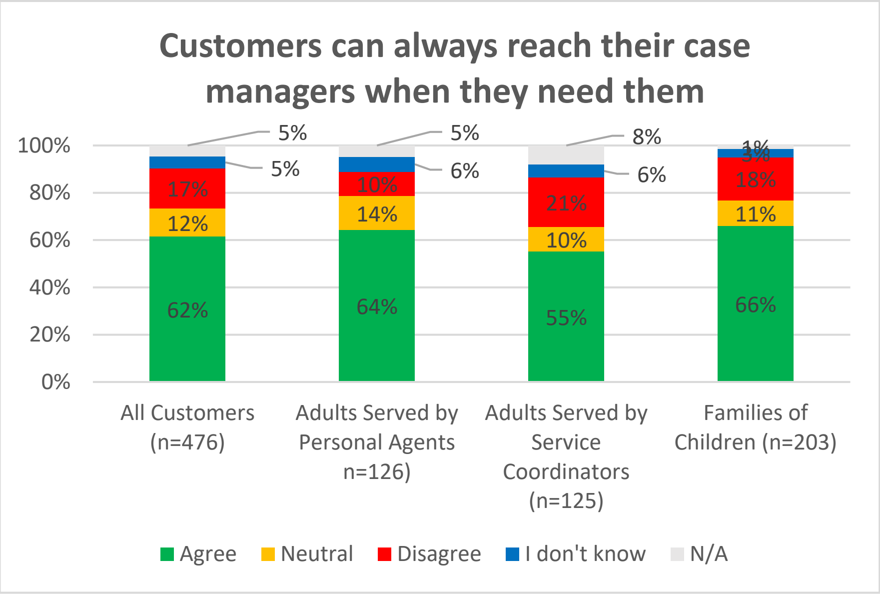


Less than two thirds of adults with I/DD (63%) report they know their case manager's phone number, whereas 84% of families of children said they know the phone number for the service coordinator. Among customers of brokerages, 63% indicate they know the personal agent's phone number, whereas 52% of people served by service coordinators report having this knowledge.

In nearly every focus group discussion, the issue of preferred method of communication arose. "When will they start communicating the way we do – using text, social media and online?" one young mom asked. Many people complained about the disjointed communication that occurs over secure emails from government agencies that expire after a certain number of days, secure email systems that don't maintain threads (making it hard to track conversations), the challenges of case managers without cell phones (or case managers unwilling to provide those numbers), and the capacity of families consumed by inefficient forms of communication, piles of paperwork and manual processes. "Even my doctor's office has better ways to share information with me than my case manager does" noted another person. Some participants in focus groups talked about the idea of a secure website or dashboard where information and records could be accessed, and communication (email, chats, texts) could occur in an environment that both respects privacy and offers transparency. One focus group suggested the case management system develop something like "MyChart" for DD services, noting that it might free up time for the case managers and give people with I/DD, families, providers, and others in a circle of support an easy way to share and keep track of records and information.

Responsiveness

All stakeholder feedback sources indicated that consistent responsiveness is a major concern, for both adults receiving services and families of customers of all ages, as well as for many professionals. The survey data reflects this perspective, with only 62% of customers indicating they can always reach their case manager when they need them. The responses did not indicate significant differences between families and people with disabilities but did show a difference between people working with personal agents (64% in agreement) versus service coordinators 55% in agreement). Among professionals, the perception that people can always reach their case manager was even lower, with only 40% agreeing.



Focus group and survey comments consistently reflected a very different perspective than CMEs' described expectations for responses, which were often described as one or two working days for non-emergency contacts. Families, people with disabilities and service providers all talked about how challenging it is to get case managers to call or email them. Dozens of comments about responsiveness included simple requests, such as "Please answer our emails and phone calls!" or "Please tell me answers to my questions" or "Show up to meetings," as well as the following comments from customers:

- "The DD case worker currently assigned to my son does not return phone calls, does not attend meetings and does the absolute bare minimum."
- "When contacted by the family please respond back within 2 weeks."
- "I hope there are better service coordinators out there because ours is never available. And never returns calls. She is never involved in anything with the client."
- "We have met our service coordinator one time since my son was 15. He will be 18 in August. I quit trying to call him because he never answered the phone anyway. And never got back to me if I left a message. I got so frustrated with the whole process, I gave up trying to figure it out."
- "We have only had two case managers one was very present and engaged the current one has never met us in person and gave no explanation when she missed an evaluation meeting she said she would attend. She had someone else call and check in on us two or three times."
- "Our service coordinator does not respond unless I reach out to her supervisor."
- "Our service coordinator is only part time. It is very inconvenient for us to have a part time SC. If we need something we are directed to the person of the day or we wait for one of the 3 days our SC works."

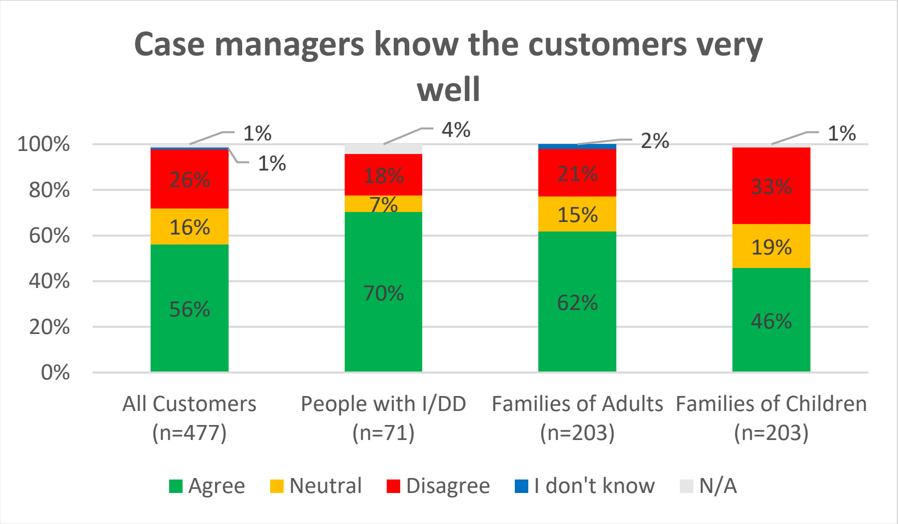
Throughout the focus groups and in survey open-ended responses, people talked about how case managers often seemed too busy; that their caseloads must be too high because they never seem to have enough time. Several people talked about feeling guilty about "bothering" their case manager with requests for help or for information, believing that there must be others who have greater needs demanding the time of the case managers. Others spoke about the complaints they heard directly from case managers about their workload. This was an active, unsolicited discussion in several of the focus groups, with people wondering aloud if the challenges with responsiveness relate to caseloads, bureaucratic demands, "too much paperwork," and/or the abilities of the individual case managers. One survey respondent provided this insight, "When in a crisis, I reached out to my son's case manager requesting help and didn't get a response for another month, and [then] only once my son's psychologist contacted her. I also contacted her supervisor but got nothing. Once we saw her, she apologized and said there were other families more in need with worse crises."

Many service providers also commented on the challenges of high caseloads, eg, "I routinely see case managers who are unable to provide enough care to any individual client because their caseload is too large. I think the most important thing to do is to get more case managers on board and reduce their workload, which should also help with the other big problem, which is case managers finding other jobs after very short lengths of time." Over a third of the case management staff respondents made comments about caseloads and/or not having enough time to do the job they want to do. This comment was typical of the feedback, "Case managers are spread too thin to support clients adequately. State mandated paperwork, meetings, trainings and case notes are time consuming and detract from the level of support provided. The state keeps raising expectations of the CM without providing additional funding for more staff to reduce case loads. That's what would really help the clients if you are sincere. Our case managers are dedicated, but time ties their hands. We should be funded by the number of clients rather than billables."

Trust relationships

People who have a trusted relationship with a good service coordinator or personal agent value this tremendously. When provided the opportunity for open-ended comments, nearly seventy different survey participants wrote about the valuable assistance and support their case manager provides, frequently calling these individuals out by name. In the focus groups, there were stark differences in the perspectives among individuals and families who spoke of these trusted relationships as compared to those who do not, even within the same case management entity, across all groups. Case managers often agreed that time to build a trusted relationship is important, with one respondent writing "When service coordinators are able to meet with families more often, the contact creates a trusting relationship. Then the service coordinator is able to acknowledge the person's choices more clearly and set up the ISP goals to be more person centered and person driven."

In focus groups and open-ended responses, people expressed an appreciation for the opportunity to have a quality case manager whom they trust, which was described as largely driven by consistency (including maintaining the same case manager over time), reliability, responsiveness, level of knowledge, empathy, and the ability to connect with people with I/DD.



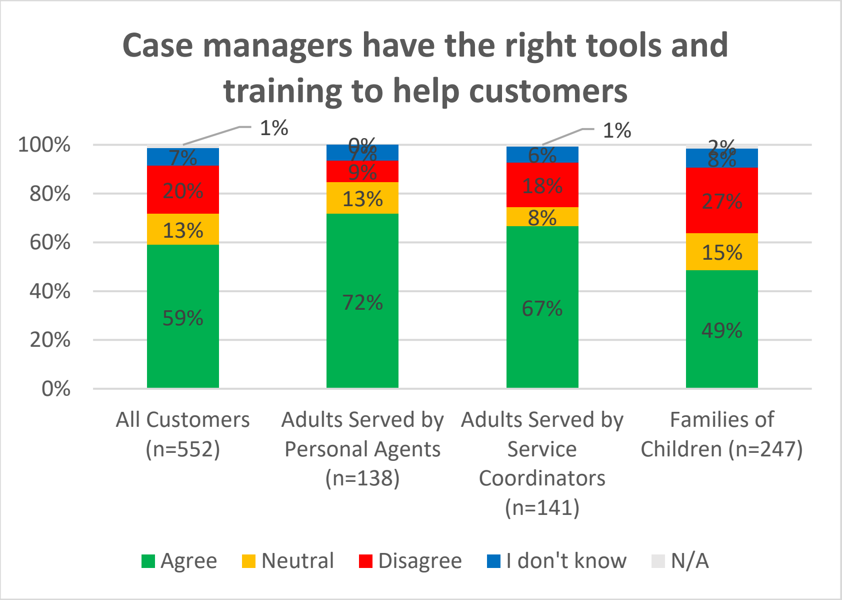
Survey data related to the how well case managers know their customers indicated some differences across the groups. Adults and their families served by personal agents agreed that case managers know their customers very well at a slightly higher rate (68%) than adults and their families served by service coordinators (63%). Only 46% of families of children do agree that their service coordinator knows them well. Interestingly, many service providers indicated that they perceive that children’s case management is more individualized and supportive than adult case management, contrary to many family respondents.

In the survey, the vast majority (89%) of customers reported that they agree that having the same case manager over a long period of time is important to them. This level of agreement was consistent across all people, including people with I/DD, family members of adults and children with I/DD and professionals, regardless of the type of case management they experience. One family described it this way, “Our family absolutely loves the person we were blessed with to help our son. She has been a gift to our family and is a true advocate and an extremely compassionate person. I really don’t think he would be doing as well as he is without her support. We were asked a while back if we'd like to go to brokerage and we all agreed there was no one better.”

When asked explicitly about the importance of the longitudinal relationship with case managers, people talked about how long it takes to develop understanding and appreciation. “I am so glad [case manager] is part of our lives and is a both a safety net and ‘wings’ for our son. She really gets him because she has known him for so long. She has helped him be safe when we had turmoil and she helps him think about his life dreams.” Another survey respondent wrote, “Our case manager is available through email or phone and is very good about communication in a timely manner! We feel very fortunate for her. We did not have that attentive case management prior to her and we are hoping to keep her as our case manager. I think it’s a great system when the case manager knows the client and the support system and it’s helpful for the client to see consistency in it support. Longevity in these relationships is critical to the client.”

As discussed in Section A, unexpected or unrequested changes in case managers often generate frustration and dissatisfaction, and turnover concerns came up in every forum. “We had zero complaints about our original case manager. Since being changed twice we've had no real solutions or communication.” This lack of consistency degrades trust and confidence in relying on a system that may change at any time.

Trust is also evident in the extent to which customers perceive that their case manager will have the right tools and training to help and support them. Generally, more than half (59%) of all customers agreed that their case manager had the right tools and training. This was slightly less among families of children; nearly 3 in 10 families of children did not feel that their case managers have the tools and training they need to help them.


Case managers have the right tools and training to help customers

Language and cultural needs

Most customers (88%) report that their case managers speak the same language as they do. A different experience is indicated among those customers who reported primarily speaking another language other than English at home, with 74% of these customers report having a case manager who speaks the same language as they do. The languages presented among the customers include Spanish, Sign Language, Arabic, Vietnamese, and Cantonese. Additionally, some respondents selected “other language” and described their family member as “non-verbal” or “doesn’t speak.”

One Spanish speaking family reported challenges they face with receiving information in Spanish, saying “They give a plan in English but they do not have the ability to give us the plans in Spanish. They have no way to give us important information in Spanish.” Another family indicated that they moved between counties in order to receive better Spanish language and communication support.

Nearly three in four customers report that their cultural and language needs and preferences are supported by their case manager. However, this experience is somewhat different among those who identify as a race or ethnicity other than white, decreasing to 68% of these customers. Among those who are non-English speaking, just 45% of customers agree that their cultural and language needs and preferences are supported by their case manager.

In a focus group with Spanish-speaking families, there was some discussion about the challenges of balancing language-access needs, ethnic cultural support, and disability culture. One family commented that simply being a native Spanish speaker did not make a case manager qualified to help Hispanic families, and sometimes the roots from another culture (eg negative societal perceptions about people with disabilities) were actually made worse by lack of cultural understanding and a lack of understanding the American disability rights perspective.

An interview with an African immigrant from a refugee community provided additional perspective, “Other organizations don’t help us, no one hires interpreters for any language besides Spanish. We have to build trust in our own community first. County case managers who do not have an understanding of the disability experience are a problem when they are working with immigrants. The cultural bias can be even worse from people from our own community. It is hard already and we are isolated. Many families are trapped at home with their disabled child. Ask me what help I want -- don’t tell me I should just accept the money and hire my family member and stay home. Help us connect to community.”

C. Person-centered thinking and planning; Self-determination

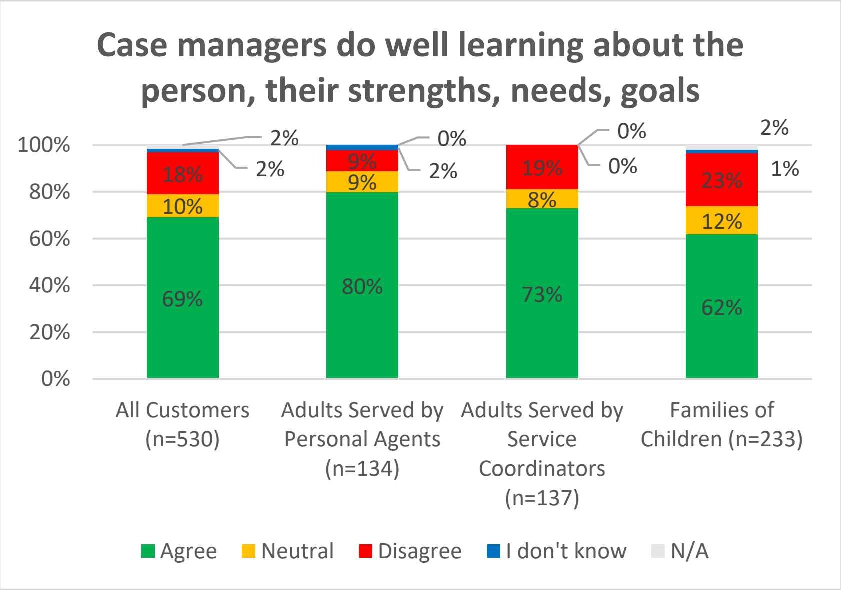
Summary

- Person-centered planning approaches and processes vary across individuals and entities
- Just over two-thirds of people feel case managers do a good job learning about the person and their strengths, needs and goals, with the least confidence expressed among families of children
- Only about half of people report that customers determine who is involved in person-centered planning process and less than half lead their own plan development
- Two-thirds agree that customers make the decisions about what is most important in planning
- Many stakeholders express concern about case manager’s time and capacity available to conduct solid person-centered practices, including getting to know the person
- Few people feel case managers help with long-term planning (3-5 years)

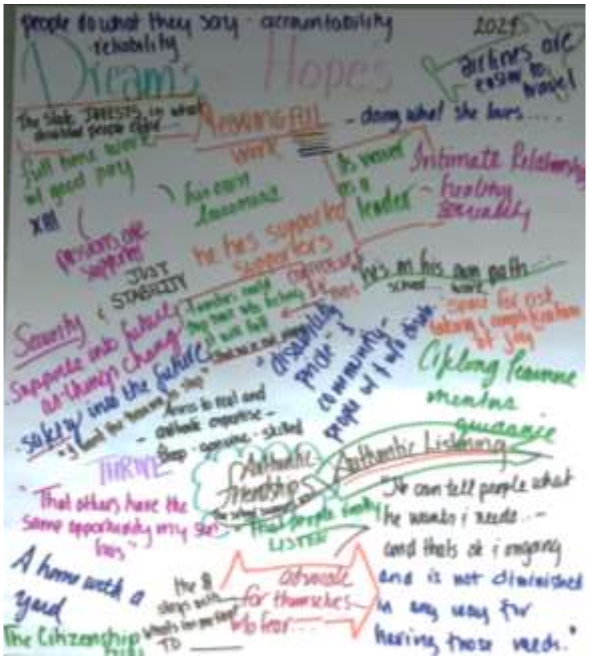
- About two-thirds of customers feel case managers help with jobs, housing/residential changes, or learning something new
- Less than half of people think case managers help with connecting to other people who are important to them
- The vast majority of people agree that identifying supports that will help a person reach their goals is most important, while about half believe how many hours of paid support a person can receive is most important
- Nearly one-fifth of people do not believe case managers help make sure the customer has support to communicate
- People in the survey, focus groups and interviews expressed concerns about the role of case management and others in being able to promote and protect the ability of people with I/DD to exercise self-determination

Learning about the person

Assessing a person's needs is one of the core activities of case management, and an integral part of the development of a Medicaid-funded plan of care. Yet developing a meaningful person-centered plan is much more, requiring case managers to go well beyond the activities of determining the level of care, completing the formal functional assessment, reviewing medical and school records, and gathering the many other pieces of data that exist about a person. Quality person-centered planning includes learning, understanding and respecting what is important to a person in their everyday life and finding ways to best support those things they value, while also meeting their basic health and safety needs.



When asked whether customers believe case managers are successful in learning about the person and their goals, strengths and needs, different groups had different perspectives, but overall 69% of respondents agree, and 18% of respondents disagree, that case managers do a good job on this. In the focus groups, families and adults with disabilities who have been enrolled in Oregon DD services for more than a decade sometimes referenced "the old days" of graphic facilitation and big person-centered plans, with MAPS, PATHS, and Essential Lifestyle Plans, and talked about how the new ISP process and assessment makes it harder to communicate everything that is important to build a good plan. Many of these individuals also noted a loss of self-determination in the process, describing it as something that gets done "to" people. Comments from one focus group included, "Where is the dignity in the assessment process? The identification of risks is humiliating and taken out of context. Case managers are so limited by the forms and the thinking, it is hard to get to conversations about gifts and dreams and strengths."

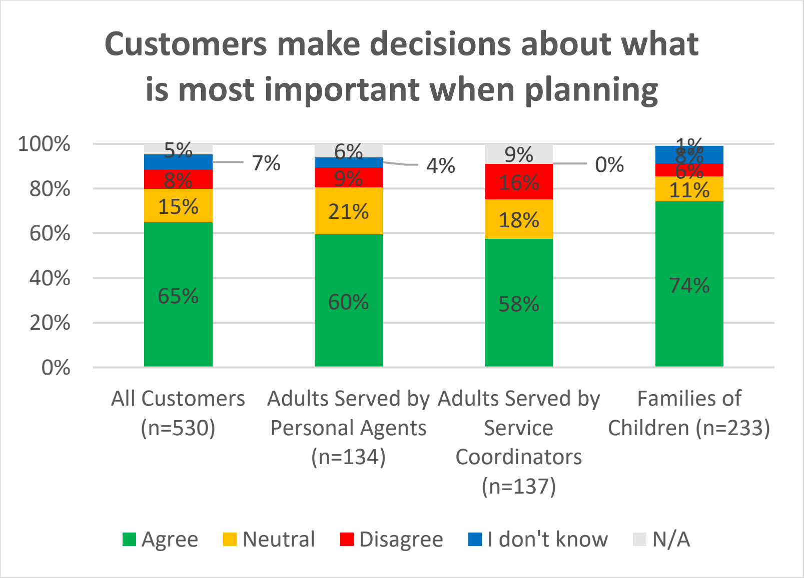


One family commented on the importance of a collaborative approach, saying "His brokerage provider is excellent in understanding my son's needs and always asks him the same questions she asks her other clients and we decide the answer to his best ability together." Youth with I/DD in another focus group offered clearly stated advice about the process, such as "Don't judge me by my IEP. Have an open mind about me. Talk to me, not just my mom. Don't talk for me -- help me make some decisions. Listen to me. Respect my choices."

One case manager told a story about her excitement when participating in a well-facilitated PATH process for a transition-age youth turning 18 that involved the CDDP service coordinator, Brokerage personal agent, high school transition coordinator, service provider, family and friends – and how this investment of time and energy seemed to allow for really comprehensive understanding what was important to the young adult, resulting in a great plan that included a mix of paid, community and natural supports as he moved into adulthood. Yet when the case manager asked to be trained in the person-centered thinking and the person-centered planning process to be able to facilitate similarly, she was told by her supervisor that it was too time-consuming and expensive.

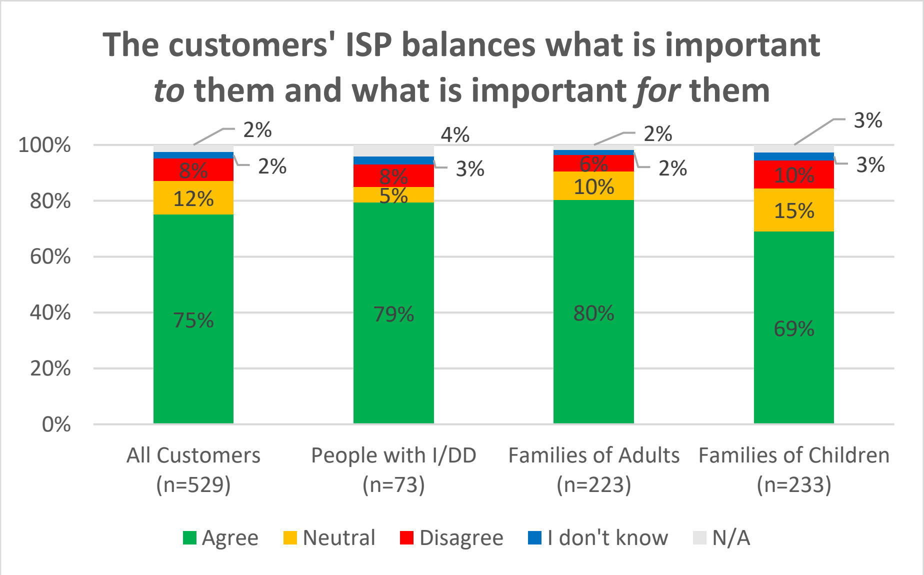
Person-centered planning decisions

Developing a person-centered plan is a core responsibility of case management. When asked on the survey about the person-centered planning process, 54% of all customers (n=529) indicated that the person/their family decided who would participate in the process, 46% of people with I/DD and their families indicated that they lead their planning, and 65% report that the customer makes the decisions about what is most important when they are planning their supports and services.



Additionally, many service providers commented about their role (or lack thereof) in the process, and the inconsistency as to when they are included, and how. One provider wrote "Need to include all entities of a person's life when renewing the person's yearly ISP. Hard to support a person if everyone who is involved doesn't have their part of supporting a person included as all entities of a person's life bridge together to support the person fully. Especially if the person is having issues in work, at a day program, or community inclusion program. All members in this person's life need to be heard." Providers talked about the lack of partnership with CMEs in planning, and a perceived conflict of interest problem if they contribute to the planning process. “The workload does not allow case managers to know people well enough to develop good ISPs. Many are in over their head,” commented one provider. This was reinforced by comments from some families of individuals receiving residential services, “I believe over the years case management has become the person managing paperwork and not providing real advocacy for the individual in service. My son’s service coordinator knows him only because she reads about him or depends on the provider to inform her.” Service providers also said they feel the ISP has become a billing tool more than a person-centered plan.

“I don't know what the heck Person Centered Planning is.” In both the survey and the focus groups there were many customers who did not understand the process, the expectations, or the foundational values of person-centered planning. Younger families of children often described their understanding of planning as assessment, allocation of hours, and filling out paperwork -- nothing more. Many families seem to be looking for a more transactional relationship with their case manager, “I have asked repeatedly for items in the home and I always met with the resistance and request for more paperwork. Please just get us what we need without more goals.” One survey respondent wrote, [It would] “be nice if there was a straightforward place we could look to see exactly what to expect from our case managers. When we first got one, we just were told how many hours we qualified for - that was it. The next case manager came in and was confused why my son didn't have any supports or referrals.” Others talked about how ISPs have become “one size fits none” and overkill for people seeking limited support, which then may unnecessarily increase the use of paid supports. One family said it this way, “The ISP is a lot when we only need a little.”


