

2015 Annual Public Feedback Forum Series

Outcomes

September – December 2015

Forum Collaborators:

Maine Developmental Services Oversight & Advisory Board
Volunteer Correspondent Program of Maine
Maine Parent Federation
U Maine Center for Community Inclusion & Disability Studies
Speaking Up for Us
Maine Developmental Disabilities Council

Public Feedback Forum Series 2015 Outcomes

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Public Feedback Forum 2015

Executive Summary

The Public Feedback Forum Series gathered input about Maine services for adults with intellectual disabilities or autism from September to December 2015. Information was gathered from **151 individuals** who receive services from OADS (or who are on the waiting list), **67 family members** and allies, and **149 DSPs, CCMs, or administrator/other providers**.

Public Feedback Forum 2015 collaborators include Maine Developmental Services Oversight & Advisory Board (MDSOAB), Volunteer Correspondent Program of Maine (VCP Maine), Maine Parent Federation (MPF), U Maine Center for Community Inclusion and Disability Studies (CCIDS), Speaking Up for Us (SUFU), and Maine Developmental Disabilities Council (Maine DDC)

Forums were held in Houlton, Biddeford, Norway, and Brunswick. Online surveys were developed for individuals who use OADS services¹, family members/guardians/allies, and community service providers. People who wanted assistance completing a survey called the Maine Parent Federation's toll-free number or requested assistance at forum events and the SUFU Conference.

Information was sorted into topic areas and analyzed for common themes. This report is an overview of the forum series outcomes. Section 1 features services provided by OADS, including communication with OADS, Adult Protective Services, Crisis Services, and Guardianship (both public and private). Section 2 outlines Case Management, and Section 3 presents Futures Planning: the PCP, the SIS, and Transition. Section 4 outlines Working and Finding Work; and Section 5 is about Transportation. Section 6 contains Conclusions and Recommendations.

1. Communication with Department

- **Individuals** report difficulty understanding information from OADS.
- **Family members and allies** find the DHHS website difficult to navigate. When asked about their satisfaction with information from OADS about changes in their family member's services, they were (in descending order) neutral, satisfied/very satisfied, or dissatisfied/very dissatisfied. Families moving to Maine from other states had a difficult time getting any information from DHHS about services, and one reported that DHHS lost all the documentation sent about her son.
- A majority of **Providers** report difficulty communicating with OADS. The top three barriers identified were (in descending order) "messages are not shared uniformly across interested parties" (nearly 60%), "contact person does not return call or e-mail" (54%), and "official response or directive conflicts with each other or with prior directive" (47.1%).

Department Services

"Department Services" are defined for the purpose of this document as those provided by the Department directly to individuals. We focus on Adult Protective Services (APS), Crisis Services, and Guardianship in this section; case management is reported in a subsequent section.

A. Adult Protective Services (APS)

¹ | Surveys available upon request to mainedsoab@gmail.com, or by calling 622-5370.

There are two types of APS: one focuses on people who are elderly, and the other, which is the topic of this report, focuses on adults with intellectual/developmental disabilities and ASD.

Neither *individuals* who use OADS services nor their *family members and allies* had comments about APS.

More providers agreed than disagreed that APS, when they respond at all, responds to issues of concern in a timely manner, and that APS investigations are helpful to them in their work (case managers, direct support professionals, and administrators were included in this survey). The following issues were identified:

- ***APS is not helpful*** (13 comments) Inconsistencies in procedures across districts, lack of effective intervention, and less smooth functioning than in previous years were all identified.
- ***Decision to ignore statute and no longer share written reports is unhelpful/dangerous*** (12 comments)
- ***Overburdened system*** (7 comments) Specifically, a need for more investigators was noted.
- ***Lack of collaboration across districts*** (4 comments)

B. Crisis Services

As noted in the 2014 Public Feedback Forum Report, Crisis Services continues to be under-resourced and under-staffed. As one commenter wrote, "***Crisis Services is in crisis!***" (survey comment). Of the 6 discrete types of crisis responses named in statute, the team's ability to offer all 6 types differs across regions in the state.

Of the people commenting on Crisis Services, a slight majority reported difficulty getting Crisis team assistance in a timely manner. A majority believed the current Crisis Service capacity does not meet the needs of the system. Given that Crisis Services has never been staffed at the level identified in the 1995 Community Consent Decree, yet the number of individuals with disabilities living in the community has increased significantly over the past 21 years, this is not surprising.

The 29 comments about Crisis Services fell into two general categories:

- ***Not enough resources (crisis beds and staff)*** (N=13)
- ***Communication is poor (long response times, and issues with call-in number)*** (N=12)

The remaining commenters noted a lack of consistency across districts, and suggested that both crisis workers and case managers be trained to work with people with dual diagnoses (mental illness and intellectual disability).

C. Guardianship

A majority of individuals attending forum events and responding to survey questions have either private or public guardians. Of those who have a guardian, half report that they would like to "be my own guardian" some day. Most did not know about ***Supported Decision Making*** as an option, and nearly all had an interest in learning more. Without a guardian, individuals believed they would have control of their own finances, be able to go places without staff supervision, be

able to assume responsibility for their own lives, and, in the words of one person, ... **to have my own future.**

Family members noted that there were no systemic alternatives (other than full guardianship) offered when their family member reached the age of majority. They wanted information and training about alternatives to guardianship like Supported Decision Making.

Providers discussed guardians who are uninvolved in the lives of their wards. They would like trainings about guardianship. Providers and family members were concerned about the conflict of interest arising from the Department serving as guardian for wards of the state. In theory, the state is the guardian. In practice, the case manager represents the state. The individual has little recourse if he or she disagrees with the case manager's decisions, and cannot change case managers like those with private or no guardians can do. The funding agency has ultimate decision-making power in determining the individual's services.

2. Case Management

Individuals continue to have positive regard for their case managers. Case managers have become the primary, if not only, source for information about current and available services, changes, and other systemic topics.

Case managers report feeling overwhelmed by increased responsibilities added to case management. Some believe they no longer offer quality case management. The added pre-meeting meetings and complicated documentation of the current PCP process results in more running around, and less actual planning, than with the previous protocol. Updating EIS and other documentation, which cannot be accomplished while on the road over an unsecured connection, results in either taking work home every night or neglecting documentation entirely.

3. Future Planning

A. Maine's Person-Centered Planning

Most individuals attend at least part of their PCP meetings. They, family members, and providers think the current PCP process is less person-centered than before and stifles the team's creative process.

B. Supports Intensity Scale

Again, all three populations reported dissatisfaction with, and objection to, the current SIS Interview/Rate Setting Package model. There was inconsistency across interviewers. While the SIS yields useful information, many guardians and providers report that the associated rate package is much less than the individual currently receives. Overall, they believe that implementation of this model will result in less individualization of services and less meaningful community inclusion than currently exists.

C. Transition

Families moving to Maine from other states report being unable to get answers or assistance from DHHS personnel. One mother reported sending all her son's records, which were lost by OADS. Another family reported no success in identifying someone to address their questions and concerns.

4. Working and Finding Work

Individuals continue to prefer work over other activities. Despite this, they report difficulty getting help to find or keep a job, other than from family members and case managers.

A. Vocational Rehabilitation

Vocational Rehabilitation, or Voc Rehab, did not yield a single positive comment from individuals, guardians, or providers at any level. The service was identified as very slow, unresponsive to the desires of the individual, lacking in appropriate aspirations for individuals, and difficult to work with. Cases are often closed before the individual has secured employment.

B. Employment Specialists

Employment Specialists help the individual learn job tasks, and support them onsite. There were questions about the level and kinds of training these specialists receive. Case managers have difficulty getting employment specialists to respond to online "vendor calls" for services.

C. Career Planning

There appear to be too few resources for this new service. Some people had questions about how Career Planners fit into the employment support system.

5. Transportation

Like Voc Rehab, Transportation was a topic everyone seemed to agree upon: it is terrible.

Individuals report drivers who arrive early, late, or not at all; or who drive too fast, smoke, swear, yell at them, and have questionable hygiene, or who "scare the bejeezus out of me!" They report being stuffed into small cars without adequate room, or missing appointments because no accessible vehicle was available the day of the appointment although it was requested. Some people have lost jobs or day program hours because of consistently inconsistent transportation.

Guardians and family members report rude brokers or contractors, lack of consistent or safe drivers, and an unresponsive complaint process. They identified an unequal process: individuals cannot be late or miss a ride more than twice or they are denied services; but there appear to be no consequences (accountability) for transportation brokers or contractors.

Case managers and providers worry about individuals losing medical specialists, being left alone up to an hour early at a facility or picked up more than an hour late, delivered to the wrong location, driving with people who are smoking and talking on cell phones (both prohibited), and engaging in all kinds of unsafe behavior. Many providers have re-assumed transporting their clients out of fear for their safety. Although the transportation regulations identify requirements for brokers and transportation contractors, there appears to be little to no attention given to them.

6. Conclusions and Recommendations

There are key issues and recommendations for each area identified above. Please refer to pages 42-46 for recommendations.

Public Feedback Forum 2015

Outcomes

This report is the result of an information-gathering effort by six collaborators from September to December of 2015. The purpose of the Public Feedback Forum Series was to gather input about Maine services for adults with intellectual disabilities or autism. Information was gathered from individuals who receive services, family members, guardians, and allies, and service providers, including case managers, administrators, and direct support professionals (DSPs).

Public Feedback Forum 2015 collaborators include

- Maine Developmental Services Oversight & Advisory Board (MDSOAB)
- Volunteer Correspondent Program of Maine (VCP Maine)
- Maine Parent Federation (MPF)
- U Maine Center for Community Inclusion and Disability Studies (CCIDS)
- Speaking Up for Us (SUFU)
- Maine Developmental Disabilities Council (Maine DDC)

A series of public feedback forums were held in Houlton, Biddeford, Norway, and Brunswick, and three additional case manager mini-forums were held during information sessions with CCMs. The forum series collaborators focus on regions in a three-year cycle and this was the second cycle group. Speaking Up for Us (SUFU) invited collaborators to attend the SUFU Annual Conference to gather information from self-advocates.

Online surveys were developed for individuals who use OADS services², family members/guardians/allies, and community service providers. Surveys were available statewide and those wanting assistance completing a survey called the Maine Parent Federation's toll-free number or requested assistance at forum events and the SUFU Conference. Each survey group responded to questions written specifically for them, although some topics appeared on all three surveys. Forums were intended to be open-ended, and prompt questions were available if needed to start the dialogue. There was at least one note-taker at each forum who captured both the general discussion and as many individual quotes as possible.

Information was sorted into topic areas and analyzed for common themes. This report is an overview of the forum series outcomes. Section 1 features services provided by OADS, including communication with OADS, Adult Protective Services, and Crisis Services, and Guardianship (both public and private). Section 2 presents Futures Planning: the PCP, the SIS, and Transition. Section 3 outlines Working and Finding Work; and Section 4 is about Transportation.

Measures of satisfaction with services for individuals and guardians and, for providers, questions about various roles were gathered via surveys but will not be presented here.

² Survey raw data available upon request to mainedsoab@gmail.com, or by calling 622-5370.

Survey and Forum Participants

We gathered feedback from **151 individuals** who receive services from OADS (or who are on the waiting list), **67 family members** and allies, and **149 DSPs, CCMs, or administrator/other providers**.

