

# **Public Feedback Forum 2015**

**Outcomes**

# FEEDBACK Participants

- **151** Individuals who use services
  - 82 surveys
  - 69 forum participants
- **67** Family/guardians/allies
  - 46 surveys
  - 21 forum participants
- **230** Providers
  - 46 CCMs, 1 ISC
  - 89 DSPs
  - 97 Administrators, others
- **TOTAL: 450**

# Theme Topics 1

(not in order of frequency)

- **Communication** with DHHS
- **Department Services:**
  - Adult Protective Services
  - Crisis Services
  - Guardianship
- **Planning for Future**
  - PCP
  - SIS
  - Transition

# Theme Topics 2

- **Case Management**
- **Working, and Finding Work**, and...
- **TRANSPORTATION**



# Communication

or not....

- **Individuals**
  - **“When I get a letter from the state, can't understand it.”**
- **Family/Guardians/Allies**
  - **"I find navigating state services to be very time consuming..."**
- **Providers:**
  - **"Cannot move forward without answers..."**

# Communication- What's Next?

- **Work with contractor experienced in modifying text reading levels.**
- **Ensure that all are available in more than one format (i.e. text, auditory, YouTube clip)**
- **Create web page for individuals with alternate formats**
- **Create a web page for family members, guardians, allies, with relevant information**

# Communication Discussion

- 1. What would be helpful to your family member?**
- 1. What would be helpful to YOU?**

# **Crisis Services:**

**“The Crisis System is in  
crisis....”**

**OADS Developmental Services, in 34-B  
Chapter 5 Sec. 5206, is directed to**

***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.***

**Since 1995, *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.***

# **Crisis Services- What's Next?**

- 1. Staff Crisis Services at the level identified in Community Consent Decree.**
- 2. Continue increasing staffing to meet ratio of crisis workers/people receiving services identified in CCD.**

# Guardianship

- **Half the survey respondents, and half the forum participants, reported being under full guardianship.**
- **Of these, half expressed the desire to be their own guardian (sever the guardian relationship).**

# Why?

- **I'd like to know my own money situation, open my own bank account, be in control of my own money...**
- **Walk to the park, to the post office. I have to do it with staff and be supervised...**
- **I'd like to pay the bills, the house...(you'd like to have responsibilities)- yah.**
- **I would like to have my own future...**

# Family members and providers said...

**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...** (family member, survey response)

# Guardianship- What's Next?

- **Contract with an external agency to review alternatives to Maine's current public guardianship structure.**
- **Support the Supported Decision Making 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.**
- **Require training for ISCs representing public guardians. Provide oversight by an external group.**

# Guardianship- Discussion

- **What would be helpful to people with disabilities who want or need support?**
- **What would be helpful to family members?**

# **Case Managers on case management**

**We Take Our Work Home With Us...**

# CCM Comments

- **Too much paperwork, too many on caseload** (8 comments)
- **Too many added responsibilities**, not enough time (5 comments)
- **Too little attention to quality of services** (5 comments)
- **"Transportation is awful"** (4 comments)
- **Too many meetings with PCP** (2 comments)

# Individuals talk about the PCP

- **Most reported attending at least part of his or her meeting**
- **Most believed the PCP helps them get needed services**
- **Many reported feeling nervous at the PCP meeting**

# Why?

- *"I just get nervous because I have so many people at the meeting..."*
- *It's stressful with staff... 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...*
- *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.*
- **"That meeting was like a war zone.. "**

# Family, Guardians, Allies

- ***"I feel that the PCP process isn't person centered at all..."***

# And DSPs, CCMs on PCP

- "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)

# Person Centered Planning- What's Next?

- **Return to the previous meeting structure.**
- **At the same time, work with scholars and practitioners who have a record of research and experience in person-centered planning to redesign a truly person-centered approach that is truly an ongoing process.**

# Person-Centered Planning- Discussion

- 1. What do you know about Person-Centered Planning?**
- 2. What do you think could improve the planning process?**

# Working, and Finding Work

- **Jobs are hard to get...** (individual, Houlton)
- **I know what I want, I want a job, and I want to work...** (individual, Brunswick forum)
- **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)
- **I've been out of a job a couple of years. Something weird happened, the 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)

# Family, etc. on Work

- *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...*
- *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.*

***"Working with VR is  
hard..."***

(case manager, Houlton)

# Voc Rehab...Thoughts?

- 1. What kinds of experiences with work has your family member had?**
- 2. What would be helpful to him or her in terms of employment?**

*"If you knew them, you  
wouldn't want to ride  
with most of them..."*

**Transportation**

# Comments from the Transported

- *...they have different people in there [different drivers], and it scares the bejeezus outta me (individual, Biddeford)*
- *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 ... so I get squeezed in with people I don't know. Having people in my personal space is hard for me.*
- *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.*

- ***Some drivers don't buckle up. Going at 50 miles an hour.***
- ***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 Logisticcare but nothing happened.***
- ***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...***
- ***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."***

# Family members...

- *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.*
- *"Who's doing quality management for transportation? Probably nobody.... We want accountability!"*

# And Case Managers

.On late rides:

- *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...*

# On variety of drivers

- *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!*
- *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.*

# On unsafe conditions...

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

## **And finally...**

*"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."*

# Transportation-

## Our ideas

- *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.*
- The system needs to be redesigned so that individuals get the transportation that works best for him or her.

# **Transportation- Discussion**

**What kind of transportation system  
would you like to see?**

**What are the “non-negotiables?”**

**What needs to change?**

**What should we ask  
about in 2017?**

**What have we overlooked?**

# THANK YOU!

## **Maine Developmental Services Oversight & Advisory Board (Maine DSOAB)**

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