The customers' ISP balances what is important *to* them and what is important *for* them

Survey data indicate that three-quarters of people believe their individual support plans are balanced and represent both the things that are important to them (goals, preferences) and the things that are important for them (health and safety needs), with small differences across all groups.

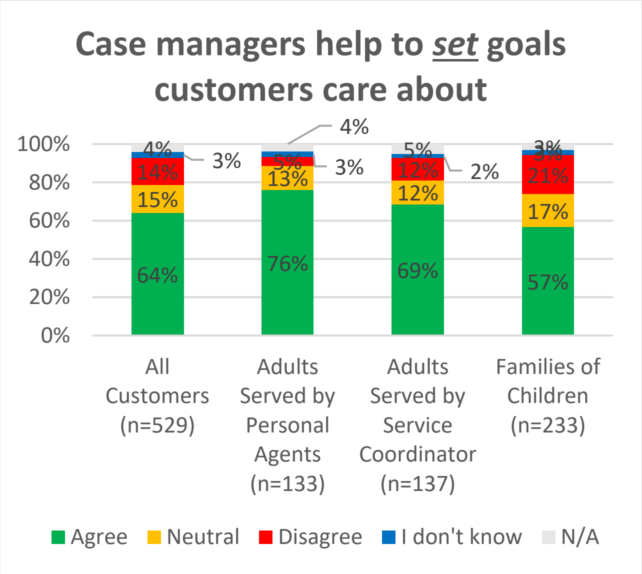
Some adults with I/DD report that the ISP process does not feel like it is something they understand, let alone a process that they feel like they are supported to lead. “When I have my ISP meetings, it’s hard because it’s boring to me. I don’t understand all the things in the ISP and would like to be able to have a copy in front of me during the meeting and have somebody help me follow along at my own speed that way I will understand what everyone is talking about. When I don’t, it makes me zone out.”

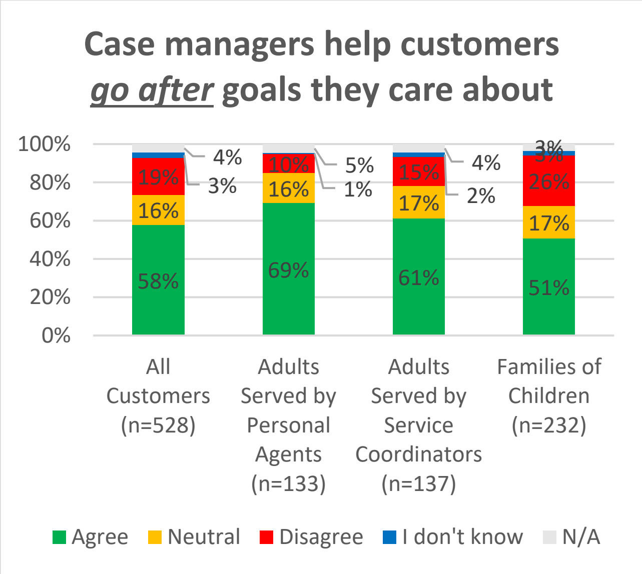
Many CME staff also expressed similar frustrations about person-centered planning, “Person centered planning is not working, it has just become a form to fill out, families are largely uninterested in it.” Another CME leader said, “People need support to think outside of the PCI Form, ISP form, etc. So much of everything we do is about having some jargon in every box that staff are now stuck in this way of thinking. It really kills creativity." Other CME feedback noted that the state training for SC/PAs has moved away from helping people develop and maintain person-centered thinking and planning skills and competencies, and resources and time are too limited for case managers to do more professional development. Another CME lead stated, "Sometimes it is difficult for a person to articulate what they want and need. The system says it is person-centered, but the tools we are given are not person-centered. The system wants to standardize rather than customize so people are forced to fit into structures of support that don't fit their needs."

In the focus groups, other families with different experiences also talked about case managers who take the time to "listen deeply" and work to develop strength-based support plans, relying upon a team approach, understanding family context, focusing on the person (and, it was noted, not even bringing the ISP form into the planning conversations, filling it out later). One group of families agreed that the center of the work of the case manager in the process is to "strengthen and amplify" the person's voice so that their daily life, with and without supports, is based upon their hopes and dreams.

Establishing and pursuing goals

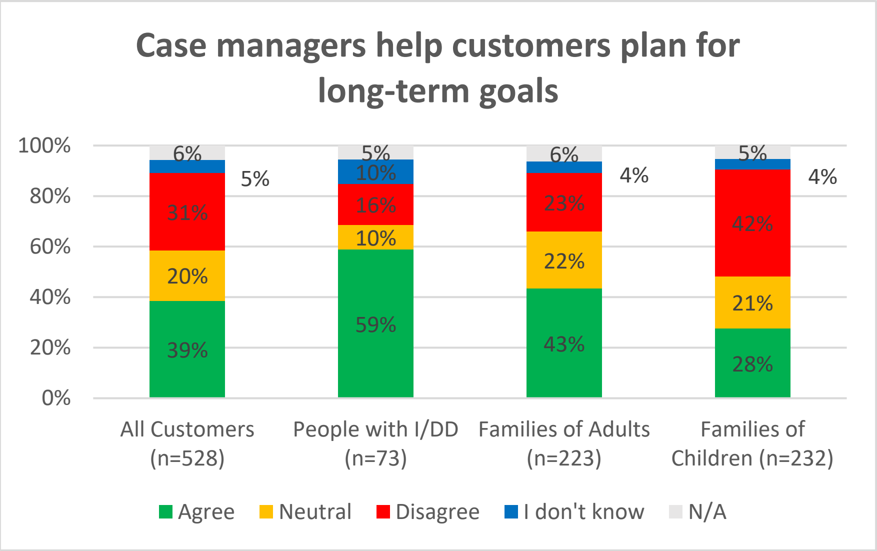
In the survey, participants were asked several questions about how case managers help them with their goals; more customers feel supported by their case manager in creating their goals (64%) than in going after them (58%). And when asked about long-term goals (3-5 years out), the number of customers who feel that their case manager helps them plan for long-term goals drops precipitously to 39%.


Case managers help to *set* goals customers care about


Case managers help customers *go after* goals they care about

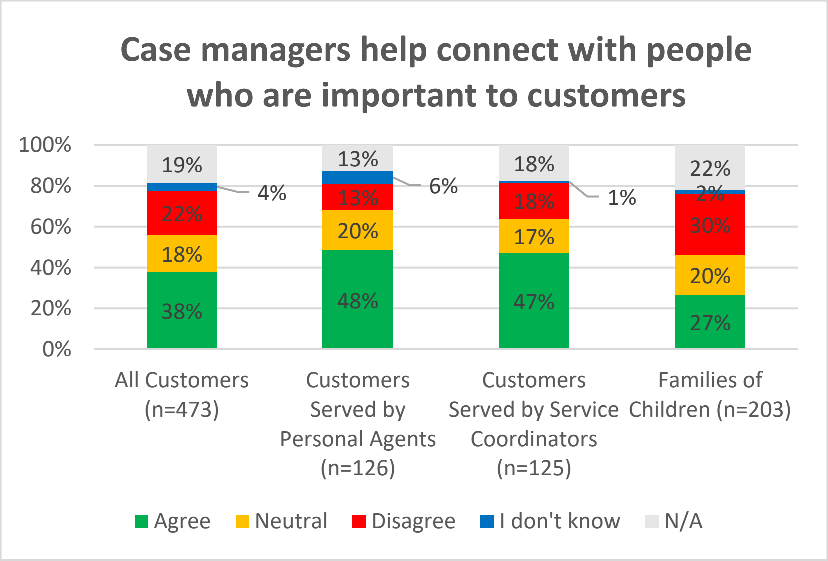
However, in nearly every focus group, youth and adults with I/DD talked about wanting to rely upon their services and supports to help them not only to survive on a day-to-day basis, but to help them achieve their dreams – goals like more independence, having money, moving out of their family's home, learning to drive, owning pets, getting married, parenting, working in a career ("not just any old job"), volunteering and helping others, being able to travel, and having a deep community of friends, to name a few. Goals that are unlikely to be achieved in a one-year plan.

Families also talked about how goals and needs change over life stages, as does the role of the family, and this should be considered more. One focus group talked about wanting the opportunity to build five year goals with a meaningful path towards their desired outcomes, including planning for what happens when parents die, especially for people with higher intensity support needs. In this discussion, all agreed that case managers were not well prepared to help them with these hard conversations, but they wish they would be. This was also reflected in the survey by another parent, "My son is receiving outstanding case management services. My husband and I, now advanced in our age, do worry somewhat about his care when we are no longer able to provide natural supports and advocate for him." Several participants suggested more accountability for both case managers and for service providers, tied back to the person's goals.



Support for a person's goals

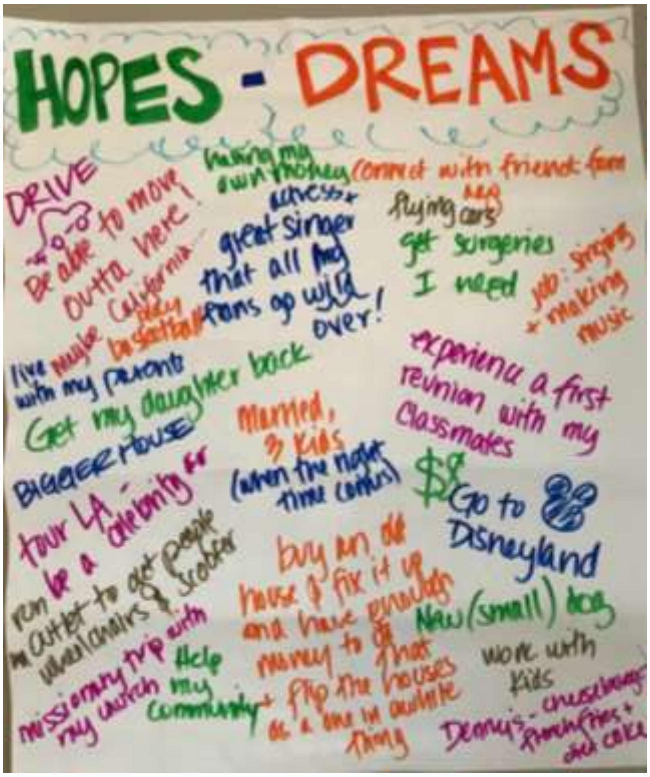
Between one-half and two-thirds of customers agree that case managers will help when they want to strive for a goal that will require assistance, supports and planning, depending upon the type of goal. When asked about whether case managers help people if they want to work or change jobs, 68% of adults and their families working with personal agents, and 61% of adults and their families served by service coordinators, agreed case managers would help. Among adults and families of adults, 58% agreed that case managers will help people move if they want to live someplace else. When a person wants to learn something new, 68% of adults/families served by personal agents, 55% of adults/families served by service coordinators, and 38% of families of children think that case managers will help them with a learning or skills development goal. Thirty-eight percent of adults with I/DD and 33% of families of adults agree that their case manager helps people find self-advocacy groups, if they are interested. And, in terms of development of social capital and relationships, less than half of customer survey respondents agreed that case managers help people connect to people who are important to them.



In the focus groups, people talked about wanting case managers to help them explore new possibilities when planning and in building out supports and services, which might mean having to find unique ways to get things done, including with typical community resources (communities of faith, recreation centers, local businesses, colleges, housing developers, other non-disability organizations). Many families want case managers to know and understand those local opportunities and community assets, but reported mixed experiences with case managers' ability and capacity to help build plans and identify both natural and paid support to achieve "big" goals such as employment or housing changes. "We need to move from limitations to the aspirations – begin to map out a real vision. Create possibilities and support the dreams, not just the deficits."

Several providers commented that for people with more intense support needs, person-centered planning has moved away from aspirational or hard to achieve goals related to self-determination, community inclusion, non-disability social opportunities, and employment because the case managers just do not have time to get to know people and their dreams, and so plans are weighted towards medical, health, supervision and safety issues. One service provider put it this way, "We have some good/smart case managers, however the workloads do not allow for expanding on their role, so it is reduced to abuse/health and safety prevention vs being on the offensive towards higher quality of life."

Case managers also talked about the challenges. "Lack of housing and natural supports is a constant issue and limits independence for customers. Meaningful goal planning is difficult as crisis management is often forefront. Housing, food insecurity, and maintaining consistent providers makes it difficult to goal plan as basic needs are not set up for success."



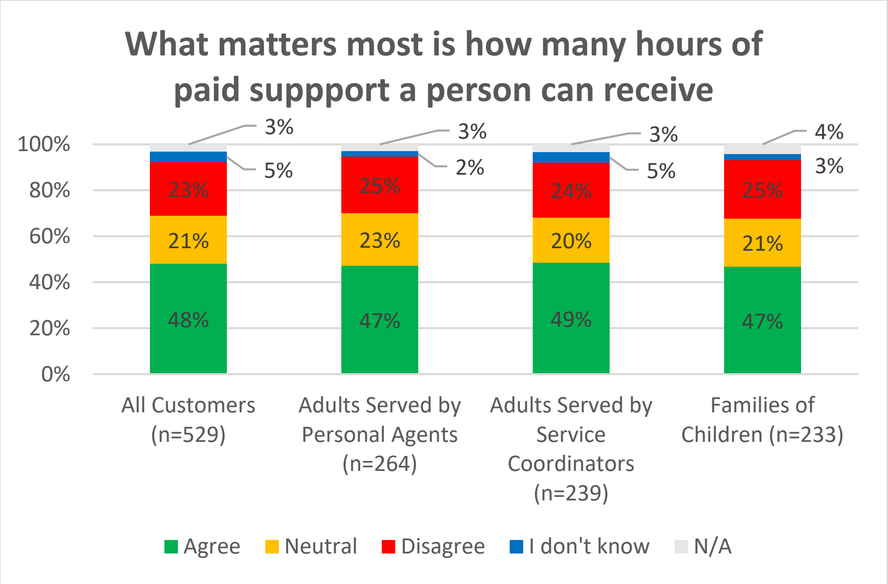
Person-centered thinking

In meetings with groups, interviews, and discussions with many stakeholders, concerns about a combination of change factors -- the challenges with consistently executing good person-centered planning, time and capacity of case managers, the functional assessment process, bringing so many new people into services so quickly, the influx of new resources that came with the "K Plan" – culminated in many comments about all of this change creating a shift in focus away from person-centered practices, away from developing support plans focused on what is important to the person, and away from encouraging self-determination. One CME leader described the shift, "We've moved from a system where all services started with and flowed from a person's goals to one focused primarily on units of need and risk management."

Comments reflect confusion among some families about not only the roles and responsibilities of case managers and the process of person-centered planning, but also the purpose of the ISP and the values underpinning Oregon's DD system. A parent described it this way, "Our service coordinator has never talked to us about our dreams. We like him, he’s a kind guy but he doesn’t do much. He comes once a year and does the questions to figure out the hours and tell us what we get. That’s it.” Many adults with disabilities talked about their expectations of planning, “Look at your history, think about your future, help you decide things, do not make decisions for you.”

Another family, whose daughter has been receiving services for over 30 years, talked about the importance of flexibility as life changes, and how the system has become less flexible over time. They noted that “frequently the opportunities presented do not match needs, as they are not individualized,” and the supports and solutions are not drawn out of what is important to the person being supported.

When asked what matters most when planning, the vast majority (86%) of customers agreed that identifying supports that will help a person reach their goals is most important, and less than 2% disagreed. Additionally, when asked whether what matters most is how many hours of paid support a person can receive, slightly less than half of customers agreed, while about one quarter disagreed. Among people with I/DD, the number was slightly higher than families, with 59% agreeing that the hours of paid support matter most.

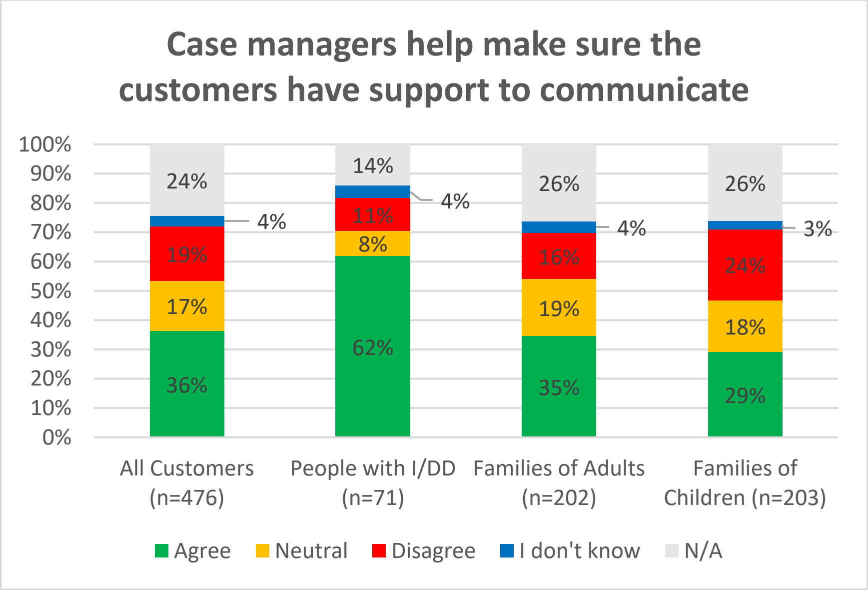


Focus group participants also talked about ensuring some accountability around goals, as well as an understanding that preferred outcomes and how people move towards them must remain fluid, not static. Participants pointed out the importance of creativity in helping a person build a good life, and that the “empathetic thinkers” who help with planning and solutioning may not have the same skill set as people who are great at managing compliance and paperwork requirements, and perhaps those differences should be considered.

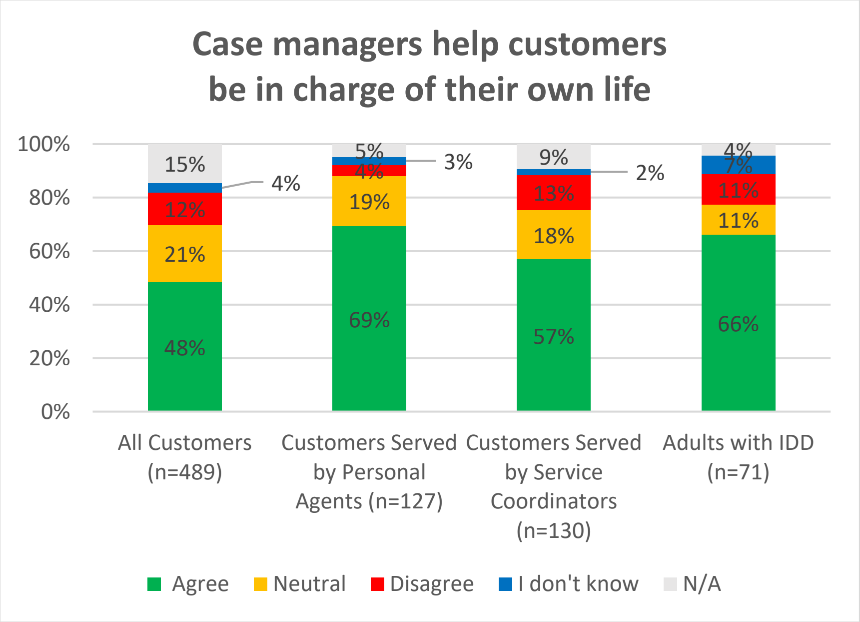
Self-Determination

Whether through technology or spoken word, gesture or behavior, writing or signing – the opportunity to communicate preferences and decisions is fundamental to exercising self-determination. Among adults, less than half of the respondents agreed that the case manager makes sure the customer has support to communicate. Families of children expressed an even stronger level of discord, with only 29% agreeing. When asked about hopes for the future, a group of families talked about authentic listening. One parent described their dream for their son, ”He can tell people what he wants and needs, and that’s OK and ongoing. And he is not diminished in any way for having those needs.”

While several questions on the survey asked about aspects of choice and control, respondents were also asked another very direct question related to encouraging self-determination – whether case managers help people to be in charge of their own life. Over two-thirds (69%) of adult survey respondents working with personal agents agreed and 4% disagreed. Among adult survey respondents served by service coordinators, 57% agreed that their case manager helps them be in charge of their own life, while 13% disagreed, while less than one-third (31%) of families of children agreed and 16% disagreed.


Case managers help make sure the customers have support to communicate

When asked about person-centered thinking and self-determination, several case managers expressed frustration and concern related to encouraging and maintaining self-determination for adults living at home within the complexities of the family context. This was especially true when family members have multiple simultaneous roles: serving as paid service providers, guardians and/or supporting the person to make decisions about their lives and choices. Several case managers, service providers, and families, talked about how the focus on paid resources in the home has made it harder to keep the person's self-determination central, and the conflict of interest issues that have been layered into people's lives without enough understanding of the implications.


Case managers help customers be in charge of their own life

Another CME leader was very blunt in their assessment, "This [the K Plan] has changed the landscape in Oregon to highly demanding systems of entitlement, which many times leads to what does the family want vs the needs of the individual with the disability. Many families [as paid providers] are counting on the income as a way of life, rather than what would assist the person to have more opportunities to be integrated into the community."

Additionally, one parent of a newly-eligible 19-year old shared that they had been told by a case manager that they needed to have a guardianship in place prior to applying for DD services. Upon hearing this story, a few other families indicated that they had also felt “pressured” to pursue guardianship as their son or daughter reached age 18, or that professionals (educators, doctors, case managers) presumed this to be the path throughout adolescence, without much conversation. Most had not been provided information or resources about alternatives or suggestions as to who might be able to offer legal guidance. The lack of opportunity and support for fully informed choice about legal restrictions at this critical transition juncture conflicts with the goals of self-determination.

D. Systems and Resource Navigation; Community Capacity Development and Connections

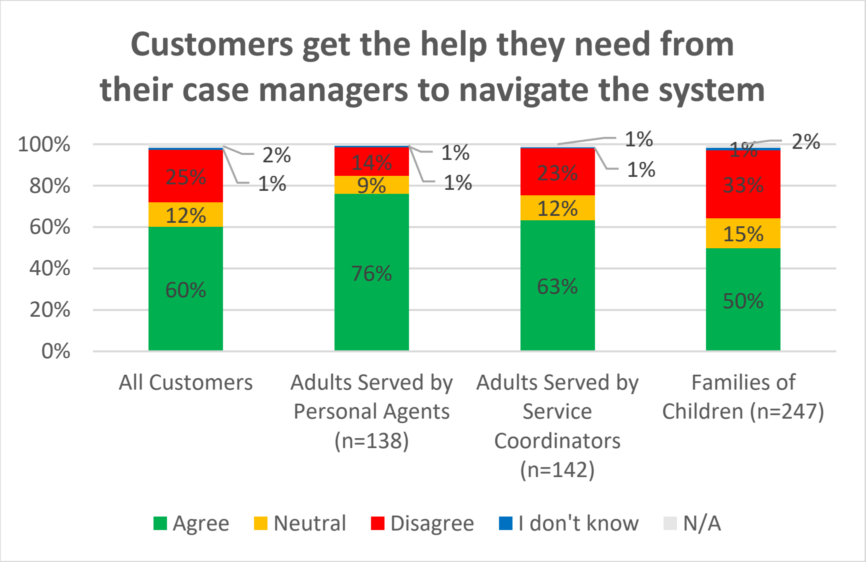
Summary

- Fewer families of children expressed confidence in case managers to provide systems navigation and connections to resources than adults with I/DD and their families
- People are unclear about the role of case managers in supporting them to access and engage in other systems, including health care
- Survey respondents and focus groups indicate case managers are more involved in supporting employment goals than in other domains
- About half of the survey respondents indicate case managers help people find and connect to things they enjoy in the community; among families of children this drops to 41%
- Relationships and trust with case managers are affected by their ability to connect people to scarce external resources such as housing and transportation, as well as delays in approvals for certain services (that may also not be within the case manager’s control)
- Just under two-thirds of people feel that case managers are able to provide information about services and supports that can meet their needs; yet only one third of people indicate they have enough information to compare and choose providers aligned with their needs
- Case management entities have limited ability and time to help develop and grow provider capacity, limited opportunity to identify and develop relationships with community resources
- Less than half of survey respondents indicated that case managers help them find community resources and natural supports (beyond paid service providers) to help them achieve their goals
- Families value peer networks as a critical source of information about services and supports, resources and opportunities
- About half of adults surveyed believe case managers will connect individuals to self-advocacy groups when desired

Systems navigation

Case managers serve as guides and support for customers in their interactions with publicly-funded systems of services and supports, including DD services, and people value this assistance. In every focus group, people with I/DD and families mentioned gratitude for the case managers for their help with paperwork related to Medicaid and DD services, and “just trying to get things done in this bureaucratic labyrinth,” frequently mentioning the high volume of confusing forms and documents. In the survey, over three quarters of people working with personal agents expressed agreement that they get the systems navigation help they need, while 55% of people working with service coordinators agreed.

