HMA

HEALTH MANAGEMENT ASSOCIATES

Stakeholder Perspectives on Oregon Case Management Services

PREPARED FOR
OREGON OFFICE OF DEVELOPMENTAL DISABILITIES SERVICES

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Table of Contents

Background i

Methodology and Approach 1

A. Enrollment and Choice 11

B. Accessible assistance, communication, reliability and trust 17

C. Person-centered thinking and planning; Self-determination 23

D. Systems and Resource Navigation; Community Capacity Development and Connections 32

E. Oversight and Monitoring; Follow Up Activities 41

Appendices

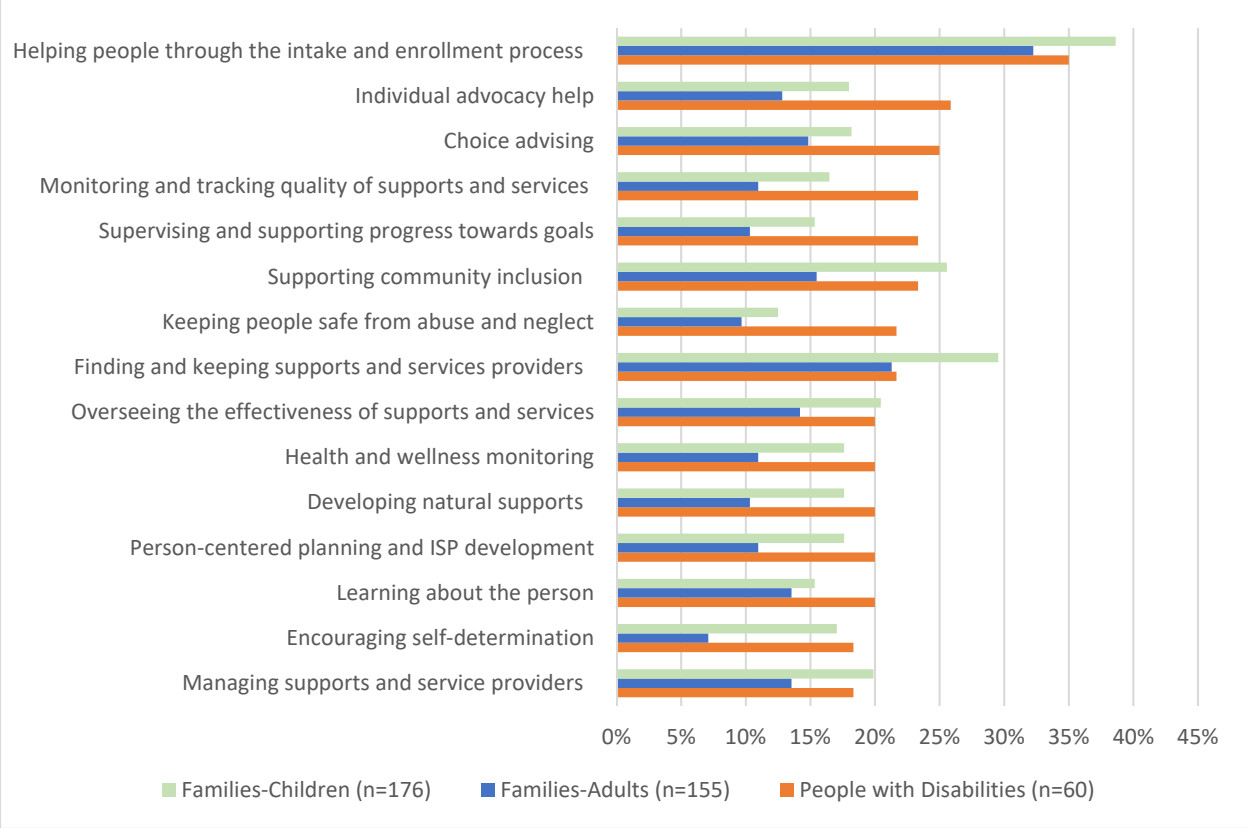
Appendix A: First Person Survey

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

[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).

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.

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:

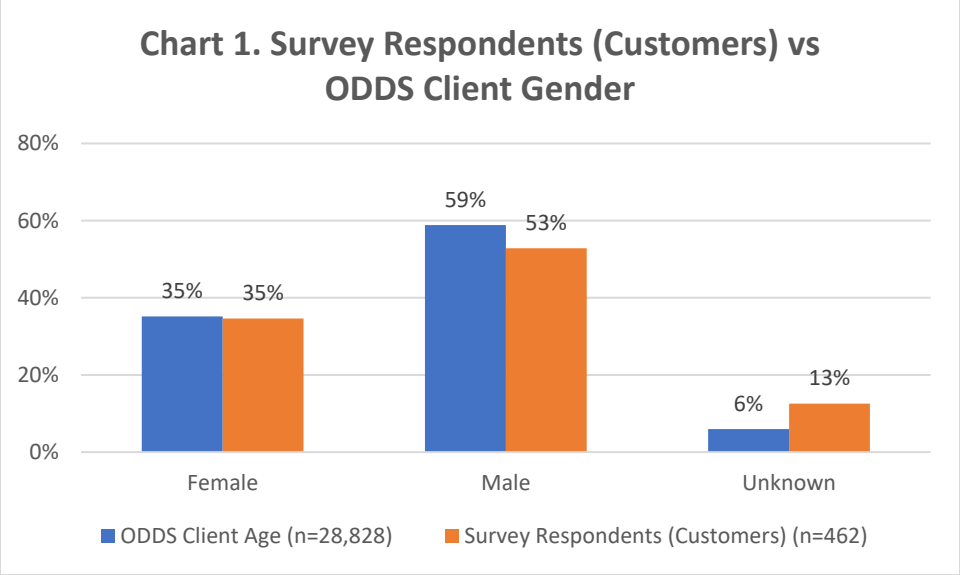
- 44% (n=31) work with CDDP service coordinators;
- 39% (n=28) work with Brokerage personal agents; and
- 17% (n=12) do not know what kind of case manager they have.

Among families/guardians of adults with I/DD:

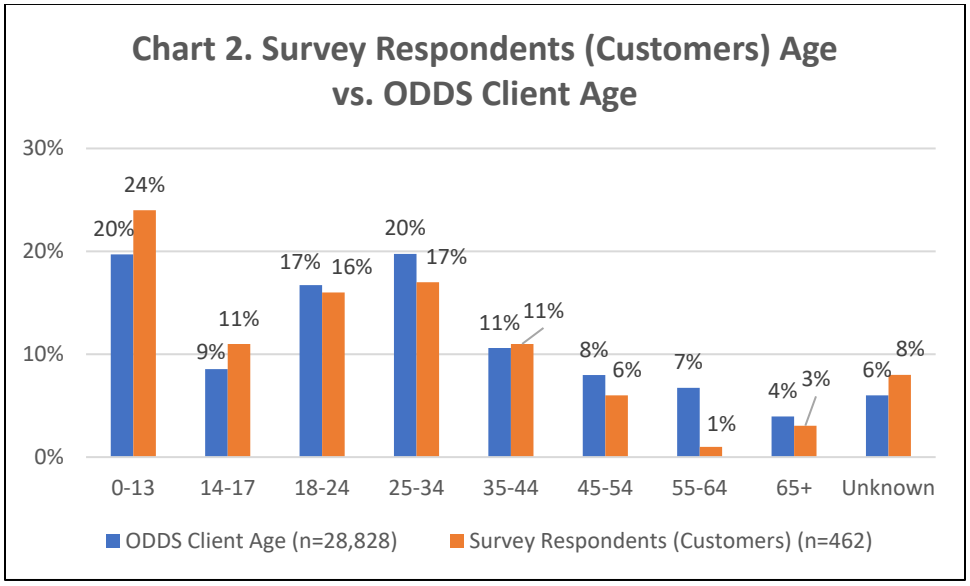
- 46% (n=90) work with CDDP service coordinators;
- 49% (n=96) work with Brokerage personal agents; and
- 4% (n=8) do not know what kind of case manager they have.

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.

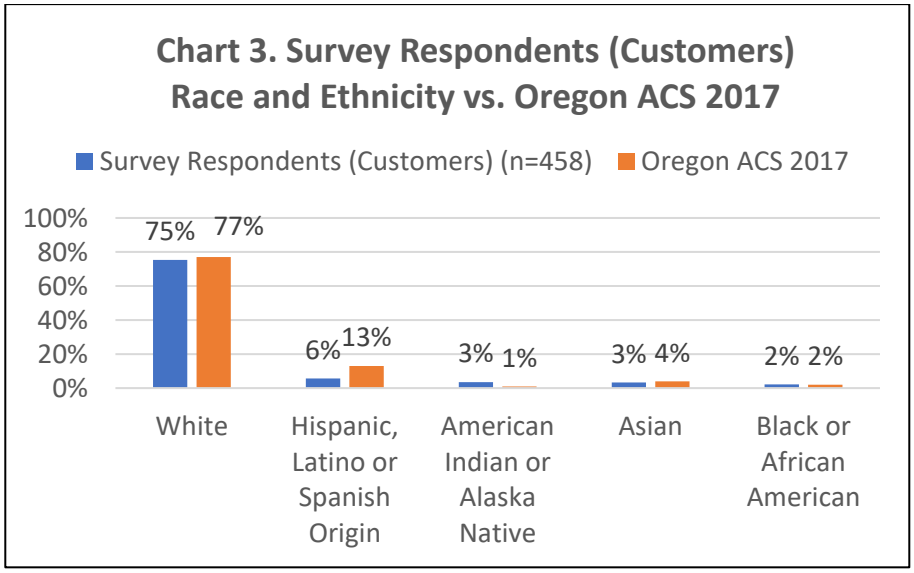


As shown in Chart 2, more than one third (38% or 159) of people with I/DD represented in the survey (usually by family members) were age 17 or younger. People with I/DD who are young adults (age 18 to 24) represented 18% (n=76) of the survey respondents, with 19% (n=80) representing ages 25 to 34 and 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

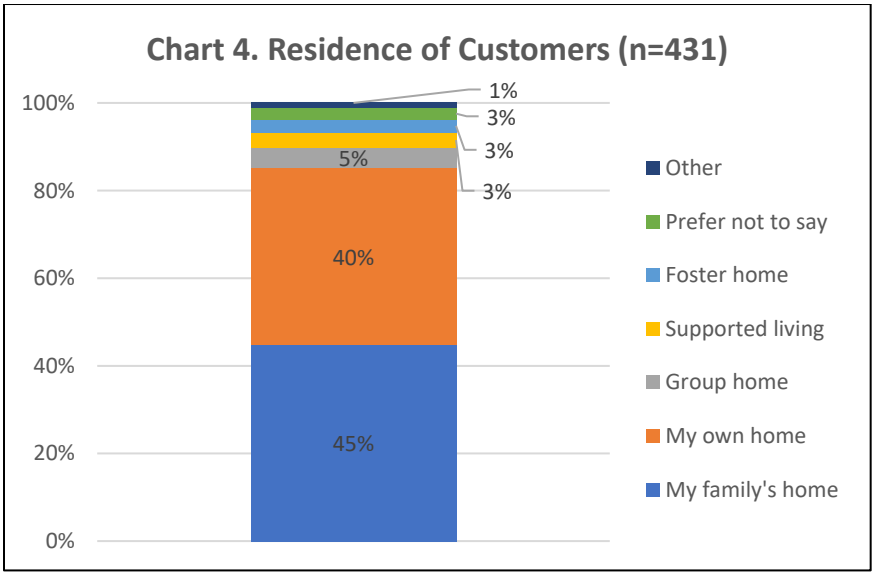
Seven percent (n=36) of survey participants reported they mainly spoke a language other than English at home. Specifically, 2% (n=9) use sign language and another 1% (n=4) each speak Spanish, Vietnamese, Arabic, or Cantonese. Two percent (n=9) of respondents who reported "other" indicated the person 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%**
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	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.