Individuals who completed surveys (**N= 82**) range in age from 18 to 66+ years. Most survey participants were between the ages of 30 and 65. Counties represented in the survey include Cumberland (19), Penobscot (22), York (18), and Aroostook (8). There were 3 respondents from Waldo and Sagadahoc, 2 from Kennebec, and 1 from Hancock, Lincoln, Piscataquis, Somerset, and Washington counties. Two did not know in which county he or she lived. A majority of survey respondents have a guardian for everything (52%) or for some things (9%).

Individuals attended forums at the following locations:

Norway: 10

Biddeford: 7

Brunswick (3 sessions): 39

Houlton: 13

Total = 69

Family Members and Allies completing surveys (**N= 46**) included 25 parents, 12 guardians, 4 volunteer correspondents, 2 siblings, 2 other family members, and 1 friend. Twenty-eight were associated with an individual aged 31-63, 12 with someone between 20 and 30 who receives services, 3 were associated with someone over age 63, one with someone older than 20 and not receiving services, and 2 with youth in transition. All counties were represented.

Family members and allies attended forums at the following locations:

Norway: 0

Biddeford: 3

Brunswick: 13

Houlton: 5

Total: 21

Providers completing surveys (**N=90**) included 19 DSPs, 5 CCMs, 1 ISC, 54 administrators or supervisors, and 11 provider/others. Every county in Maine was represented. More than 60% of the CCMs, 63% of the DSPs, and 75% of the administrator/supervisors have been in their position more than five years.

Providers were represented at the forums in the following numbers:

Norway: 13 (7 CCMs, 5 shared living providers, and 1 director)

Biddeford: 10

Brunswick: 18 (6 DSPs, 2 CCMs, and 6 administrators/others)

Houlton: 18 (10 DSPs, 2 CCMs, and 6 administrators)

Total: 59

Communication with OADS, DHHS

The Office of Aging and Disability Services (OADS) continues to take steps to improve communication with the individuals they serve, their families, and those in service provision. While somewhat better than before, communication remains in need of improvement. Timeliness of responses, clarity of information, consistency of responses across people, across regions, and across databases and websites, and inefficiency within offices that often result in a loss of services for the client, are all areas in need of attention and improvement. Clear, consistent, timely, easy-to access information that is developed WITH, not FOR, stakeholders could help the Department address these problems in communication. There are a number of organizations available and willing to assist- to date, however, this has not been utilized.

When I get a letter from the state, can't understand it. (individual, Norway forum)

Individuals who use OADS services overwhelmingly reported difficulty understanding information received from "the state," as many call it. They reported a mismatch between their reading level and the language level in the information and, for those with Internet access, *not a single person* reported that they could find answers or understand information on the OADS website. All 16 individual participants at one forum raised their hands when asked "Who needs help understanding what the state is trying to tell you [by mail]?"

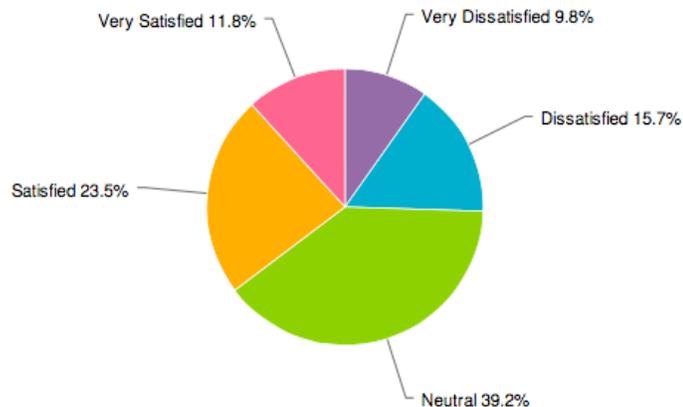
Sometimes I get mail from the state, I don't get it very often and I can't read very good so it is hard to understand. I would like to understand it. (individual, Brunswick forum)

I find navigating state services to be very time consuming...(family member, survey)

Family members reported their experiences seeking and receiving information from DHHS/OADS, and three families attending the Brunswick evening forum spoke about seeking information about Maine services for adults with ID/DD/ASD before moving to the state.

Family members who were asked to rate their satisfaction with information received from and their communication with OADS about their family member's services were mostly neutral (n=46):

44. How satisfied are you with the amount of information you receive from OADS about changes in your family member's, ward's or friend's current services, or new services?



One family member made the following comment after contacting the state:

I have, on occasion, been talked to in a demeaning manner. I do feel that those who work in public services should have skills to work with people who have many questions and are willing to be helpful... (survey response)

Transitioning to Maine: The three families who moved back to Maine each reported great difficulty getting information about Maine services for their adult children prior to moving, and reported the following:

Maine was very slow processing things. Before I moved, called DHHS. I sent them all the medical records. When I moved, they didn't have any of his records. I had to redo everything....(family member, Brunswick)

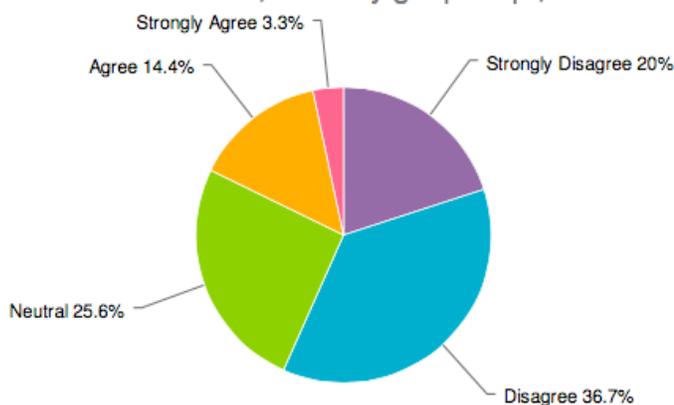
We moved ... to Maine 16 months ago. My son moved here a year ago. He lived on his own with supports for the past 11 years. It's taken so long to get booked with anything with the state (9 months, and he still doesn't have services)... Our son is driving us crazy, he's 34 years old had lived on his own, we have different ideas of how to live in a place. (member of different family, Brunswick)

The family from whom the second quote came spent the months before moving back to Maine trying to contact someone at OADS who could give them information, and were not able to connect with any knowledgeable staff.

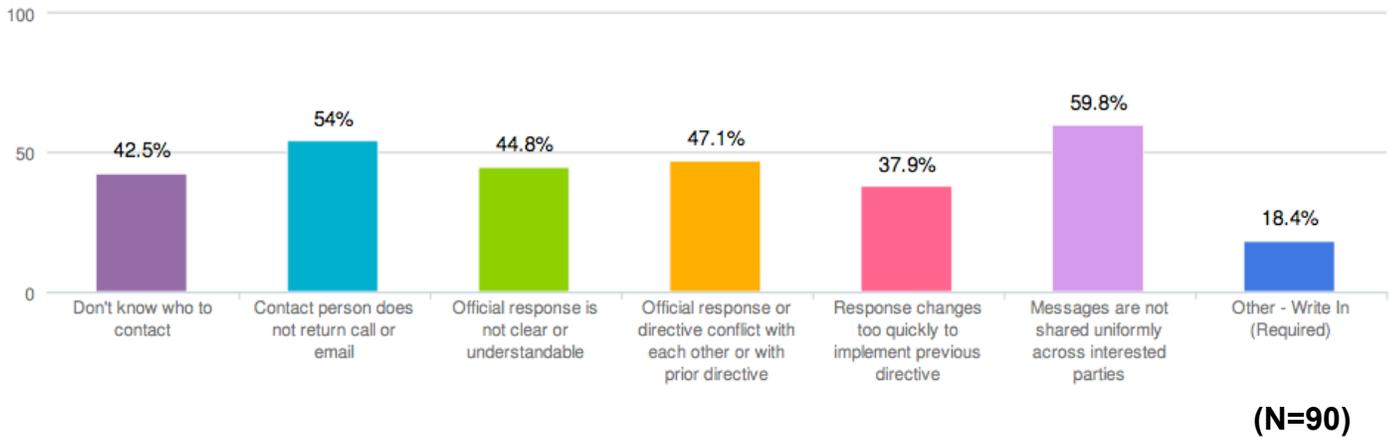
Cannot move forward without answers...(survey response)

Providers at all levels (direct support, case managers, and administrators) also reported having difficulty communicating with the Department, although this area appears to be improving. When compared to the 2014 survey responses, slightly more 2015 respondents agreed than disagreed with the following statement (N=90):

65. When I have questions about services or rules, I usually get prompt, clear answers from the Department.



66. What are the barriers to prompt, ongoing communication with the Department and its representatives?



When asked to identify barriers in their own words, survey and forum respondents report:

1. Information is not being disseminated in enough time to be useful or is not updated often enough to be useful (27 comments)

*For example, we got notification for a training the day **after** the training, because [notifications] get passed through so many people before they get to us. (case manager, survey response)*

The Maine.gov website isn't accurate. [AGENCY] hasn't had work supports for 10 years. It's out of date and inaccurate. If case managers aren't familiar, they look online. If the site doesn't have accurate information, it is a big deal. (case manager, forum)

2. Information is inconsistent and contradictory across offices, regions, staff members... "mixed messages" (22 comments)

No one has the ability to approve anything, everyone has to check with everyone else before making a decision... (direct support professional, online survey)

Waste time following a process, to be told that I need to follow a different process... (administrator, survey)

3. They do not know who to call, which slows down the process (15)

I spend a lot of time chasing down the right person for the right answer and often feel like a 2 hour chase could have been handled in 2 minutes ... (case manager, survey)

The process of getting changes made to EIS is unknown to most and knowing who to contact in regards to changes in service location or EIS is difficult and when you contact the wrong resource coordinator- oh, don't they get mad, but the first one doesn't direct you to the other one... (provider, survey)

4. Calls are not answered, or not returned (14)

Our local DHHS region is HIGHLY responsive. Have found that central offices OADS does not respond to emails or phone calls...(provider, survey)

"When Community Case Managers call MaineCare, we're on hold for about an hour. If they can't talk, when there's not a rep available, then we don't get a call back. We just pray when we do get someone that it's not a new person or someone who is not trained, or it's a long process because we have to start all over again (provider, survey)

5. Too many changes in Central Office, workers are spread too thin (13)

We call, but get put on hold, "we're extremely busy right now"...the phone numbers are useless...they don't have enough people working there...(case manager, forum)

Too many people changing roles and positions not filled... The depth of institutional knowledge is very thin. (administrator, survey)

6. Inconsistency between OADS and MaineCare (11)

MaineCare reviews are an issue. We serve people who lost funding because they didn't complete the review... which was because the review was never sent! We go round and round about this on the phone, which takes lots of valuable time... (administrator, survey)

*There are different databases for food stamps and MaineCare or whatever, and they must change the information in **each** database. If it doesn't get changed in one of them, it can create a huge issue. (CCM, forum)*

7. No collaboration; directives are made but no input is sought (7)

I feel like no input is getting asked, they just hand out a position [rule, protocol] and we deal with it. I think there should be more input while they're developing things" (SLP, forum)

... the State's inability to maintain consistency, transparency and involve providers in decision making when appropriate [is a barrier to service provision]..." (administrator, survey)

8. Not enough direct or appropriate communication with individuals (6)

Our belief is that the general public can operate a computer or perhaps read is contradiction to the reality of client's ability, some cannot read at all. (DSP, Biddeford forum)

9. Too many changes are happening, and too quickly (6)

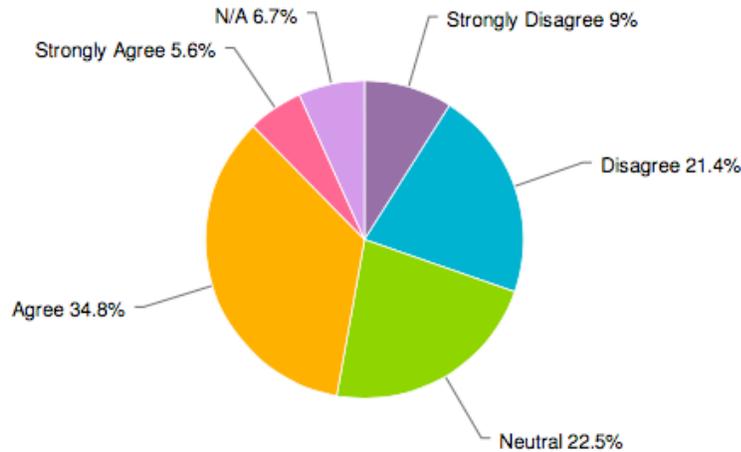
Making decisions based on inconsistent and ever changing messages is a significant challenge... (administrator, survey)

Adult Protective Services, Crisis Services

Individuals and family members were not asked via the survey did not offer comments at forums about Adult Protective Services (APS) or Crisis Services. Service providers, who have the most contact with both offices, had much to share about both.

