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June 2017 Medical Professional Engagement Session
on Stigma & SUDs in the Medical System

As background, in the Fall of 2015, PRO-A was asked by DDAP to examine how medical professionals in recovery perceive the understanding of addiction and recovery within the medical profession. We did so by identifying and contacting recovering physicians, nurses, pharmacists and medical professions to explore their perceptions of stigma within the medical community and how it impacts the engagement of persons with substance use disorders. We developed a survey and collected responses to inform the process. We found was how reticent recovering medical professionals were in completing the survey, even though it was completely anonymous and asked no identifying information about the person or the employer. The anecdotal feedback we received was that the perceived risks to the person in recovery in even completing an entirely anonymous survey was too great.

We had the opportunity this year to use our 2015-2016 survey to inform an engagement meeting with a group of medical professionals at a large hospital system in northeastern Pennsylvania. We wanted to do this to explore how medical professionals viewed persons who have SUDs and the development of a system of care in which recovery is seen as a reality and persons served are done so without stigma or discrimination. This was a sample of convenience, and represented a group of nurses, medical researchers, hospital coordinators and a physician who were interested enough in this topic to sit in on an engagement meeting to discuss stigma and developing a more recovery informed process in medical institutions. We believe that opening up conversations about SUDs and recovery with medical staff can lead to better engagement and care for members of our community seeking help with and SUD problem.

This was an informal process and consisted of a meeting with 11 persons who were nurses, medical researchers, hospital coordinators and a physician. While by no means is this to be considered representative of all such medical systems, we believe that such conversations must occur across our healthcare system if we are to reduce stigma and improve care. We opened the meeting with a brief overview of what the project was about and identified that this was an informal information seeking process and that we would not be collecting or reporting any person or institution identifying information. We asked them to review the engagement session handout (Attachment #1) and we asked them to read the 2015 Survey results (Attachment #2) and the actual survey (Attachment #3) in order that they understand the context of our engagement session.

This was an exploratory project to get a sense of how persons with SUDs are perceived within a medical setting and what may improve care and reduce stigma and discrimination at all levels of our care systems.

Key findings from the June 2017 engagement session:

1. What are your reactions to our 2016 medical system survey on Stigma?

   None of the attendees were surprised by the survey results. They noted that stigma and a lack of understanding about substance use conditions was commonplace in their medical care settings.

   - One member remarked that they were not surprised because they had seen examples of stigma against persons with SUDs as recently as this week.
   - In the dialogue that ensued, several persons noted examples of persons with SUDs not being treated very professionally and there was reflection on that this is a barrier in engaging a patient in a change process.
   - Several people noted that part of the problem is that with an SUD, the thing that is "broken" is not something that traditional medical systems are adept at "fixing."

2. Do you think that stigma and discrimination against persons with Substance Use Conditions is a significant problem within our medical care system here in Pennsylvania?

   Attendees acknowledged that stigma is a serious problem and:

   - Impacts on the quality and access to care in their system.
   - There were a few recovering participants and family members of persons with SUDs who shared stories that highlighted how stigma had a negative impact on access to care.
   - It was also noted that treating medical professionals lack the time to address these issues in the limited amount of time that they have with patients.

3. What is working well in your system in respect to getting people help with an SUD problem?

   There seemed nearly universal agreement that there is not a whole lot of good things happening within their systems of care in respect to SUD care.

   - It was noted that successful "warm handoffs" have had some impact on how some medical professionals perceive persons with SUDs.
   - Two persons referenced a substance abuse study by a family practice physician within the system into better ways to screen patients for SUDs.
   - There was acknowledgment that there is a lot of work to do to improve care in this area.

4. Is information about how to access SUDS services widespread within your service system?

   None of the attendees identified widespread access to accurate information on SUD services within their systems.

   - Some noted that information was only present when someone with lived experience brings the information into a specific area of a system.
   - It was noted that the information within the system was often dated and at times inaccurate.
   - It was noted that some of the access points to care (like care through the SCA) was not well known.

- It was noted that information on relevant laws (like Act 106 mandates for treatment, family and intervention services) are not well known.
- One person noted that while it is not as prevalent as it should be, access to information is becoming more common.

5. How can understanding about substance use conditions and recovery, and access to care be improved within your system? What would it take to make things better than they are?

- There was discussion on how the SUD is typically not the presenting diagnoses, and that most commonly the person presents with an acute physical health diagnosis related to the SUD. The SUD, if listed gets identified as a 3rd or 4th tier diagnosis and gets lost in the treatment process
- It was noted that attitudes needed to change across the whole medical care system. Multiple attendees noted that medical personnel, including physicians in the Emergency Department see overdose reversals with Narcan as enabling – and that essentially these people were not worth saving as they just go back out and do it again.
- There was a discussion on substance use conditions as a brain disorder and that there is a lack of understanding of what happens in an overdose reversal and that the person is in instantaneous withdrawal and that the craving response for drugs overrides executive functioning.
- As part of this discussion, the notion of persons in the medical care system who are in recovery as potential living examples that people can and do get better was discussed. One attendee stated that they did not believe that within their lifetime a person could live in open recovery employed within the medical care system without facing stigma and discrimination. Nearly all attendees agreed with this perspective.
- One person noted that training needed to include a focus on help and compassion.
- Several persons noted that there needed to be a recovery movement (which was then explained as something that is developing and improved communication on the efficacy of care.