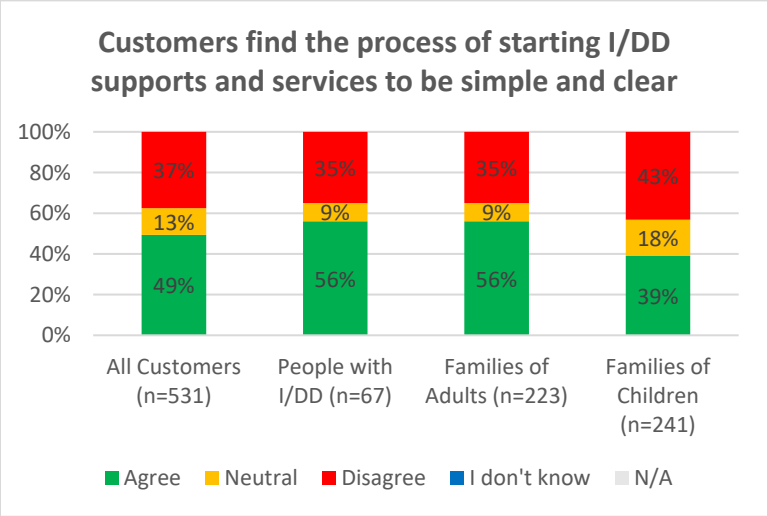
A. Enrollment and Choice

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.

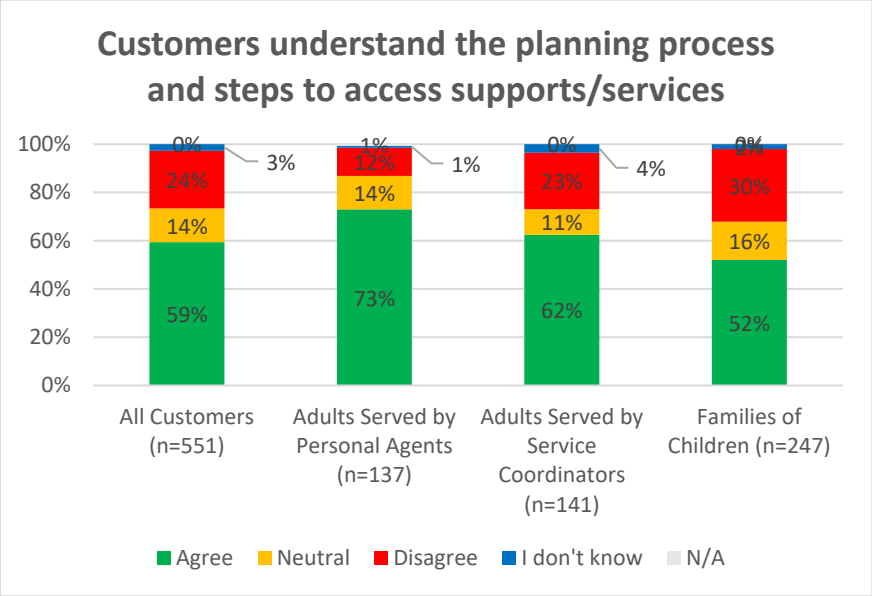


Through comments provided in the survey and in focus groups, many talked about the process taking far longer than anticipated to get to the point that services start. Families would appreciate access to straightforward, understandable information -- preferably available online -- and the opportunity 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.



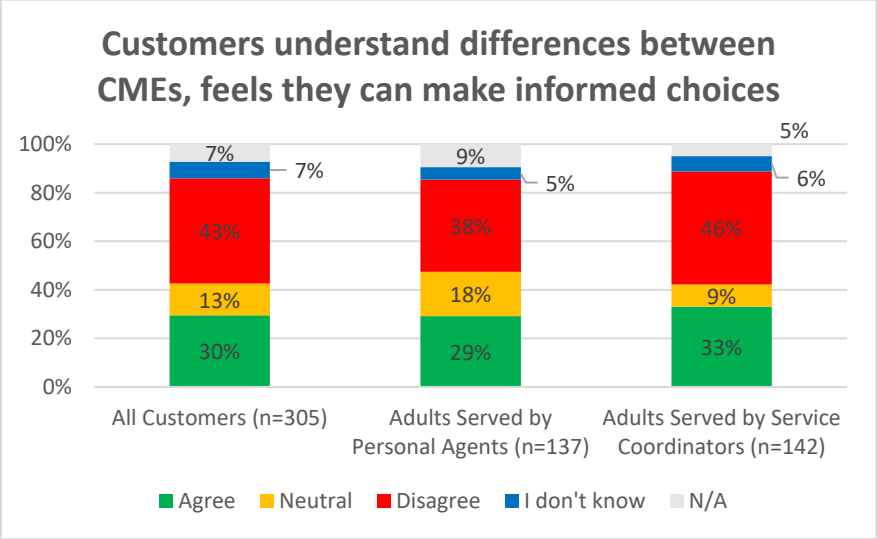
Survey results indicate that only 59% of customers understand the planning process and the steps involved to access supports and services. Among families of children, this number drops to 52%. Many people mentioned the need for better website(s) and electronic information, and wanting to be able to access 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.

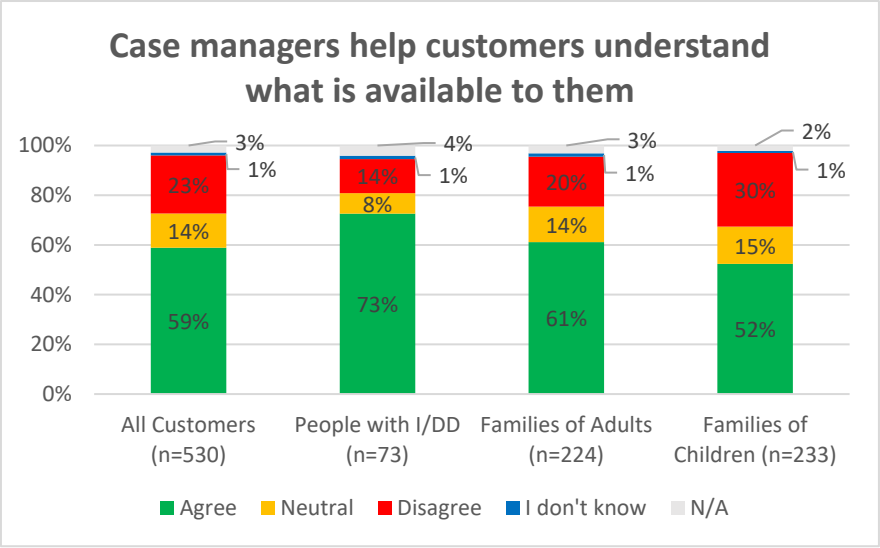
For example, “Arbitrarily pulling our established child case worker off and assigning a transition case worker while in the middle of freshman year of high school because he is approaching age 16 in 6 months was unnecessarily stressful and deprived us of an important advocate/ally in IEP meetings at 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).



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.

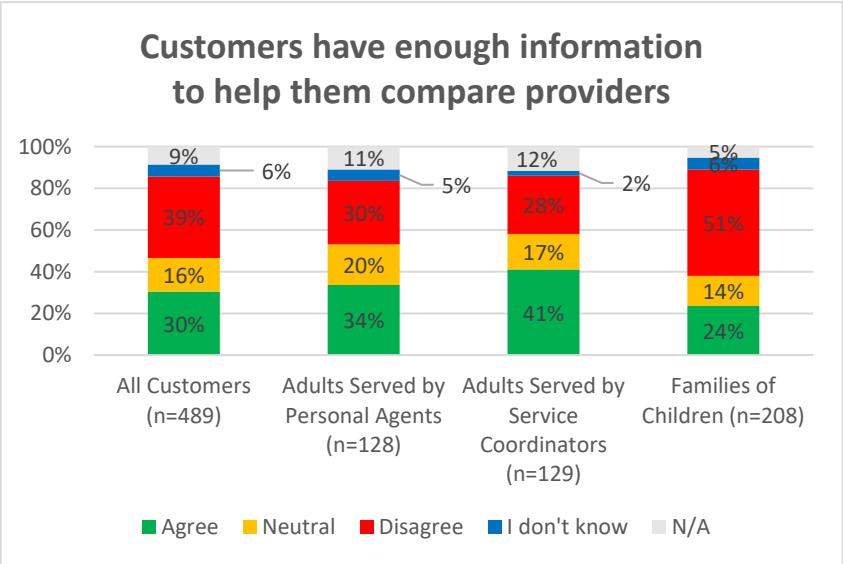
People often indicated that they turn to other families and self-advocates to learn about service and support options, as well as searching the internet, and they bring those resources and ideas to their case managers. "I feel like I know more than my case manager does" was not an uncommon refrain from 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:

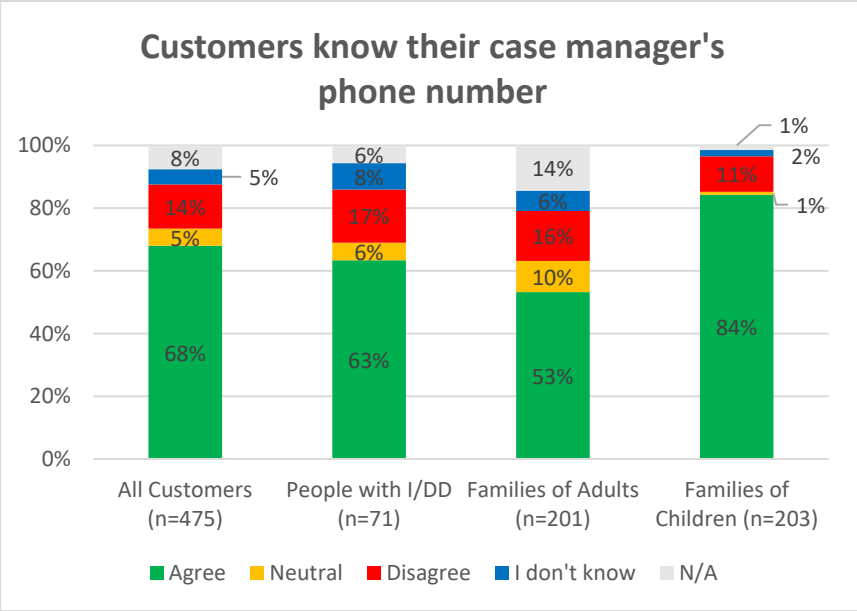
	Adult Residential Setting (n=35)	Adult Family Home (n=135)	Adult Own Home (n=80)	Children (all settings) (n=203)	Adult Personal Agent (n=126)	Adult Service Coord. (n=124)
Meet in person with Case Manager:						
Every month	43%	10%	19%	5%	10%	22%
Every 3 months	26%	28%	24%	19%	27%	27%
Every 6 months	14%	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.