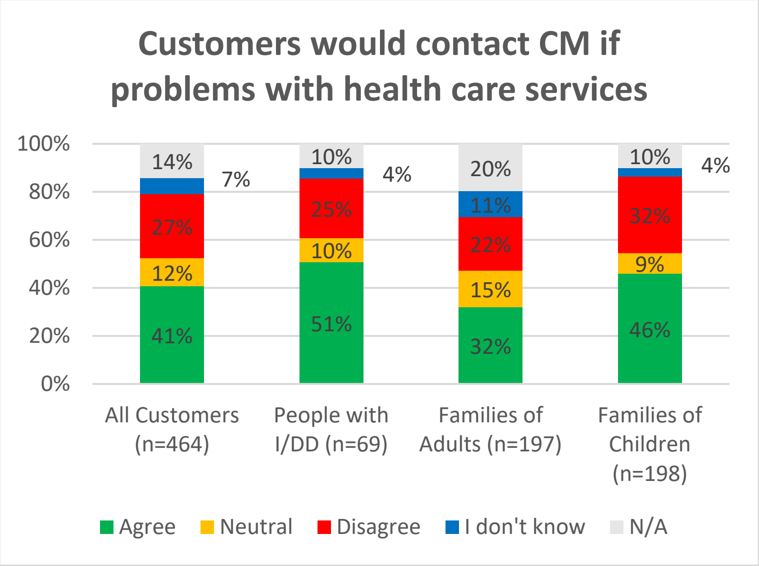
The highest dissatisfaction level came from families of children, with one-third indicating they do not get the navigation help they need. Comments from younger families included perspectives such as, “I never felt my child was advocated for by our service coordinator. She’s a ‘company gal’ who made excuses why every request was going to take 6 months or more and require ridiculous amount of effort on our already stressed selves. We had to find every resource and beg assistance rather than her coming to us with ideas for support. We had serious problems with school, finding support workers, health issues. We got no support from our service coordinator.”



Case managers report a range of their own experiences in their system navigation responsibilities – some expressing confidence and others feeling overwhelmed. “As a case manager I feel very poorly equipped to help people navigate other systems like coordinated care organizations, child welfare, and social security.” Another stated, “I believe that case managers may have the tools for many of these things, but not the time.” Differences in opinion and understanding about the role of the case manager in systems navigation outside of DD services surfaced. “I had no idea my case manager could help me with _________” was a common refrain, with references to accessing health care and durable medical equipment/supplies, attending individualized education program (IEP) meetings, assistance with vocational rehabilitation, help with social security, connecting to nutrition programs, and accessing public transportation benefits.

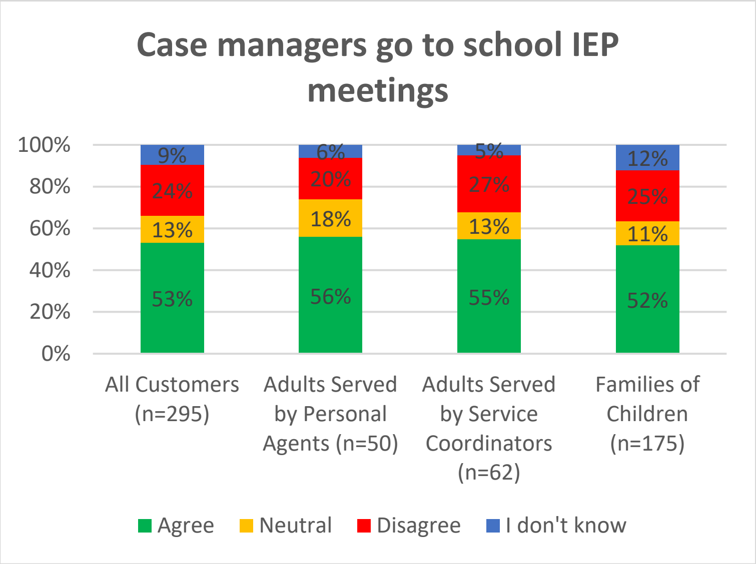
Health Care

Many respondents – especially those receiving in-home supports – do not report relying upon their case manager for assistance with medical and physical health needs. One family said, “We get no assistance with things like getting access to medical care. Incontinence supplies, catheters – we are providing everything. We are paying for everything ourselves because the system is just too hard.” Over a quarter of customer repondents report they would *not* turn to their case manager if they had a problem with their health care services; just over half of adults with I/DD would contact their case manager. One-third of adult respondents from the Brokerages see their personal agent as support for health care services, whereas nearly 40% of adult customers of the CDDPs would contact their case manager in the case of a health care service issue.



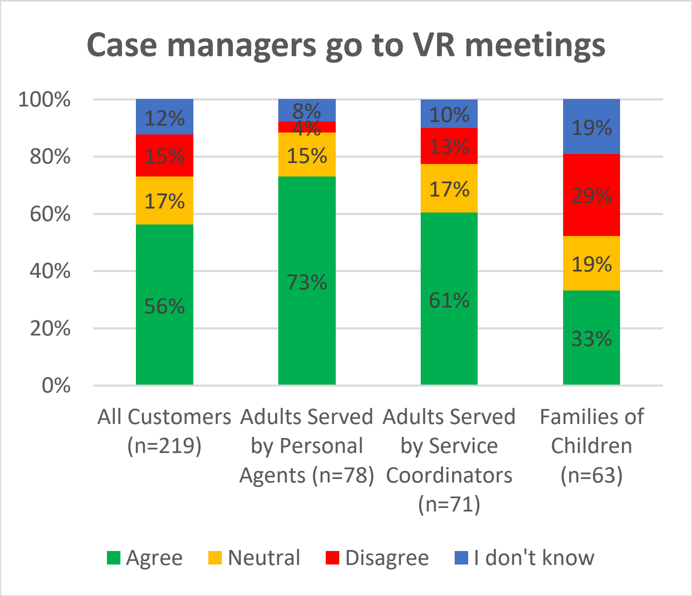
Education

Many families of children talked about the challenges of systems coordination with the schools and DD services, and wanting case management support to align plans and goals. Among those who indicated that the question about case managers attending individualized educational program (IEP) meetings was applicable (either currently or in the past), just over half indicated that their case manager went to school IEP meetings when they wanted them to do so. One frequently-heard story: service coordinators for children coming to a short portion of an IEP meeting but not having the time to stay through the whole meeting. Multiple families from different parts of the state reported that case managers often attend school meetings for 15-20 minutes and then leave, even as the rest of the team meets longer. Families note that turnover also affects engagement with schools, “Our service coordinator changed last summer. We met the new service coordinator but they have not met our daughter or shown up to any IEP meetings and we were needing help and requested it multiple times. We still are needing help but don’t believe help is there.” In particular, families whose primary language is Spanish expressed deep frustrations, trying to navigate schools as well as other systems. One tearful Latina mom said, “Life is just really hard. I go to social workers, teachers, doctors – but no one helps us.”



Vocational Rehabilitation (VR)

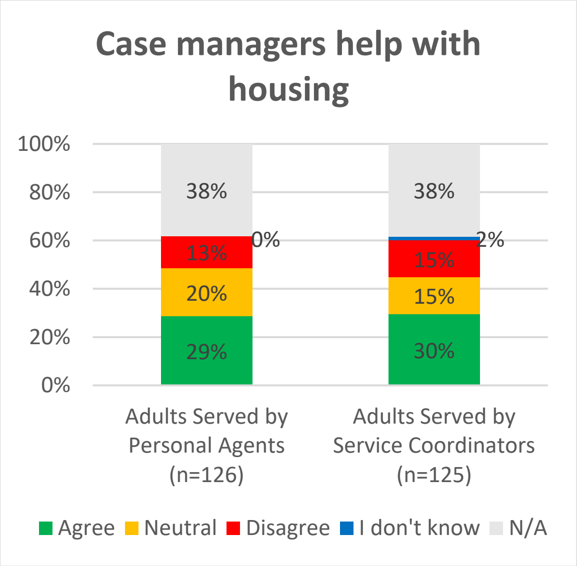
Among people who responded to the VR question as applicable to them, there was substantial variation. Seventy-three percent of customers served by personal agents and 61% of adult customers served by service coordinators agreed that, when they wanted them to, case managers go to VR meetings. However, among families of children for whom this question was applicable, only 33% agreed and 29% did not agree that case managers attend VR meetings when requested to do so. This data is particularly concerning, given that the transition period for youth moving from adolescence into adulthood is a point in time that requires extensive coordination and collaboration across education, employment, human services, and other systems.



Qualitative responses and conversations were also very mixed. One family said, “Our service coordinator helped B through the VR process, obtained a job coach, and successfully helped B get a job. It was a long process, but in the end was life changing for B. The service coordinator has done an excellent job supporting B. He has held B accountable when necessary and listens to B's concerns and requests." Yet another articulated frustration, "Work – only 6 hours per week. Expectations are so low – he exceeds them all the time. He wants a career, not just a job. He wants to connect to more people. The paid service providers are in the way of connections – hard to connect to community with them and the case manager and VR are not helping him expand his options." And a 79-year old woman with I/DD bemoaned how the state's focus on employment for everyone is tying the hands of her case manager to support her preferred goals (because her day program will soon cease), expressing great sadness and frustration.

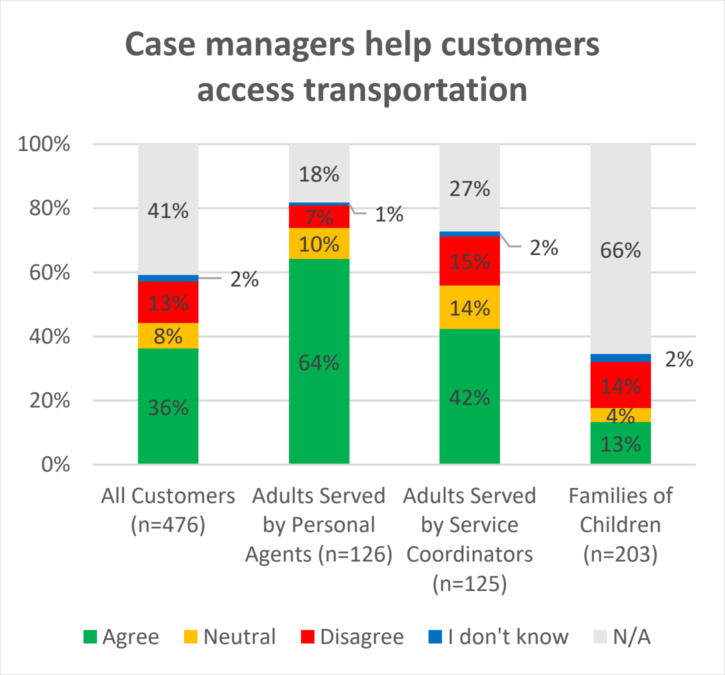
Transportation, Housing and Technology

Access to transportation and housing are particularly challenging issues for nearly all people with disabilities (as well as many other individuals). Regardless of type of case management entity, under one-third of customers report that case managers help with housing, while 43% of professionals believe case managers do not help with access to housing.

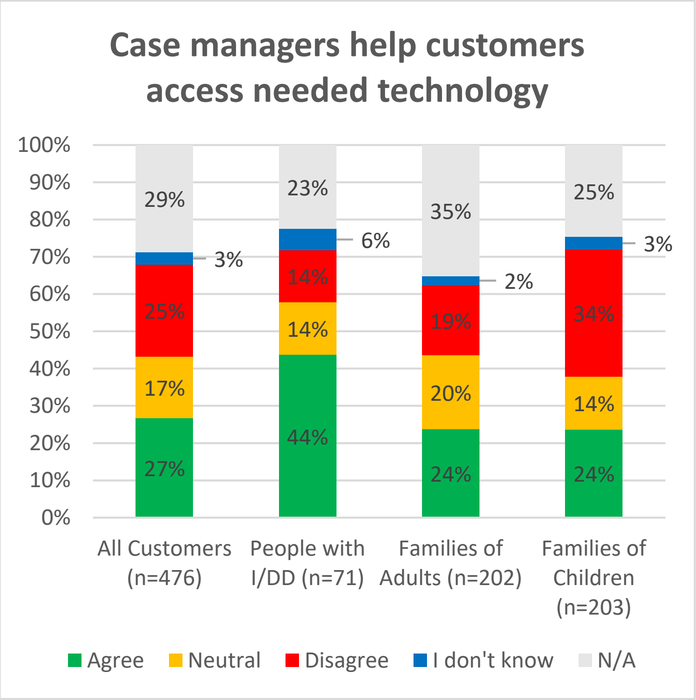


Among adults served by personal agents, nearly two-thirds agreed that case managers help with transportation, while 42% of adults working with service coordinators agreed. As one case manager explained, "Case managers are faced with lack of options to present to individuals. In many counties public transportation is limited or doesn't exist. Satisfaction with case managers is dependent on the services they can receive, and case managers are faced with not having options to offer individuals and lack of support."

Nearly every person with a disability in the focus groups, interviews and group discussions communicated frustration around transportation, wishing case managers would help more with finding more flexible transportation options. "No car, no driver, no go, no community," one young adult said.

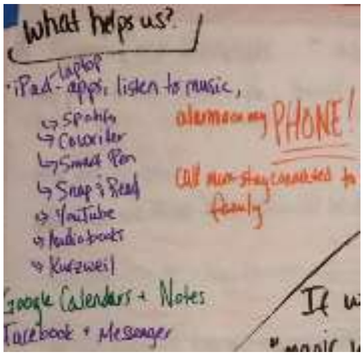


At the same time, lack of understanding about options and existing means to access transportation were also subjects of conversation. For example, in one rural-area focus group, an adult with I/DD talked about the challenges of using para-transit for medical appointments. For each of her doctor's appointments, she was meeting her staff at the physician's office (as they were supporting her through the appointments), believing that the support person could not assist her with "medical" transportation to and from the doctor. A case manager in attendance was able to explain the options and clear up confusion about allowable transportation costs. Others in attendance listened keenly, also seeking information.



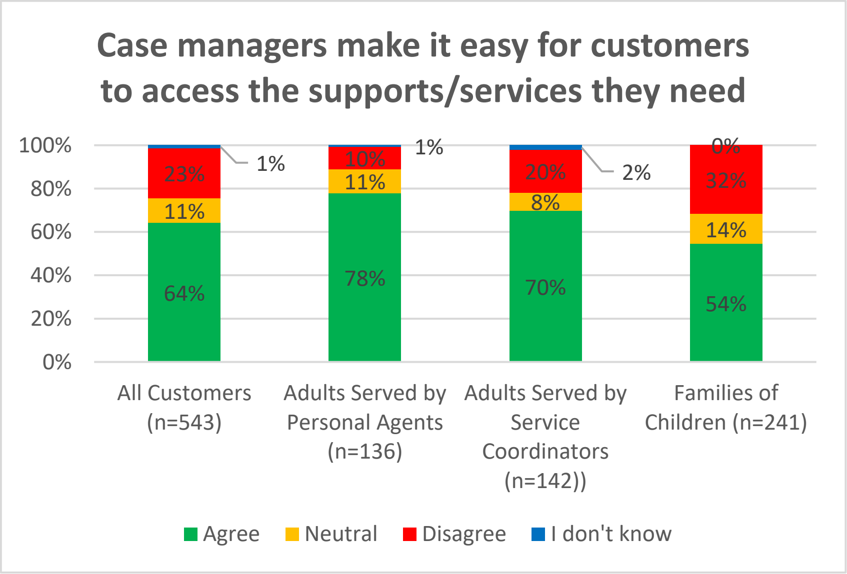
In the survey, just under half of adults with I/DD (44%) agreed that case managers help them access the technology they need, whereas among families the level of agreement was much lower. Perhaps reflecting generational expectations, families of children were most likely to disagree that case managers help with technology, at 34%.

And, in the youth focus group, nearly every idea the young adults offered about how they prefer to "navigate" towards their goals involved technology – phones, communication devices, electronic calendars, social media, using music to help with anxiety or stress. They voiced opinions that technology would help them with independence – along with family, friends and community – and, they talked about needing help to find and access the right technologies.



Finding and accessing service providers

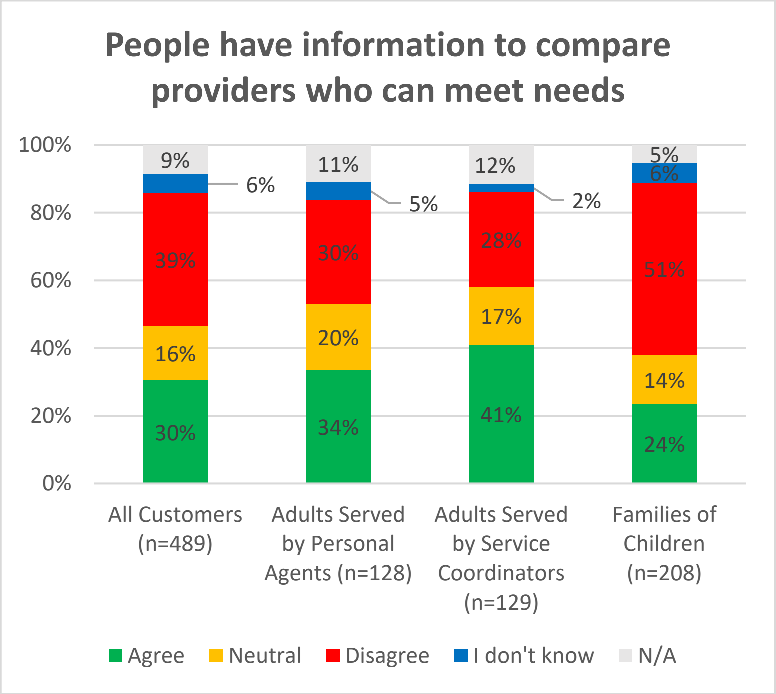
Dozens of comments in the surveys, interviews, focus groups and discussions related to the challenges everyone -- case managers, people seeking supports and families in the DD community -- face in identifying and being able to access qualified service providers, especially those aligned with the persons' needs and preferences. The critical importance of the case manager's role, including their skills and the resources available to them, was frequently cited as stakeholders talked about finding and retaining the daily supports people with I/DD need to live, work, volunteer, participate and contribute in the community. When asked whether case managers make it easy to access services and supports, there were distinct



differences in the level of agreement across respondents working with different types of case management. Only slightly more than half of families of children (54%) agree that case managers make it easy for customers, and nearly a third disagreed with this notion. Among adult consumers, 78% of those working with personal agents agreed and 10% disagreed, while 70% of adult consumers working with service coordinators agreed and 20% disagreed.

“There seems to be a disconnect between services offered and the ability to actually receive them. Our family has been waiting for over a year for the possibility of installing a safety gate and or fence to keep our daughter from wandering. Our case worker made numerous phone calls and reach outside with little info back received. The assessor finally came out last summer and we've nothing more since,” one family shared.

When asked if people receive enough information to compare local providers who could meet an individual’s needs, more customers disagreed (39%) than agreed (30%). Among adult customers working with service coordinators, the response was slightly more positive, with 41% of people indicating they have the information and 28% disagreeing in this group. Families of children expressed the highest dissatisfaction of all groups on this question, with more than half feeling that they do not have what they need and less than a quarter indicating they have enough information. Provider comparisons also came up in meetings and discussions about the need for online resources and access to information, with families noting that they turn to other families and people with I/DD to understand the strengths, weaknesses and reputations of various providers. One person suggested that CMEs needed to help create “Yelp” type reviews for providers in order to further transparency and choice.



Many families expressed surprise upon learning that other service options exist beyond finding, hiring and overseeing personal support workers as an employer of record. “Can you tell me the words to ask for? How do I get my case manager to find a professional provider who has the right training and abilities to work with my child?” asked one parent.

There exists a wide range of perceptions and some uncertainty about the case manager’s role and responsibilities related to helping customers to find and engage service providers, such as:

> “We would like to have someone who is more clear about what they are supposed to do for us and what kind of help they are supposed to provide us with.”
>
> “Help us with finding providers and contacting them and not just handing us a lots of numbers and telling us to let them know how it goes.”

> "Case management hasn't really ever done much for my child. He has been enrolled since he was 3 but now as an adult in transition they really don't have anything to offer or assist him with. His dad and I really provide all the support for him. I'm not really even sure what the purpose of my case manager is other than to someday maybe get some support?"

> "My family member has been with the brokerage for years. We have arranged the providers and manage them. We are still vague on what would be available other than paying for service providers and respite care. Also not much info is forthcoming on community inclusion activities."

> "We need more expertise. We are constantly having to educate, educate, educate. I would really love to have someone who knows my child's disability. Someone who will help navigate insurance. Someone who will help us find real qualified providers, not just PSWs. I am constantly bringing research and data into the conversation – I need them to understand more and how to work with our family."

Provider capacity development

Case management entity staff and leaders talked about how there is little opportunity to help develop new providers, and so case managers feel like they are caught in a "catch-22" – they need more local service provider capacity in order to do a good job supporting their customers and their needs/goals, but they do not have the time or resources to help identify, establish and grow quality providers. One case manager talked about how the pressure to encourage families to rely on personal support workers (regardless of the person's preferences) comes from multiple forces, including the overall workforce shortage challenges, the lack of case manager capacity to help find and use a more stable and skilled provider base, "rate structures that, frankly, disadvantage DSPs and our more skilled providers" and the need to individualize supports without many workforce options. Another case manager wrote, "Many of the issues lately have been a drastic shortage of direct service workers available through our contracted agencies. The agencies have been unable to hire and maintain their workforce…We can write great person-centered plans, but what is the point when we can't find the workers to help."

Another CME expressed confidence, "We have maintained capacity in all service elements to allow people to have choice, even in urgent situations. We have developed mostly small local non-profit providers who are responsive to community needs." However, participants receiving case management from that same CME shared different views in a focus group, "For our adult children, we don't have the same range of approaches, ideas, what are the options? Can the case manager provide more ideas on what this service person can do? I don't know what is possible – we need them to help us to support the vision and our goals. Sometimes you just don't know where to go. We don't know what we don't know."

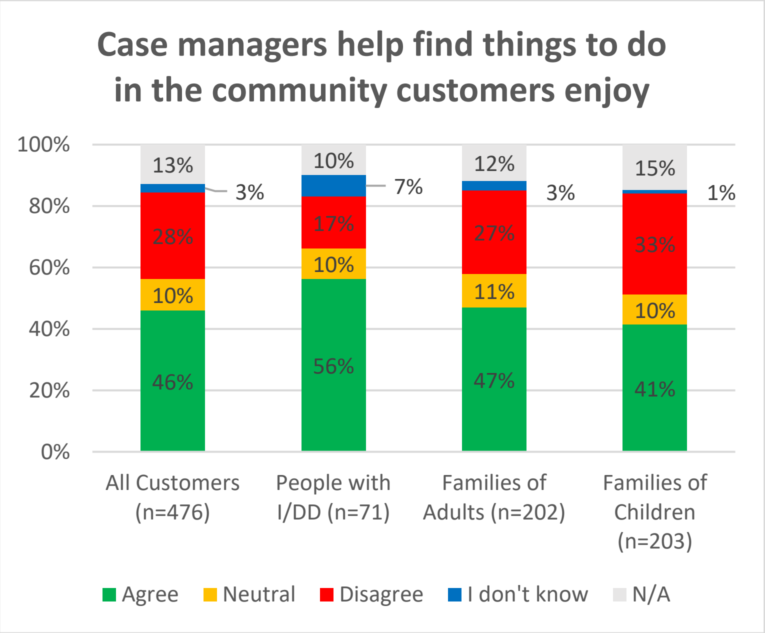
A different CME offered this perspective, "Personal agents used to play a bigger role in overall capacity development. It's much harder for them to engage in this area due to the change in their workload. Five years ago, a PA was managing about one half million a year in service dollars. Today, they manage three times that amount or more, depending on who they serve. Capacity development falls largely to leadership within the brokerage today."

Community capacity development and connections

Building thoughtful person-centered plans to support community inclusion, choice and individual goals involves much more for the case managers than identifying and contracting paid service providers to meet a need. Natural supports, "generic" community resources, local assets and networks are equally important considerations and options. Based upon stakeholder feedback, case managers' approaches to finding, understanding and connecting within Oregon's communities on behalf of their customers varies greatly, as do the expectations around this concept.

In the survey, less than half of customers respondents indicated that they agreed that case managers help them find other people, supports and community resources – beyond the paid providers – to help them achieve their goals. One father articulated his thoughts on this, "I would love to see case managers helping to be the bridge to community organizations and events – helping people connect to the YMCA, t-ball, and other local resources. Be the link that creates opportunity, accessibility, understanding and community connections with people who may not accept us or know how to include us right away."

When asked about whether case managers help customers find things they enjoy doing in the community, more than half of people with I/DD agreed, while families were not quite as positive. One parent wrote about the "need to be included to change the culture of our communities – we need support in accessing the other things families take for granted." One focus group of families talked about the idea of the case manager as the facilitator of access and connections in the broader community, "like an advance team, scouting out people and places that will welcome us, where we can show up and be a normal family like everyone else."



Another family talked about the case manager as a "seed planter – someone who germinates ideas, helps us envision a life for our son we would have never imagined by gently pushing us out into the community and thinking ahead more. It is hard to let go; my husband wants to wrap him in a titanium bubble to keep him safe, but our case manager is helping my son explore, be happy out in the world."