Adult Protective Services

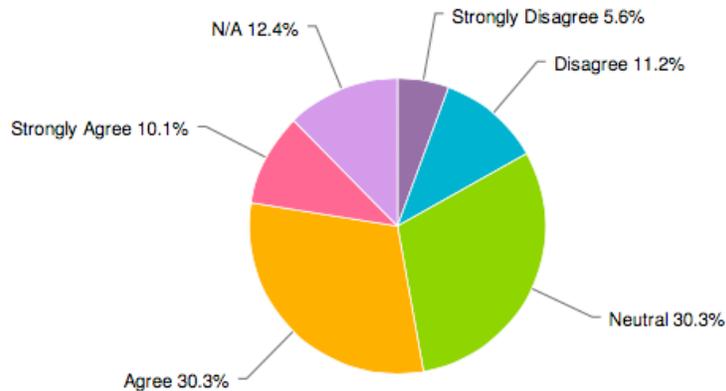
(APS) responds to issues of concern in a timely manner.



N=89

Of the 89 service providers who responded to the statement "APS responds to issues of concern in a timely manner," 40.4% agreed or strongly agreed, 22.5% were neutral, and 29.4% disagreed or strongly disagreed. When asked if APS investigation results were helpful to their work, the results were as follows (**N=89**):

APS investigation results are helpful to me in my position.



There were at least forty individual comments to the question "What else would you like to say about APS?" These comments fell into the five broad categories below.

APS is helpful (6 comments)

There were two APS workers named as "wonderful" and "great to work with" (Z.K. and J.O., respectively), and there were 4 positive comments about their services that echoed this respondent:

Although rare, our interactions with APS have been professional and productive...

APS is not helpful (13 comments)

The most frequently expressed concern noted that APS appears inconsistent in its responses across districts, not helpful, or "less functional than before."

Each APS worker follows their own set of rules, so nothing is steady across the board. One sees a client as needing services and another would come in and say they have seen worse and that this person doesn't currently need the services...

They really don't have much teeth. I've see clients in near abuse or substandard living conditions continue in those situations even after APS is called ...

The results [written reports] would be helpful if we received them... (12 comments)

Although sharing reports (with some exceptions) is permitted in rule, during the past year APS consistently declined to share written investigation reports with providers. This is viewed as unhelpful at best, and dangerous at worst.

Most critically, the [APS] rules have not been changed to reflect current practice of the department, and this is not conducive to the interests of consumers...

I feel that the new process makes it much easier for a bad apple to jump from one agency to another. I think this system puts individuals at risk...

The APS system appears to be overburdened...(7 comments)

Some people noted that there seem to be too many cases and too few investigators.

You need more people in this area to ensure they [investigations] are completed in a timely manner. Three weeks to a month out in too long. As well as not talking to all the parties involved...

Lack of collaboration across offices (4 comments)

One administrator expressed concern that the Department doesn't adequately follow up on APS investigations, which reflects less on the APS Office itself and more on its supervisory entity. In a similar vein, one CCM expressed frustration about a lack of coordination between APS and Crisis Services:

What level crisis does it take to get services? I have a fellow who's following through the cracks, been in crisis after crisis...Crisis [Services] has contacted APS, they have not responded. They say he's his own guardian...(provider, Biddeford forum)

Crisis Services: Crisis services need help to respond to the community need ... (survey comment)

OADS Developmental Services, in 34-B Chapter 5 Sec. 5206, is directed to 1. ...***maintain the capacity to intervene in personal crises that could lead to the loss of the home, program or employment of a person with an intellectual disability or autism.***

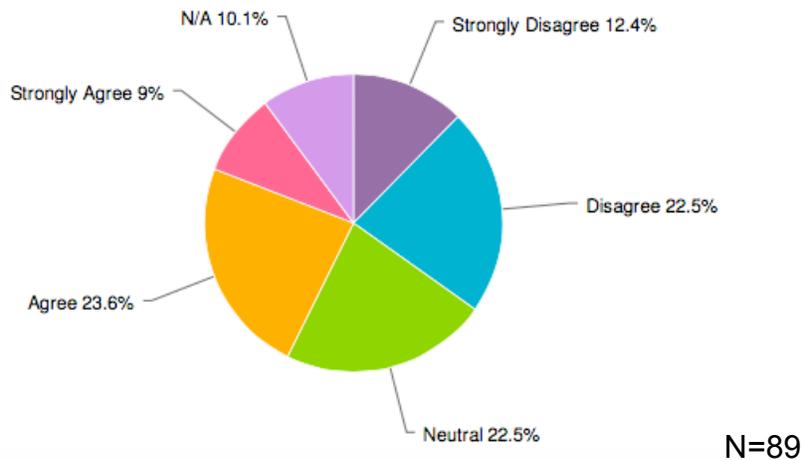
At present, there are 4 Crisis Supervisors and 44 Crisis staff. There are two crisis beds each in

four regions of the state for a total of 8 beds staffed by OADS Crisis workers. Crisis workers respond to calls about individuals on the wait lists in addition to those currently receiving services.

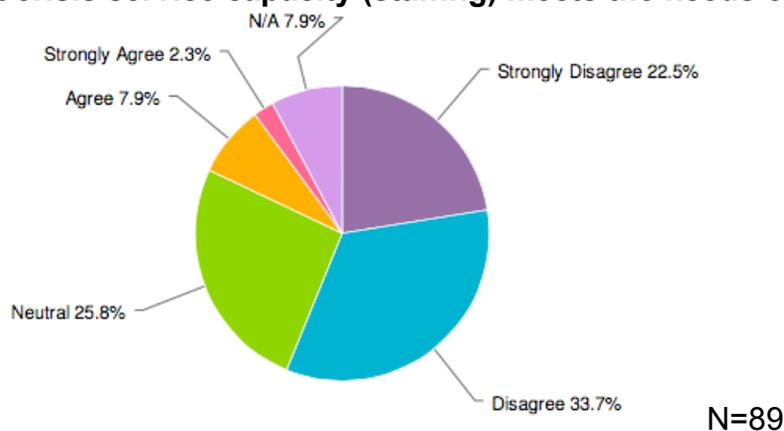
The Community Consent Decree negotiation in 1995 established the parameters of Crisis Prevention and Intervention Services. It called for no less than 12 crisis beds statewide. At the time, there were at least as many people living in Pineland as were living in the community. ***The number of crisis workers has not increased at the same rate as the increase in people being served- especially when considering those on the wait lists.***

This year's view of Crisis Services looks very similar to responses from the 2014 Public Feedback Forum. Of the 89 providers who responded, more disagreed than agreed with the statement,

It is easy for me to get assistance from the Crisis Team System when needed.



More providers disagreed than agreed with the following statement about staffing of Crisis Services: **The current crisis service capacity (staffing) meets the needs of the system.**



When questioned about their familiarity with Crisis Service offerings, a majority knew about phone support, crisis residence, and transitional/emergency housing and respite. They were less familiar with the proactive services offered by Crisis Services.

Value	Percent		Count
Prevention Services	40.7%		35
Crisis Telephone Services	93.0%		80
Mobile Crisis Outreach Services	51.2%		44
In-home Crisis Services	50.0%		43
Crisis Residential Services	72.1%		62
Transitional/Emergency Housing and Respite	60.5%		52
	Total		86

There were 29 comments made about Crisis Services, and these fell into two broad categories: **Not enough resources (N=13)**, and **communication issues (N=12)**. Four comments did not fit into either category.

Resources: Not enough crisis beds, or staff...(DSP, survey comment)

As noted earlier, Crisis Services has never been staffed to the level recommended 21 years ago, when there were far fewer people living in the community. It is not surprising, then, that staff members relying on this service believe it is under-resourced. There were 7 comments that are nearly identical to the heading of this section. Other comments include:

There are too few crisis workers covering a huge area. They can't respond in person, and the home ends up calling the police because they needed help. It's almost understood that [because this home is rural] there is no point in calling crisis. The police will bring the individual to the hospital.

Should be more options than to send people to the local Emergency Room hospital. We support a person in Bangor who needed housing in a crisis situation and only options available for her were Augusta or Houlton. Neither was acceptable...

Communication: When I call crisis, they take a long time to get back ... (provider, Norway)

Communication with Crisis Services continues to be an issue. Survey respondents cited the long wait for a return call (N=5), difficulty getting through on the general Crisis line (N=4), and the need for three different crisis numbers: aging, mental health, and intellectual disability (N=3). Comments include:

If they get a call back, it's late enough that case managers have found a different avenue...

There should be one crisis number for aging, one for mental health, and one for intellectual and developmental disability. It is challenging for the caller to find the right placement. They can end up talking to the wrong people if they don't say the right thing to the operator...

You don't want to hear you have the wrong number when you're in crisis. Some [people] are intimidated, and when they hit a roadblock, they won't call again.