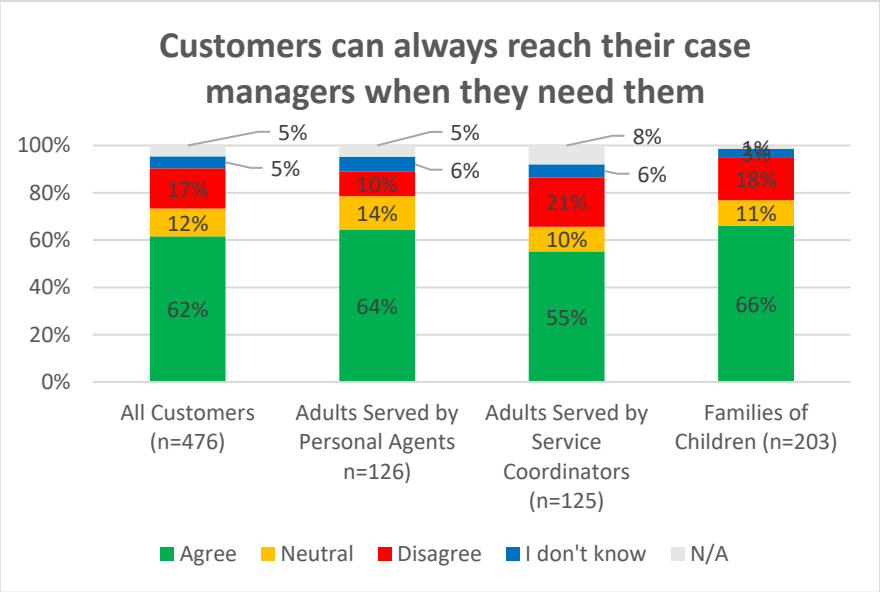


Less than two thirds of adults with I/DD (63%) report they know their case manager's phone number, whereas 84% of families of children said they know the phone number for the service coordinator. Among customers of brokerages, 63% indicate they know the personal agent's phone number, whereas 52% of people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

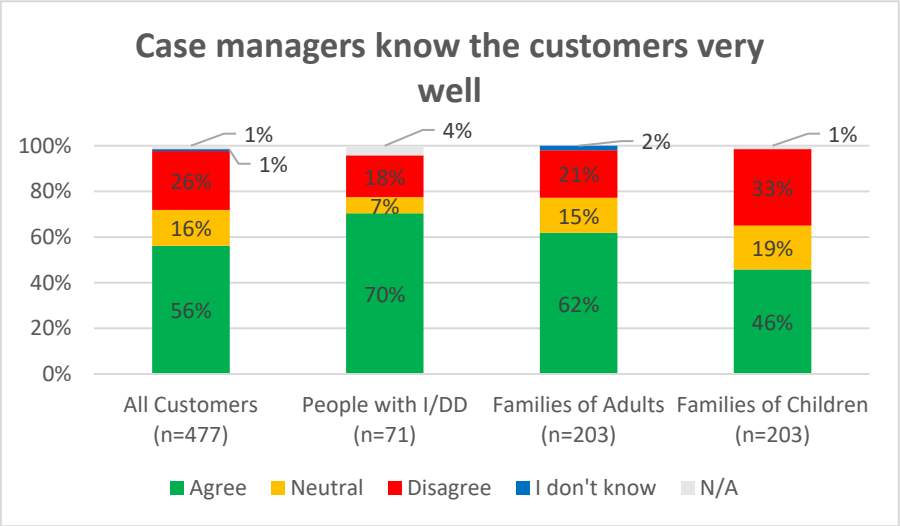
psychologist contacted her. I also contacted her supervisor but got nothing. Once we saw her, she apologized and said there were other families more in need with worse crises."

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

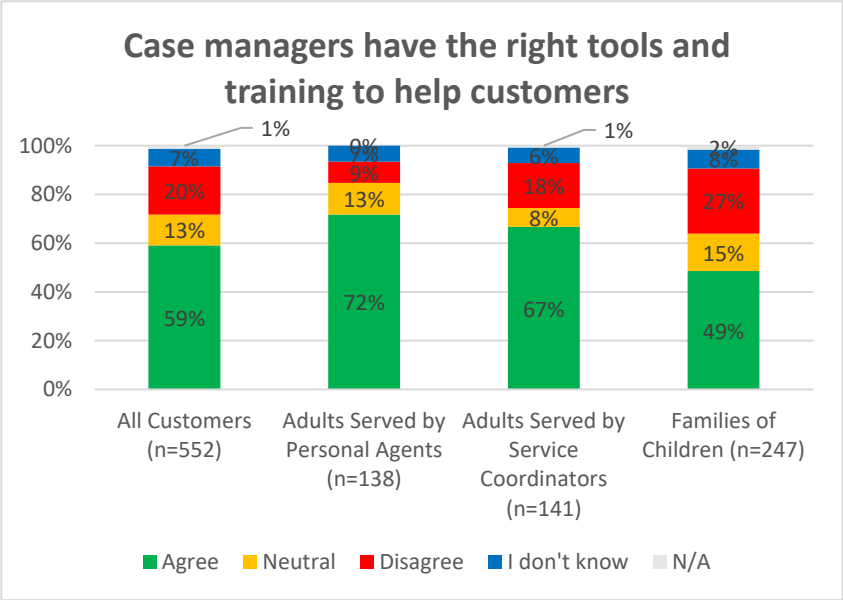
that they perceive that children's case management is more individualized and supportive than adult case management, contrary to many family respondents.

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.



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

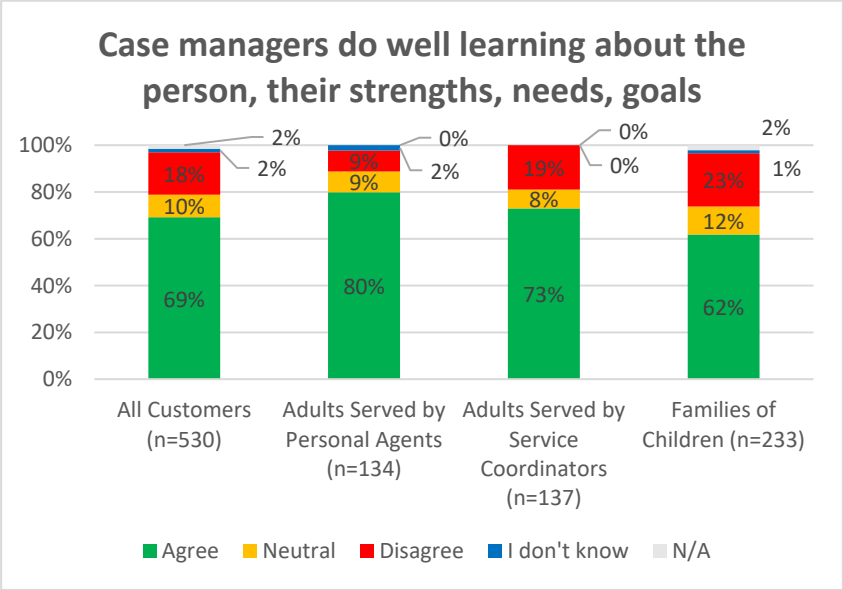
Summary

- 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

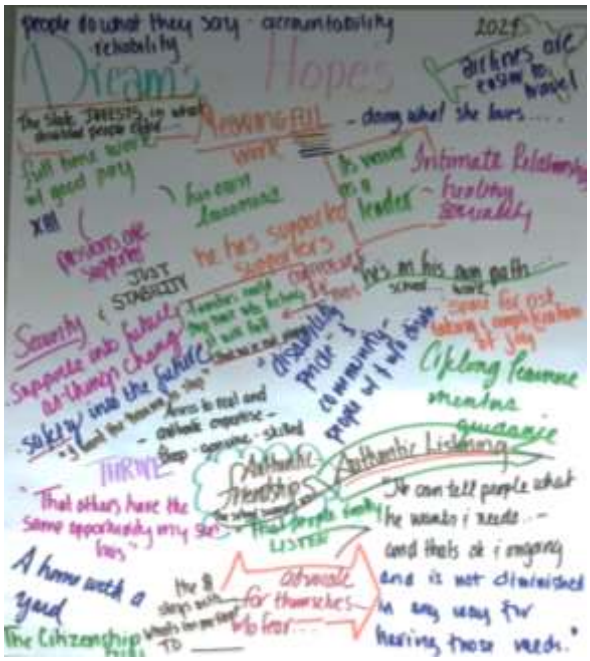
Learning about the person

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."

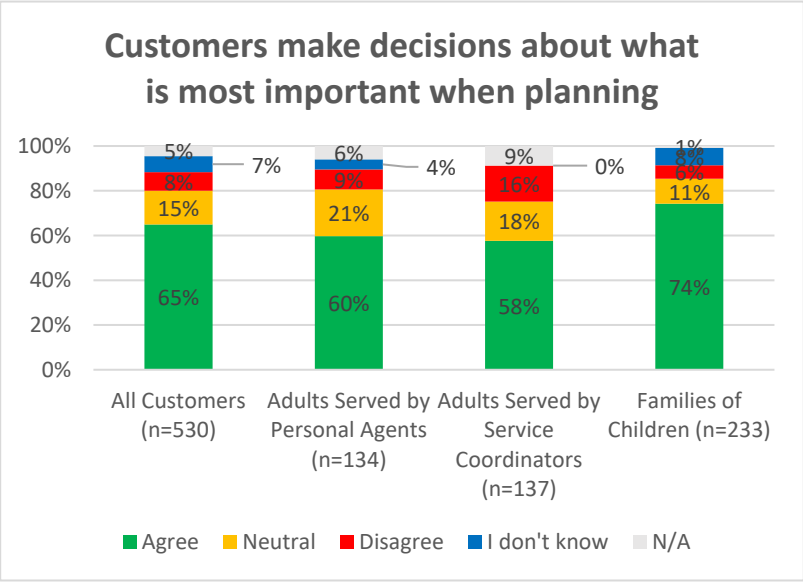
One family commented on the importance of a collaborative approach, saying “His brokerage provider is excellent in understanding my son’s needs and always asks him the same questions she asks her other clients and we decide the answer to his best ability together.” Youth with I/DD in another focus group 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

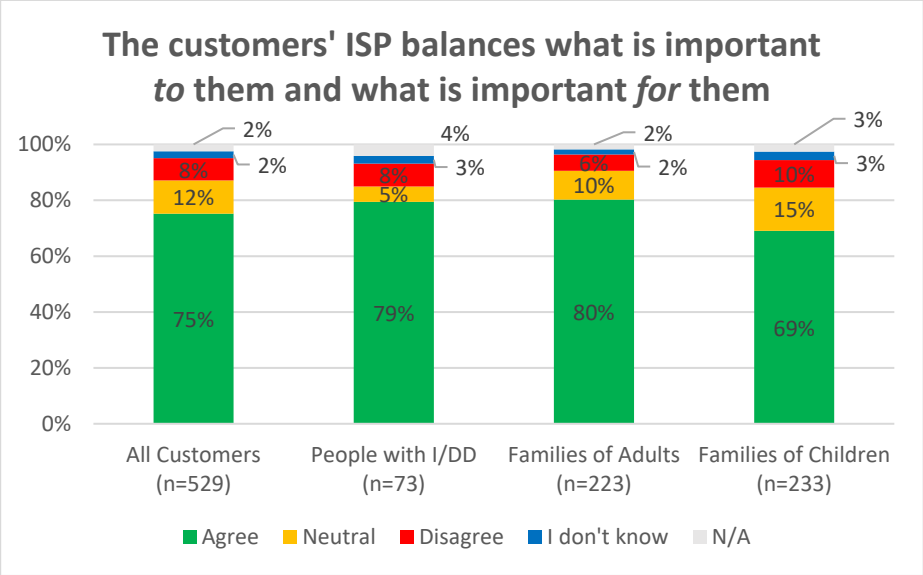
Developing a person-centered plan is a core responsibility of case management. When asked on the survey about the person-centered planning process, 54% of all customers (n=529) indicated that the person/their family decided who would participate in the process, 46% of people with I/DD and their families 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.”