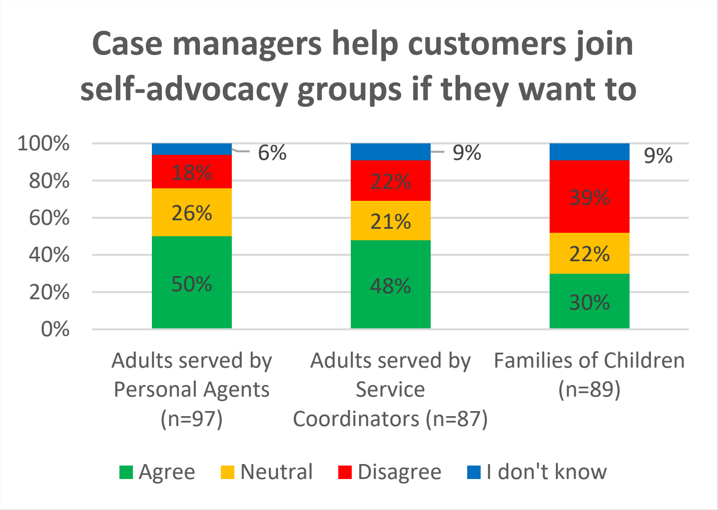
People with I/DD who contributed their views in the groups had expansive and creative ideas about what is available in the community for them – and there were differing perspectives on whether providers or case managers should help with finding and accessing these options. Many talked about how case managers have been helpful in figuring out how to participate in a wide range of activities – with and without paid supports – including working, volunteering, learning to drive, getting involved in politics, joining clubs, taking college courses, working out, playing sports, community social events, using library computers, helping younger children, saving the planet, and more. The common thread in all of these conversations related to the "right amount" of support for each person, allowing for independence and interdependence within the community. "I don't want my support worker to drive me around. I want to take the bus so I can meet people and be independent. Help me learn to take the bus instead of having her always follow me around," one young woman explained.

Family Support and Self-Advocacy

While the survey did not ask questions about family support issues, in the focus groups many families talked about the need for case managers to work with their sons and daughters in the context of the family, including adult children, and to help find family-focused resources for families of both children and adults. Families frequently cited peer-to-peer networks as important community resources that case managers should link people to, including the Oregon Family Networks supported by ODDS and the Oregon Council on Developmental Disabilities, as well as several other organizations where families can connect and learn from one another.

Parents spoke about relying upon peer networks to learn about services, technology, community resources and best practices as well as developing social relationships with others who are on a similar journey. Many indicated that they see other families (both formal and informal networks, through organizations and through social media) as their primary "navigation support," often trusting the peer relationships more than case managers -- including as related to information about DD services. "I wish I didn't feel like I know more than my case manager, but I do" lamented one parent. They seek advice from other families on all aspects of the system, including how to "prepare" for assessments and ISP meetings, reputations of provider agencies, how to manage PSWs, how to become a PSW, and "the kinds of things other families have been able to get and how they did it." And some focus group participants said they felt more forgiving of case management turnover and communication challenges when they had other families to turn to. Gaps in family peer networks were also noted by participants – opportunities for parents of middle-age and older adults with I/DD (especially those living in the family home), adult siblings of people with I/DD, culturally supported non-English speaking families, and grandparents raising grandchildren with disabilities.

Among survey respondents who indicated that the question was applicable, about half of adult customers agreed that case managers help people join self-advocacy groups, while families of youth expressed less agreement.



In the focus groups, most adults with disabilities did not initiate discussions about self-advocacy groups or peer networks, nor did people talk about the role of case managers in supporting peer-to-peer connections or membership in organized self-advocacy groups. Adults with disabilities were more likely to talk about providers as key connectors to other self-advocates and to community resources than case managers. In the focus group of youth and young adults, the participants talked about individual self-advocacy and being supported to be heard, as well as seeking help from case managers to find communities of people based upon shared interests (not necessarily disability related.) Families in one group did discuss the importance of "disability pride and empowerment," and the need for case managers with the knowledge and skills to help individuals experience positive interactions about their own disability and support needs.

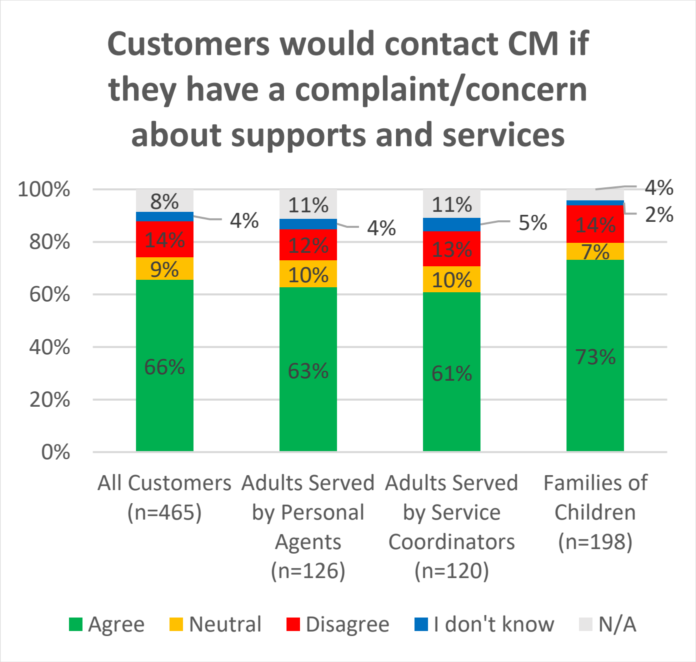
E. Oversight and Monitoring; Follow Up Activities

Summary

- Adults receiving I/DD services and families do not have a clear understanding of the role of case management entities related to overseeing implementation of supports and services
- Only about one-quarter of people indicated that they do not need more help to find service providers; about 40% agree they need more help managing service providers
- Less than half of survey respondents indicated they would contact their case manager if they experience problems with their health care
- About half of people surveyed see their case manager as someone who will help customers solve problems, or would contact the case manager in a crisis or under threat of harm
- Nearly two-thirds of adults with I/DD report they would contact their case manager if they had problems with family, while only one-third of family members of adults believe they would
- One-third of families of adults, and over one-half of families of children, report having no back-up plans if supports are not available; options for after-hours contact with CMEs varies greatly
- Stakeholders from multiple perspectives agree that teamwork across case managers and providers is very important, nearly a quarter of customers do not agree that this occurs
- Customers indicate communication about, sharing of, and access to their personal information, including ISP and service records, assessment data, progress notes and timekeeping, is inconsistent and not user-friendly
- People with I/DD and families are unclear about the role of case managers and other entities in supporting them as employers, and expressed dissatisfaction with training options

Oversight and Monitoring

An important part of case management is helping people with I/DD and their families with monitoring and improving the quality of supports. Case managers are responsible for ensuring that people's health and safety needs are met, services are provided in a manner consistent with the ISP and aligned with needs and goals, rights are protected, preferences are addressed, and people are satisfied with services.



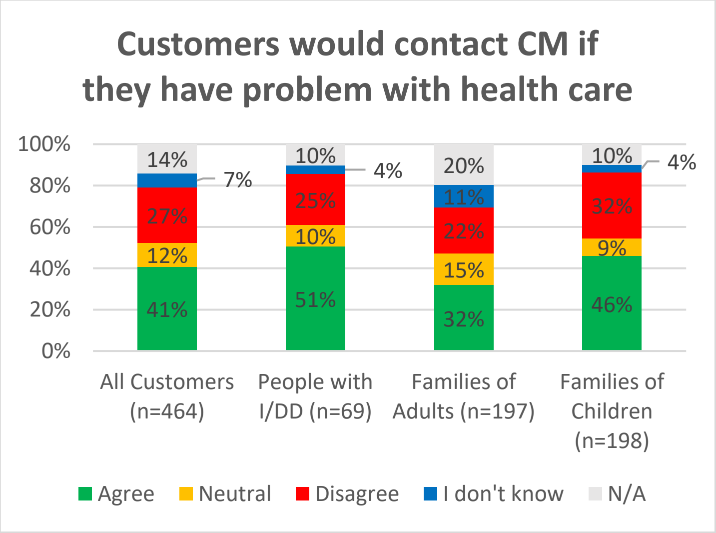
In the survey, the majority (66%) of customers agreed they would contact the case manager if they had a complaint or concern about their services and supports. This is one of the few areas where the perspectives of families of children were more positive than adult customers. Interestingly, 11% of respondents receiving case management in the adult system selected "not applicable."

In the focus groups, meetings and interviews, the complexities of monitoring activities were expressed in other ways, often related to the triangulation of case manager-provider-customer, challenges with communication, and lack of clarity related to roles and responsibilities.

"Our son is in a foster home with three other adults with I/DD. The service coordinator visits the home monthly to review issues with the owner. I cannot remember a random phone call to check in with the parent guardian." Another participant talked about the challenge of "the case manager, the middle-man of the agency between the personal care provider and my family and the friction it creates," wondering whether they should be talking to the case manager or the agency supervisor when there are problems.

People also talked about timeliness in solving problems that do not rise to the level of an emergency, but might require support for the issue during non-working hours. "We might need weekend or after-hours access to our case managers, sometimes things are not a total crisis but they are urgent and we just can't wait."

ODDS data shows that about 75% of customers are covered by Medicaid-funded Coordinated Care Organizations (CCOs), yet very few individuals mentioned the I/DD case managers' role in supporting medical/health care needs in the qualitative discussions. And in the survey, just over half of adults with I/DD said they would engage their case manager if they had a problem with health care as compared to one-third of families of adults and 46% of families of children.



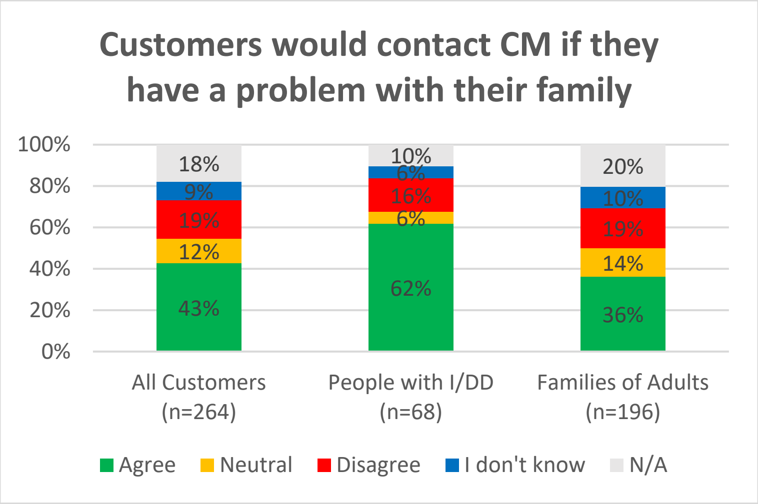
When professionals from the health care system were interviewed (CCO and physician perspectives), concerns were expressed about the lack of coordination and connection between DD services and clinical care. These individuals raised questions about how to support people with complex medical needs when there is limited to no shared planning across systems, and customers are caught between entities with different processes, accountability expectations and some overlapping benefits. This was reinforced by some families of children, who expressed frustration in accessing durable medical equipment, incontinence supplies, and navigating support needs during hospitalizations.

Family Conflict

In the focus groups, adults with I/DD talked about the importance of a skilled case manager who can work well with them individually as well as with their family, and help navigate conflict when parents disagree with an adult's choices. "Listen to me, but respect my family" was a theme that emerged in multiple discussions. At the same time, families expressed frustration when they are "left out of the loop," fearing that things may fall through the cracks. "I don't want to be a guardian, I want to be a parent, and part of parenting – even in adulthood – is remaining engaged and partnering in supports and decisions. But I don't feel like the system respects that."

In the survey, nearly two-thirds of adults with I/DD said they would contact their case manager about problems with their family, while 16% disagreed and would not. Among families of adults, just over one-third said they thought their family member would reach out to case management in these situations, whereas just under one-fifth said they would not.

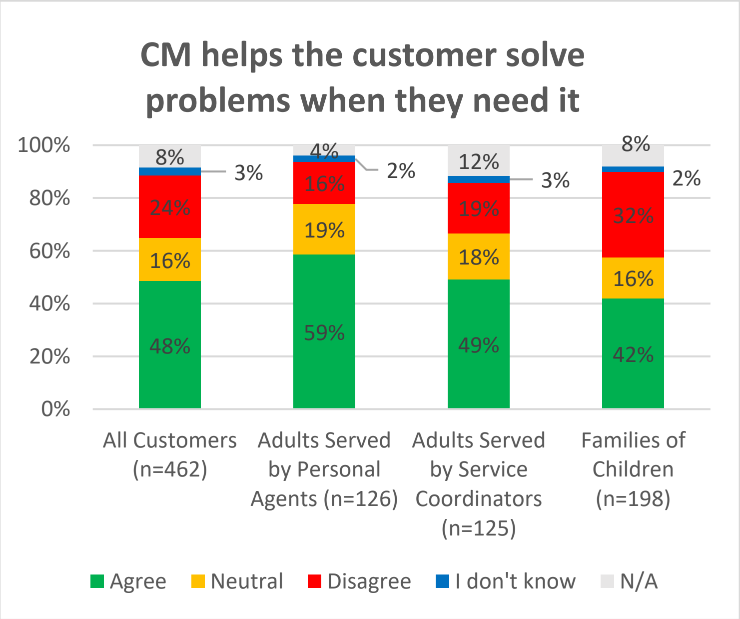
One provider shared, “Case managers are not prepared to navigate disagreements between adults receiving services and their parents. We have to walk a fine line as providers, and the case managers are challenged in engaging around family issues and don’t help us.”


Customers would contact CM if they have a problem with their family

Another comment, “I wish case managers were equipped to do more social work. People are living with paid family members, and we see exploitation in these relationships, but right now there is no way to manage this, as it doesn’t rise to the level of abuse. We need more accountability with the in-home provider system. People are becoming institutionalized in their own homes.”

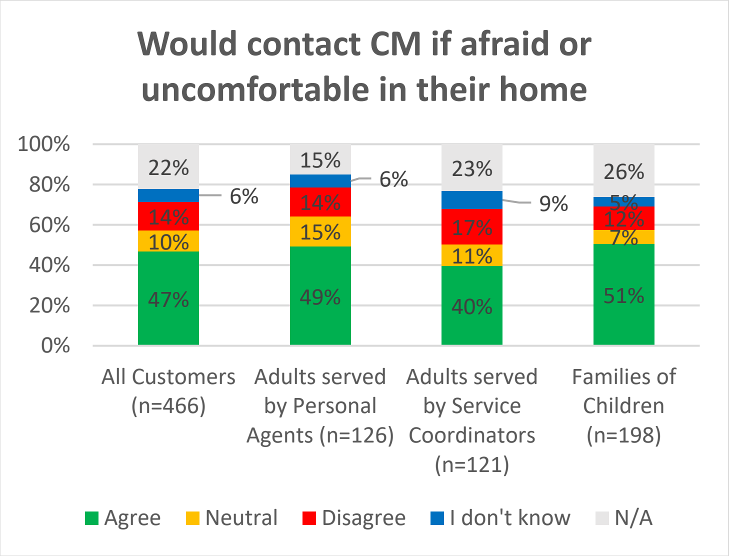
Follow-up: Solving Problems

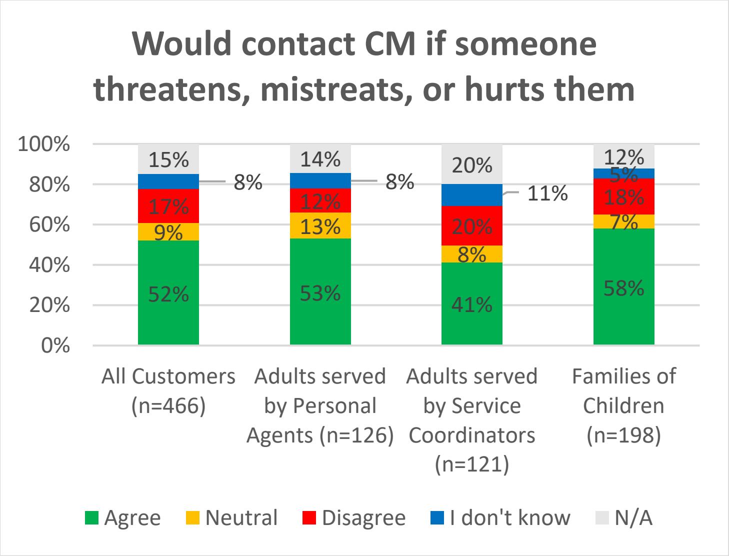
People with I/DD and families often rely upon their case managers to help them resolve problems, but some families and adults do not feel as though they get this support. “Case managers hands are tied. Friction between the case manager and the client because things take so long. The system is not responsive.” Others expressed gratitude for case managers who have helped with documentation snags, problems with providers, and addressing safety concerns.

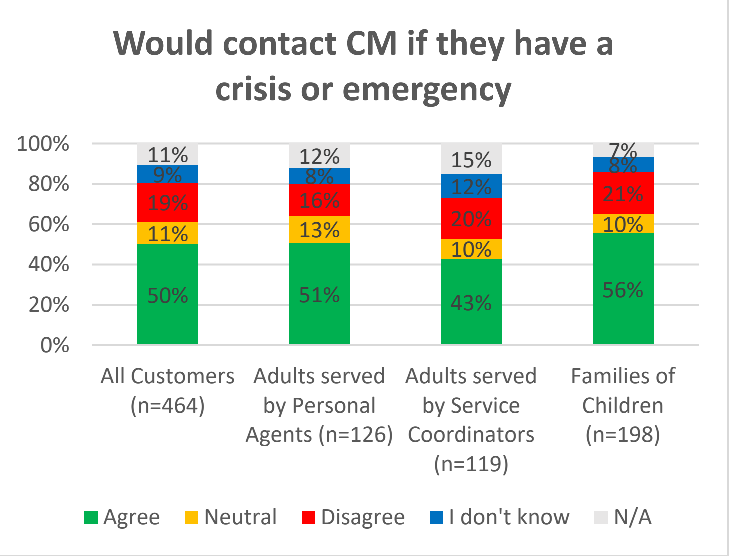

CM helps the customer solve problems when they need it

In the survey, there was some variation across types of case management and between adults and children, but overall just under half of respondents agreed that case managers help people solve problems when needed, and just under a quarter did not agree. Many comments related to the complexity of the system and the responsiveness of case managers also cited difficulties, “We need an interpreter to maneuver this system. Case managers seem to want to help, but always say management changed mind. Or not allowed or it's a state rule. This system is not family friendly.”

Avoiding Harm







Helping to keep people safe from abuse, neglect, exploitation, and working to prevent crisis situations – and respond to them when they do occur – are core responsibilities for case managers, regardless of setting or service type. In the focus groups, adults with I/DD often talked about this aspect of their relationship with the case manager, indicating that they understood this to be an important part of a case manager's job. In the group discussions, families were more likely to think about this role in the future context and less in the present, implying that family involvement reduces the current need and envisioning the case manager that "helps keep them safe when I am gone."

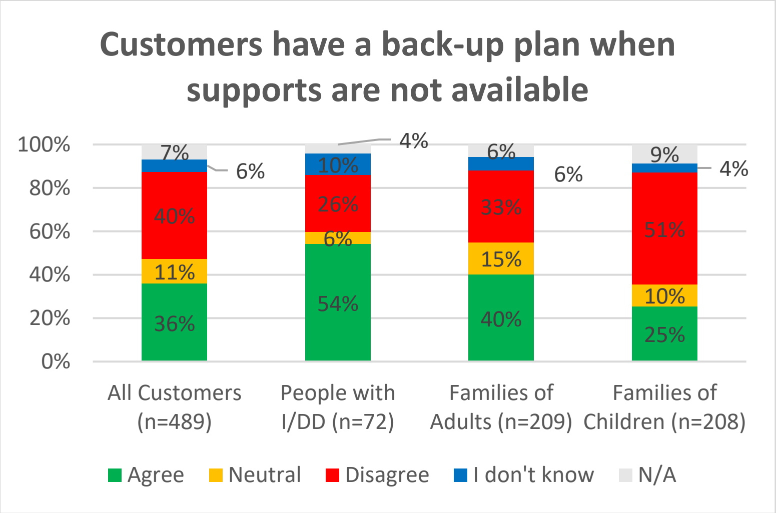
Survey questions related to whether or not customers would reach out to the case manager in situations involving potential abuse, neglect or crisis yielded fairly consistent responses overall, with lower levels of agreement among adult customers working with service coordinators.

Few commenters or participants in the focus groups and other discussions addressed issues related to abuse and neglect. Residential providers talked about inconsistency across the state, "Each county seems to have a different interpretation of abuse investigations. We worry about different issues in different counties. Each county gives us different information, takes different approaches, monitors inconsistently."

Families did talk more about crisis concerns in the groups, worrying that the challenges with responsiveness in the case management system creates problems that may erupt in crisis. One parent described it this way, "They have to prioritize people who are in dangerous situations, and so we get ‘back-burnered’ due to other people’s needs. This can drag on for a long time and then we become the crisis, the dangerous situation.”

Back up plans

A sizeable number of survey respondents revealed they that they do not have a back-up plan when supports are not available. Among families of children, over half indicated they have no back-up plan, while among families of adults, one-third said they did not. Adults with I/DD were slightly more confident in their back-up situation, with just over a quarter of them saying they do not have back up plans.



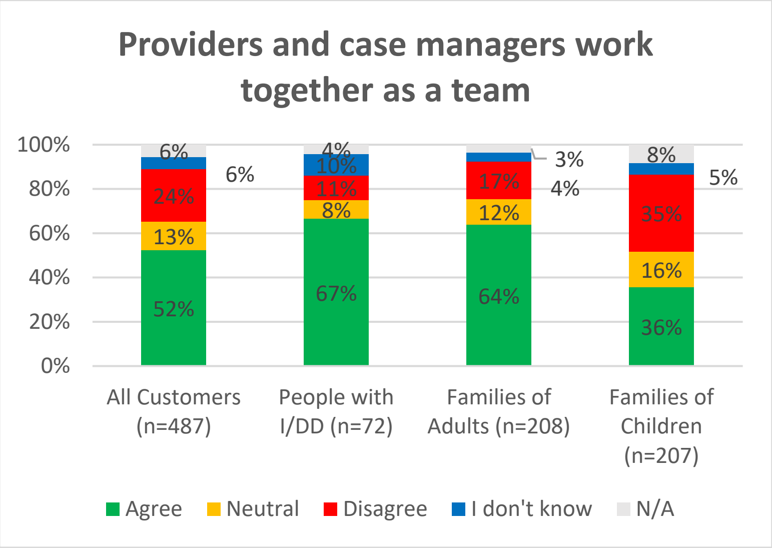
In one focus group, people talked about how the current low unemployment situation creates a “provider’s market,” meaning that even if a case manager strives to help a person receiving in-home supports to develop a good back-up plan, it is nearly impossible to find available and willing providers who can step in with short notice. Even among people who have chosen to work with agencies, families reported that if a direct support worker is sick or has a conflict, there are few options other than re-arranging their own schedules.

Case management entities have varying policies related to after-hours contacts, and the role of case managers in assisting with unanticipated gaps in supports and services. Some CMEs ensure that outgoing messages include emergency contact information, others offer cell phone numbers for urgent matters. Some CMEs indicated that urgent matters may be routed to leadership during off hours, through various mechanisms. When asked about non-business hours, one CME responded, “There is none. We’re not a 24/7 business operation... For after-hours reporting, our voice mail out of office messages say that the person can leave a message and get a call back the next business day or if it’s an emergency they should call 911.” In another case, a brokerage has set up a single after-hours phone number that is staffed by rotating “on-call” personal agents who each take shifts to cover any calls.

Collaboration between case management and providers

The majority of people with disabilities and families of adults expressed a generally favorable impression when asked about supports and service providers working together as a team with the case manager, with over two thirds agreeing that cooperation occurs. However, families of children were evenly split among those who see this teamwork and those who do not.

In the group meetings and discussions, there were very strong views voiced on this topic by different stakeholders. Case management entities talked about the lack of management that is occurring in some provider agencies, leaving case managers to negotiate between in-home DSPs and their supervisors when contacted by customers with concerns about services. Adults with I/DD who are working with PSWs are not always certain who to call if there are problems with workers. This was echoed by some families, who spoke of confusion about who could help with provider issues, and an uncertainty about the case manager’s role when there needed to be better coordination or communication with providers related to in-home services.