Two of the remaining comments mentioned training: one person asked if crisis workers could be dually trained in MH/ID crisis management, and the other noted the need for case managers to be oriented to crisis: *The more training for case managers, the better for the clients.* The remaining comments noted a lack of consistency across regions: *"There is absolutely **no consistency.** What happens depends on the regional coordinator."*

Emergency Room Use

Several community case managers commented on the frequent use of hospital emergency rooms instead of crisis services. One person noted a need for emergency staff

to be engaged to learn about the specific needs of I/DD population and how to seek out support from local DS service providers. (provider, survey comment)

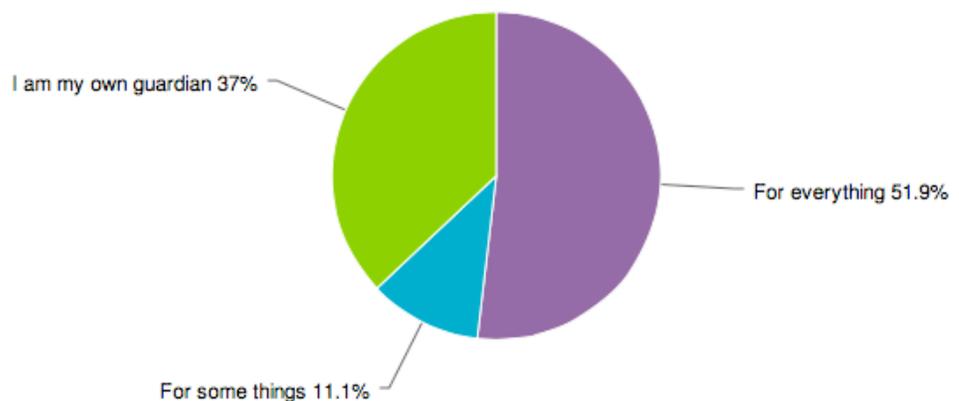
One person was critical of how some homes seem to use the emergency room:

Some homes [that] receive state funding are using the emergency room for respite. One home was using the ER and police to compensate because they didn't have funds to hire extra staff. If they had two [staff] people on for two of the three people in the home, police would be called for problems while they tried to get another staff person there. There have been lots of problems! (case manager, survey comment)

Guardianship

For many adults with developmental disabilities, being under guardianship of others is a way of life. Of the 81 individuals using services who responded to guardianship questions on the survey, more than half have a guardian (either private or public- the survey did not differentiate):

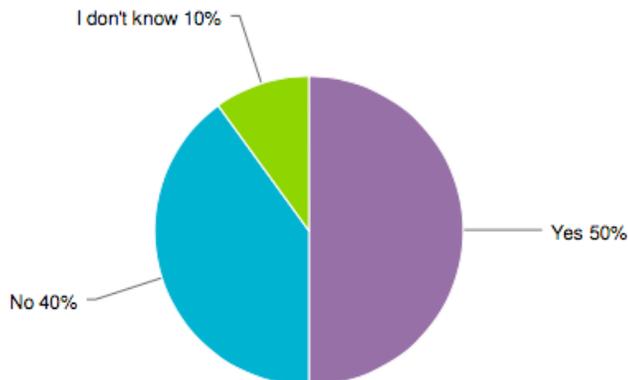
Do you have a guardian?



Forum respondents also seemed to include more people with than without a guardian.

At least half the survey respondents and more than half the forum participants currently under guardianship wished to become his or her own guardian:

Do you want to be your own guardian some day?



Of the individuals who attended the forums, one individual in Houlton said she wanted a guardian (she specifically named Karen Mason), and at least 43 mentioned wanting to be his or her own guardian (three had recently petitioned for and won guardianship). Some of the reasons people noted for this included

I'd like to know my own money situation, open my own bank account, be in control of my own money. (individual, Brunswick)

Walk to the park, to the post office. I have to do it with staff and be supervised (consumer, Biddeford)

I'd like to pay the bills, the house...(you'd like to have responsibilities)- yah. (individual, Brunswick)

I would like to have my own future... (individual, Biddeford)

Family members, while not asked about guardianship on the survey, spoke about the topic at forums, and a few commented on the survey. Family members would like to have information about alternatives to guardianship, and believed that parents should be included in trainings about things like supported decision-making.

Parents spoke of feeling pressured into seeking guardianship when their child turned 18, and said that nobody spoke with them about possible alternatives to full guardianship:

...the system didn't offer anything else," noted a Biddeford forum participant.

One family member who is guardian for his/her family member commented about the lack of meaningful options:

I strongly feel that state guardianship isn't in the best interest of consumers and feel that there should be other options available for consumers... (survey response)

One parent noted that guardianship should be approached as a systemic issue rather than an individual question:

I think the issue is to challenge the whole system, it shouldn't be either/or, doesn't translate that the family member has to be it....the state doesn't want to seem to look at the whole system (family member, Biddeford)

Providers spoke about guardians who weren't involved in the person's life, some guardians who were too involved in the person's life, and were particularly concerned about guardianship when the guardian is an aging family member. One provider explained,

There was a situation, when the father passed away, the individual [with a disability] got everything, so the family sought becoming the guardian. The family believes that as soon as that individual passes, they'll be able to get the money. It is not a therapeutic household.... (provider, Biddeford)

They, like family members, were concerned about the ethics of the state being guardian:

If someone has state guardian, that person has too much influence. It is a huge conflict of interest. (survey response)

Since the Individual Service Coordinator functions as the representative for the state, and the state is also the employer of the ISC, there is an inherent conflict of interest when the individual wants the ISC to advocate for changes in services. Technically the ISC is not the guardian, but in practice they make the same decisions as a private guardian. This relationship is particularly problematic in light of the proposed SIS/rate setting model:

We see a real serious problem with the state being guardian, particularly with the new SIS, the gigantic conflict of interest with assessments, making decisions. How does that status transfer to the caseworker? (provider, Biddeford)

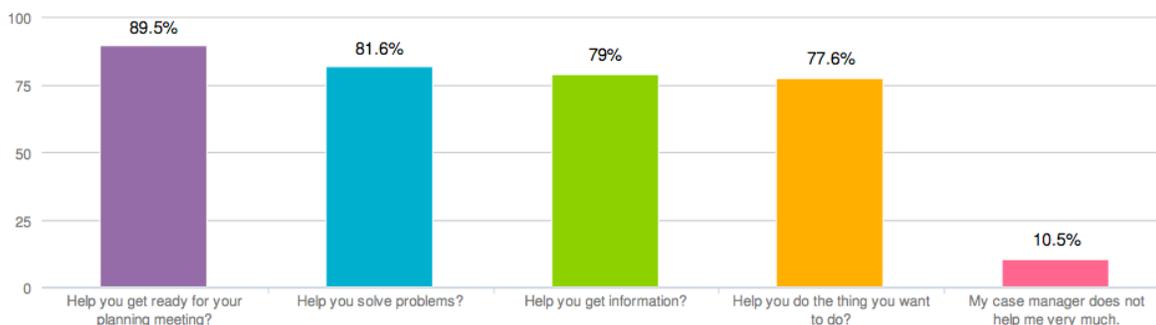
Individuals, family members/allies, and providers all identified a need for guardianship training to be offered from a number of perspectives, including alternatives to guardianship (i.e. Supported Decision Making), how to be a guardian, and the limits of the power of the guardian.

Case Management

She Helped Me Live a Normal Life ...Online survey respondent

More than three quarters of the individuals who responded to the survey believe that his or her case manager helps them with important activities like preparing for meetings, solving problems, bringing new information, and helping him or her do desired activities.

10. Does your case manager (check all that apply):



When asked "**What is the most helpful thing your case manager did for you this year?**", responses included

1. **Help with finances** (10 comments)
2. **Help with employment and daytime activities** (5 comments for each)
3. **Help with housing** (5 comments)
4. **Going out to eat, shop, or do other community activities** (16 comments). "She went above and beyond to get me to the Northeast Roller Derby Convention", one individual said, and another said "She was right on the ball getting me to camp."

Individuals also seem to enjoy face-to-face contact with their case managers, especially if it involves going for a meal or coffee.

What would you like your case manager to help you with in the future?

Things that individuals want help with include:

1. Housing (11)

Responses ranged from moving up north to be closer to family, to moving out of the family home to an apartment of his or her own.

2. Finances (10)

Get my money quicker said one respondent, although most wanted help with budgeting and money management.

3. Special Trips and Activities (11)

Many named particular activities like taking a trip or vacation. One person wants help planning her wedding, and another said *I like to cook a lot, I'd like to find more opportunities to cook.*

4. Employment (9)

Right now I only get \$477 per month from social security, so I can't afford to live anywhere else, but I don't have a job. There are things I can do, but I spent a year working with vocational rehab and they didn't find the right thing for me...(individual, about CCM, survey comment)

5. Transportation (8)

Transportation continues to be a topic of much frustration for individuals who use brokered transportation systems. Most wanted help getting reliable transportation, while one person responded "*I would like case manager to help cancel rides because Logisticare isn't listening to clients*" (individual, survey comment)

6. Education and Reaching Goals (6)

Responses about lifelong learning included going back to class, help getting certification to be a Zumba instructor, and ... *helping get my license, get ready for my driving Test.*

I Don't Know What [Case Managers] are Supposed to Do... (individual, survey comment)

While the majority of comments about case managers were positive, 10.5% of the respondents did not find their case manager to be helpful. They noted case managers they'd never met, others who visit rarely, and some who aren't available when needed.

Comments included

1. Absent case managers (6)

I don't know who my case manager is- never comes to see me. (survey comment)

2. Slow to respond/not returning calls (5)

I would like him to respond more quickly. I had a job in the making, he made me wait almost four years, and then the job disappeared. (survey comment)

3. Unhelpful in general (5)

[Be here] when I need her to be here. (survey comment)

4. Uninvolved in the person's life

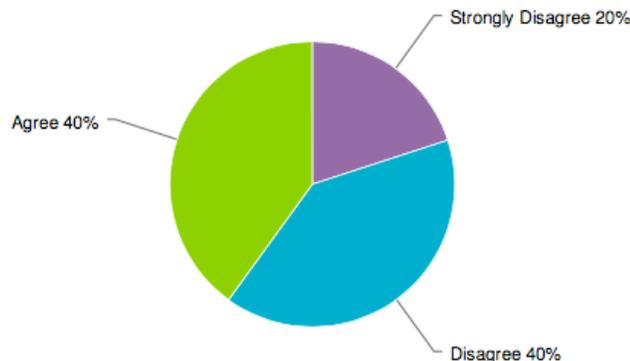
[to] Not think about their schedule, but think about MY schedule and what I want to do for making changes (emphasis in original)

We Take Our Work Home With Us... (case manager, survey response)

Family members and providers were not asked specific questions about case management on the surveys unless they were case managers themselves. Five **case managers and one ISC** responded to the survey. Case managers attended several forums and, in three locations, a separate forum was held specifically for case managers.

Most case managers/ISC reported that they spend 4 to 9 hours every week traveling to and from appointments, a timeframe for which they do not get paid. Most report having a caseload of 31-40 individuals; the only exception was the ISC, who reports having more than 50 people on his or her caseload. More case managers/ISCs strongly disagreed with a statement that their caseloads were manageable than those agreeing with the statement.

27. As a community case manager, I feel my clients have enough variety in service choices in geographic work area.



More disagreed than agreed that there is enough variety in service choices for their clients, and the same percentage disagreed that there were enough quality services in their geographic area.

A majority of the caseworkers were neutral about the relevance and helpfulness of OADS Case Manager trainings. They would like to have trainings in the following:

1. CRMA/First Aid/CPR
2. Critical thinking and conflict resolution
3. navigating unattainable resources
4. SIS/Rep Payee (in addition to current training)
5. Guardianship
6. Three Person Committee process and requirements, and
7. Writing behavioral plans.