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.”

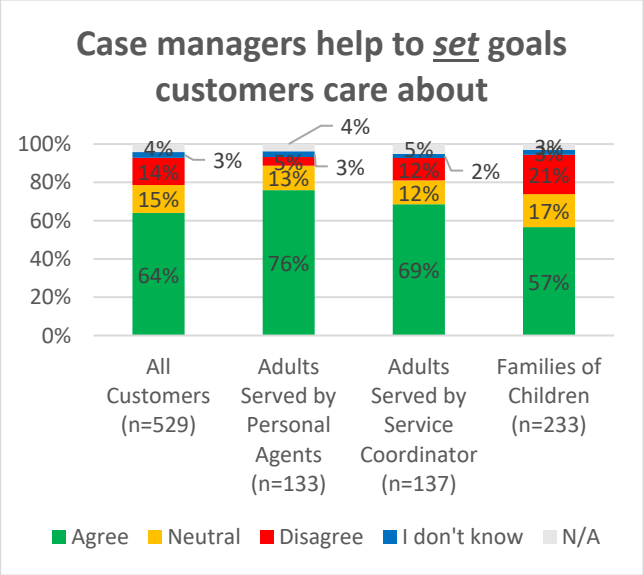
Many CME staff also expressed similar frustrations about person-centered planning, “Person centered planning is not working, it has just become a form to fill out, families are largely uninterested in it.” Another CME leader said, “People need support to think outside of the PCI Form, ISP form, etc. So much

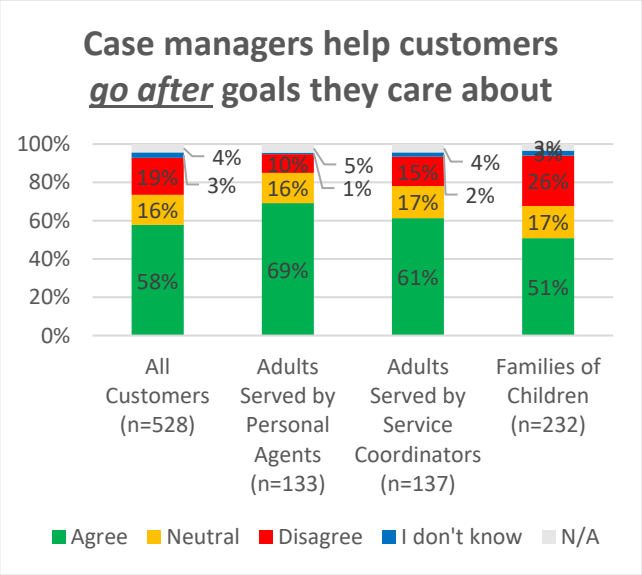
of everything we do is about having some jargon in every box that staff are now stuck in this way of thinking. It really kills creativity." Other CME feedback noted that the state training for SC/PAs has moved away from helping people develop and maintain person-centered thinking and planning skills 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

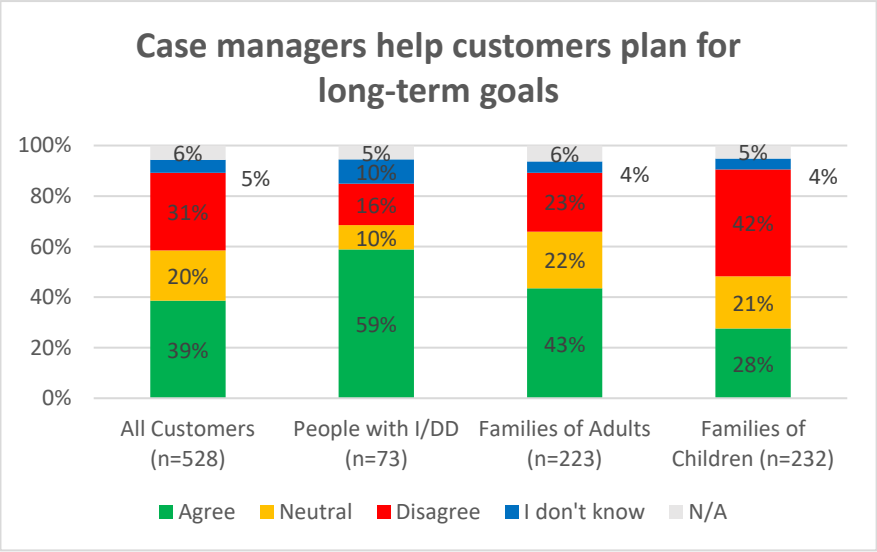
In the survey, participants were asked several questions about how case managers help them with their goals; more customers feel supported by their case manager in creating their goals (64%) than in going after them (58%). And when asked about long-term goals (3-5 years out), the number of customers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





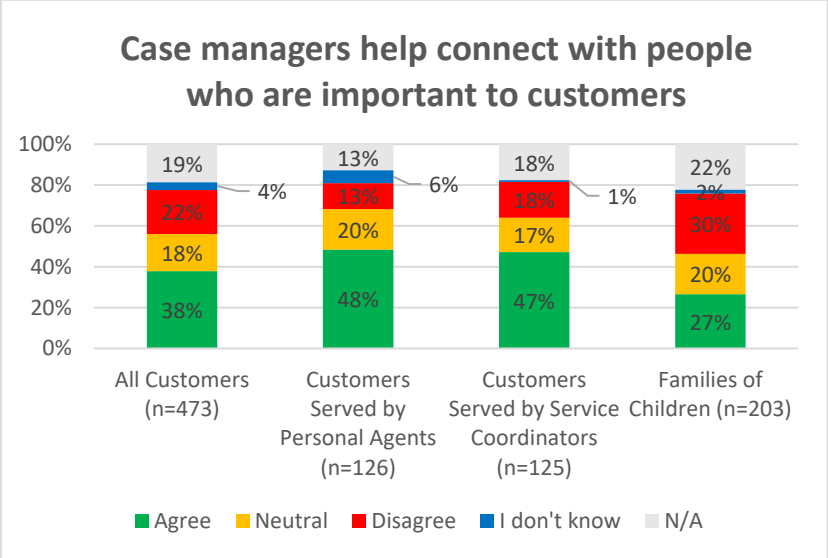
However, in nearly every focus group, youth and adults with I/DD talked about wanting to rely upon their services and supports to help them not only to survive on a day-to-day basis, but to help them achieve their dreams – goals like more independence, having money, moving out of their family's home, 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.

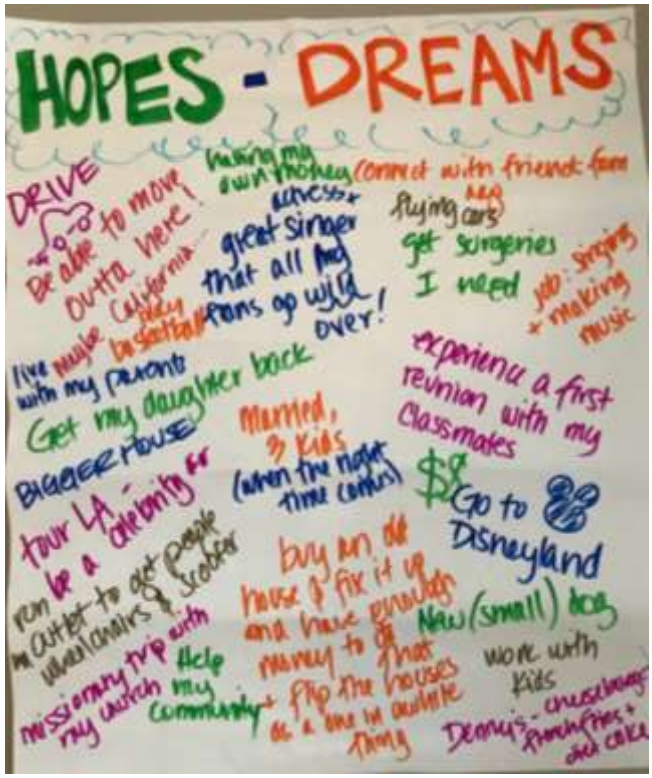


Support for a person's goals

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

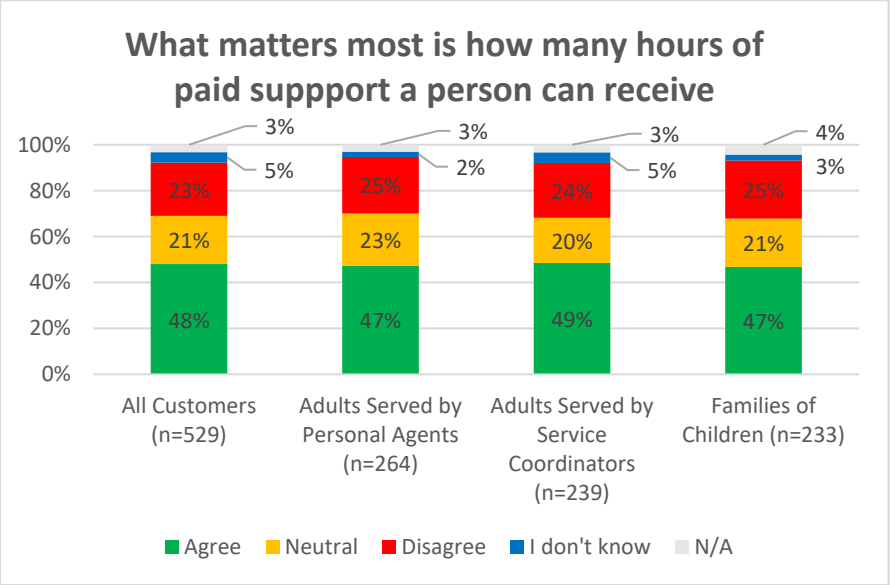
In meetings with groups, interviews, and discussions with many stakeholders, concerns about a combination of change factors -- the challenges with consistently executing good person-centered planning, time and capacity of case managers, the functional assessment process, bringing so many new people into 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.