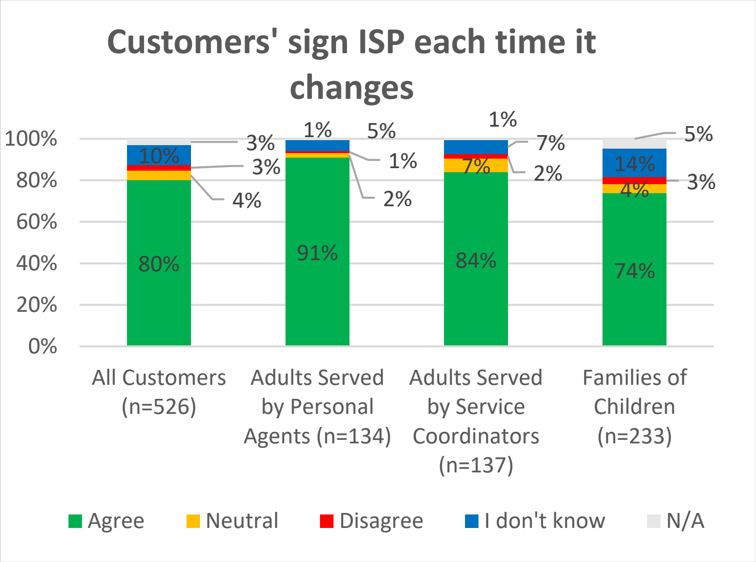
Many providers articulated strong opinions as well. They talked of inconsistencies across counties, and between CDDPs and brokerages. Typical of many comments, one provider put it this way, “I have worked collaboratively with some amazing case managers. I also have a lot of experience with case managers who don’t assume positive intent and almost never respond to emails. As a service provider, my main source of burnout is this inter-agency dysfunction, and when it happens it is the client who loses. Would be so nice to work instead as a unified team with a shared purpose.” Some providers indicated they do not feel valued as part of a team with case management, as this comment reflects, “It would be wonderful if they were more involved in the ISP process and the lives of clients. they are very often ‘too busy’ to attend team meetings or problem solve with the team about supports.”

Other provider comments included frustrations such as, “It often feels many case managers are against us (providers) vs working with us. This is so different then it felt years ago when they were our second set of eyes that helped ensure we were providing the best supports.” Another said, “Brokerages are totally rights oriented, not interested in partnerships with providers, and CDDPs seem to think that their most important role is to make sure providers are not hurting people.”

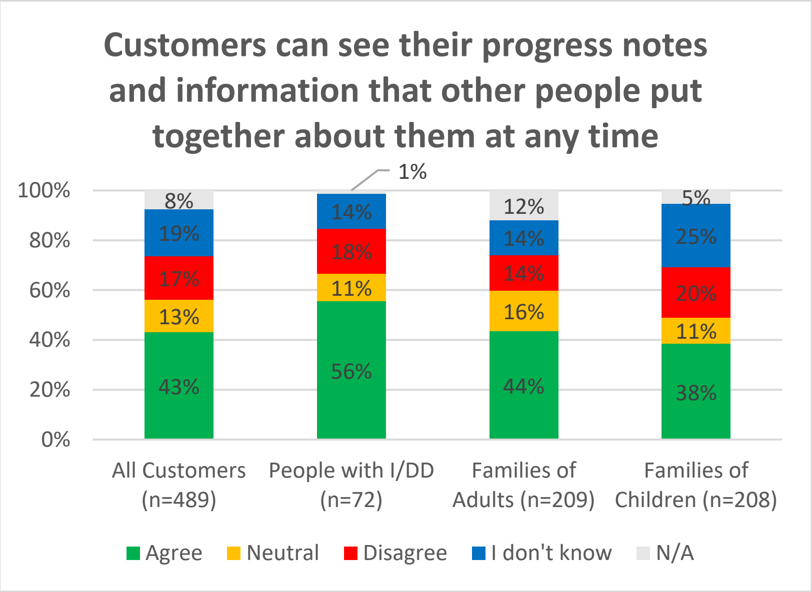
A focus group of adults with I/DD put the importance of teamwork this way: “Case managers should make sure everyone working with you is on the same page. It is really hard when they are not.”

Documentation, Records and Communication

Communication issues related to records and personal information were also noted by stakeholders. The vast majority of survey participants (80%) agreed that customers sign their ISP each time it changes, with few disagreeing. Families of children were less certain about this question, with 18% indicating “I don’t know” or “neutral.” In the focus groups, some parents of children were not certain what the ISP document is, nor whether they had participated in its development, which may account for some of this discrepancy.



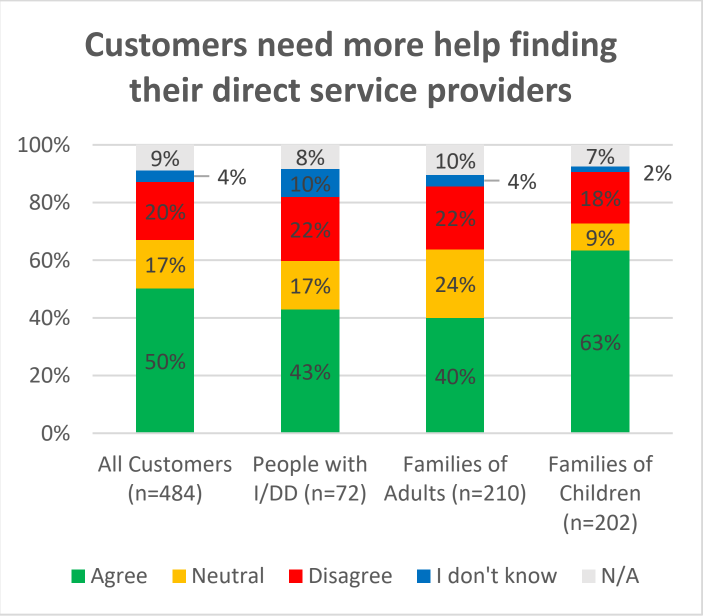
Several people commented on information-sharing, privacy issues and concerns, and how different entities are managing this. In the survey, fewer than half of respondents indicated they can see their progress notes and personal records at any time. At the same time, three quarters of people expressed confidence that their ISP is only provided to the people they have agreed to share it with, with only 3% disagreeing, and 23% of respondents expressing uncertainty or indicating this question was not applicable to them. One provider said, “Case managers sending packages in the mail with 200 page files about a person -- I don’t want to be part of that. If that’s how they introduce someone – how is that person-centered? Does this person even know that these records were sent, before they have met us and they have decided that what we do is aligned with their needs?”



In the focus groups, adults with disabilities talked about privacy issues, and wanting to control their own information, especially related to implementation of the functional assessment and risk documentation. Several expressed discomfort with the change in policy related to prohibiting their case manager from conducting assessments, making comments such as, “I don’t want to talk to a stranger about personal stuff.” Families also talked about feelings of humiliation and embarrassment generated by the new assessment, how the process is traumatic for some people, and how the assessment process may damage the relationship with case management.

Finding, managing service providers

In every part of the stakeholder engagement process, the challenges of finding, hiring, maintaining and managing service providers was a frequently discussed topic. Among survey respondents, half agreed that people need more assistance in finding service providers, whereas only one-fifth disagreed. Nearly two-thirds of families of children indicated people need more help finding service providers.



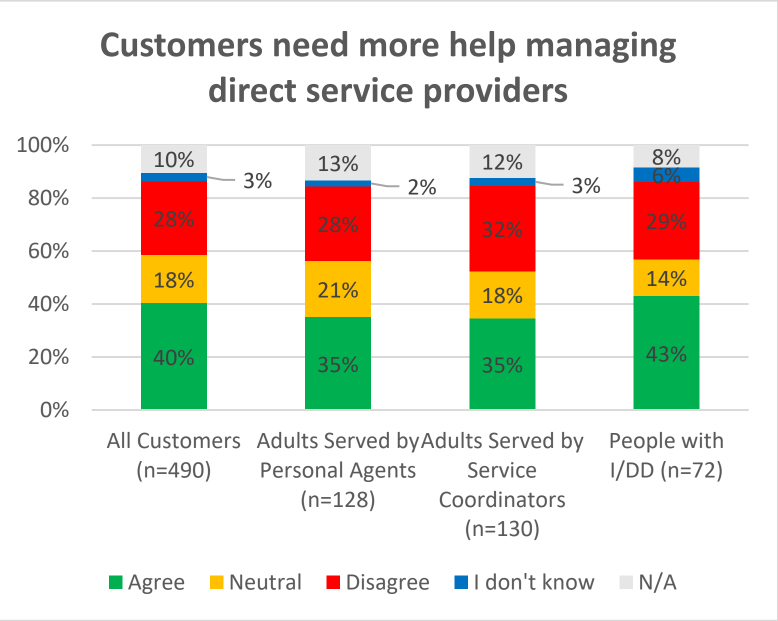
Comments from survey respondents frequently mentioned challenges with background checks and enrollment of new providers or providers offering new services, and frustrations that case managers do not have the ability to move this process forward more quickly. “The process of hiring personal support workers is too complicated and lengthy. More support and help in this area is needed" is a statement consistent with many comments.

Others expressed frustration with finding workers generally, "My case manager does not help me find PSW's I must always find them on my own. I have asked repeatedly and they tell me to look on my own or say they will help and I never hear from them." Another respondent said, "We have a support service budget that we can't even spend because of the lack of qualified providers - and when we do, staff only last a few weeks before doing something inappropriate."

In the focus groups and in other discussions, dissatisfaction with case management referrals to the Oregon Home Care Commission (HCC) list was also a common complaint. The HCC registry was described as "not user friendly" and "made for the aging community," while another participant indicated, "HCC workers don't know anything about people with IDD. They quit after a few days because they can't handle it. My case manager can't even keep up with the turnover of these people in our house."

A parent whose family member has been involved in services for nearly 20 years shared, "We lost a lot of small providers being innovative when the state got rid of the independent contractors. The choice should not be only a big agency or having to hire personal workers. We liked it when we had people thinking out of the box and it is harder to find that now. It puts more on us as families, not less – even though there are more paid service hours, they are not as valuable – and case managers can't really help us find the providers we want and need."

In the survey, just over one-third of adult customers indicated they need more help managing direct service providers, whereas this number was higher among families of children. In the focus groups, it became clear that some families are afraid to hold workers to account because of the workforce challenges. Especially in rural areas of the state, people feel they have few to no choices about who to hire. Fear of staff quitting to go work with "easier" clients was expressed frequently; people are afraid to talk to case managers about problems because they don't want to damage the relationships with the direct support staff. For example, one parent talked about a PSW often running their own personal errands while supporting their adult family member, charging support time and mileage for these trips, and justifying hours spent this way as "community inclusion." Yet, this family did not tell their case manager, nor discuss it with the worker, for fear the worker would quit. One respondent shared, "When people are paid for services, there should be same expectations – paid families/PSWs should be treated the same as professional providers. The case managers have no oversight on PSWs. Some people are not able to do things they want and need because the PSW needs hours."



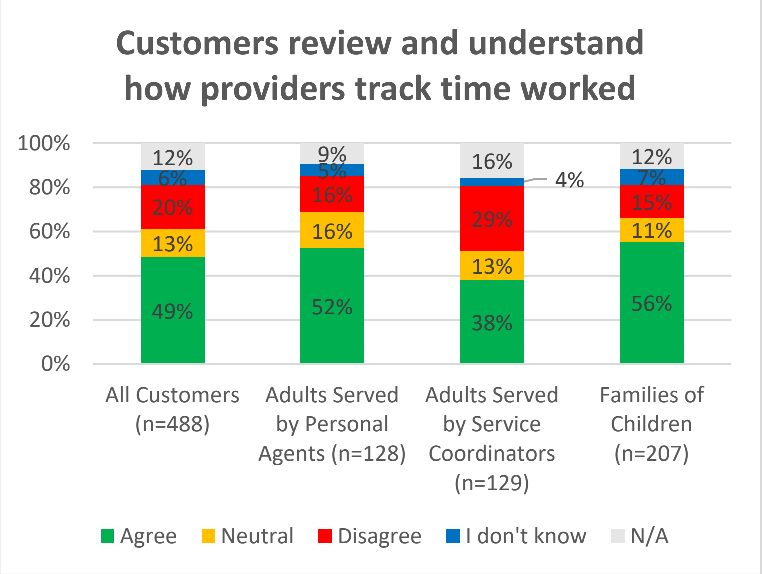
Other families talked about how they would like to see a culture of openness and information sharing with the case manager about provider issues, “they need to know what the workers are doing,” and see improved communication between case managers, families, people receiving supports and providers as the key to improving accountability.

Understanding and Managing ‘Employer of Record’ Responsibilities

Many families in the focus groups seemed to have a limited understanding about the rules and responsibilities related to serving as an employer of record, and were uncertain who could provide accurate information. People spoke openly about using PSWs to cover carpools, watch siblings when working with a child with a disability, help with chores around the family home that are not directly related to the person with a disability, and more. “What am I supposed to do when my child is not interested in engaging with the worker, and we have promised them the hours? They end up helping with the laundry and the dishes instead. Is that a problem?” one parent asked. In another group, parents talked about needing more clear and understandable information, as they stated outright that they do not understand what PSWs can and cannot do, and they are not sure who is supposed to help them with this learning. “I am happy to work within the boundaries of the system,” one parent stated, “but I don’t know where those lines are.”

Families turn to case managers seeking training resources related to both managing and serving as PSWs and are frustrated by the current options. “Our CME provides no local trainings. Families do not know what is allowable and that changes often.” One discussion centered on the lack of in-person interactive learning options, and the challenges of relying so heavily on online learning when trying to help an adult with I/DD learn to manage their own supports. Families in one focus group asked, “Where is the support for the workers to learn how to implement the ISP, to know how to use the time well to support my son/daughter in the tasks, skills, goals, and not just be a companion or supervisor?
Is that the role of the case manager, to teach them that? If not, then whose role is that?”

The tools available to help assist with provider management were also raised frequently, with questions about how case managers can or cannot help families and people employing PSWs. There were many negative comments about Public Partnerships, LLC (PPL) and eXPRS, and frustrations in seeking assistance from CMEs and PPL. “The disconnect between the case managers and PPL is huge. PPL in general is a horrific experience and I can’t imagine what it is like for a person experiencing I/DD trying to navigate it. Get a new system!” one commenter lamented.



Survey responses related to overseeing workers’ time indicate that only about half of customers agree that they review and understand how service providers track the time they work with people. Adults with I/DD in one group talked about wanting simpler ways to track their supports’ time and to sign off on timecards, including when and how they can review this information. They want to maintain control – “If I am the boss then I need to make sure they are doing their job and I need to know it" – while expressing some frustration with the current processes. It was suggested that there should be an easy app or a user-friendly website where timesheets could be stored for approval by people with I/DD and families, and so people would not feel pressured to approve timesheets "on the fly."

Several people with I/DD talked about wanting direct and ongoing support in serving as an employer, including in the interviewing, hiring and oversight of staff, and they see the case manager as the person who should provide this support. Some case management entities are providing some of this assistance to adults and families hiring PSWs, while others indicated that their case managers do not have time to participate in activities such as interviewing potential workers.

APPENDIX A: FIRST PERSON SURVEY

SURVEY FOR PEOPLE WITH I/DD WHO RECEIVE SERVICES

Welcome to the Oregon Survey on I/DD Case Management Roles and Responsibilities

Your voice is important – we really want to hear from you!

This is a chance to share your opinions and ideas.
We hope you will.

This survey will be used to help understand what is working well, and what could be better, in the Oregon case management system for people with intellectual/developmental disabilities.

Health Management Associates (HMA) is conducting this survey on behalf of the Oregon Office of Developmental Disabilities Services (ODDS). We hope to learn about experiences with case management for people with I/DD in Oregon from you, the people who are most important – people receiving services, families and other stakeholders.

Completing The Survey

Filling out the survey is your choice – it is completely voluntary. All answers are anonymous. Your answers will not be released, nor will they be shared with ODDS or anyone else. We will not be able to identify the people who took the survey.

There are no right or wrong answers;
it's your opinion that matters!

If you have questions about the survey, please contact Robyn Odendahl, 720-638-6710 or rodendahl@healthmanagement.com.

If you need help taking the survey in a different language, please contact Melissa Crawford at Melissa.E.Crawford@state.or.us or 503-945-5811.

Completing this survey (or choosing not to complete this survey) will not affect your ability to receive services and supports in Oregon.

The survey will take most people about 15-20 minutes to complete.

Thank you for filling out this survey!

Background: Case Management

Case management is the system, people and processes involved in helping people with I/DD (and their families) access supports and services. In Oregon, we have two different names for case managers:

- **service coordinators** (state staff who provide case management for children in certain programs, and local agency staff who provide case management for children and adults who get services from Community Developmental Disabilities Programs, CDDPs.)
- **personal agents** (regional Brokerage staff who provide case management for adults who get services from Support Services Brokerages.)

Every person who receives I/DD services funded by ODDS has either a service coordinator or a personal agent. Currently, all children under age 18 have service coordinators, as do adults who live in residential settings (group homes, supported living, adult foster care.)

Adults 18 and older receiving in-home and non-residential services may choose either a CDDP service coordinator or a Brokerage personal agent.

SURVEY FOR PEOPLE WITH I/DD WHO RECEIVE SERVICES

1. Please select **one** category that you feel best describes you.
   - ☐ Person with intellectual/developmental disabilities (I/DD)
   - ☐ Family member of a person with I/DD:

   PLEASE STOP HERE, AND TAKE THE OTHER SURVEY FOR FAMILY/GUARDIANS
   - ☐ Guardian, fiduciary, or legal representative of a person with I/DD:

   PLEASE STOP HERE, AND TAKE THE OTHER SURVEY FOR FAMILY/GUARDIANS

2. Please select the type of case manager who currently helps you.
   - ☐ Service Coordinator from a Community Developmental Disabilities Program (CDDP)
   - ☐ Personal Agent from a Support Services Brokerage
   - ☐ I don't know

For each question below, please select the answer
that is closest to your perspective,
or choose "I don't know" or "not applicable."
There are NO right or wrong answers – we want to hear your thoughts.

PART 1: Case Management Processes

1. I found the process of getting started (enrolling in) I/DD supports and services to be simple and clear.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

2. My service coordinator/personal agent makes it easy for me to access the supports and services I need.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

3. I understand my rights related to supports and services I receive.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

4. I understand the supports planning process and the steps to access supports and services.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

5. My service coordinator/personal agent has the right tools and training to help me.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

6. I get the help I need from my service coordinator/personal agent to navigate the system.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

7. I picked my service coordinator/personal agent.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

8. My family or legal representative picked my service coordinator/personal agent.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

9. I understand the differences between case management entities and I feel I can make informed choices about who provides my case management services.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

10. Having the same service coordinator/personal agent over a long period of time is important to me.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

11. Having a service coordinator/personal agent who specializes in (knows more about) certain things (for example, children’s services or employment or group homes) is important to me.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

12. My service coordinator/personal agent speaks the same language as I do.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

13. My cultural and language needs and preferences are supported by my service coordinator/ personal agent.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

PART 2: Planning and Decisions

14. My service coordinator/personal agent does a good job learning about me, my strengths, my needs and my goals.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

15. My service coordinator/ personal agent helps me understand what supports and services are available to me.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

16. I lead my person-centered planning process.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

17. I choose who is involved in my person-centered planning process.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

18. I make decisions about what is most important when we are planning my supports and services.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

19. When we are planning, what matters most to me is how many hours of paid support I can receive.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

20. When we are planning, what matters most to me is identifying supports who can help me reach my goals.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

21. My individual support plan (ISP) balances what is important to me (my goals and preferences) and what is important for me (my support needs to be healthy and safe).

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

22. I sign my ISP each time it changes.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

23. My ISP is only shared with the people I have chosen to share it with.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

24. My service coordinator/personal agent helps me set goals I care about.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

25. My service coordinator/personal agent helps me go after goals I care about.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

26. My service coordinator/personal agent helps me plan for long-term (3-5 year) goals.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

27. If I want to live someplace else, my service coordinator/personal agent will help me towards that goal.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

28. If I want to work (or change jobs), my service coordinator/personal agent will help me towards that goal.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

29. If I want to learn something new, my service coordinator/personal agent will help me towards that goal.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know			☐ Does not apply to me	

PART 3: Help with Services and Supports

30. My service coordinator/personal agent helps me to be in charge of my own life.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know			☐ Does not apply to me	

31. I need more help finding my direct service providers.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know			☐ Does not apply to me	

32. I need more help managing my direct service providers.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know			☐ Does not apply to me	

33. My service coordinator/personal agent helps me find service providers who are good at helping me reach my goals.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know			☐ Does not apply to me	

34. My service coordinator/personal agent helps me find other people, supports and community resources (not just paid service providers) who are good at helping me reach my goals.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know			☐ Does not apply to me	

35. My supports and service providers work together as a team with my service coordinator/personal agent.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know			☐ Does not apply to me	

36. I review and understand how my service providers track the time they work with me.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know			☐ Does not apply to me	

37. I can see my progress notes and information that other people put together about me any time I would like to.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know			☐ Does not apply to me	

38. I have enough information about local providers to help me compare providers who can meet my needs.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

39. I have a back-up plan when my supports are not available.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

PART 4: Working Together

40. My service coordinator/personal agent knows me very well.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

41. My service coordinator/personal agent meets with me at home or where I want to meet.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

42. My service coordinator/personal agent meets with me on days and at times that work well for me.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

43. I know my service coordinator/personal agent’s phone number.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

44. I can always reach my service coordinator/personal agent when I need them.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

45. My service coordinator/personal agent contacts me too often.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

46. My service coordinator/personal agent does not contact me often enough.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

47. I meet <u>in person</u> with my service coordinator/personal agent at least: (select one)
- ☐ every month
- ☐ every 3 months
- ☐ every 6 months
- ☐ once a year
- ☐ I have not met with my service coordinator/personal agent in person

48. I communicate with my service coordinator/personal agent (by phone, text, email, etc.) at least: (select one)
- ☐ every month
- ☐ every 3 months
- ☐ every 6 months
- ☐ once a year
- ☐ I do not communicate with my service coordinator/personal agent

49. My service coordinator/personal agent answers my questions in ways I can understand.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

50. My service coordinator/personal agent helps me with housing.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

51. My service coordinator/personal agent helps make sure I have enough food to eat.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

52. My service coordinator/personal agent helps me make sure I see my doctors.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

53. My service coordinator/personal agent helps me make sure I have the medicine I need.

☐ Strongly Disagree	☐ Disagree	☐ Neutral	☐ Agree	☐ Strongly Agree
☐ I don’t know		☐ Does not apply to me		

54. My service coordinator/personal agent helps me make sure I have the technology I need.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

55. My service coordinator/personal agent helps me make sure I have support to communicate.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

56. My service coordinator/personal agent helps me connect with people who are important to me.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

57. My service coordinator/personal agent goes (or went) to IEP meetings with me at school if I want them to.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

58. My service coordinator/personal agent goes to vocational rehabilitation meetings with me if I want them to.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

59. My service coordinator/personal agent talks to me about working and having a job.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

60. My service coordinator/personal agent helps me to have the right supports to find a job.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

61. My service coordinator/ personal agent helps me access transportation.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

62. My service coordinator/personal agent helps me join self-advocacy groups if I want to.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

63. My service coordinator/personal agent helps me find things to do in the community that I enjoy.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don’t know		☐ Does not apply to me		

PART 5: Problem-Solving

64. When I need help with a problem, my service coordinator/personal agent helps me solve it.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

65. When I need help with a system, my service coordinator/personal agent helps me advocate.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

66. I would contact my service coordinator/personal agent if I have a complaint or concern about my supports and services.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

67. I would contact my service coordinator/personal agent if I have a problem with my family.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

68. I would contact my service coordinator/personal agent if I have a problem with my health care.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

69. I would contact my service coordinator/personal agent if I am afraid or uncomfortable in my home.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

70. I would contact my service coordinator/personal agent if someone threatens, mistreats, or hurts me in any way.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

71. I would contact my service coordinator/personal agent if I have a crisis or emergency.

☐ Strongly Agree	☐ Agree	☐ Neutral	☐ Disagree	☐ Strongly Disagree
☐ I don't know		☐ Does not apply to me		

PART 6: Future Improvements

72. Which case management activities would you like to see improved, expanded or enhanced? (Select all that apply)
    - ☐ Helping people through the intake and enrollment process
    - ☐ Choice advising: helping people choose service coordinator/personal agents and service settings
    - ☐ Learning about the person: information gathering and assessment of needs
    - ☐ Person-centered planning and ISP development
    - ☐ Finding and keeping supports and services providers
    - ☐ Managing supports and service providers
    - ☐ Developing natural supports
    - ☐ Supporting community inclusion
    - ☐ Keeping people safe from abuse and neglect
    - ☐ Health and wellness monitoring
    - ☐ Supervising and supporting progress towards goals
    - ☐ Overseeing the effectiveness of supports and services
    - ☐ Monitoring and tracking quality of supports and services
    - ☐ Encouraging self-determination
    - ☐ Individual advocacy help
    - ☐ Assistance with other systems navigation – for example, with coordinated care organizations, education, childcare, child welfare, vocational rehabilitation, social security, etc.
    - ☐ Other:______________________________

73. Do you have other thoughts about case management (the services provided by your service coordinator or personal agent) that you would like to share?

PART 7: About You (Demographic Information)

Answering the following questions will help us understand whether we are hearing from different people with different experiences across Oregon in this survey.

Please answer if you can – all information will remain confidential and anonymous. If you are not sure about an answer, please give us your best response!