Caseworker comments fell into these general categories:

1. **Too much paperwork, too many on caseload** (8 comments)

Reduce the paperwork [so I am] able to spend more quality time with clients. (CCM, survey)

Increased documentation without a clear purpose also increases the work load without a corresponding increase in the quality of services... (CCM, survey)

2. **Too many added responsibilities, not enough time** (5 comments)

We take our work home w/us in the evenings and on weekends and holiday, b/c we are constantly stressing about getting things done on time, doing things properly, making sure nothing is forgotten or overlooked, thinking about what takes priority and what must not get done next, worrying about how we are going to time manage our next day.... (survey comment)

...reduced responsibilities, seems like so much has been added to our plate in the past 10 years, it's become unmanageable and feels like I haven't done quality case management in a couple of years. (survey comment)

3. **Too little attention to quality of services** (5 comments)

There is no accurate reflection of the quality of services rendered and that often is a risk to the client. (survey comment)

4. **"Transportation is awful"** (4 comments)

Transportation is awful; ...a lot of agencies who won't provide services to (ie: Career planning) and transportation is spotty at best... (forum comment)

Logisticare has been so unreliable (no shows, early or late pick ups, etc). (survey comment)

5. **Too many meetings with PCP** (2 comments)

Survey statements from case managers clearly indicated that they care deeply about their clients but that they find the increased responsibilities on their plates overwhelming.

One person concluded, *...after 16 years in the field I'm considering leaving the Developmental Services field due to burn out from overwhelming pressures.*" (survey comment)

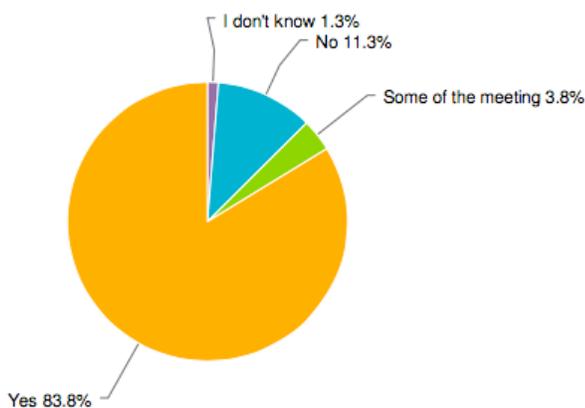
Future Planning: PCP, SIS, and Transition

Personal Planning Process (PCP)

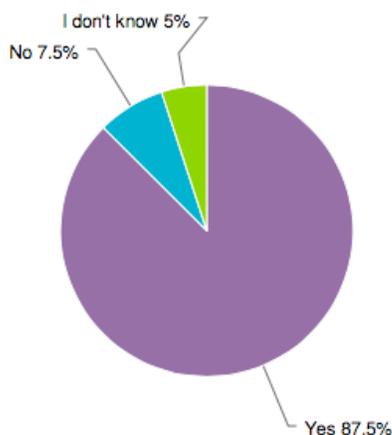
It's a personal care plan, you have goals... (individual, Brunswick forum)

We were surprised to find that many individuals attending the live forums did not know initially if they had a person-centered plan, or if they'd ever had a planning meeting. Considering that the PCP is intended to be the starting point for and the map that guides all planning, it is puzzling that so many people did not immediately recognize the process. Most of those responding to the individual online survey attend their PCP meeting, and believe that their PCP helps them get the services they want during the year:

Attend PCP (N=80)



Believe PCP helps them get services (N=80)



A few of those attending their PCP meeting report that they run their meeting *"with a little help,"* (Brunswick forum), and one person reported that she fired her case manager, got a new CCM, and she "kicked people out" of her meeting when they weren't helpful to the process:

For a long time, at meetings, they were talking very bad about me. Q: so, have you left these people off the invitation list? A: Yeah. Q: And, did it go better? A: Yes, it went a lot better, without my family member there... (Brunswick forum)

I just get nervous because I have so many people at the meeting...(Brunswick forum)

The #1 reason that individuals named as making them nervous was the number of people at the meeting. More than 80% of individuals who talked about their PCP meeting feel that other people speaking about them at the meeting create stress for them. Many said they have trouble

communicating what they want with their case manager or staff. Others didn't like the lack of privacy and respect from others:

It's stressful with staff, at the house- they drive me nuts... They just hog a lot of the time at the meeting, it's just stressful. They talk, there's too much talking. Sometimes I get to say things. They go on, and on, and talk about me... (individual, Brunswick)

...it really depends on who you really want to know what's going on with you, in your life. I don't like everybody knowing everything, going on with me. It's like DHHS wants to know every little thing... privacy is not being respected. (individual, Brunswick)

That meeting was like a war zone...

PCP meetings can also be a site where guardians, staff, or others holding power over the individual, and the individual are put in a position of publicly disagreeing with each other. One person commented

Well, from what I've noticed...the meetings usually go really well when the parents and the clients are on the same track about the future, where things are going. When they don't agree, they're not so good.

Others responded to the facilitator's follow-up comment in the following way:

(Facilitator): those of you who have guardians, do you work these things out, or do you just argue about it at the meeting?

- *Ind: we pretty much just argue about it. We always do.*
- *Ind: Yeah, the second the meeting starts, the arguing starts. Usually for PCP meetings, for clients, meetings are really stressful. If they're not on the same track, they're just yelling.*

Finally, one person made an interesting observation about the timing of her planning meetings:

...and another thing I realize, is the timing of the meeting, when they are, they are after program, and that's stressful, because I'm already tired. It's stressful.

These comments suggest that many PCP meetings have not been facilitated with the person at the center of the discussion; or, at least, there is a need for more respectful dialogue where the individual is the subject, rather than the object.

I feel that the PCP process isn't person centered at all... (survey comment)

Family members were also skeptical of the planning process. Two separate survey comments began with *"the system is supposed to be person-centered but..."*, suggesting that they have a clear idea of the person-centered process. One person went on to note seeing little change in how the meetings are conducted post-change, and the other noted

...the people who provide direct support seem to have no idea what that means. They all know how to give medication and fill out all the required paperwork. They seem to know little, though, about how to support choice and community integration. (survey comment)

Since direct support professionals do not receive much orientation to or training in person-centered thinking, this is hardly surprising.

Two service providers had guardedly positive things to say about the new Planning process:

I think it's working...I'm seeing some glitches, because...I'm seeing it to be all over the place, the way case managers are doing it (provider, Biddeford)

Other service providers, however, noted that the new process take too much of the case manager's and client's time, and lacks some of the elements of a truly person-centered planning process (9 comments):

I think the whole name, person-centered plan, and seeing how its done, it contradicts...i.e. you have to have three goals. Not everybody wants to volunteer, some people don't want to go work, some people don't want a cooking plan...but you have to have these goals. (DSP, Biddeford)

"I feel like we've gotten away from the person, each group does it separately, and it used to be, we bounced ideas off each other, and we came up with good, attainable goals. It was exciting...but now, it's so separated... (DSP, Biddeford)

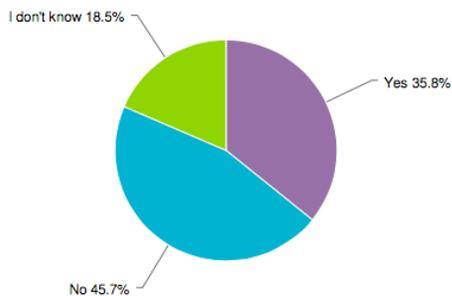
The most frequent comment about planning at forums, and appearing in survey comments, was concern about the Supports Intensity Scale Interview, the potential for reduced amounts of service, and especially for the way it appears to take precedence over the Personal Planning process:

PCP is proscribed pretty clearly in the statute, and the SIS model subverts that pretty clearly. It stands in clear contrast. There is no place for the planning team to have any say about the budget. It becomes impossible to talk about one without the other. (provider, forum comment)

The Supports Intensity Scale and Rate Setting Model

When asked "Do you know what a SIS Interview is?" more individuals responded no or I don't know than responded yes:

Do you know what a Supports Intensity Scale (SIS) interview is?



N

=81

[I found out about the SIS] **[When] I had to sit through it...** (survey comment)

Of the 20 people who could identify from whom they learned about the SIS interview, 11 reported learning about it at the actual interview. Five people learned about the SIS before the interview

from SUFU meetings, from Karen Mason at a meeting, or from other meetings; and one each reported learning from a caseworker, guardian, and a friend. One person did not remember where he or she learned about the SIS.

Individuals and family members/friends expressed both confusion about and concern with the SIS process. For individuals, they didn't understand the process, were worried about losing services and overwhelmingly did not like being put into categories (levels and tiers).

The SIS quickly became a discussion at one forum when the facilitator asked "*Is there something that happened in the past year that you're not happy with?*"

Responses

I don't like getting called a 1, 2, or 3.

I don't like losing money for the programs because of the SIS. Don't understand it very well and don't like the number. I was interviewed a while back, don't understand the facts of it...

I got a phone-call saying that I'm in section 1 [Level 1], and if they choose me, I have to move out of my group home.

it's an emotional subject..., people feel singled out, and it makes people feel bad. Because it makes us feel different, if we're smarter than other people [SIS Level is lower than others they know].

Yeah, that's it. I feel like I am being put into categories...

The facilitator asked participants to raise his or her hand if they didn't like being put into categories. Everyone nodded when one person said, "*I think we all don't...*"

I feel like we're going backward... (family member, Houlton)

Comments from family members, friends, and allies fell into five general categories:

1. ***Haven't gotten any/enough information about the SIS*** (N=8)

Despite my efforts to get more information, I was put on hold and to wait to get her retested. (family member, Brunswick)

2. ***The SIS is not appropriate for determining service levels and funds*** (N=5)

I think that the SIS tool needs to be more detailed to reflect needs not easily assessed by the current tool (online survey comment)

3. ***The SIS scores cannot/do not reflect my child's complex characteristics*** (N=5)

The SIS is not an accurate assessment of my child's needs. The 2nd interview was much better but I still don't believe this is a totally accurate tool for assessing a persons abilities/needs... (family member/guardian/ally, online survey)

4. **The SIS interviewers influence the responses, hold too much power** (N=4)

I've done the SIS twice with my son. The second time, the interviewer argued with us about answers, we had to be assertive. I believe that some others who took SIS may have changed their answer because of the interviewer... (family member, Biddeford)

5. **The SIS process is degrading to individuals** (N=3)

The "outlier" cases (those individuals who require extra support) process is very degrading to the individual and family. The family is dealing with enough-they do no need to hear from the provider that they need to "present" the case as to why they need additional support for safety reasons. (family member/guardian/ally, survey)

"... We're trying to figure out what we're going to do..." (provider, Biddeford forum)

There were more than 70 **service provider comments** about the SIS from both the forums and the survey, although there were no questions about the SIS on the provider survey. These comments fell into seven broad categories:

1. **The process is flawed** (N=17)

Responses in this category ranged from observations about methodological problems with how the SIS is being used, to comments about OADS policies related to the SIS (i.e. not releasing full report), to difficulties inherent in the process (ie. getting guardians to understand that they, rather than the agency or case manager, must start the process if there is a disagreement with the SIS outcome).