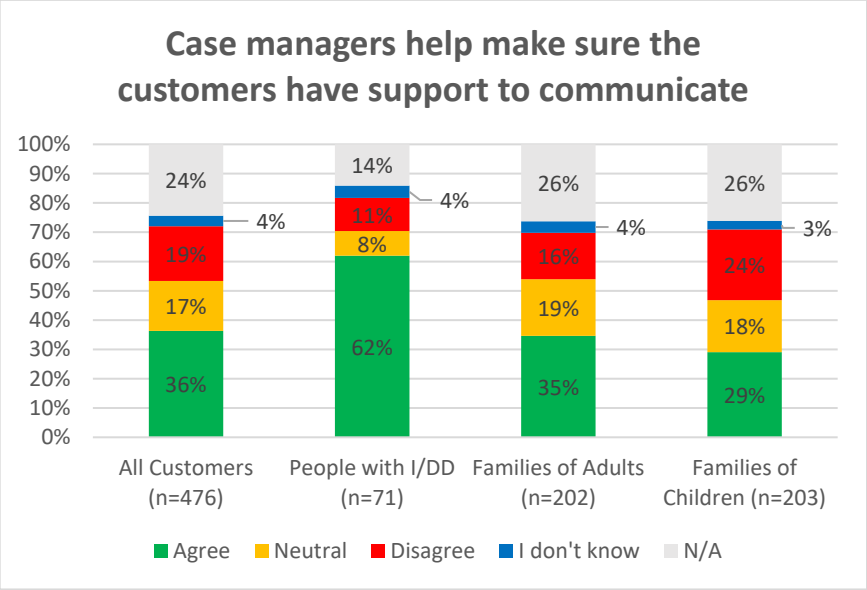


Focus group participants also talked about ensuring some accountability around goals, as well as an understanding that preferred outcomes and how people move towards them must remain fluid, not static. Participants pointed out the importance of creativity in helping a person build a good life, and that 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.

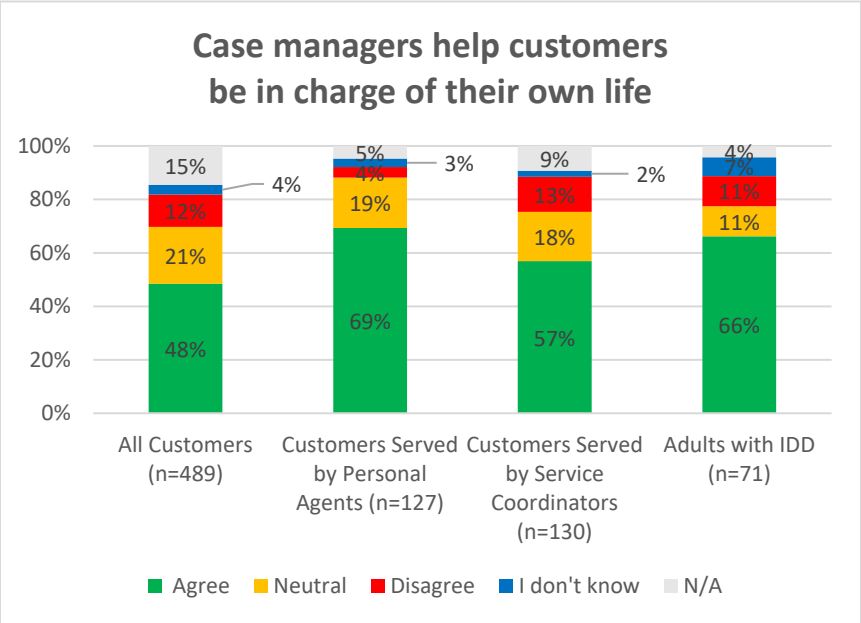
Self-Determination

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.



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.



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

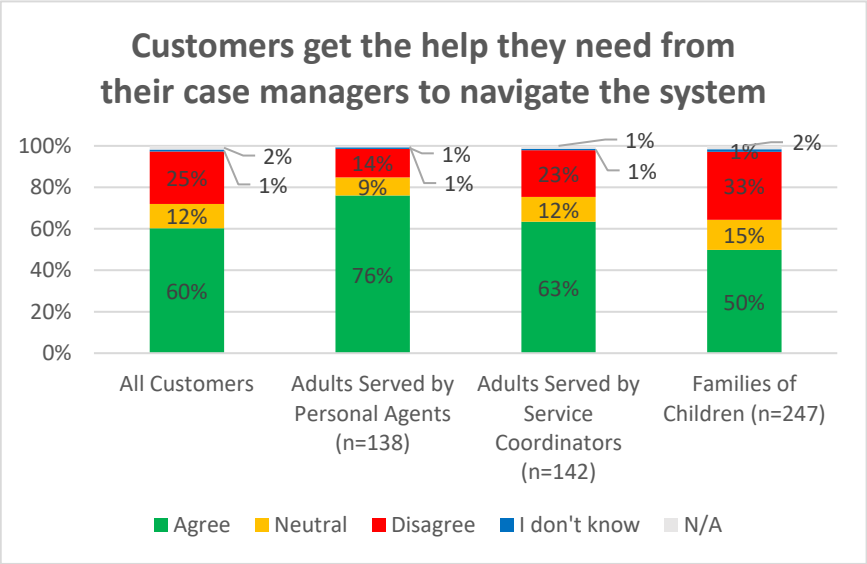
Summary

- 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.

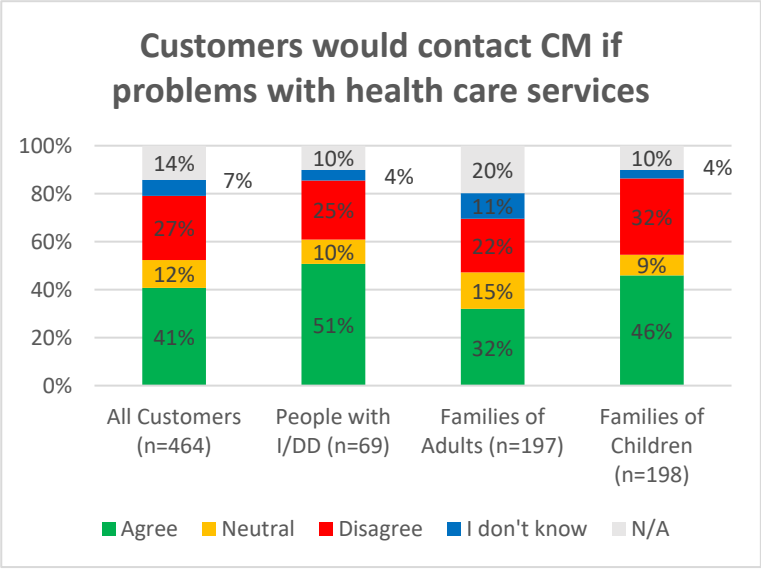
The highest dissatisfaction level came from families of children, with one-third indicating they do not get the navigation help they need. Comments from younger families included perspectives such as, "I never felt my child was advocated for by our service coordinator. She's a 'company gal' who made 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."



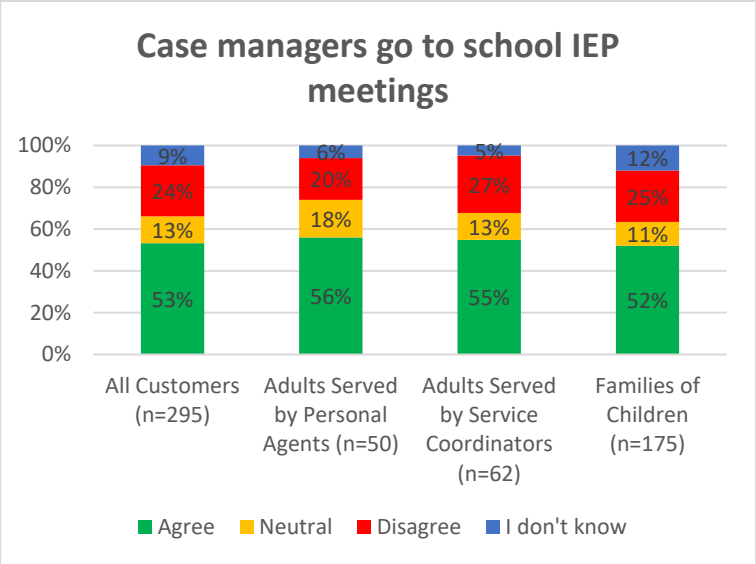
Case managers report a range of their own experiences in their system navigation responsibilities – some expressing confidence and others feeling overwhelmed. "As a case manager I feel very poorly equipped to help people navigate other systems like coordinated care organizations, child welfare, and social 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.



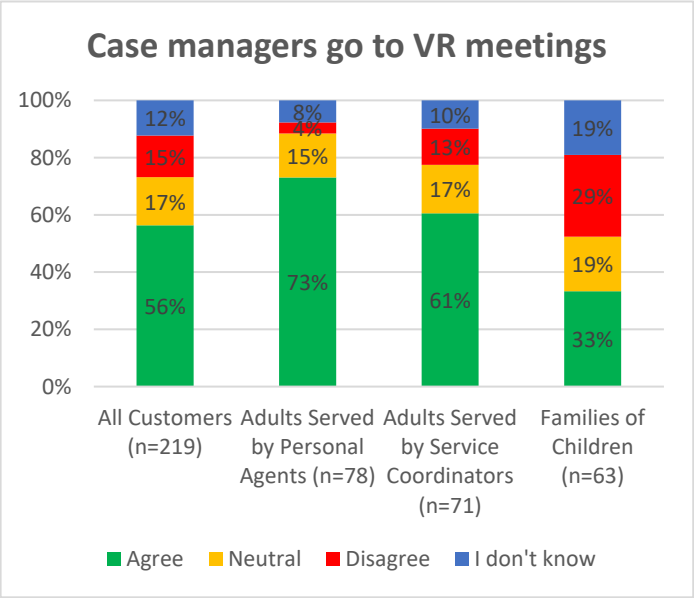
Education



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.



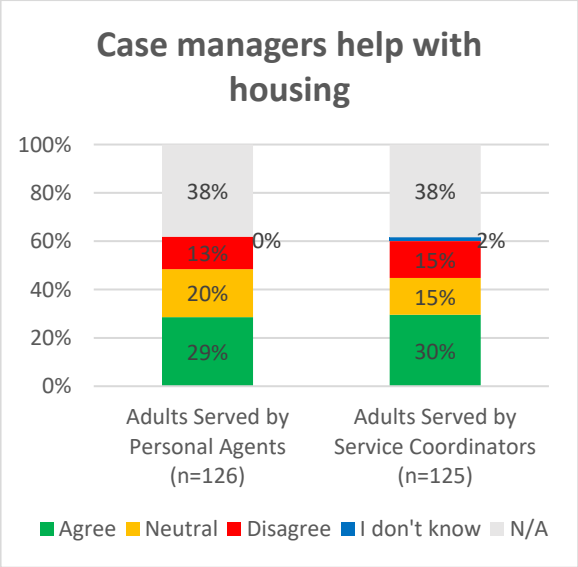
However, among families of children for whom this question was applicable, only 33% agreed and 29% did not agree that case managers attend VR meetings when requested to do so. This data is particularly concerning, given that the transition period for youth moving from adolescence into adulthood is a 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.