1. When did you first start receiving I/DD services?
   - ☐ Before June 30, 2001
   - ☐ After July 1, 2001 to June 30, 2013
   - ☐ July 1, 2013 to Present
   - ☐ I don't know
   - ☐ Prefer not to say

2. What is the zip code where you live?

   ☐ ☐ ☐ ☐ ☐

3. Where do you live?
   - ☐ My own home
   - ☐ My family's home
   - ☐ Supportive living home
   - ☐ Group home
   - ☐ Foster home
   - ☐ Prefer not to say
   - ☐ Other, please describe: ____

4. Where do you receive day (non-residential) services and supports? (Select all that apply)
   - ☐ Community workplace / place of employment
   - ☐ General broader community
   - ☐ My own home
   - ☐ My family's home
   - ☐ Provider's facility or group program
   - ☐ School / education site
   - ☐ Other _______________

5. What is your gender?
   - ☐ Female
   - ☐ Male
   - ☐ Nonbinary
   - ☐ Prefer not to say

6. How old are you?
   - ☐ Under 18
   - ☐ 18-24
   - ☐ 25-34
   - ☐ 35-44
   - ☐ 45-54
   - ☐ 55-64
   - ☐ 65-74
   - ☐ 75-84
   - ☐ 85 or older
   - ☐ Prefer not to say

7. What categories best describe you? (Select all that apply.)
   - ☐ American Indian or Alaska Native
   - ☐ Black or African American
   - ☐ White
   - ☐ Prefer not to say
   - ☐ I don’t know
   - ☐ Asian
   - ☐ Native Hawaiian or Other Pacific Islander
   - ☐ Hispanic, Latino, or Spanish origin
   - ☐ Other race, ethnicity, or origin

8. What language do you mainly speak at home?
   - ☐ English
   - ☐ Spanish
   - ☐ Vietnamese
   - ☐ Polish
   - ☐ Prefer not to say
   - ☐ Another language (please specify). ____
   - ☐ Chinese
   - ☐ Portuguese
   - ☐ Russian
   - ☐ Korean

9. What is your household (pre-tax) income?
   - ☐ Less than $10,000
   - ☐ $10,000-$19,999
   - ☐ $20,000 to $29,999
   - ☐ $30,000 to $49,999
   - ☐ $50,000 to $74,999
   - ☐ $75,000 to $99,999
   - ☐ Over $100,000
   - ☐ Prefer not to say

10. Who helped you to complete this survey?
   - ☐ No one – I did it myself
   - ☐ Family member
   - ☐ My guardian, fiduciary, or legal representative
   - ☐ My Service Coordinator from a Community Developmental Disabilities Program (CDDP)
   - ☐ My Personal Agent from a Support Services Brokerage
   - ☐ My Service Provider
   - ☐ Friend
   - ☐ Other: _______________________________

Thank you for completing the survey! Your input is important to us and will help us improve Oregon’s I/DD services and supports.

Appendix B. Questions for Case Management Entities

1. What you see as your agency's best practices in case management? Where does your organization really shine?
2. What are the most challenging aspects of providing person-centered case management in Oregon? Where does your agency need more support to implement best practices?
3. How do you collaborate with other CME(s) and service providers to offer Choice Advising?
4. Beyond the Case Management Tier 1 and Tier 2 training through ODDS, what, if any, training (and certification, as applicable) in person-centered practices does your team participate in? If you do engage in other person-centered thinking training, how is this implemented at all levels of the organization and across different roles and positions? How are the competencies of person-centered practices evaluated within and across your organization?
5. How do you organize your case managers and their caseloads? (eg children/adult; geography; topical) What are your current caseload ratios?
6. Can you please share any information related to your agency's practices for the discovery and identification of preferred outcomes and goals, natural supports and important relationships, and understanding of talents, gifts and interests of the individuals your agency serves (beyond the state required functional needs assessment process)?
7. How does your agency monitor ongoing progress towards goals for the people you serve, and assuring each person's desired outcomes are being addressed through the provision of services and supports (both paid and unpaid)?
8. What are your procedures for the identification of local service providers and generic local community resources, and the sharing and management of the information gathered about these assets and resources? What are your expectations of case managers in developing, contributing and sharing these resources?
9. What are your expectations of your case managers in terms of response time when they have been contacted by clients and families? Do you provide written guidelines for response timeframes? How does your organization handle non-emergency contacts outside of normal business hours? What process (if any) do you use to evaluate the responsiveness of your case managers and your agency?
10. What is your agency's procedure for selection of the individual's case manager, and the process for individuals to change case managers? How are clients informed of their right to request a change in case manager?

APPENDIX E: Analysis of Oregon I/DD Case Management, 2020

HEALTH MANAGEMENT ASSOCIATES

Oregon's Case Management System for People with Intellectual/Developmental Disabilities

PREPARED FOR OREGON OFFICE DEVELOPMENTAL DISABILITIES SERVICES

SHARON LEWIS, HMA
MARY SOWERS, NASDDDS

OCTOBER 2020

Research and Consulting in the Fields of Health and Human Services Policy, Health Economics and Finance, Program Evaluation, Data Analysis, and Health System Restructuring

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Intake, eligibility and enrollment processes could be simpler and better supported. 8

The service delivery model in Oregon adds complexity and places additional demands on case management capacity. 10

Defining the priority roles and responsibilities of case managers more clearly could improve consistency. 15

Improving person-centered thinking, planning and practice is foundational. 19

Oregon utilizes a unique approach to payment for case management services that is not in alignment with federal Medicaid fee-for-service billing requirements. 20

Investing in IT infrastructure could help address capacity challenges, including paperwork requirements that reduce the availability of case managers to work with the people they are serving, as well as the goals of making case management simpler and easier to access. 22

Oregon's bifurcated approach to the case management structure is not typical. 25

Addendum: Responding to the events of 2020. 28

HMA would like to thank Mary Sowers, National Association of State Directors of Developmental Disabilities Services, and Sherrie Anderson, Supports Development Associates, for their contributions to this paper and the related activities of the Oregon case management project.

Introduction

Case Management is a foundational element of the home and community-based service (HCBS) system for people with intellectual or developmental disabilities (I/DD). Case Management Entities (CMEs) help people with I/DD learn about community resources, make and implement plans for the future, access the supports and services they may need, and ensure that those supports and services are working well. In Oregon, case management services are delivered through Community Developmental Disabilities Programs (CDDPs), Support Services Brokerages, and state staff for a small number of children on certain waivers. Case managers in Oregon are also known as Service Coordinators (CDDPs and state staff) and Personal Agents (Brokerages).

Oregon case management services for people with I/DD are currently authorized through five 1915(c) waivers, as well as through the 1915(k) Community First Choice State Plan Option to provide Support System Activities. Additionally, Oregon relies upon a concurrent 1915(b)(4) selective contracting program waiver that allows the state to restrict the provision of case management and support system activities to CDDPs, Brokerages, and state case management.

In its HCBS Technical Guide for 1915(c), CMS defines case management as ***"Services that assist participants in gaining access to needed waiver and other state plan services, as well as medical, social, educational and other services, regardless of the funding source for the services to which access is gained."***[1] In the regulations for 1915(k), instead of case management, CMS requires a support system that "appropriately assesses and counsels an individual before enrollment, and provides appropriate information, counseling, training and assistance to ensure that an individual is able to manage the services."[2] Additionally, the 1915(k) rules require that support activities provide information, counseling, training and assistance to participants in plain language and in a manner understandable to the person receiving services, as well as including, at least the following:

- (i) Person-centered planning and how it is applied.
- (ii) Range and scope of individual choices and options.
- (iii) Process for changing the person-centered service plan and, if applicable, service budget.
- (iv) Grievance process.
- (v) Information on the risks and responsibilities of self-direction.
- (vi) The ability to freely choose from available home and community-based attendant providers, available service delivery models and if applicable, financial management entities.
- (vii) Individual rights, including appeal rights.
- (viii) Reassessment and review schedules.
- (ix) Defining goals, needs, and preferences of Community First Choice services and supports.
- (x) Identifying and accessing services, supports, and resources.
- (xi) Development of risk management agreements." [3]

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[1] Centers for Medicare & Medicaid Services (CMS). (January 2019). Instructions, Technical Guide and Review Criteria for §1915(c) Home and Community-Based Waiver, Version 3.6. Retrieved from https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf

[2] 42 C.F.R. § 441.555(a) and (b)

[3] 42 C.F.R. § 441.555(b)(2)

Regardless of what it is called or how the service is authorized, case management is critical to both people with I/DD seeking support (and their families), and the state agency responsible for overseeing I/DD programs, the Office of Developmental Disabilities Services (ODDS). For individuals and families, case managers (CMs) provide the human touch that helps people discover, define and achieve what is important and necessary for a good life, which includes ensuring access to quality supports, providing information and referrals, helping with coordination and navigation, advocating to address needs and reach goals, addressing changes and transitions, and more. On the systems side, case management helps to provide important local oversight for the state, often serving as a key source of data and information on a host of statutory requirements, including assuring individual eligibility, individual health and welfare, service plan implementation (by qualified providers), and program integrity.

Approach to this Report

In 2018, the ODDS Strategic Plan acknowledged the need for improvement and change in case management, with an action item to "Develop and implement a strategy to reform the case management system to be effective, easy for people and families to understand, access, and navigate; and ensure that every case management entity consistently follows the expectation to operate in a fully person-centered approach."[4]

Under a contract from ODDS, Health Management Associates (HMA) conducted an extensive stakeholder outreach and engagement process from December 2018 through March 2019, to learn from people all over the state about what is, and what is not, working in the Oregon case management system for people with I/DD, families, providers and case managers. The results were compiled into a report[5] in May 2019, and were also shared at the June 2019 Oregon Conference on I/DD Case Management for Service Coordinators and Personal Agents (aka "The SC/PA Conference.")

HMA, in partnership with Supports Development Associates (SDA), also facilitated a stakeholder workgroup (the Case Management Blueprint Group) from March 2019 – December 2019, who collaboratively worked to consider and discuss the stakeholder feedback from the outreach report to develop a draft set of recommendations, which have been considered to help inform this report.

Additionally, HMA, with assistance from SDA and the National Association of State Directors of Developmental Disabilities Services (NASDDDS), reviewed a wide range of documents and policies, held discussions with case management and state staff, and considered best practices from other states to inform the development of findings and recommendations in this report.

History and Background: 2001 to Now

The current structure of Oregon's case management system was established nearly twenty years ago, to support implementation of the *Staley* lawsuit settlement and the delivery of in-home brokerage supports in a manner distinct from comprehensive services. The division of labor and the roles and responsibilities for targeted case management (TCM) were clear and aligned to the waiver and program structures, with few exceptions.

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[4] Oregon Department of Human Services. (June 2018). Oregon Developmental Disabilities System Strategic Plan 2018-2023. Retrieved from https://www.oregon.gov/DHS/SENIORS-DISABILITIES/DD/Compass/Oregon-IDD-System-Strategic-Plan.pdf

[5] Health Management Associates. (May 2019). Stakeholder Perspectives on Oregon Case Management Services. Retrieved from https://www.oregon.gov/DHS/SENIORS-DISABILITIES/DD/Compass/case-management-stakeholder-engagement-report-combined-2019-05.pdf

Oregon I/DD System, prior to 1915(k) implementation			
2011	**Authority/Program**	**Population served**	**Enrollment**
CDDP	1915(c) Comprehensive Waiver	Adults and children receiving 24-hour services, often reliant upon “traditional” agency providers	~7,000
Brokerage	1915(c) Support Services Waiver	Adults living with family or in their own home, receiving limited self-directed supports under a capped budget ($21,500)	~7,300
State staff	Three 1915(c) Children’s Waivers	Children with intensive behavioral or medical support needs (allow for disregard of family income)	~400
CDDP	TCM, Family Support	Children not eligible for Medicaid waivers ($1200 cap)	~1,200
CDDP	Case Management Administrative functions	Intake and eligibility determination, program enrollment, abuse investigation, crisis response	~21,000

County case management was first established in the 1970’s, evolving over the past four decades into the current CDDPs. Prior to 2013, CDDP case management focused primarily upon working with people receiving residential and day services in provider-controlled settings, as well as working with families of children receiving targeted case management with some very limited family support funding. In today’s system, CDDPs provide case management to a very different mix of participants relying upon many different providers, including children and adults living in family homes hiring Personal Support Workers. CDDP responsibilities, implemented through Intergovernmental Grant Agreements, include functions that the Brokerages are not contracted to provide, such as intake and eligibility, provider licensing and oversight, certification of children’s foster homes, and adult abuse investigations.

Across Oregon’s thirty-six counties, fourteen counties implement case management services directly using county staff, whereas eleven counties sub-contract case management to private entities and eleven counties have CDDPs that contract directly with the state. The CDDPs each serve a single county geography, although some of the subcontracted entities support multiple counties. The more populous urban counties (e.g., Multnomah, Clackamas, Washington, Marion, Lane, Deschutes) tend to maintain government-operated programs, and the more rural counties often rely on subcontracting with private entities to fulfill this responsibility.

Support Services Brokerages, contracted private entities, were originally designed to assist adults living with family or in their own home, self-directing their services and supports with limited state resources, but with the flexibility to prioritize within a smaller, capped budget. The Brokerages contract directly with the state. The role of a Personal Agent was originally envisioned to be a supports broker and navigator to facilitate person-centered planning and help people manage the decisions and trade-offs involved in balancing limited paid services with natural supports and community resources. There are currently fourteen regional Brokerages, most of which serve people in at least two or three counties, with only two of fourteen Brokerages working in a single county.

When Oregon decided to pursue the 1915(k) Community First Choice State Plan Option, effective in July 2013, there was little to no time for planning for changes to case management, despite the magnitude of this systems change. The “K Plan” created an entitlement to state plan services for all eligible adults, essentially erasing many of the distinctions between comprehensive and support services. The Community First Choice option brought a new set of federal rules and requirements, including assessment changes. At the same time, the state established an eligibility pathway for children with

I/DD who met institutional level of care to disregard parental income (beyond the small number of slots on the model waivers), opening the door to a significant increase in enrollment of children from families of all income levels. As these service delivery and system financing changes occurred initially, the only major change to the case management structure was the establishment of choice between CDDPs and Brokerage case management for adults selecting in-home supports. For people receiving residential services CDDP case management was maintained, while the new population of children receiving support services was added to the CDDP caseloads. Children accessing the intensive in-home support waivers (CIIS) continue to receive case management provided by state staff.

Within the same period that the State began implementation of the "K Plan," additional regulatory and program changes occurred at both the state and federal level, including new collective bargaining agreements, new employment requirements under the federal Fair Labor Standards Act, implementation of a new state payment system (eXPRS), changes to ODDS functional assessment processes, and new federal home and community-based services regulations from the Center for Medicare & Medicaid Services (CMS). The number of complex changes that occurred in a relatively short period of time left little opportunity for a redesign of case management. In the ensuing years, case management was moved from the targeted case management authority to the waivers, and the Comprehensive Waiver and the Support Services Waiver have been restructured into one waiver for adults and another for children (while CIIS remains under the three separate model waivers.[6])

This history is important to note as the state considers reforming case management. There is a certain level of "change exhaustion" among stakeholders. And many of the areas of challenge are rooted in the legacy structures and the disconnect between case management responsibilities designed for a different service delivery system.

Summary of Findings

Oregon currently faces a unique set of opportunities and challenges in seeking to reform case management to be simpler, more responsive and predictable, and easier for people with I/DD and their families to access and navigate, while maintaining the long-standing Oregon values of community inclusion, self-determination, choice and control, respect, person-centeredness, and equal opportunity for people with I/DD.

The gaps and challenges in Oregon's I/DD case management system create inconsistencies in policy and practice, capacity challenges among case managers, and frustration among people receiving supports and their families. At the same time, Oregon has long acknowledged the importance of case management that leverages local relationships and resources and seeks to ensure community participation and inclusion. As discovered through stakeholder outreach, many Oregonians are content with their case management services while others see little to no value, or do not even know that they receive case management services.

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[6] From CMS Technical Guide and Review Criteria for §1915(c) Home and Community-Based Waiver, v 3.6: A "model" waiver is limited to serving no more than 200 individuals at any point in time during the waiver period, and may serve fewer than 200 persons, depending on the participant limit that a state establishes. Except for assuring that the waiver will serve no more than 200 individuals at any point in time, "model" and "regular" waivers are no different. A regular waiver also may serve a relatively small number of individuals. A state may subsequently convert a model waiver to a regular waiver in order to serve more than 200 individuals. The conversion may be requested via the submission of a waiver amendment or when the waiver is renewed. Provided that no other major changes are proposed, the conversion of a model to a regular waiver is not considered to be a request for a new waiver.

As the Oregon service delivery system has shifted, case management has not been re-imagined, and instead has adapted through incremental change. The complexity of systemic process and procedure in a compliance-oriented environment has negatively affected the opportunities for case management to encourage and facilitate self-determination, person-centered practices, and choice and control exercised by people with I/DD. Increased focus on process and compliance from the federal level has reduced the available resources and time for many case managers to engage in meaningful relationship building. However, the state is actively seeking to address the challenges and maintains a strong commitment to the values articulated in the ODDS Strategic Plan.

The findings and recommendations in this report are organized under the following themes, described in detailed narrative, below:

- **Intake, eligibility and enrollment processes could be simpler and better supported.**
    - Better assistance for individuals and families prior to eligibility would be beneficial.
    - Current sequencing that requires important decisions related to choice of supports and services -- prior to thoughtful exploration, information gathering, development of preferences and goals and person-centered planning -- is problematic.
- **The service delivery model in Oregon adds complexity and places demands on case management capacity.**
    - Identifying and securing providers able to meet individual's needs and achieve outcomes is difficult.
    - With the extent of independent and small providers in Oregon, monitoring of supports and services is demanding**.**
    - Requiring case managers to implement support brokering responsibilities related to employer authority creates challenges.
- **Defining the priority roles and responsibilities of case managers more clearly could reduce inconsistency.**
    - Case management responsibilities need to balance systems functions with functions related to serving as the agent of the person.
    - Case Manager caseloads and capacities vary greatly.
    - Oregon establishes minimum state-level requirements for case manager but leaves a fair amount of discretion to the case management entities, contributing to inconsistencies.
    - Back up planning and policies related to responsiveness outside of business hours varies.
- **Improving person-centered thinking, planning and practice is foundational.**
    - Person-centered thinking, planning and practice should be ongoing and iterative, and infused into every aspect of the service system, from intake through implementation of service delivery and through quality improvement.
    - The sequencing of person-centered planning conversations is also critically important.
    - The redesign of the ISP process, including the ISP form, should support planning processes and documentation that are flexible and adjust to the needs of the person.

- **Oregon utilizes a unique approach to payment of providers of case management services that is not in alignment with federal Medicaid requirements for fee-for-service reimbursement.**
- **Investing in IT infrastructure could help address capacity challenges, including paperwork requirements that reduce the availability of case managers to work with the people they are serving, as well as the goals of making case management simpler and easier to access.**
- **Oregon's bifurcated approach to the case management structure is not typical.**

Additionally, it must be noted that ODDS is also currently working to redesign the Individual Support Plan (ISP) Process through a separate initiative. While there is some overlap in the findings in the Case Management Project, and much of the feedback from stakeholders is relevant to both, this report does not strive to make extensive or detailed recommendations related to the ISP process, including person-centered thinking and planning.

Intake, eligibility and enrollment processes could be simpler and better supported.

One of the challenging "legacy" concerns that Oregon faces in aligning current case management efforts with federal requirements and best practices, as well as the state's goals for simplicity and ease of access, resides in the sequence, process and staff responsibilities during the initial intake, eligibility and case management enrollment process.

Better assistance for individuals and families prior to eligibility would be beneficial. When a person (or family, as applicable) is first interested in learning more about Oregon I/DD services, and seeking to understand program and support options, stakeholders report it can be challenging to find their way to good information, and to be referred to a CDDP. In most counties, a call to a CDDP may become an intake referral, resulting in an eligibility appointment, which then proceeds to an application for eligibility managed by a CDDP eligibility specialist. Many families report "falling through the cracks" at this stage in the process, not understanding exactly what it is they are applying for, what the paperwork requirements are, and what to expect in terms of timelines. These delays and frustrations sometimes make it challenging for people or families, once they are made eligible, to trust the case management system and enter the planning process open to developing a vision for a good life.

CDDPs determine what kind of communication occurs prior to the intake process – there are no state requirements. Oregon's regulatory definition of "intake" simply means "the activity of completing the Request for Eligibility Determination (form 0552) and necessary releases of information prior to the submission of a completed application to the CDDP."[7] To ensure consistency in communications, standard information provided by the state to individuals with I/DD and families regarding support options would be extremely beneficial, and could help shed light on the wide range of available community opportunities beyond Medicaid-funded I/DD services.

The intake and eligibility process can be an opportunity for learning through person-centered conversations (perhaps grounded in the LifeCourse Principles[8] that Oregon seeks to embed in the ISP process), to better understand what a person or family is seeking and why – and to ensure that any applications for publicly-funded programs align with the articulated needs and preferences of the

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[7] Ore. Admin. Rules 411-320-0020 (21) (2019). Retrieved from https://www.dhs.state.or.us/policy/spd/rules/411_320.pdf

[8] UMKC Institute for Human Development. (n.d.) The Charting the LifeCourse Framework. Retrieved from https://www.lifecoursetools.com/principles/

person/family, as well as ensuring that any immediate or critical needs are addressed while waiting for eligibility determination processes to occur. Currently, the intake and eligibility roles (including training) as defined in Oregon are system and process-oriented, not person-centered, and eligibility specialists often do not seem to have the time and capacity for the "soft" conversations that establish the first impressions and assist people/families in understanding the eligibility, enrollment, planning and service implementation process.

In one state's alternative, Missouri, people and families are able to access a pre-eligibility "navigator" who supports individuals and families with information, initial exploration, finding local resources, connecting to peers, etc., often helping to put together a short visual navigation "plan" focused on an immediate goal. Then ***if*** it is determined that eligibility-based services are necessary, the navigator supports the person/family through the eligibility process, assisting with "translating" requests and forms, answering questions, and encouraging continued engagement with the eligibility specialist throughout the process. The navigator will maintain communication and support as long as needed, providing a warm handoff to a case manager and continuing peer supports if desired. Or if the person/family is not determined eligible for services, the navigator can continue to support person-centered thinking and planning and identification of non-eligibility based supports.

Current sequencing that requires important decisions related to choice of supports and services, prior to exploration of preferences and goals, information gathering and person-centered planning, is problematic. When they are first enrolling, individuals and families are required to determine what type of services and setting they are seeking, prior to selecting a case management entity and participating in a full-blown person-centered planning process. In reviewing regulatory and training guidance related to "Choice Advising" there is minimal practical instruction for using person-centered values, skills, and practices at the very initial point of conversation about service/support options, and in many places these conversations are taking place with eligibility specialists. The training information actually refers to Choice Advising as happening before person-centered planning, whereas some very basic expectations of exploration and identification of vision, preferences, needs, community and social networks and resources, and personal/family strengths would most certainly better inform the choice that people might make in identifying service and support preferences.

The sequencing and implementation of these decisions is not aligned with federal requirements for person-centered planning, nor can the process be considered truly "conflict-free" given the different interests of the CDDPs and the Brokerages. There are benefits to each entity for certain individuals to select the organization, or choose to go elsewhere, that likely create bias in some choice advising. As described by CMS in the Balancing Incentive Program, "Many of these conflicts of interest may not be conscious decisions on the part of agents; rather, in many cases, they are outgrowths of inherent incentives or disincentives built into the system that may or may not promote the interests of the individual receiving services."[9] While the language in the Oregon 1915(k) and the 1915(c) Adults' HCBS Waiver Appendix D, describing person-centered planning and choice advising, is consistent with the rule at 42 CFR 441.301, the sequence and process as implemented is potentially non-compliant, or at least not consistent with person-centered thinking and practice.

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[9] Centers for Medicare & Medicaid Services. (2015). State Balancing Incentive Payments Program Initial Announcement. Retrieved from https://www.reginfo.gov/public/do/DownloadDocument?objectID=28869301

Additionally, the 1915(b)(4) waiver indicates that beneficiaries will be given a choice of case management providers in their service area, which is accurate for less than one-third of the participants in I/DD case management, due to the limited access to Brokerages based upon setting chosen. Only adults who are seeking in-home supports (or case management only) have the opportunity to choose the case management entity.

Absent a structural change that would either provide additional case management options or eliminate the limitation on Brokerage services (making them available to all eligible individuals), the state could consider addressing this concern through the aforementioned access to an independent third party "navigator" or "choice counselor" (which could include peer-to-peer support) to offer independent and informed decision-making assistance. Or, as many states have done, developing – or, bringing knowledgeable I/DD expertise and change to – an independent "No Wrong Door" (NWD) system could serve as an unbiased source for information and referral, eligibility and enrollment and choice counseling, as have been established in many states, including Wisconsin[10] and Washington, D.C.[11] The work done in Colorado to investigate and pilot a NWD independent of Aging and Disability Resource Centers may also be of interest to Oregon.[12]

The service delivery model in Oregon adds complexity and places additional demands on case management capacity.

Due to authorizing and funding many of the I/DD services under the 1915(k) Community First Choice (CFC) State Plan Option and the nature of the provider networks in Oregon, there are intertwined case management issues related to service delivery design that affect case managers in important ways:

- service definitions and provider qualifications broadly established as ADL/IADL assistance or skills training,
- heavy reliance on services delivered by a very dispersed and fragmented provider workforce, with a high number of independent providers (personal support workers) and individual adult foster care homes without a provider agency to offer support and additional quality oversight, and
- the challenges of operationalizing an employer authority model (through which people receiving supports select, hire, and manage individual workers) with case managers serving as support brokers.