The PCP is proscribed pretty clearly in the statute, and the SIS model subverts that pretty clearly. It stands in clear contrast. There is no place for the planning team to have any say about the budget. It become impossible to talk about one without the other... (administrator, forum comment)

There needs to be a better process to get it coordinated. They keep changing the process. Case managers do all the SIS scheduling. It's more work for the case manager to give the scheduler the info than to do it myself. (house manager, forum comment)

Quite frankly, we're telling the state what they can't do, because...that's how we get paid...I think that's kind of hurtful for the person (DSP, forum comment)

2. **Some people will lose services, some people will be too expensive for agencies to serve;** (N=17)

It is inevitable that a few people who are currently over-staffed may see a decrease in staff support; however, agency staff who have taken the funding models and projected the impact of the proposed SIS Level/Rate Level model believe that more than a few people will be negatively

impacted and, in some cases, agencies won't be able to provide the level of support the individual needs with the amount of funds available to that person.

I'm always fearful that there aren't going to be enough funds for all the services needed. The residential home could be taking most of money [in the budget]. There may be no funds for other services that are needed because of how the money is allocated. Now [case managers] are supposed to be accountants. (case manager, forum comment)

Some will get booted, because some agencies will not want to assume the risk... the reality is, if it is implemented as it is intended ... That person will need to find another place to live. And nobody else will want to take them... (provider, Biddeford)

3. **The SIS process doesn't include important information or doesn't capture some information well** (N=10)

The assessors are probably very good at what they do, but they don't know the person. We know the person, and we want to be sure we're answering [questions] so that the individuals will get the right services. (DSP, forum comment)

4. **The process is difficult for individuals** (N=9)

Although originally designed as an alternative to the previous deficit-based assessments that assigned all the responsibility on the evaluated individual, the SIS interview asks participants to focus on needs, rather than strengths.

I've had people who it's taken me days, to get them to calm down after their SIS interview. (house manager, forum comment)

Accurate answers [to SIS questions] can be hurtful when the individual is in the room... We encourage self-advocacy, but it was too much to expect the person to interpret and answer all of the questions in a way that would present an accurate snapshot of that person's needs. (provider, survey comment)

5. **The process is inconsistent across interviewers or between sections** (N=7)

I did two interviews with this person, the second interviewer put pressure us on to change our answers... (DSP, forum comment)

I've been a part of lots and lots of SIS assessments with different people doing the assessing. They're explained in a lot of ways. Answers can be different depending on who you have for an assessor, and how they're explaining it to the group providing answers. (house manager, forum comment)

6. **Interview protocol does not ask the right questions** (N=6)

We have a lady with extensive behavioral issues. The questions asked were not appropriate for her behavioral issues, especially when out in the community. We're talking swearing, offensive behaviors, all kinds of stuff. We are constantly coaching and role modeling.... [They

ask] 'Does she steal? No. Does she throw things? No, she doesn't destroy property.' They are not asking the right questions for her. For what her needs are. (DSP, forum comment)

7. **The SIS people were pleasant** (N=2)

Didn't have any problems with SIS people. Outcome had been received from first time, and it was sent to everyone. It was sent to her and she forwarded it to the client. Two SIS people were pleasant to work with. (provider, survey comment)

Transition to Adult Services, and Transition to Maine:

It just makes not sense, all the hoops, we have to go through to get what they need...
(parent, forum comment)

While there has been a concerted effort in the past two years to improve the process of transitioning from children's services to adult services, family members are not yet experiencing the benefits. With little collaboration across agencies and schools providing, for the most part, the barest of transition services - often transition becomes a checklist in the IEP, rather than an ongoing process- transition planning remains an area in need of improvement. One parent summed up her experiences with transition this way:

I think when families go from a system that is all inclusive... having that whole thing delivered to them, and the responsibility for those services, is the school system, not the parents- we have enough to do. And suddenly we're thrust into a system where everything is totally dependent on you...it's like trying to find a light switch in the dark, where are you going to go. ...I'm fearful for families who can't come out on a Thursday night, can't find coverage, [get their questions answered] I spend a lot of time researching this, and I'm confused as hell... (parent, Brunswick forum)

Three families who recently moved back to Maine from other states experienced a system that appeared closed from the outside: two were unable, despite their efforts, to get information about Maine ID/DD/ASD services before moving. The third sent all her son's records, only to arrive in state to discover that all the documentation, although received, was lost.

Maine, the way life should be. When this slogan is put out...(shakes head) I like Maine, I grew up here. But it is not great for support services. Transition [into the state for adults with DD] is horrible. (guardian, Brunswick)

The resources aren't getting to people who need to know about them... (provider, forum comment)

Case managers and service providers continue to observe the difficulties that arise from the differences between children's services, which are entitlement-based (must be provided), and adult services, which are eligibility-based (provided only when are available). Parents, children's case managers, and special education teachers have little awareness of the differences between the systems or how and when to explore adult services.

A lot of parents don't know what a person receives between adult services and children's services are not same. (case manager, survey comment)

Children's case managers don't always apply for the [Mainecare Section 21/29] waiver. Maybe this is due to training. Some are trained around transition and the waivers, and some are not. (case manager, forum comment)

Adult service providers often do not or will not participate in transition planning before the individual graduates from school, despite laws and regulations requiring them to do so:

*During the IEP, there needs to be better representation from adult services, not just invite them to come and they don't show up... and information provided **in advance** to the families. (case manager, forum comment)*

Finally, the wait list for Section 21 or Section 29 services continues to be a barrier with serious consequences:

A real issue I see is the huge discrepancy between children's services and adult services...as we're experiencing individuals graduating from children's services, who have received very intense educational services, they come to this abrupt end... (provider, Norway forum)

Working and Finding Work

I know what I want, I want a job, and I want to work... (individual, Brunswick forum)

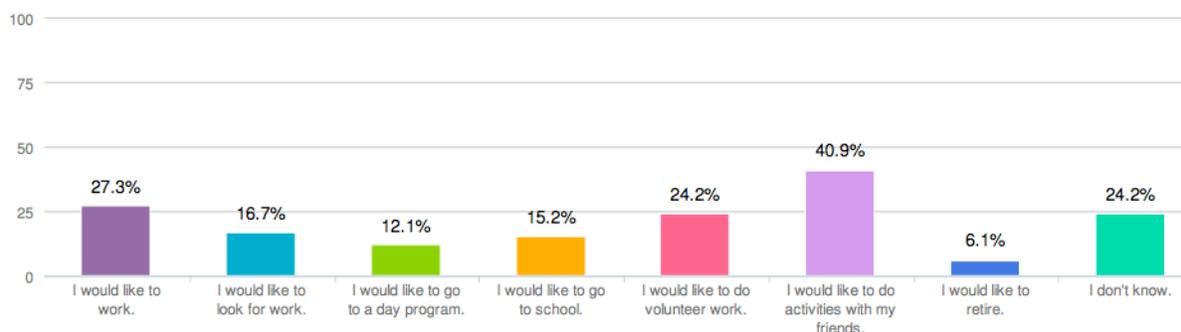
Individuals who use supports overwhelmingly said they want to work. Of the survey respondents, 52.6% either have a job or are looking for a job. Of those who are not working, 71.5% would like either to have a job or be looking for a job. When asked at the forums "What is one good thing that happened to you in the last year," getting a job was the second most popular response. The one thing that most forum participants wanted to change in the next year is also to get a job (or to get a better paying job).

One person, who used to work but now goes to a day program, said

I'm interested in working... It's been a long time... I really liked to work, it's important to me to do something, instead of watching television or something like that. (Individual, forum response)

Responses of forum participants mirrored survey responses. Many would like to have a job, have a different job, or have help to find a job, and have time with friends. **(N=66)**

31. What other things would you like to be doing?



Vocational Rehabilitation: Jobs are hard to get... (individual, Houlton)

Individuals identified two major things getting in the way of their employment: lack of job options (especially for those living in Houlton), and lack of help to find a job. None of the forum participants named Vocational Rehabilitation (VR) as a source of employment help; responses named case managers (4 responses), friends (3 responses), and family members (2 responses).

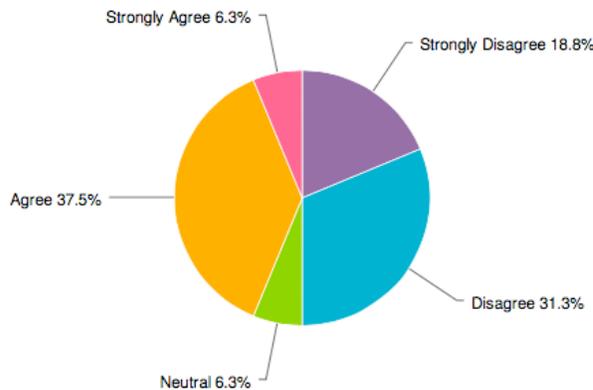
One person said that her case manager has a lot of clients and hasn't been able to help lately, and added

I've been out of a job a couple of years. Something weird happened, then I got a letter [from VR] that said that I chose to close the account, but I didn't, so my caseworker is working on that... (individual, Brunswick)

I wish my friend had more on-site work support... (family/friend survey response)

Seventy percent of the family members and friends who responded to the survey agreed with the statement "My family member...has choices about the type of job she or he has or would like to have." They were more divided on the amount of employment support available:

My family member, ward or friend receives enough support to find or keep a job.



Voc Rehab was a terrible experience for her... (parent, survey response)

Family members and friends did not have good things to say about VR assistance in employment; in fact, they saw VR as unhelpful at best:

He had a lot of involvement with VR, but it led nowhere. They couldn't even find him part-time employment at a place where he'd volunteered for years. Now he has no support and isn't able to get there, so he's lost that part of his life. (family member, Brunswick)

My daughter works 25 hours, and has for years. Then when she came off the waitlist, an agency has begun working with her. [She had to stop working at her job because of VR requirements] They [Community Services provider] pick her up from work two days a week and walk around, basically. (survey comment)

Some families were critical of how Maine allots its resources:

...he's worked full time for the past 10 years. We arrived here, and in order to maintain MaineCare, he has to work part-time. That is outrageous ...it's bad for his self-esteem...(parent, forum comment)

Too much money and too many services are programmed and are leisure and/or recreation based. Too many opportunities for "work" are not work at all. People are wasting away in day programs and group homes. People want real lives... The funding needs to be redirected and made more accessible to the many who want to live valued lives. (survey comment)

Working with VR is hard...(case manager, Houlton)

We did not ask specific questions about Vocational Rehabilitation or employment supports on the online survey. Employment came up as a question in forums for individuals using services and forums for case managers. Of the 52 comments made by case managers about employment supports, one comment was positive:

I've found division for the blind in VR to be incredibly helpful.

The remaining 51 comments could be categorized into

- general comments about VR (N=13),
- Low expectations (N=11)
- VR staff (10)
- communicating and interacting with VR (N=7)
- Career planning (N=6), and
- Employment specialists (N=5).

Overall, I haven't found VR to be very helpful... (case manager, forum)

The comment above reflects the tone of the general comments about VR. Some comments addressed systemic problems with VR. Six people believe that VR counselors have too many people on their caseloads, or that there aren't enough counselors for the region/district covered.) One person added,

[I] want to see some accountability for neglect. There is a lack of VR following through, and not having time to address issues... (case manager, forum comment)

Four comments noted that VR's structure and/or process can be an obstacle to employment:

it's been disappointing...for people who are interested in work, and go through VR to get funds, for job development, to test out ideas and maybe get work, VR changed from Fee for service to "milestone payment", which doesn't match at all for that person who wants to pursue that goal. ...the payment structure that changed last year makes that nearly impossible. (case manager, forum comment)

In general, case managers viewed VR as " ... just a steppingstone that we need to use to say we've tried everything." (forum comment)

Communicating with VR is a nightmare... (forum comment)

"Even when families call, they have to chase them down and find out the status [of the case]...the case manager quoted above continued. VR staff were called unprofessional, rude to clients, and inappropriate with clients with developmental disabilities- either not taking care to ensure that the client understood the plan, or, in once case,

A VR counselor had the adult dismissed from their meeting...