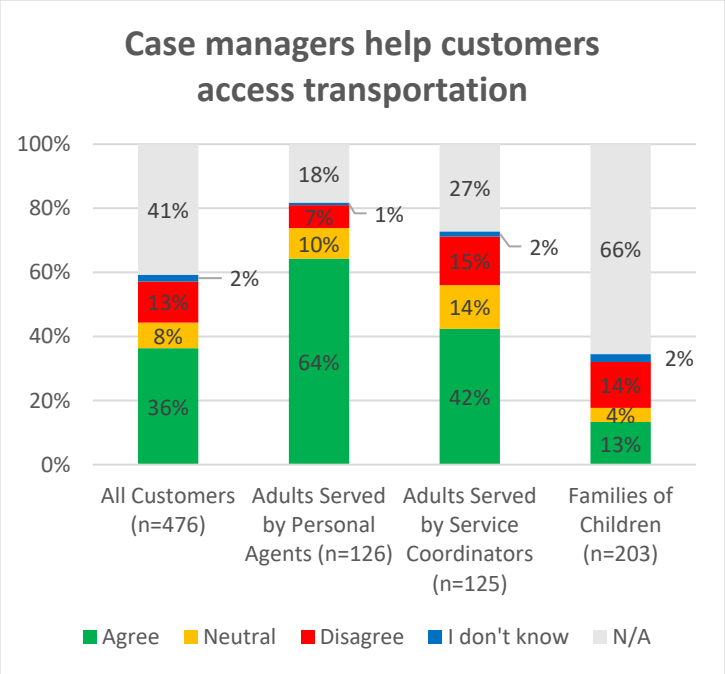
Transportation, Housing and Technology

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.



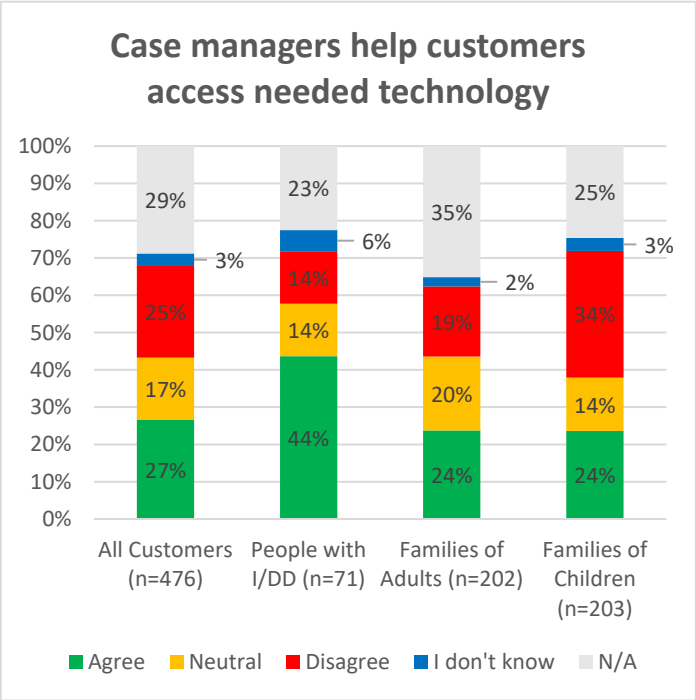
Among adults served by personal agents, nearly two-thirds agreed that case managers help with transportation, while 42% of adults working with service coordinators agreed. As one case manager explained, "Case managers are faced with lack of options to present to individuals. In many counties public transportation 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.



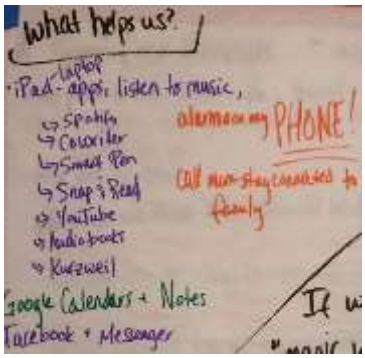
At the same time, lack of understanding about options and existing means to access transportation were also subjects of conversation. For example, in one rural-area focus group, an adult with I/DD talked about the challenges of using para-transit for medical appointments. For each of her doctor's appointments, 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.



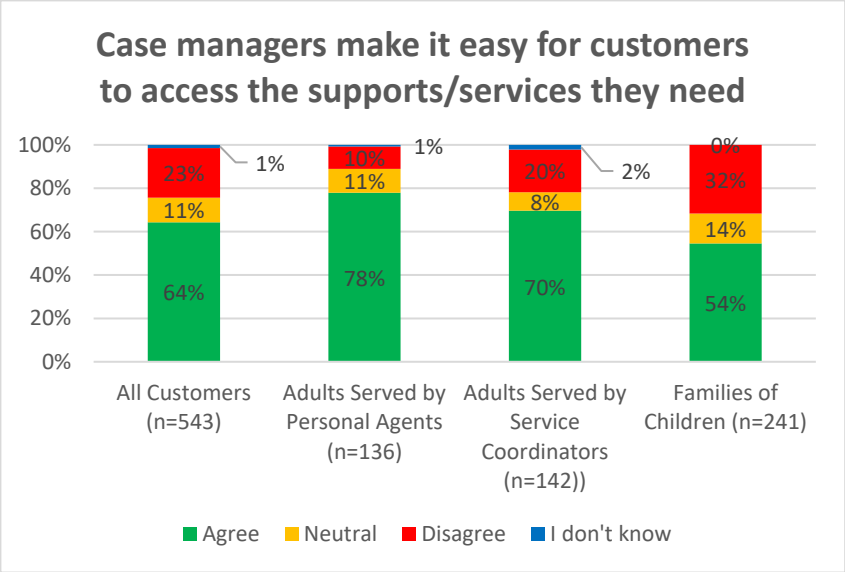
In the survey, just under half of adults with I/DD (44%) agreed that case managers help them access the technology they need, whereas among families the level of agreement was much lower. Perhaps reflecting generational expectations, families of children were most likely to disagree that case managers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

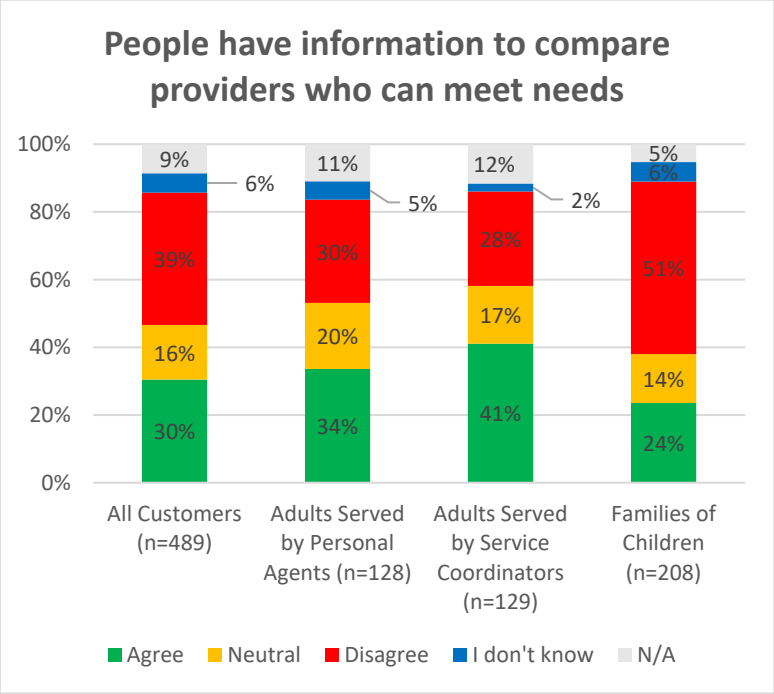
Dozens of comments in the surveys, interviews, focus groups and discussions related to the challenges everyone -- case managers, people seeking supports and families in the DD community -- face in identifying and being able to access qualified service providers, especially those aligned with the persons’ 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."

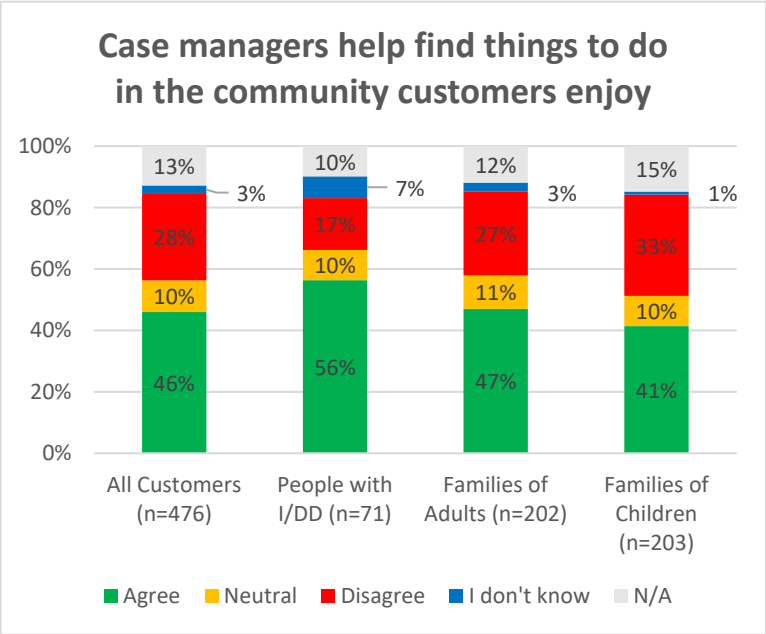
Community capacity development and connections

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."

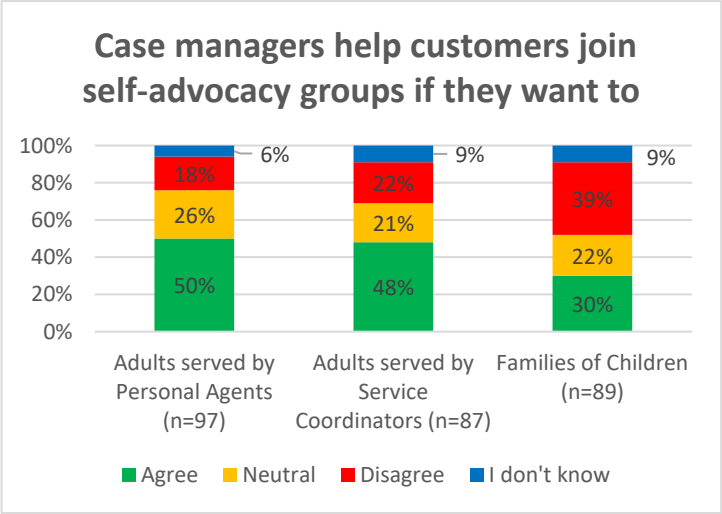
People with I/DD who contributed their views in the groups had expansive and creative ideas about what is available in the community for them – and there were differing perspectives on whether providers or case managers should help with finding and accessing these options. Many talked about how case 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.