Through restructuring in recent years, Oregon has established one HCBS 1915(c) waiver for adults and one primary HCBS 1915(c) waiver for children, along with retaining three small model HCBS waivers for children with intensive needs. The employment-related services in the 1915(c) waivers have well-articulated expectations and provider qualifications, with milestone and outcome payments, giving case managers and providers clear paths for accountability. The remainder of the high-utilization HCBS – residential services, day habilitation, and in-home services – are authorized through the 1915(k) CFC State Plan Option, and are broadly defined as assistance with activities of daily living, instrumental activities of daily living, and health related tasks in the form of hands-on assistance, supervision, and

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[10] Wisconsin Department of Health Services. (April 6, 2020). Aging and Disability Resource Centers (ADRC) Consumer Page. Retrieved from https://www.dhs.wisconsin.gov/adrc/index.htm

[11] Department on Disability Services. (n.d.). No Wrong Door. Retrieved from https://dds.dc.gov/page/no-wrong-door

[12] Colorado Department of Health Care Policy & Financing. (n.d.). No Wrong Door Implementation Grant. Retrieved from https://www.colorado.gov/pacific/hcpf/no-wrong-door-implementation-grant

cueing as well as with the acquisition, maintenance, and enhancement of skills to accomplish those activities/tasks.

Identifying and securing providers able to meet individual needs and achieve outcomes is difficult. As is true in much of the country, Oregon's I/DD system struggles with adequate workforce availability, with a turnover rate for direct support professionals (DSPs) at over 47% and a vacancy rate for full-time jobs at 10%.[13] Layered with the workforce shortage is the challenge of finding supports with the skills and abilities sought by people receiving supports and families. Among people who responded to the stakeholder survey, fewer than one-third indicated they have enough information to compare service providers to find someone who meets their needs.

The 1915(k) structure in Oregon and the broad service definition for personal attendant care (under the regulatory requirements for Independent Providers and Community Living Supports) encourage a workforce of generalists. People receiving supports (and their families) are defining expectations for their providers at the individual level, which is intentional in a self-directed model, but also requires additional effort on the case manager's part. Under the federal regulations for 1915(k), people have the right to:

- train providers in the specific areas of support needed, and to have the provider perform the needed assistance in a manner that comports with the individual's personal, cultural, and/or religious preferences;
- establish additional staff qualifications based on the individual's needs and preferences; and
- access other training provided by or through the State so that their provider(s) can meet any additional qualifications required or desired by individuals.[14]

Consistent with this, the administrative rules for Community Living Support agencies[15] and Independent Providers[16] set out a minimal framework related to qualifications, process and procedure in the delivery of support services. Case managers work with team members to build out the specifics in ISPs and provider agreements, aligned to each person's goals and needs. But with a limited workforce available, nominal options to support specific or unique training needs, and lack of budget authority to prioritize solutions, this has become a tremendous challenge for case managers and people receiving supports as they seek to identify and engage qualified providers appropriate to each person's unique situation, under the broad definition of personal care attendant services. Other states often target needs and desired outcomes with a range of specific 1915(c) services, and seek to develop provider capacity for the services, such as housing support services, peer-to-peer navigation, parenting skills development, travel training, community inclusion facilitation, financial literacy support and more, whereas Oregon relies on individual workers to have the skills to address various domains as part of the personal attendant care service. Further, the state does not provide an opportunity to train personal support workers (PSWs) outside of the state offerings, and anticipates that agency providers will cover training costs, including

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[13] Oregon Department of Human Services, Office of Developmental Disabilities Services. (March 2019). Director Message. Retrieved from https://www.oregon.gov/DHS/SENIORS-DISABILITIES/DD/DirectorMessages/NCI-Staff-Stability-Survey-Message-DD-Dir.pdf

[14] 42 C.F.R. § 441.565

[15] Ore. Admin. Rules 411-450 (2020). Retrieved from https://www.oregon.gov/DHS/SENIORS-DISABILITIES/DD/ODDSRules/411-450.pdf

[16] Ore. Admin. Rules 411-375 (2019). Retrieved from https://www.oregon.gov/DHS/SENIORS-DISABILITIES/DD/ODDSRules/411-375.pdf

paid worker time, as part of overhead. This creates tension when people or families hope to engage DSPs or PSWs in individually-tailored training opportunities, including shadowing or mentoring, as PSWs are not able to be paid, and in-home provider rates may be insufficient to absorb these costs.

Additionally, Oregonians with I/DD increasingly report having no access to community living support agencies in many parts of the state, having to rely on personal support workers as the only option regardless of their preferences. Self-directing under an employer authority is a preferred model when it is a choice, not the only solution. The state may want to consider supporting local capacity development for additional provider agencies offering integrated community living supports.

With the extent of independent and small providers in Oregon, monitoring of supports and services is demanding. The vast number of providers in Oregon creates a challenging service monitoring environment for both case management entities and the state agency, straining capacity necessary for compliance oversight and quality/performance monitoring. Among the approximately 21,000 people who received residential or in-home services in 2018-19, nearly 15,000 relied upon in-home services provided by over 22,000 PSWs and 209 community living support agencies, over 2,900 adults lived in foster homes operated by over 1,300 providers, while another 135 agencies supported people in group homes.

Oregon's case managers have limited tools for service monitoring across this dispersed workforce. As part of their monitoring responsibilities, each case manager performs an annual assessment of services, gathered through direct observation and by asking questions of the person receiving supports and caregiver(s) who know them well.[17] The required assessment question topics are a good framework, balancing process and outcomes, aligned with CMS HCBS requirements.[18] They are in a yes/no format, which may be helpful for aggregate data management, but may be less effective when utilized for case management monitoring on an individual level. The need to monitor quality is critically important for Oregonians with I/DD, and yet having an opportunity to directly observe tens of thousands of providers is unlikely; service monitoring for unlicensed providers in particular is heavily reliant upon this self-report, without an additional validation methodology. Provider progress notes can offer additional insights, but absent stronger requirements and standards, this may be limited. Many case managers indicate often it is challenging to receive adequate and timely progress notes from providers of all types, despite the state requirements. And, in at least one county, the ongoing review of timesheets and progress notes is considered a compliance and program integrity activity, performed by other staff who "report any identified timekeeping issues to case managers"[19] which may defeat the purpose of gathering progress notes if they are not considered and utilized by case managers in a timely manner to ensure that providers are delivering services consistent with the person-centered plan.

Case managers play a key role for the state through the performance of activities to ensure sound service authorization procedures and which form the foundation for all future service billings on behalf of the individual. Through ongoing service monitoring, case managers fulfill an obligation to ensure the health and welfare of the individuals served and to ensure services were delivered in accordance with all

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[17] Ore. Admin. Rules 411-415-0090 (2019). Retrieved from OAR 411-415-0090. Retrieved from https://www.dhs.state.or.us/policy/spd/rules/411_415.pdf

[18] Centers for Medicare & Medicaid Services (CMS). (January 2019). Instructions, Technical Guide and Review Criteria for §1915(c) Home and Community-Based Waiver, Version 3.6. Retrieved from https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf

[19] Multnomah County Auditor's Office. October 2019). "Services for People with Intellectual and Developmental Disabilities, Quality of Care at Risk," p. 3.

established Medicaid requirements. These latter activities are often facilitated by a thorough review of provider service documentation as compared to the approved person centered plan. Electronic visit verification contributes to service monitoring by providing additional information on actual delivery of service but has limited impact on the qualitative aspects of monitoring.

Oregon also has an increasing number of family members providing paid services and supports, which requires case managers to have strong conflict management skills and tools to ensure that the supports are being delivered in a manner consistent with the best interests of the person supported and do not reduce community engagement. Family members serving as paid providers would benefit from additional conversations, training and information helping them understand roles and responsibilities, as well as how serving in a paid capacity affects relationships. Oregon may want to look to Maryland's requirements for paid family providers as an example of good policy and implementation tools, as described in the service definitions in the state's 1915(c) HCBS Waivers:

> To ensure the use of a legal guardian or relative (who is not a spouse) to provide services is in the best interest of the participant, the following criteria must be met and documented in the participant's Person-Centered Plan (PCP):
>
> 1. Choice of the legal guardian or relative as the provider truly reflects the participant's wishes and desires;
> 2. The provision of services by the legal guardian or relative is in the best interests of the participant and his or her family;
> 3. The provision of services by the legal guardian or relative is appropriate and based on the participant's identified support needs;
> 4. The services provided by the legal guardian or relative will increase the participant's independence and community integration;
> 5. There are documented steps in the PCP that will be taken to expand the participant's circle of support so that he or she is able to maintain and improve his or her health, safety, independence, and level of community integration on an ongoing basis should the legal guardian or relative acting in the capacity of employee be no longer be available;
> 6. A Supportive Decision Making (SDM) agreement is established that identifies the people (beyond family members) who will support the participant in making her or his own decisions; and
> 7. The legal guardian or relative must sign a service agreement to provide assurances that he or she will implement the PCP and provide the services in accordance with applicable federal and State laws and regulations governing the program.

Maryland conducts an annual review of randomly selected, statistically valid sample of services provided by legal guardians and relatives to "ensure payment is made only for services rendered and the services rendered are in the best interest of the participant." [20]

<u>**Requiring case managers to implement support brokering responsibilities creates challenges.**</u> Support brokers assist people "in directing their services and serve as a liaison between the individual and the program, assisting individuals with whatever is needed to identify potential personnel requirements, resources to meet those requirements, and the services and supports to sustain individuals as they direct their own services and supports. The supports broker acts as an agent of the individual and takes

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[20] Maryland Community Pathways Waiver Renewal. (effective July 2018). Retrieved from https://dda.health.maryland.gov/Documents/Community%20Pathways%20Waiver%20Renewal%20Approved%20Waiver%20effective%20July%201,%202018%20.pdf

direction from the individual." [21] NASDDDS recommends that states carefully consider the challenges likely to emerge when expecting case managers to also service as support brokers, "Taking on the functions… may be more time-consuming for the case manager and may also need to be taken into account in establishing caseloads."[22]

While Oregon no longer offers a full budget authority self-direction model[23], under the employer authority option there are still important functions that need attention and support. Many of these functions are fragmented across different entities. The state's contract for financial management services is focused only upon payroll functions, requiring the contractor to provide some limited customer service to common law employers (CLEs) through web-based information and phone support. The Home Care Commission (HCC) is responsible for offering training to PSWs, and offers a registry of potential workers, but many people with I/DD and families report this is of limited use to them. The HCC's Employer Resource Connection (formerly STEPS) has six regional consultant entities across the state offering training and consultation for CLEs. And, under the Oregon case management rules, case managers are responsible for:

- Providing assistance in finding and arranging resources, services, and supports.
- Providing information and technical assistance to an individual, and as applicable the legal or designated representative of the individual, in order to make informed decisions. This may include, but is not limited to, information about support needs, settings, programs, and types of providers.
- Assuring that a person is identified to act as a common law employer for the personal support worker.

This leaves gaps in the process. Case managers, as well as people and families, report struggling to have the time and capacity to assist in the identification of potential PSWs and DSPs, development of interview questions, participation in interviews, engaging in the hiring process, supporting individuals when there are challenges in the employer/employee relationship and more. Many people also rely upon multiple providers and may need assistance with coordination across providers on a frequent (weekly or monthly) basis, which is not possible for many case managers to do within the time they have available.

Given the capacity challenges, the state may want to consider establishing a separate support brokering service that could allow for a more coordinated approach and reduce the capacity issue for case managers, while also developing a cadre of specialized support broker providers with the requisite deep knowledge, skills and abilities to promote effective self-direction practices. Additionally, stakeholders would benefit from the creation of a consolidated webpage with information about working as an employer and options for self-direction. Missouri offers a good example of such an approach.[24]

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[21] Moseley, Charles, Ed.D, (July 2004). Support Brokerage Issues in Self-Directed Services. NASDDDS Technical Report. Retrieved from https://www.nasddds.org/uploads/documents/IssuesInSupportBrokerage.pdf

[22] Cooper, Robin E. (April 2019). National Association of State Directors of Developmental Disabilities Services, "Medicaid and Case Management for People with Developmental Disabilities: Structure, Practice, and Issues (, Third Edition). National Association of State Directors of Developmental Disabilities Services (," April 2019.).

[23] Prior to the implementation of the Community First Choice Option, full budget and employer authority was available through Oregon's Support Waiver for adults, supported by the brokerages whose personal agents assisted individuals with both the budget functions and the employer functions for self-directed services.

[24] Missouri Department of Mental Health. (n.d.). Self-Directed Supports. Retrieved from https://dmh.mo.gov/dev-disabilities/programs/self-directed-supports

Defining the priority roles and responsibilities of case managers more clearly could improve consistency.

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) describes case management activities as generally falling into two categories, system functions and individual/family functions, in which the case manager serves as either an agent of the state or an agent of the person receiving supports.[25] In the category of system functions, states often include the key elements of case management as described in the federal Targeted Case Management regulation – assessment, development of person-centered plans, referral activities, monitoring and follow-up, oversight of provider performance, and collateral contacts that may help identify and meet the person's needs.[26] Human functions, those most focused on engagement and support of the person/family, often include requirements for high quality person-centered planning; provision of information and assistance; problem-solving related to supports, quality and goals; knowledgeable and thoughtful strategies to address both what is important to a person and for a person; navigation support as individuals/families engage with various systems; communication related to rights and responsibilities; facilitation to support the development of individual skills to meet needs and achieve goals; and other activities aligned with the overarching purpose of assisting people with I/DD to access the supports and services they need to live a good life.[27]

Case management responsibilities need to balance systems functions with functions related to serving as the agent of the person. Waiver case management has no specific federal statutory definition, and states have a fair amount of latitude to meet the core definition as described in the CMS HCBS Technical Guide, "Services that assist participants in gaining access to needed waiver and other state plan services, as well as medical, social, educational and other services, regardless of the funding source for the services to which access is gained."[28] Oregon's regulatory framework for case management emphasizes process and procedure related to the core system activities, and offers limited guidance related to activities focused on case managers as agents for the person. From current Oregon Administrative Rule:

> "(3) Case management services are delivered using person-centered practices to assist individuals in accessing needed medical, employment, social, educational, and other services. Case management services include, but are not limited to:
> (a) Assessment and periodic reassessment of individual needs and preferences;
> (b) Development and periodic revision of the Individual Support Plan;
> (c) Referral and related activities;
> (d) Monitoring; and
> (e) Follow-up activities.
>
> (4) Services provided under these rules are intended to identify, strengthen, expand, and where required, supplement private, public, formal, and informal support available to individuals with intellectual or developmental disabilities. The case management services described in these

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[25] Cooper, Robin E. (April 2019). Medicaid and Case Management for People with Disabilities: Structure, Practice, Issues (Third Edition). National Association of State Directors of Developmental Disabilities Services (NASDDDS).

[26] 42 C.F.R. § 440.169

[27] Cooper, Robin E. (April 2019). Medicaid and Case Management for People with Disabilities: Structure, Practice, Issues (Third Edition). National Association of State Directors of Developmental Disabilities Services (NASDDDS).

[28] Centers for Medicare & Medicaid Services (CMS). (January 2019). Instructions, Technical Guide and Review Criteria for §1915(c) Home and Community-Based Waiver, Version 3.6, p. 142. Retrieved from https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf

> rules encourage the exercising of self-determination in the design and direction of the individual receiving services."[29]

As described in Oregon's regulations, there are essentially three types of case management service activities that involve engagement with the person – ISP planning (including assessments), monthly or quarterly contacts, and service monitoring. The purpose of a case management contact is described as addressing health and safety risks, ensuring that support needs have not significantly changed, and assuring customer satisfaction.[30] Some monitoring requirements in the rule do touch upon human-focused functions, but use a lens of compliance and oversight, described as "assessing" elements of the person's plan and supports, including whether the ISP is being implemented as expected, whether rights are protected, whether services are compliant, and whether the needs and preferences of the individual are being met. There is little described in the case management rule that would address more flexible and person-centered activities that might help case managers better meet the expectations as articulated in paragraph (4), above. Further, Oregon's guidance related to case management contacts[31] and service monitoring[32] offer a fairly narrow and compliance oriented description of activities implemented by the case managers, leaving less room for activities and conversations that would help case managers develop understanding with the person to identify and design supports consistent with their preferences, to encourage self-determination, to develop and facilitate access to non-provider supports and activities in support of the person's goals, and to assist individuals on an iterative and ongoing basis (as opposed to just within the context of annual planning).

Oregon may want to make clear the expectation of case management time spent as the agent and advocate for the person and implementing person-centered practices, not just completing the system function tasks, and incentivize this through definitional, regulatory, payment and performance policy. For example, in the Oregon rules and guidance, there is little describing how case management should work in partnership with people receiving supports and services and their family to develop skills over time. The focus seems to be on articulating processes, and not necessarily having a role in fostering a deeper shared understanding and person-centered practice. It may be helpful for the state to develop specific expectations. For example, in Missouri, along with typical systems functions of planning, resources, managing documentation, and monitoring services, the role of supports coordinators (case managers) explicitly describes other defined functions and expected activities, such as "Building Relationships: Establishing strong, trusting relationships with the person being supported and the others involved with that person" and "Networking: Developing community relationships and community support systems which benefit the lives of individuals with developmental disabilities and their families."[33]

Case Manager caseloads and capacities vary greatly. Oregon I/DD case managers and their customers experience a wide range of caseload ratios, from as few as 25 to as many as 82 (self-reported data). Each CDDP determines the caseload ratios for their staff, while Brokerages are limited to a maximum of 45.

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[29] Ore. Admin. Rules 411-415-0010 (2019). Retrieved from https://www.dhs.state.or.us/policy/spd/rules/411_415.pdf

[30] Ore. Admin. Rules 411-415-0090 (1) (2019). Retrieved from https://www.dhs.state.or.us/policy/spd/rules/411_415.pdf

[31] Oregon Office of Developmental Disabilities Services. (July 2018). Case Management Contact Requirement Technical Guide. Retrieved from http://www.dhs.state.or.us/spd/tools/dd/cm/Case-Management-Contact-Requirements-Technical-Guide.pdf

[32] Oregon Department of Human Services. (August 2005). Monthly Monitoring of Sites. Retrieved from http://www.dhs.state.or.us/spd/tools/dd/cm/Service%20Monitoring%20Guidelines%20v2012.pdf

[33] Missouri Department of Mental Health. (October 2019). Learning the Basics Support Coordination. Retrieved from https://dmh.mo.gov/media/pdf/learning-basics-support-coordination

Nationally, there is no defined best practice in determining caseload size; optimal ratios depend upon many variables such as staffing structure and team support, responsibilities of each case manager, population served, frequency of contact requirements, travel time/geographic region served, and other factors. In the NASDDDS survey, ten states indicated that their caseloads were at 1:35 or below, and eight states had ratios between 1:40 and 1:45. While twenty states report that they establish maximum caseloads for their I/DD case management, another twenty-five do not, instead relying upon quality management and performance requirements to hold CMEs accountable.[34] The variation in caseload size across Oregon may not be cause for concern as a policy matter, but inconsistencies in responsiveness and stakeholder perceptions that many case managers are unable to fulfill their responsibilities and do not have inadequate time due to caseloads, are indicators of capacity challenges that should be addressed.

Within the CDDPs, there are a range of approaches to building teams, organizing internally, and trying to ensure a “good match” with people served. The larger CDDPs have a higher degree of specialization, with several reporting separate teams based upon settings (residential vs in-home) and/or teams who specialize in children or adults. A small number of CDDPs have teams established to meet specific cultural and language needs. Every CDDP makes different decisions related to which groups or case managers have smaller caseloads; sometimes it is people in residential services, others reduce the ratios further when the team is focused upon in-home services or children. Many CDDPs organize caseloads for people living in group homes by house, seeking to avoid multiple service coordinators working with a single home or provider. This approach is understandable from an efficiency and systems perspective but may not always meet the needs of the individuals served nor support choice. As would be expected, most Brokerages do not organize teams based upon topical or population specialization, except for some assignments aligned to geography.

The wide variation in the organizational size of Oregon CMEs produces a vexing challenge in creating statewide rules and guidance related to caseload and/or specialization, further compounded by the lack of payment differentiation. However, there may be value in setting caseload expectations in statewide policy, given the large number of CMEs in Oregon and the wide range of inconsistent ratios currently implemented. Setting a single caseload ratio for all program participants statewide would not be advisable, yet ODDS may want to consider further data analysis of case management encounter data disaggregated by subpopulations, geography, level of support need, frequency of contact as defined in the ISP, and (as available) outcome or customer satisfaction data, to inform the development of maximum caseload guidelines for different groups of people, based upon such an analysis. For example, an optimal caseload size for children living in family homes may be different from the caseload size for adults living group homes. An added benefit to this approach would be the establishment of a mechanism to assist in more granular predictions of future need aligned with the population and improved transparency in funding requests for case management.

Oregon’s requirements for case manager qualifications leave a fair amount of discretion to the case management entities, contributing to inconsistencies. Along with 35 other states, Oregon requires case managers to have a bachelor’s degree, or an equivalent combination of education and experience. However, Oregon does not require I/DD-specific experience or expertise, as compared to 26 other states

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[34] Cooper, Robin E. (April 2019). Medicaid and Case Management for People with Disabilities: Structure, Practice, Issues (Third Edition). National Association of State Directors of Developmental Disabilities Services (NASDDDS).

that require that CMs have prior experience supporting with people with I/DD.[35] This can sometimes create challenges in ensuring case management staff have the requisite knowledge and experience to offer quality case management, especially in entities that prioritize internal promotional opportunities for staff across a wide range of departments or divisions unrelated to the delivery of ID/DD supports and services.

Additionally, Oregon's training standards and expectations could be further refined to align with the values and goals espoused by the state and by stakeholders. The phrase "person-centered" is used liberally throughout current administrative rules related to roles and responsibilities of case managers. It refers both to how they are expected to do their work and in relation to forms that are to be used. What is not easily accessible nor clear is an actual definition of what "person-centered" means, both generally and within different aspects of practice. This makes it difficult to operationalize, and thus more likely to be widely defined against more inconsistent expectations at the local level. Similarly, many of the current policies, including "core competency based training" refers more to knowledge-based expectations, expecting "basic awareness…exposure to…understand…know," as opposed to demonstration of skilled use of the practice. Finally, the state would benefit from examining the current flexibility for case managers to fulfill ongoing annual training requirements relative to what might be accomplished with an established set of standards, and an approach that scaffolds learning with experience and includes demonstration of competencies, not just hours clocked. For example, Pennsylvania has established regulatory requirements that annual training must encompass six topical areas, including "The application of person-centered practices, community integration, individual choice and assisting individuals to develop and maintain relationships."[36]

Back up planning and policies related to responsiveness outside of business hours varies.

The 1915 (k) CFC Option includes a statutory requirement for back-up systems or mechanisms to ensure continuity of supports.[37] While the Oregon 1915(b)(4) describes back-up options, including assistive technology and access to alternate providers, many people and families in the stakeholder outreach process indicated that they did not feel that they had an adequate contingency plan. The ISP Instruction Manual[38] covers back-up planning as part of the Risk Management Section, but in the Oregon Administrative Rules, back up plans do not seem to be referenced, nor are they included in the CME Quality Assurance Field Review Process.

Separately, case management entities have implemented a wide range of approaches and set varying expectations related to contacts outside of business hours. All CMEs advise customers to utilize county crisis lines and/or 9-1-1 as warranted, but each CME has established a different standard regarding urgent but non-emergency contacts with case managers, and the state has not articulated the specific operational requirements. The state may want to provide additional policy clarity related to both back up plans and expectations of CMEs related to non-business hours.

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[35] Cooper, Robin E. (April 2019). Medicaid and Case Management for People with Disabilities: Structure, Practice, Issues (Third Edition). National Association of State Directors of Developmental Disabilities Services (NASDDDS).

[36] 55 Pa. Code § 6100.143.

[37] 42 C.F.R. § 441.520

[38] Oregon ISP. (February 2018). Oregon ISP Instructions, p. 35. Retrieved from https://oregonisp.org/wp-content/uploads/2018/02/Oregon-ISP-Instructions-02-28-2018.docx

Improving person-centered thinking, planning and practice is foundational.

Oregon has a long history of leadership in person-centered thinking, planning and practice, going back decades. Leaders from the person-centered planning "movement" – those professionals who have dedicated their lives to the creation, development, thinking and scaling of the practice – people such as Jack Pearpointe, John and Connie Lyle O'Brien, Michael Smull and others, spent countless hours in Oregon mentoring and assisting people in their learning and building of local knowledge and technical assistance resources in the 1990's and early 2000's. As the I/DD system has evolved and grown, focused attention on person-centered practices has waned, despite extensive language in rules and regulations intended to support the idea procedurally.