They report that making counselor supervisors aware of the problems does not result in improved interactions with their clients. Several case managers noted that their clients did not want to go through job search process because the person did not want to engage with VR again:

I have someone going through an assessment in Ellsworth. There is one assessor, [name]. If your client and [name] don't get along- that person is out of luck. It's a rural area.

I have someone who worked for two years, but hated her job, and doesn't want to go through process of finding a new one because of the VR counselor. The counselor says she needs a compelling reason to change her job. For most of us, hating your job is a compelling enough reason to look for another one.

They try to talk my clients out of working... (case manager comment)

*" Cleaning is always **the** option [with VR]... or stocking shelves. The VR person says that those are good work options for Maine" said another case manager. There were reports that VR counselors did not follow up on the kinds of work clients said they wanted and instead steered them to jobs that were available at the moment. Some clients worked with VR for months, only to receive a letter that they were considered "not work-ready."*

One case manager summed up the problem of low expectations this way:

I talk to my clients about what they are going to say to the people at Voc Rehab. At the meeting they say, 'Here's what I want for a job.' And the Voc Rehab person says, 'How about cleaning or dishwashing?'

On Employment Specialists and Career Planning

Case managers expressed two main concerns about **employment specialists**: that they didn't seem very well-prepared for the job, and that agencies who offer this service do not respond to vendor calls. One case manager asked, " Are agencies accidentally filtering [their emails] so they don't answer?" Another asked, "What exactly is the employment specialist's training?"

Comments about **career planning** primarily reflected confusion about how it fits into the VR process:

*Why does VR need to be involved, when the Career Planner has developed a list of potential employers? Why hand that back to VR for a **referral**...?*

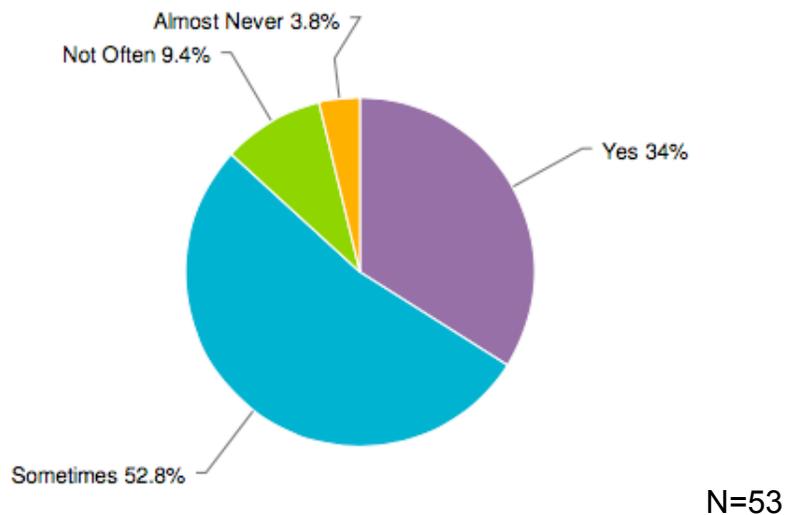
Other comments about career planning noted that it is a good idea, but there is a lack of resources. They were hopeful that, in time, more career planners will be trained and ready to provide services.

Transportation: *If you knew them, you wouldn't want to ride with most of them...*
(individual, Norway forum)

Of all the topics discussed at forums and appearing on surveys, transportation received the most comments by far. Access to reliable transportation is critical for work and community involvement, especially for those living in rural areas. Maine DHHS switched to a brokered system of transportation nearly three years ago in which regional brokers, selected by DHHS through an rfp process, contract with drivers who deliver the service.

This system appears to have improved very little (if at all) since it was instituted. One of the most frequent statements about the brokered transportation system is the unreliability of the drivers. When asked *"Does your driver pick you up on time?"* only 34% of the individuals responding to the survey chose "yes." Many of the respondents have provider-operated transportation as agencies, worried about their clients being left in the wrong place, left too early, or not picked up, chose to become their own brokers.

does your driver pick you up on time?



Sometimes they show up early, other times they're on time, or they are late. Sometimes they don't show up at all ...(survey comment)

There were 93 comments from individuals who are dissatisfied with the use brokered transportation system. Here is the beginning of a conversation about transportation at one forum:

(facilitator) What is one thing you hope will change in the next year?

- *I want transportation to change! (7 other people raised their hands in agreement)*
- *They don't come on Saturdays.*
- *They don't show up when they're supposed to.*

- *They don't show up at all!*
- *Three no-shows and they won't pick you up anymore.*
- *My driver screwed me up!*
- *[when the driver] doesn't pick me up- I will have to stay at home.*

The most frequent statement from individuals who use brokered transportation is about the unreliability of the system (N=36). Some people reported losing jobs because their ride regularly did not arrive on time (or at all), missing appointments, being dropped from medical specialists' caseloads because they missed too many appointments or were late- up to an hour and 45 minutes, in one report, and- most troubling- leaving people at the wrong place, neglecting to pick people up, and dropping people off early outside buildings, requiring them to stand outside and wait for the door to be unlocked. Individuals noted other problems with reliability:

I hate the transportation service...they don't get my phone number right, when they come, I don't know if they're coming early or late...I don't know when they are there. I have to guess. (individual, Brunswick)

My rides come at different times. I have to hurry and get ready early in the morning, and then wait for them to show up. Waiting and not knowing when they will come is hard for me, and sometimes I get anxious or frustrated about waiting. At least once or twice every week they are so late that I get to my day program late. When that happens, I miss out... My mother and case manager have been trying to make transportation better from the very first day I started using it, but nobody returns calls. (survey comment)

I'D LIKE TO HAVE BETTER DRIVERS (individual, survey comment)

The second most frequent comments were about the quality of drivers (N=20). Some people have to tolerate different drivers every day, which can be problematic. As one woman stated,

...they have different people in there [different drivers], and it scares the bejeezus outta me (individual, Biddeford)

Individuals reported being forced to use vehicles that are inappropriate for the person's needs and does not match their request:

The drivers who pick me up are always different. They drive different cars. Some of the cars are very small and don't fit me and my backpack too well, and there are other people with their bags and equipment in the cars, so I get squeezed in with people I don't know. Having people in my personal space is hard for me. (survey comment)

Sometimes they pick me up with a van. It is hard for me to get in. I have requested a bus (individual, about CM, survey comment)

Some drivers are difficult for individuals to share a vehicle with:

Driver that picks me up, he stinks because he wears the same clothes all of the time. (Individual, Norway)

Sometimes they smoke in the car and it smells like cigarette smoke and I don't like that.
(survey comment)

Other drivers have questionable driving skills:

Some drivers don't buckle up. Going at 50 miles an hour. (individual, Norway)

I was in an accident with cops, an ambulance and my aunt showed up, brought me to the hospital...The same driver ran over a birdbath [the next day]. She totally ignored our warnings but she just drove off. We reported this to Logisticare but nothing happened.
(individual, Norway)

Finally, some drivers seem to lack respectful interaction skills:

Some drivers I like some I don't because they don't talk with me ...It needs better people that don't treat you like dirt... (survey comment)

Some drivers are very schedule oriented. They are really, really high strung. They say, "We have to follow the schedule and I have to leave now." Some really nasty drivers. We've tried to change transportation companies, but we don't know how. I've been late to program and have been losing hours because they're picking me up late. (survey comment)

We want accountability! (survey comment)

Family members, guardians, and allies noted the poor reliability and quality of transportation. Without safe, dependable transportation, individuals lose access to work and community involvement:

RELIABLE TRANSPORTATION to meet his needs is a MUST. (survey comment)

(It is) not giving individuals the opportunity to participate in community without adequate transportation (guardian, Houlton)

Several people noted that calling the contractor or broker did not result in any noticeable change in the service. One parent commented:

I called when my son's ride didn't show up. I was told that they didn't have him on their schedule. I told them it was a standing scheduled and this was not acceptable. Person said I was being rude and passed me on to the supervisor. (guardian, Houlton)

Finally, there was a question about accountability. As one guardian asked,

Who's doing quality management for transportation? Probably nobody....

The state isn't holding them accountable at all for the poor service they provide... (CCM, forum)

Case managers also expressed frustration with the apparent lack of accountability for poor transportation service (9 comments).

If they [transportation broker] get caught in a mistake then they say they don't have a release to speak with you. Suddenly they have no release... (forum comment)

It's ironic that [transportation agency] finds it appropriate that if the client is late 8+ minutes, they are able to cancel, but if the transportation is late, the transportation agency can get away with it. I have a client that has hearing services every 6 weeks, and if client is 8+ minutes late, the appointment is cancelled... (forum comment)

There were 15 comments from case managers about the unreliability of the transportation service, although this was implied in nearly all other comments. Case managers at every forum site mentioned drivers who don't show up for a scheduled ride and, when the broker is called, state that they *"don't have anyone to pick up [the person] today..."* (CCM, forum comment).

Case managers talked about drivers who show up early and won't wait for the person to be ready to leave, drivers who arrive in an inaccessible vehicle to pick up someone who uses a wheelchair, drivers who show up on the wrong day or for trips that were cancelled days before, and brokers who lose paperwork and then threaten to drop someone's service because they can't find the needed documentation. One case manager shared her ongoing anxiety about transportation:

The panic attack, oh my god, did they get it, are they coming...I have someone, if she's 8 minutes late, she loses the referral (for a medical appointment), ...that's it, we have to set up the whole thing again... (forum comment)

Case managers' biggest concern, as in the preceding statement, is the impact of unreliable transportation service on their clients (31 comments). Clients are missing appointments, showing up late to or missing work, or being dropped off early and standing in the cold and without supervision for up to an hour, waiting for a building to be unlocked. They are being left to wait for a ride home for two hours, and being put into unsafe situations because of the current transportation system. Many individuals who experience anxiety about time find that not knowing if or when a ride will arrive disrupts the entire day:

I have two that are people who get anxious around time....he'll start biting himself, she'll shake and shake. The anxiety every morning that those two [clients] experienced....about the transportation showing up on time, what if it doesn't, what if I don't get to work on time...the anxiety that caused in those two young people before they even got to work was way over the roof... (forum comment)

One case manager shared a story about an individual who was anxious around new situations and especially nervous around people he didn't know:

If I do get one of my clients into a car, I would prefer it not be a different driver...I've been talking to him two months to get him in the car ...nobody he knew was in the car, he said

he's not getting in the car. The consistency would be really helpful, if there was a place to say, could you please have the same driver? (forum comment)

There were a number of stories of unsafe or uncomfortable situations case managers found alarming. Although there is a clear statement in the Transportation Regulations prohibiting drivers from smoking while transporting OADS clients, many clients and case managers (more than a dozen) reported drivers who blatantly ignore this rule. Even something as simple as getting in the right car after work or program can be a challenge:

People who use transportation have to guess which car to get in. They never have the same car or drivers. How unsafe, to be waiting and wondering which car that pulls up is there for you! (forum comment)

Unsafe conditions reported include someone in a wheelchair getting her arm pinched because her chair was improperly secured, long waits or early drop-offs mentioned earlier, and the following:

There are inappropriate travel companions. You have nonverbal person riding with people [not clients of OADS] who are fighting and dealing drugs. (CCM)

Taxis are a last resort, but one time my client, who is a non-verbal female, was not brought home for 1.5 hours after pick-up. She only lives 7 miles away. They didn't know where she was. (CCM)

Like the individual who talked about a driver who ran over a birdbath, case managers also noted drivers who were unsafe:

The broker used an outside driver. The driver was yelling, swearing, speeding, smoking, running stop signs. Completely unsafe. (CCM)

Driver [who caused an accident] was on cell phone, smoking a cigarette... (DSP, forum)

Direct support professionals and shared living providers, who often assist individuals to and from the vehicles in which they ride, spoke almost exclusively about unsafe conditions, while also noting the inconsistent arrival times and lack of accountability (15 comments). The kind of vehicle used presents problems for some:

The vehicle sometimes doesn't accommodate person's body. A lot of the drivers smoke...People get crammed into cars. One driver has a compact car—with 3 big guys with tactile defensiveness problems having to sit in the back seat...(shared living provider, Norway)

Lack of adequate training and language differences also contribute to the poor quality of transportation. One case manager told a story of an individual who had limited verbal skills, but know the driver was preparing to go in the wrong direction from her destination. The driver, who seemed to be new to the English language, could not understand her. She finally got out of the car and refused to get back in, thus keeping them both from getting lost. A shared living provider said

[The individual] has... to sit in the back seat. I tried to explain this to the driver but he didn't speak enough English to understand...