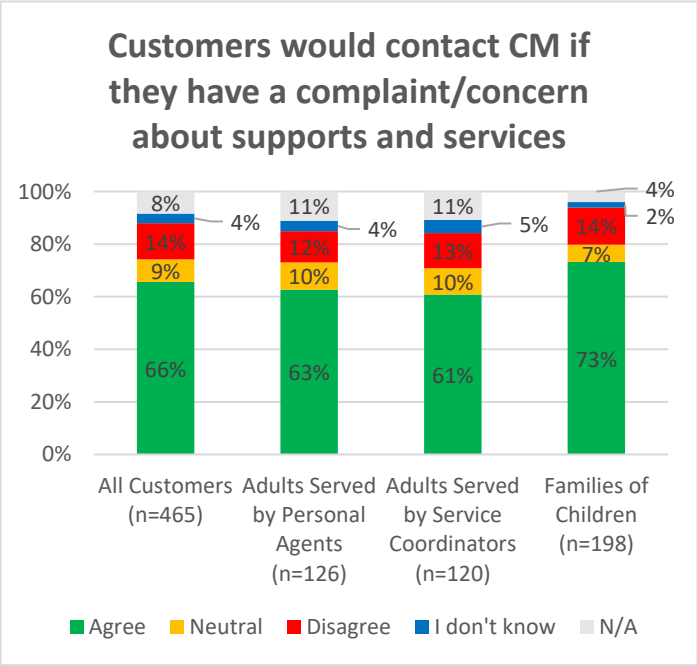
E. Oversight and Monitoring; Follow Up Activities

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.



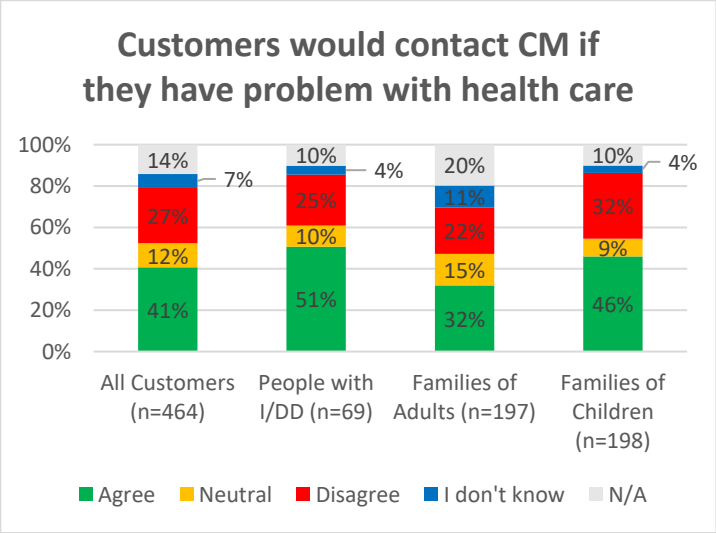
In the survey, the majority (66%) of customers agreed they would contact the case manager if they had a complaint or concern about their services and supports. This is one of the few areas where the perspectives of families of children were more positive than adult customers. Interestingly, 11% of respondents 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.



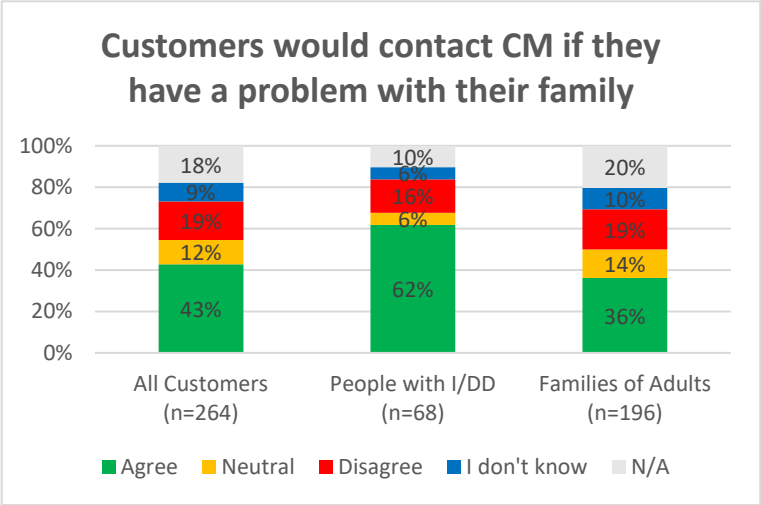
When professionals from the health care system were interviewed (CCO and physician perspectives), concerns were expressed about the lack of coordination and connection between DD services and clinical care. These individuals raised questions about how to support people with complex medical needs when 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.

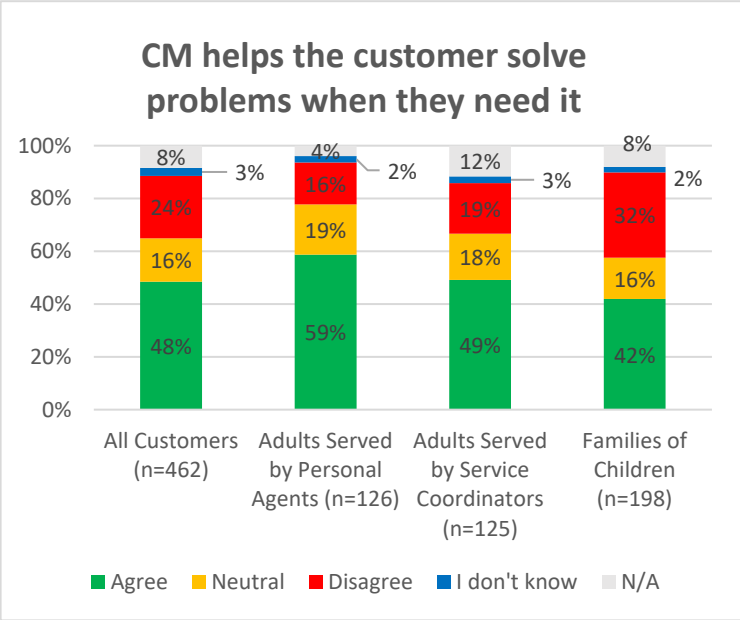
One provider shared, “Case managers are not prepared to navigate disagreements between adults receiving services and their parents. We have to walk a fine line as providers, and the case managers are challenged in engaging around family issues and don’t help us.”



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.”

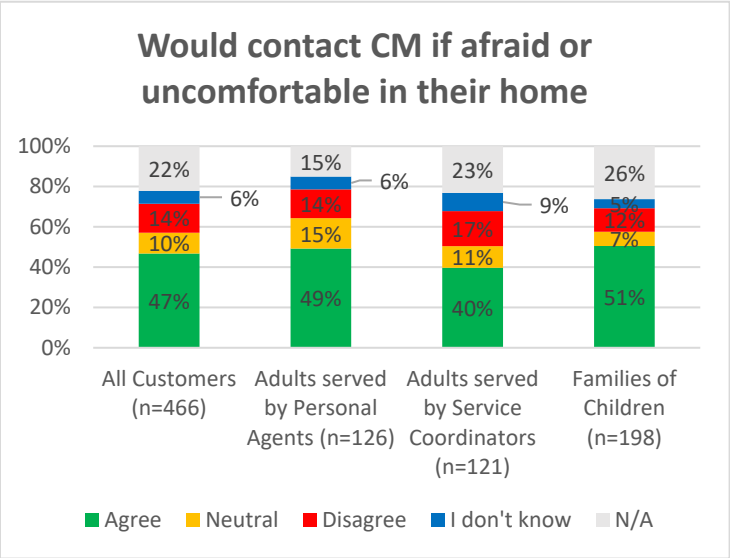
Follow-up: Solving Problems

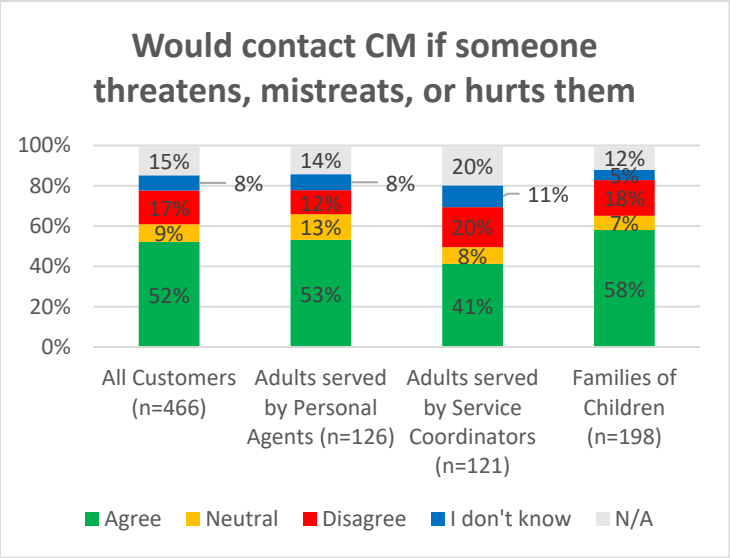
People with I/DD and families often rely upon their case managers to help them resolve problems, but some families and adults do not feel as though they get this support. “Case managers hands are tied. Friction between the case manager and the client because things take so long. The system is not responsive.”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

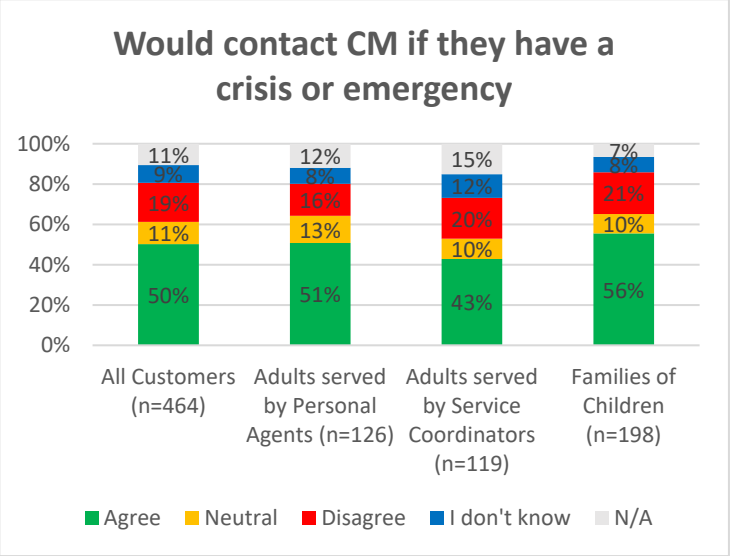


In the survey, there was some variation across types of case management and between adults and children, but overall just under half of respondents agreed that case managers help people solve problems when needed, and just under a quarter did not agree. Many comments related to the complexity of the 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.