Person-centered thinking, planning and practice should be ongoing and iterative, infused into every aspect of the service system, from intake through implementation of service delivery. It is much more than the Individual Service Plan, and it is not a discrete event. Person-centered thinking needs to be continually fostered and encouraged throughout the system, it should never be presumed that success has been achieved through training, forms or certifications; it is reliant upon consistent renewal and attention at all levels. Implemented effectively, person-centered thinking and practice helps move the balance of policy and program implementation away from deficits, limitations, and lack of ability towards capabilities, strengths, opportunities and interests, while maintaining health and safety. Person-centered practice helps promote the fundamental assumption that every person can be supported to live, learn, work, love and play as a contributing member of community.

Every conversation in a person-centered system should be seen as an opportunity to support these foundational values, starting with information and referral, as well as intake and eligibility. While reinforcement through policy and guidance is important, implementing person-centered thinking is not a compliance activity. For every front-line staff person who engages with people with I/DD and families including case managers, training that supports continuous development, improvement and demonstration of person-centered skills and competencies, as well as ongoing practice supported by mentors and leaders, should focus on the facilitation of expectations that every person can contribute and has strengths to build upon that can result in a good life, and how supports and services wrap into that equation. Teaching and learning about person-centered practice should not be focused solely or primarily on the ISP form, assessment of risks, and compliance activities, which is where much of the focus in Oregon exists now.

The sequencing of person-centered planning conversations is also critically important. In the current Oregon process, the formal functional needs assessment and the determination of available resources usually occurs before deep exploration and engagement about goals, dreams, and preferences. By primarily relying on a monthly hours allocation of staffing based upon a functional assessment, the case manager does not have the opportunity to engage in person-centered conversations related to solutions and how to best meet needs as those needs are being identified. As such, the assumption has been established that nearly every need identified in the assessment can or should be met with paid staffing. Discussions about existing natural supports, and what is working and not working in the context of these relationships, need to occur more intentionally, and as part of a broader understanding of the idea of assessment, inclusive of information and perspectives beyond the formal structured assessment instrument. In order for case managers to be effective in facilitating person-centered planning and helping the team to consider a wider range of options aligned with the needs and preferences of the person, including technology, natural supports, generic/non-disability resources and more, the state may want to consider how to incorporate findings from the functional assessment of needs into the person-centered planning process prior to determining and conveying the final allocation of paid support hours.

Additionally, the decision to allocate hours equally across the year on a monthly basis does not acknowledge the ebb and flow of people's lives and is not person-centered. While the flexibility provided for school-age children to access more expansive supports during the summer addresses part of the concern, other circumstances leave case managers, families and people receiving supports with inadequate tools to adjust services to align with their needs on a short-term or immediate basis. For example, when a person comes home from a hospital stay with additional care needs expecting to last one or two weeks, or a primary natural support is unavailable for a week or two, or even simply during months when the calendar falls in such a way that there are additional weekdays, there is no simple way for case managers to adjust hours without a formal assessment and re-allocation. The state may want to consider allowing for utilization of services against a one year, or even six-month, cap instead of a monthly amount.

The redesign of the ISP process, including the ISP form, should support planning processes and documentation that are flexible and adjust to the needs of the person. While the idea of "one ISP" was well intentioned to better support consistency, planning is less individualized as a result, and case managers are often overly focused on the form and completing every field. Federal rules require that the plan must be developed "commensurate with the level of need of the individual, and the scope of services and supports available."[39] As Oregon considers new approaches to better integrating person-centered practices into the process, the development and use of tools that support person-centered planning and the documentation of the process in a more flexible and customizable manner is paramount.

Oregon utilizes a unique approach to payment for case management services that is not in alignment with federal Medicaid fee-for-service billing requirements.

Oregon's rate methodology for case management is unusual and may not accurately reflect the funding required to support the provision of the service as required by state and federal regulations. The projected "workload model" calculation and the cost base determination does not consider differences in labor costs across different geographic regions, nor does it take into account differences in the size and scope of the organizations and their responsibilities. Additionally, the state definition of a qualified waiver case management contact as any reciprocal encounter (regardless of time/effort involved), and the billing limitation of one encounter per day per client, are factors that combine to create a situation where the time expended assisting people with more complex needs is likely not well represented in the rate. Case managers may be disadvantaged by expending additional time on behalf of a client with higher intensity needs, driving implementation practices that are not consistent with state expectations of quality over quantity. For example, several Oregon CMEs have established case management encounter "quotas" as part of their employee review processes, yet the 1915(b)(4) contemplates a very person-centered, individualized determination, "The amount of additional case management included in

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[39] 42 C.F.R. 441.540(b)

an individual support service plan is determined based on the individual's needs and the level of involvement the individual wishes the case manager to have."[40]

Both Brokerages and CDDPs function under a forecasted workload model that provides a monthly maximum budget, with each CME seeking to submit an adequate number of qualified claims in order to receive the full allocation of funding. However, the differences in enrollment requirements and caseload practices create an important distinction:

- CDDPs are expected to serve all eligible individuals, regardless of whether or not the forecast correctly predicts enrollment. Each CDDP determines its own caseload ratios. Once the CDDP reaches its allowable cap, no additional remuneration is provided under ordinary circumstances, even when eligible services are rendered to eligible individuals. CDDPs must absorb increases in encounters or in enrollment above the forecast.
- In their contracts, Brokerages have established caps on the number of individuals they serve, based upon an average caseload of 45 people. Brokerages are able to establish waitlists when they have hit capacity.

In practice, the assurance provided in the Oregon 1915(b)(4), "The case management workload budgeting model accounts for forecasted caseload growth and includes necessary resource amounts needed to add case managers where needed, therefore all Medicaid-eligible individuals determined to have a qualifying disability have access to case management services" does not necessarily result in additional staffing when there are peaks in enrollment, and at the end of each biennial budget period, certain case management entities exceed the available resources in their contracts, but must continue to enroll and serve eligible participants.

Section 1902(a)(30)(A) of the Social Security Act requires that such payments be consistent with efficiency, economy, and quality of care, and are sufficient to provide access equivalent to the general population. Medicaid fee-for-service payment requirements do not allow states to require a provider to continue services without remuneration when those services exceed an established billable allotment. Additionally, fee-for service payment caps on total claims per provider for authorized services delivered to eligible individuals are not consistent with federal payment policy. In fact, the statutory requirements at 1902(a)(37) and regulations at 42 CFR 447.45 delineate the timing and process by which payment must be made for claims submitted. There is no provision for the provision of service without payment due to a state-established limitation.

The workload model requires the CDDPs to bear some risk for the provision of services over the total budget available, which is authorized pursuant to the beginning-of-biennium projections. The state indicates it may make adjustments if the amount of actual expenditures differs from estimates over time, but in any given month encounters over the cap will not be paid. Unlike the CDDPs, the Brokerages, while subject to the same workload model for payment for eligible encounters, are governed by capacity limits established in their contracts, thereby minimizing the risk for assumption of potentially unpaid claims. The risk imparted to the CDDPs in this model of payment is not currently supported by necessary Medicaid authority.

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[40] Oregon Section 1915(b)(4) Waiver Fee-for-Service Selective Contracting Program, July 2018, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/OR_Developmental-Disabilities-Selective-Contracting-Waiver_OR-10.pdf

To ensure adherence to generally accepted payment methodologies in Medicaid fee-for-service delivery systems, the state should consider further evaluation and potential revision of the I/DD case management rate methodology. Devising a fee schedule for the provision of case management services would address potential compliance concerns. Many states have developed approved fee-for-service rate methodologies for case management that provide for monthly billing per eligible enrollee; several others bill encounters in standard 15-minute increments. If ODDS chooses to maintain encounter-based claims on a fee schedule, the state should explore strategies to ensure effective utilization controls such as annual limits on amount or duration of the service with criteria for exceeding established limits as needed, or prior authorization for necessary services above established limits.

Medicaid also offers payment methodologies allowing for the sharing of risk with providers or other entities. These arrangements require explicit approval by CMS and, depending on the specific attributes of the arrangement, may invoke additional requirements for both rate setting and CMS approvals. Should the state retain the current model of payment that is akin to a capitated or risk-based payment arrangement, the state should undertake an actuarial review of the arrangement(s) to ensure its structure and payment practices align with federal expectations for risk based payments, and may want to consider seeking CMS engagement and approval.

Finally, as Oregon considers options for rate setting methodologies as well as quality improvement, the state may also want to consider pay-for-performance incentives in case management. For example, another state developed HCBS case management rates with financial incentives aligned to specific requirements such smaller caseload ratios per case manager, meeting quarterly outcome targets, and building capacity through recruitment, retention and replacement plans.[41]

Importantly, the method and sufficiency of payment for services contributes mightily to overall case management performance. Once the state determines the optimal outcomes and structures, devising and deploying financing strategies that further those objectives will be imperative.

Investing in IT infrastructure could help address capacity challenges, including paperwork requirements that reduce the availability of case managers to work with the people they are serving, as well as the goals of making case management simpler and easier to access.

Oregon's I/DD ecosystem would greatly benefit from a robust statewide person-centered case management system with files and documents accessible to people receiving supports, families and providers, as well as case managers. Due to this gap in the state, there is an extraordinary level of inefficiency that adds to the capacity challenges within all aspects of the I/DD system, but most especially for case management. Additionally, the state does not have access to critical information about its own system and the people served.

The lack of access to a centralized system contributes to many different challenges as articulated by stakeholders and demonstrated through the review of processes, policies and procedures, including:

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[41] Centers for Medicare & Medicaid Services (CMS. (August 2017). Trends in Rate Methodologies for High-Cost, High-Volume Taxonomies. Presentation. Retrieved from https://www.medicaid.gov/sites/default/files/2019-12/trends-in-rate-august-2017.pdf

- Forms and documentation used by case managers are not connected to an accessible data management system that would reduce duplication of information collection and data entry, costing significant amounts of excess time and introducing human errors;
- Delays in rapid access to the right information at the right time and critical information-sharing across the state agency, case managers, providers, families and people receiving supports;
- Over-sharing and under-sharing of information, and requests for blanket releases of information, due to the inefficiencies of targeted and limited requests;
- Lack of access to HIPAA-compliant mechanisms that allow individuals and families to readily access and retrieve information, documents and records (which also costs the CMEs time and energy in meeting this need redundantly);
- Potential for errors and program integrity issues created by manual processes, and the inefficiency of duplicative and redundant processes implemented by CMEs intended to ensure program integrity, which also consume human capital;
- Inability of the state to effectively and efficiently communicate vital information to people receiving supports, families, and providers directly and through electronic mechanisms, without having to rely on case management entities;
- Inability to monitor and track (and, potentially, incentivize) achievement of outcomes, including limitations in capacity to effectively monitor agency providers through the electronic provision of progress notes;
- Need for a user-friendly system (or user-friendly interface and linkage to the existing eXPRS system) that would allow people with I/DD and families to better track and approve timesheets and progress notes;
- Limitations in developing person-centered planning processes and implementation practices that could reflect the complexity and individualization necessary, would allow for more fluid and ongoing updates from all team members, and would provide people receiving supports and families the opportunity to better drive and contribute as full partners to the process, instead of the current system that incentivizes the development of static annual plans that are challenging to update and leave people with I/DD feeling that the ISP is not something that is their own; and
- Lack of consistent and standardized data and information, beyond billing claims, available to the state that would allow ODDS, case management entities and providers to participate in a continuous quality improvement cycle.

This is not a new problem, but a concern that has been vexing the state for years. It has now compounded to a point that a noticeable proportion of the most valuable resource in the I/DD system – human capital – is being used for activities that do not directly benefit the people who rely upon supports. In 2012, DHS requested "funding to allow for the implementation of an already established electronic, web-based, central client record and case management system. Currently the statewide system for serving individuals with developmental disabilities is a highly decentralized structure relying on contract providers for case management and service delivery. As a result, there is no common, centralized information system for client plans, services, and outcomes. This compromises the state's ability to plan strategically, provide required regulatory and oversight functions, and develop service policies and procedures."[42] The Legislature granted ODDS funding for a Case Management IT system for

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[42] Department of Human Services. (n.d.). Program Delivery and Design Developmental Disabilities. Retrieved from https://www.oregon.gov/DHS/ABOUTDHS/DHSBUDGET/20132015%20Budget/DD%20Delivery%20and%20Design.pdf

the 2013-2015 biennium, but implementation of the 1915(k) option and new homecare rules issued by the federal Department of Labor required these funds to be repurposed for critical IT infrastructure development instead. The funding granted by the legislature has since been committed to specialized projects for maintenance and development of the eXPRS system in response to new federal and state regulations and additional programmatic changes.

The current 1915(b)(4) waiver states that "The Department is in the process of establishing an electronic case management system. This will allow the waiver case management entity to enter waiver case management progress notes electronically and indicate a billable versus a non-billable service. This will then automatically bill through the eXPRS system. This will allow the Department to pull the claims filed in eXPRS and compare them to the electronic waiver case management note to assure services billed were in compliance. The Department hopes to have this system implemented before the end of the 2019-2021 biennium."[43] While this may be a helpful approach for billing compliance purposes, the state may want to consider the need for a comprehensive system that will allow for a wider range of functions, and can support the state's strategic plan goal of, "an integrated information technology system that will support case management and provide statewide data to inform policy-making and report quality of life outcomes for individuals with I/DD."[44]

For example, a robust data system could assist the state and case managers in addressing the important need for comprehensive monitoring of health and welfare, enhanced through data analysis and review, including retrospective reviews of hospital claims and pharmacy utilization. Many states have opted for a commercial-off-the-shelf case management system that can be customized to meet state specifications, while others have developed proprietary systems unique the state's needs. Oregon may want to consider systems such as those implemented in Indiana, Hawaii, South Dakota or Ohio as examples, or commercial solutions which have integrated the Charting the LifeCourse tools into their platforms. On the other hand, states that have sought to retrofit existing systems designed for other purposes, including case management systems for other populations or programs (e.g., foster care, aging services), have found this approach costly, challenging to implement, and less effective.

Should ODDS choose to invest in an electronic case management and communication platform, if this system integrates into the broader state Medicaid enterprise system, enhanced federal match is available for both the initial development (90/10) and the ongoing maintenance of the system (75/25).[45]

Additionally, many states have found value in investing in a policy management platform that allows a web-based structure for statutory, regulatory, guidance, policy interpretation, communication and other documents to be organized and presented in a manner that allows stakeholders (both internal and external) to seek and track important information and updates in a more organized fashion. This could also reduce time spent on information management by state staff, case management entities, and providers. Currently, ODDS policy information is not presented in a cogent and cohesive manner on the

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[43] Oregon Section 1915(b)(4) Waiver Fee-for-Service Selective Contracting Program. (July 2018). Retrieved from https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/OR_Developmental-Disabilities-Selective-Contracting-Waiver_OR-10.pdf

[44] Oregon Department of Human Services. (June 2018). Oregon Developmental Disabilities System Strategic Plan 2018-2023, p. 14. Retrieved from https://www.oregon.gov/DHS/SENIORS-DISABILITIES/DD/Compass/Oregon-IDD-System-Strategic-Plan.pdf

[45] See CMS Federal Financial Participation for HIT and HIE, https://www.medicaid.gov/medicaid/data-systems/health-information-exchange/federal-financial-participation-for-hit-and-hie/index.html

website, and the multitude of transmittals, action requests and other policy documents communicated out on a weekly basis, often serve to overwhelm and confuse stakeholders, including case management entities. Taking the time to organize and consider a structure for information to cascade from federal or state law, to regulation, and through all types of sub regulatory guidance would be a valuable exercise for the state that would also serve to identify conflicting, duplicative and out-of-date information.

Oregon's bifurcated approach to the case management structure is not typical.

While it is not unusual to have different case management entities serving different populations enrolled in different waivers, states generally do not restrict access to HCBS case management based upon the services and settings a person chooses within a single waiver. As a result of the state's I/DD system history, Brokerages have been limited to serving adult enrollees living in their own or family homes, whereas CDDPs serve all I/DD enrollees. Recently, state statute requiring these differences has been updated to create additional flexibility.

The Brokerages were originally established to further self-determination, self-direction, and sustainability in Oregon under the *Staley* lawsuit, offering a distinct approach from CDDP case management. They were initially created to only assist adults receiving supports when living in family homes or on their own, under much more limited self-directed budgets, providing "higher touch" supports brokering and navigation assistance reliant upon maximizing local resources and natural supports in combination with smaller amounts of funded services. Much of the value of the program was based in the role of the Personal Agent, as person-centered facilitator of access to community and resources. After the initial launch of the Brokerages, case management for adults in the Supports Waiver moved over from the CDDPs to the Brokerages. CDDPs have always retained delegated responsibility for intake, eligibility and enrollment; provider licensing; adult protective services; state-funded family support; and crisis assistance. Further, Oregon's decision to expand access to services for children (in 2013) did not result in structural or programmatic changes to case management to reflect the distinctions between adult's and children's needs; children were simply assigned into the CDDPs (with the exception of existing state staff case management provided to children eligible for the CIIS waivers).

The structure under which a person has to change case management entities if they seek to enroll in certain services also conflicts with many of the principles and goals of the state, as well as key assumptions related to person-centered practices. The distinction between entities which have the ability to close to new enrollment while others are required to continue to accept new eligible participants also erodes the notion of equity and meaningful choice, as do the differences in capped caseloads and the potential impact on capacity and responsiveness. And restricting choice for certain parts of the population (children, people living in provider-controlled residences) does not comport with self-determination, simplicity and equity.

Oregon's I/DD program continues to experience tremendous growth. Caseloads this biennium are predicted to be 9.8% over the last biennium,[46] and as such, the current case management entities will continue to be stretched in some parts of the state while others are under-enrolled. The difference in an organization serving nearly 4,000 people relative to an organization serving 500 people is substantial.

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[46] Spring 2019 DHS-OHA Caseload Forecast, Budget Planning and Analysis, Office of Forecasting, Research and Analysis, May 2019. https://www.oregon.gov/DHS/BUSINESS-SERVICES/OFRA/ofradocuments/Spring%202019%20Caseload%20Forecast.pdf

There is value in having enough enrollment to scale initiatives, to have the flexibility to offer choice among case managers, and to develop adequate knowledge to meet a diversity of needs, including those related to culture and language. At the same time, there is also value in being small enough that leadership has relationships throughout the organization, systemic program integrity is enhanced by personal accountability, and people with I/DD and families play a meaningful role in the governance and direction of the entity.

Individualization, specialization and choice should not run counter to consistency, simplicity and equity; rather, the goal should be to achieve all of these attributes. The role of the individual case manager should tip towards the person-centered functions, which are best served through strong relationships and continuity over time. Specialization related to domains (e.g., housing, employment) or activities at certain life stages (e.g., transition-age youth, older adults) is expertise that can be supplementary and more centralized within a local or regional CME to be accessed by case managers as needed; it does not need to reside within each case manager at an individual level.

At the same time, a focused effort to improve case management for children living with families is clearly warranted. Beyond paid service coordination, families need person-centered planning that encourages high expectations, navigational support, and opportunities to understand the family role not only as caregivers but as facilitators who help develop self-determination, independence and strong self-advocacy skills. Based upon stakeholder feedback, many families of children have not been provided case management that reflects these expectations, and a top-to-bottom review of policies, procedures and program implementation for children under 18 would be beneficial, with consideration given to addressing case management requirements specific to children under age 18. The current waiver structure, with a separate waiver for children, makes this simpler.

Basing the CDDP case management structure on county boundaries creates disparities between CMEs, given the distinctions in population, geography, and local options across the state. Counties' decisions to subcontract CDDP responsibilities further dilute consistency and accountability, although for counties with lower enrollment and more rural geographies, combining populations across county lines creates economies of scale that allow for basic program operation. There are core administrative functions that need to occur within each region even when the overall caseload is very small, but in considering future options, different kinds of CMEs contracted directly with the state could easily include multiple counties (or even operate statewide) to provide direct case management services to customers while counties (as governmental units) continue to implement functions like adult protective services and provider licensing. States like Florida and Wyoming, where case management is delivered through many small independent providers, assign responsibilities in such a manner.

Case managers need to be physically present in the communities in which they are serving people, not only to ensure strong relationships with their customers, but also in order to have knowledge and relationships with community resources that can be leveraged. However, this does not require case management entities to maintain local offices and physical presence in every corner of the state; technology combined with strong management, training and teaming can support individual case managers to be successful without offices and creates the opportunity for more flexible case management structures without hewing to county boundaries. For example, in Wisconsin, the largest care management organization in the state, Inclusa, successfully serves over 7,500 people with I/DD (as well as about 7,500 older adults and people with physical disabilities) across 62 counties (out of 72 statewide) with half as many offices.[47] At Inclusa, case managers are expected to live and work in the local communities with very little time spent in the office, including structured expectations to develop relationships with a broad range of organizations and people beyond their caseload in order to best support community integration and participation, meaningful citizenship, interdependency, and opportunities to engage natural supports.

In Oregon, CIIS case management operates successfully statewide with limited local presence, and the majority of Brokerages serve multiple counties. The Brokerage structure of regional catchment areas based upon population aligns more closely to need, while still providing for a local perspective. It also provides the opportunity to add additional CMEs based upon projected and real population growth, including the development of competing CMEs when population growth allows for additional entities, creating choice and ensuring adequate capacity without overwhelming any single entity.

Continued I/DD program growth may create an opportunity to plan, pilot and develop additional case management capacity in areas of the state under the most pressure, and in areas lacking choice, with minimal disruption to the existing system. By focusing on addressing the discrepancies across population groups and the need to improve equity, the state can begin to reform the system in a manner that way that prioritizes people supported. Functions such as provider licensing or protective services do not need to exist within every CME, but every CME should be expected to support access to the full range of services and supports available for every person they serve. People receiving support should have the right to choose both their case management entity and the direct support provider(s), without conflict or being forced into change in order to meet system needs. And, regardless of structure, all of Oregon's case management entities must be expected to operate in a manner consistent with the state's clearly articulated vision and values. By holding them equally accountable to performance outcomes, not just process measures, the state can move the needle on quality and alignment to those values.

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[47] Landing Page. (n.d.). Inclusa. Retrieved from https://www.inclusa.org/

Addendum: Responding to the events of 2020

The COVID-19 Pandemic, and the ensuing economic crisis, began just as HMA was completing this report in March 2020. The year continued with layers of additional challenges, as people across Oregon grappled with systemic racism and equity issues, protests and counter-protests, devastating wildfires requiring evacuations and causing tremendous losses, and additional waves of COVID-19 infections. As of this writing, there continues to be much uncertainty about the immediate future, and how all of these events will affect the delivery of I/DD supports and services over the longer-term. This year brought to light many strengths, and some shortcomings, of the Oregon I/DD system and there are important lessons learned, related particularly to case management and individual support planning.

In the first days of the public health emergency, case management entities had to spend precious time pulling together spreadsheets and managing manual processes to identify and prioritize people at high risk, in large part due to the lack of a cohesive statewide electronic case management system. Because the state does not have access to a centralized portal or effective electronic means to communicate directly to people receiving supports and families, critical information has been harder to disseminate quickly and effectively. Case management entities and providers found themselves writing and submitting pandemic emergency preparedness plans in the middle of an emergency, while families suddenly realized the importance of having meaningful and robust individual back-up and contingency plans. Equitable access to information and assistance was highly dependent on the case management entities, including for populations who speak languages that may require translation/interpretation services not always easily accessed on a timely basis.

Self-advocates expressed frustration about not “being heard” as things unfolded and important decisions needed to be made by each person and their supports, and some felt that reliable and accessible information was hard to come by. People have belatedly realized the importance of identifying access to technology, internet connectivity and communication mechanisms in the planning process, as well as case management’s critical role in supporting people in accessing healthcare.

At the same time, the state responded very quickly to ensure the health and safety of the approximately 30,000 Oregonians who rely upon the I/DD system, partnering with local case management entities to identify and address the needs of people with I/DD, families and providers, while simultaneously pivoting to remote delivery of services and supports and managing a rapidly changing landscape. The flexibility in the current Oregon I/DD system to adapt and change, strong relationships at the local level, the level of community integration that has reduced reliance upon larger congregate care facilities, and the deep commitment of state leadership to protect Oregonians, including both people with disabilities and the providers who support them, has (so far) resulted in far fewer infections or deaths than had been predicted.

The spring and summer brought unrest to Oregon as people responded to the death of George Floyd and long-standing issues of racism and discrimination, and the state faced additional challenges assuring the health, safety and well-being of all citizens, including people with I/DD. The wildfires in September added more complexity and devastation, as over 500,000 Oregonians were evacuated, and homes and communities were destroyed. Hundreds of thousands more experienced difficulties due to poor air quality and health risks. And, another wave of COVID-19 swept through the state during the fall, keeping many schools and businesses closed or operating at reduced capacity, further challenging many communities throughout the state. Through all of this, the I/DD case managers have sought to support each person, family and their providers, again relying upon local relationships and the flexibility of the state I/DD system.

Uncertainty about the coronavirus will require both continued vigilance and flexibility in the I/DD system for the foreseeable future. The profound economic impact of the pandemic, the protests and the wildfires will affect the state budget, the Medicaid program, and the funding available for I/DD supports and services during at least the next biennium, possibly longer. Potential reductions in resources will make the implementation of creative person-centered thinking and robust, effective case management even more critical, to ensure that all Oregonians with I/DD are healthy, safe, and can continue to build good lives in our communities in a post-pandemic world.