Finally, one anecdote encompassed all the transportation issues: disrespectful drivers, unreliability of system, unsafe conditions, and lack of accountability for drivers and brokers:

We've had drivers taking clients home to their own homes-one had to clean the driver's refrigerator out. There was NO follow-up after the reports happened. (shared living provider, forum)

Conclusions and Recommendations

1. Communication with OADS

Issue: Individuals report having difficulty understanding communication from OADS.

Recommendations:

- Work with contractor experienced in evaluating and modifying text reading levels.
- Ensure that all documents impacting the lives of individuals are available in more than one format (i.e. text, auditory, YouTube clip) and
- share information with individuals, guardians, and case managers.

Issue: Individuals, family members, guardians, allies have difficulty accessing information on the OADS website.

Recommendations:

- Create web page for individuals with alternate formats for important information affecting their lives;
- Create a web page for family members, guardians, allies, with relevant information. Guardians helped sketch out the kind of information they'd like to see on a web site. This list is in the 2014 Public Feedback Forum Outcomes. Please refer to that report.
- Work with a contractor experienced in Universal Design in web formats to create these pages; require contractor to vet design, various versions with SUFU, parent groups (i.e. MCHQS) throughout the design process- not just after the project is completed.

Issue: Information disseminated by various offices at OADS often conflicts with that of other offices; information is shared too late to be useful; calls are not returned in a timely manner.

Recommendations:

- Use distance technology and the website as much as possible for transmission of information to ensure that everyone gets the same message at the same time.
- Dedicate a third web page to information updates for caseworkers and providers. Update at least weekly.
- Work with OADS Quality Management to identify barriers to timely return of telephone calls, and to implement solutions.
- Post telephone names and telephone numbers of key people online so that others do not waste time trying to find the correct number and explaining the same issue multiple times while searching for someone with an answer.

2. Adult Protective Services and Crisis Services

APS investigations, when done in a timely manner and when results are shared, were viewed by most as helpful. Issues arise when there is a lack of response to incidents where there is the potential for injury or exploitation, and when longer than 2 weeks is permitted to pass before an event is investigated.

Issue: Multiple days or weeks can pass before an event is acted upon, if it is acted upon at all.

Recommendations:

- Honor the timeline specified in Chapter 12, 6.04 G 3(c), which states "The final written report will be completed within 30 days unless an extension is granted by the APS manager."

- Ensure that every non-routine event sent to APS is acknowledged by notifying the reporter of the investigator's intent to investigate (or not) and the timeline by which this will happen.

Issue: Written reports, regardless of the seriousness of the outcome, are no longer shared outside the Department.

Recommendations:

- Follow the directive in Chapter 12, 6.04 G. 3(c) "*The final report will be forwarded to the provider agency, the person or their guardian (except when the guardian is the subject of an investigation), the person's ISC, the Department's Regional Office, the Office of Advocacy and the Consumer Advisory Board, or its successor.*" In the event that there is an issue of confidentiality, a partially de-identified copy may be shared. The MDSOAB, which is the successor to the Consumer Advisory Board, should receive de-identified reports.

Issue: Crisis Services is under-resourced. They cannot respond in a timely manner, and have little time to offer in-home and proactive resources.

Recommendations:

- Staff Crisis Services at the ratio of staff/people served recommended in Community Consent Decree, when Crisis Services was created.
- Provide CS staff with technical assistance to learn how to teach specific techniques for supporting people with challenging behavior.
- Re-orient Crisis Services toward providing trainings to provider staff, and toward providing ongoing in-home technical assistance to lessen the need for out-of-home placement.

3. Guardianship

Numerous individuals would like to be emancipated from the guardianship relationship. Individuals under guardianship and family members are interested in alternatives to guardianship. Family members want to participate in trainings relevant to guardianship. The guardian role for public wards is represented by the individual's Individualized Service Coordinator (ISC), which those outside the Department recognize as a conflict of interest for the ISC, the Department, and is not in the best interest of these individuals.

Issue: Maine currently lacks alternatives to guardianship, which individuals and family members would like to have available.

Recommendations:

- Contract with an external agency to undertake a review of viable alternatives to Maine's current public guardianship structure. Set a goal for design and adoption of an alternative public guardianship structure in the upcoming Biennial Plan.
- Support the work of the Supported Decision Making Coalition with resources, facilities when appropriate, and ongoing participation in order to pilot SDM and create a model that works for Maine. Work with the Coalition to publicize and support a Supported Decision Making training initiative.
- Provide information about, and training for, those assuming guardianship over a person with ID/DD and ASD.

Issue: Individuals who lack a private guardian have their interests represented by staff of the Department of Health and Human Services, which is also the funding source for their services. In addition, those under public guardianship are not permitted to request a different case worker.

Recommendations:

- Give people under public guardianship the option to change case managers if desired.
- Require training about guardianship for ISCs currently representing the state guardianship role.
- Institute a plan to monitor public guardianship with an agency external to the Department to oversee relationships between public guardians and individuals whom they represent.

4. Futures Planning

Maine currently requires its own version of a personal planning process for each individual receiving services. This plan is intended to determine and follow each person's services and annual goals. The Supports Intensity Scale Interview was recently adopted in conjunction with a 5 level, 3-tier rate structure offering "packages" of various services. Families with adult members receiving services in other states experience difficulty identifying resources or communicating with the Department prior to their move to Maine.

Issue: While a lot of effort and training went into the current PCP process, individuals, family members, and support team members find that it is less person-centered than ever. The final meeting has become a dry report-out rather than a brainstorming session.

Recommendations:

- Do not push forward with the recently instituted PCP; instead, return to the previous plan structure.
- At the same time, work with scholars and practitioners who have an established, recognized record of research and experience in person-centered planning to redesign a truly person-centered approach that is truly an ongoing process, rather than a complicated document to complete once per year.

Issue: Individuals experience the SIS Interview as uncomfortable and, at times, demeaning. Family members and support teams find that the SIS outcomes often do not reflect the kinds and amounts of supports the individual needs to achieve the greatest autonomy possible. The proposed process results in more mismatches than can reasonably be identified as "outliers." Finally, families and teams believe that the rate level structure precedes and subverts the person-centered process, which in statute must be the starting point of service planning.

Recommendations:

- Abandon the current plan to use the SIS to determine funding or proportions of services. This is a misapplication of the intent of the Supports Intensity Scale. The SIS yields information that can be very useful by the PCP team- but it should NOT, under any circumstances, be used to determine funding.
- Any change in the Department's model for determining services and funding should be developed WITH stakeholder groups as a back-and-forth process that allows input at key points during the model development, rather than at the end of the process when the finished project is unveiled.

5. Case Management

Again this year, individuals seem happy with their case managers and rely on them for a variety of reasons. Case workers themselves enjoy working with their clients, but find the amount of documentation and added responsibilities overwhelming, and many believe they can no longer provide quality case management services.

Issue: CCMs have too many responsibilities that increasingly pull them away from directly supporting their clients.

Recommendations:

- CCMs should not be asked to take the place of person-centered planning facilitators, quality assurance professionals, or oracles from which all communication is expected to flow. A return to the previous PCP process may ease some of the burden; improving avenues for disseminating updated information in a variety of formats may also help.
- CCMs do not have the breadth of familiarity with services across districts and providers to effectively evaluate quality of services. Develop, with the Quality Management Team, a viable plan for ongoing evaluation of service quality across the state.

6. Work and Finding Work

Individuals continue to express the desire to work. They, their family members, and their case managers identify Vocational Rehabilitation as one of the biggest obstacles to employment. VR involvement was reported to rarely end in employment; in fact, some case managers report that VR talked their clients OUT of employment.

Issue: There are systemic problems with VR services that cannot be improved with a few recommendations. Offering training for counselors on topics like disability etiquette, career exploration, job development and, most importantly, orientations that help them develop higher aspirations for individuals with intellectual disabilities and autism, is a place to start.

7. Transportation

Transportation continues, for at least the third consecutive year, to be a barrier to employment, community participation, health care, and for some, safety. Changing brokers did very little to address the underlying issues. The transportation regulations offer a structure that does not appear to be informing much of the current transportation model.

Issue: Drivers arrive early, arrive late, and sometimes do not arrive at all. The current service agreement between brokers and OADS permits transportation providers to be up to ½ hour earlier or later than scheduled.

Recommendations:

- The primary goal of community-based service is to provide adults with ID/DD and ASD the same services and experiences. **No person without a disability would be expected to tolerate a transportation provider who arrives and departs at the provider's convenience rather than the client's. Nor should individuals with disabilities.** This is unacceptable. The system needs to be redesigned so that individuals get the transportation that works best for him or her.

Issue: Some drivers smoke in the vehicle, drive in unsafe ways, and appear to have little to no training or orientation about acceptable ways to interact with people with disabilities. Some of the transport vehicles are inappropriate for the person traveling; others are just unsafe.

Recommendations:

- The model of transportation provision specified in the regulations requires a contract between the broker and contractor, training for drivers, and sets out standards for the vehicles to be used. These should be enforced.

Issue: Individuals, family members, and providers alike report no response, or rude response, from brokers. There appears to be little to no quality assurance or accountability for brokers or contracted drivers. The state is paying for sub-standard service.

Recommendations:

- Involve the Quality Management Team immediately in designing a means to evaluate transportation brokers and contractors. Develop accountability with real consequences for sub-standard service.
- Hire external disability professionals to provide training to drivers, brokers, and contractor service personnel. Going forward, require this to be completed before the broker, contractor personnel, or drivers are permitted to offer transportation.
- Work with stakeholder groups to entirely redesign the current transportation provision system. Acknowledging that transportation is problematic is not enough- there must be a solution offered.

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