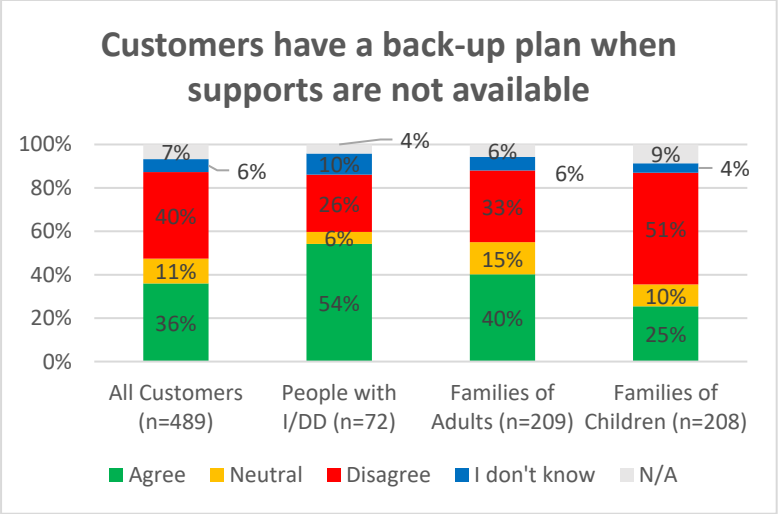
Few commenters or participants in the focus groups and other discussions addressed issues related to abuse and neglect. Residential providers talked about inconsistency across the state, "Each county seems to have a different interpretation of abuse investigations. We worry about different issues in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

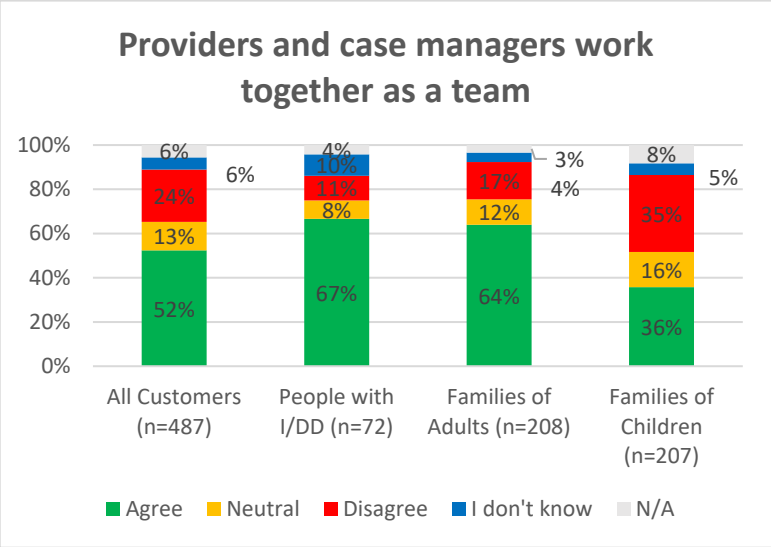
Case management entities have varying policies related to after-hours contacts, and the role of case managers in assisting with unanticipated gaps in supports and services. Some CMEs ensure that outgoing messages include emergency contact information, others offer cell phone numbers for urgent matters. 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.



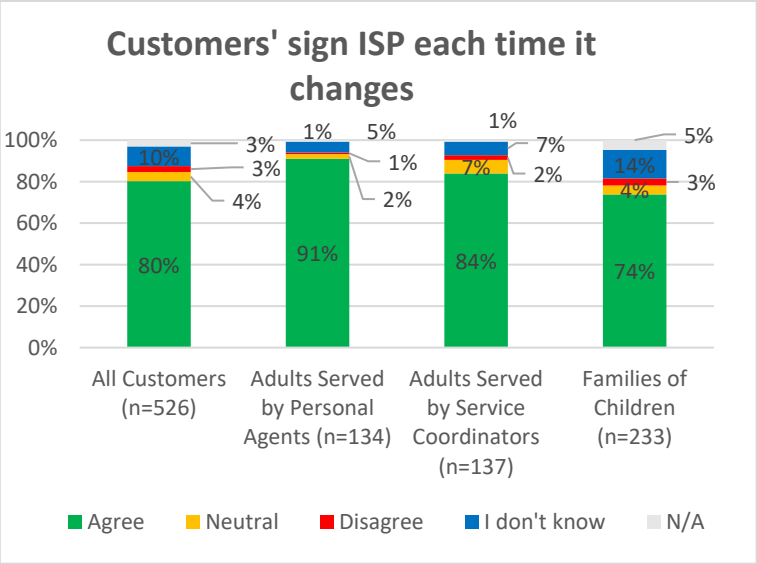
Many providers articulated strong opinions as well. They talked of inconsistencies across counties, and between CDDPs and brokerages. Typical of many comments, one provider put it this way, "I have worked collaboratively with some amazing case managers. I also have a lot of experience with case managers 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."

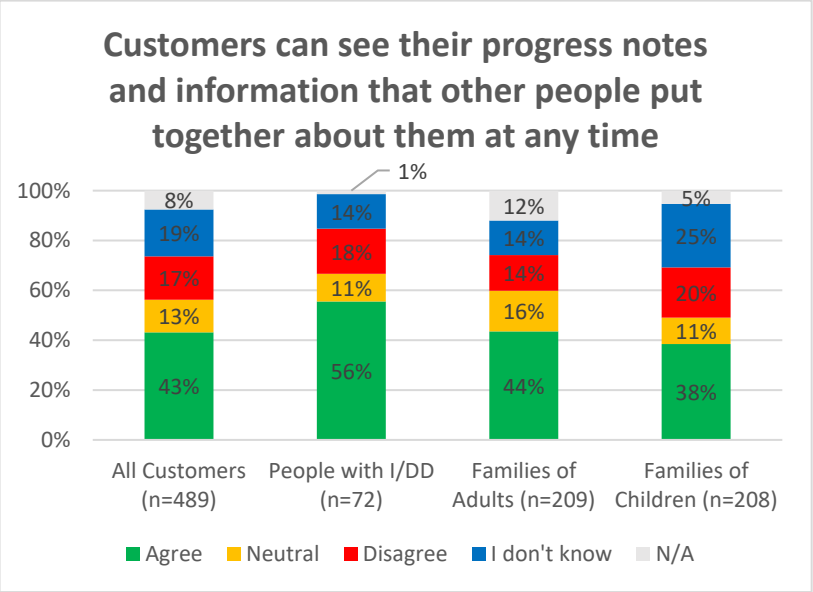
A focus group of adults with I/DD put the importance of teamwork this way: "Case managers should make sure everyone working with you is on the same page. It is really hard when they are not."

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.



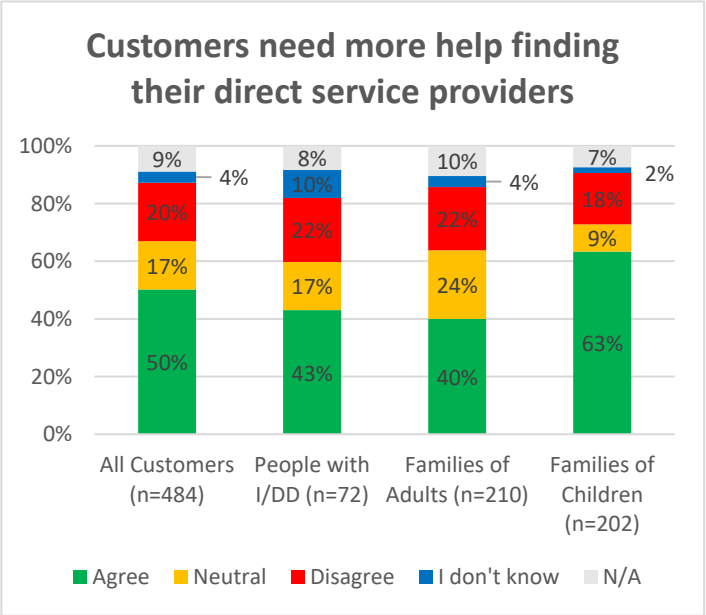
Several people commented on information-sharing, privacy issues and concerns, and how different entities are managing this. In the survey, fewer than half of respondents indicated they can see their progress notes and personal records at any time. At the same time, three quarters of people expressed 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

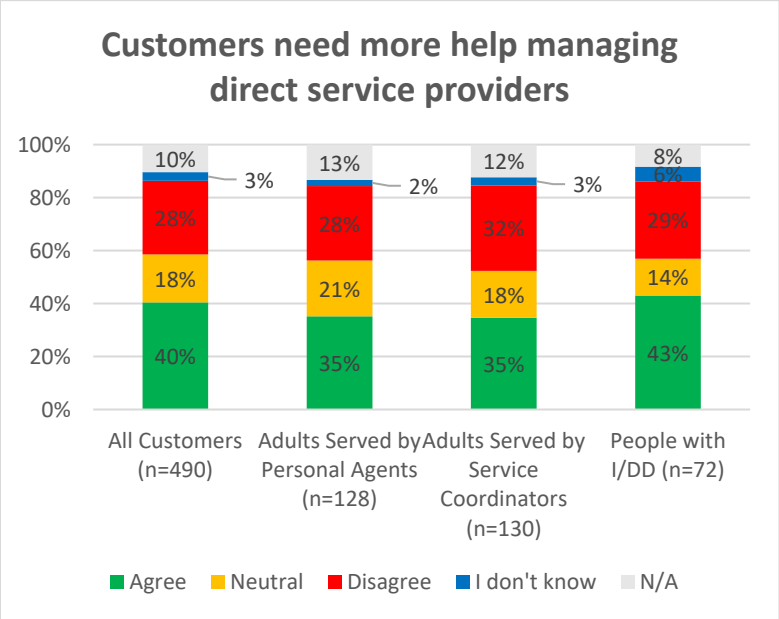
workers is too complicated and lengthy. More support and help in this area is needed" is a statement consistent with many comments.

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."



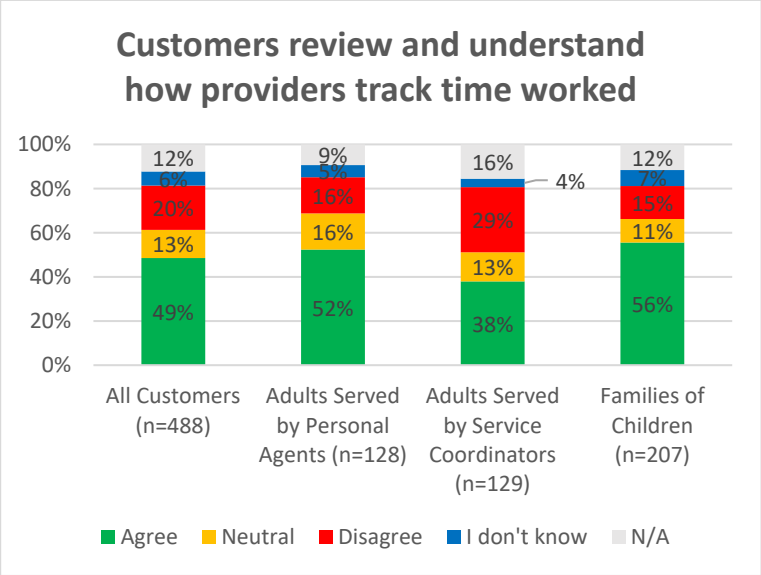
Other families talked about how they would like to see a culture of openness and information sharing with the case manager about provider issues, "they need to know what the workers are doing," and see improved communication between case managers, families, people receiving supports and providers as 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 <u>live someplace else</u>, 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 <u>work (or change jobs)</u>, 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 <u>learn something new</u>, 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 in person 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
   - ☐ Chinese
   - ☐ Portuguese
   - ☐ Russian
   - ☐ Korean
   - ☐ Prefer not to say
   - ☐ Another language (please specify). _____

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?