6. What would you recommend to eliminate SUD stigma and improve access to SUD services within our medical care system in Pennsylvania?

It was repeatedly noted that there needs to be extensive education in their medical care systems about SUDs and that the majority of medical staff no very little about SUD treatment and recovery.

- One of the participants noted that medical marijuana for pain needs to be explored and implemented with pain patients to reduce risk factors related to dependency with opiates.
- One of the participants noted that addiction will always be with us and that this is a “war” we cannot win. There was a suggestion to bring back opium dens as persons on opium do not overdose at anywhere near the same rate, they pass out first.
- Several participants talked about the need to bring recovery into the medical care environment so that persons working in the systems can meet people in recovery. The notion of having medical professionals in recovery be part of this process was discussed, but the general consensus in the room was that the risks of employment discrimination were too great.

Attachment #1:

Engagement Session on SUDs in the Medical System

Substance Use Conditions are by definition medical conditions and not moral failings – recovery is a reality for many of us, and to save lives we must improve access to care in medical care settings. We believe that stigma is one of the most significant barrier to accomplishing this critically important objective. We conducted a survey of medical professionals in recovery in 2016. Even though we specifically stated that we did not want names or any kind of person or employer identifying information, many of the people we contacted were simply not willing to fill it out or forward it to other persons whom they knew in recovery in the medical professions. We are conducting this session in order to seek your input on this important issue – ***THANK YOU FOR PARTICIPATING!***

1. What are your reactions to our 2016 medical system survey on Stigma?

2. Do you think that stigma and discrimination against persons with Substance Use Conditions is a significant problem within our medical care system here in Pennsylvania?

3. What is working well in your system in respect to getting people help with an SUD problem?

4. Is information about how to access SUDS services widespread within your service system?

5. How can understanding about substance use conditions and recovery, and access to care be improved within your system? What would it take to make things better than they are?

6. What would you recommend to eliminate SUD stigma and improve access to SUD services within our medical care system in Pennsylvania?

Attachment #2

PRO-A 2015-16 Survey of medical professionals in recovery

In the Fall of 2015, PRO-A was asked by DDAP to examine how medical professionals in recovery perceive the understanding of addiction and recovery within the medical profession. We did so by identifying and contacting recovering physicians, nurses, pharmacists and medical professions to explore their perceptions of stigma within the medical community and how it impacts the engagement of persons with substance use disorders. We then began to work to develop a survey (see attachment #1) and collect responses to inform the process.

Addiction is arguably our single largest public health crisis. We also know that stigma and discrimination are fundamentally the largest barriers to effectively dealing with addiction and that these issues are pervasive across our society. While we know that addiction is a brain disorder and that factors such as genetics, early use and exposure to trauma can be risk factors for developing addiction, unfortunately there remains a sense that it is a moral failing, which is also a common misconception across our society. One of the primary objectives of the recovery movement is getting people who can to be open with their recovery in order to dispel some of the misconceptions about what addiction is and what kind of people are impacted by addiction as there are no boundaries on who is impacted.

As background, the role of our medical institutions are critically important for many within our recovery community seeking a pathway to recovery for ourselves or for our family members. We know for example through the National Survey on Drug Use and Health (NSDUH) that approximately 18% of individuals who want treatment are currently avoiding treatment due to the feared negative consequences of stigma and discrimination in the workplace and in their communities. We also know that while an estimated 20% of patients seen in family practice have SUDs, substance abuse was diagnosed in only 9% of general and family practice visits, 8% of internal medicine visits, and 5.1% of psychiatric visits. There is also a significant relationship between hospital readmission rates and undertreated or untreated substance use disorders.

Understanding how medical professionals with lived experience perceive SUD Stigma within medical institution culture in relation to our community of recovery and those still experiencing addiction is critically important. If we better understand how SUDs are perceived within the medical culture, we can improve access to care and acceptance of the dignity and worth of persons seeking help by those working within our medical institutions. A person in recovery within such a system would have a unique perspective of internal medical institutional culture and perceptions.

Through our survey, we wanted to begin to explore how persons with lived experience with addiction see their own systems and how comfortable they feel being open about their experiences with addiction as well as how they perceived the strengths, challenges and opportunities within the medical care communities.

Soon after embarking on this process, we began to run into challenges. We had hoped that we would be able to make contacts through medical professionals we knew and would be able to connect with their respective recovering medical professional contacts. We began to see that there were few people who wanted to answer our survey questions, and those that did found that their contacts were not willing to follow through, even though the entire process was anonymous.

Of the few surveys we got back (n=12), the responses that we received are suggestive of a lack of understanding and empathy about addiction, resources for help and the need for education about addiction and recovery within our medical institutions.

Selected survey Responses (n=12)

Q1 What is your recovery / lived experience as a family member of a person with a Substance Use Disorder (SUD) like for you as a medical professional?

"My lived experience has been a journey of shame and embarrassment working in the medical profession. My supervisor was not supportive of my "family problem". She expressed to me personally that I should allow my son to figure his own problem out and I should continue to come to work and his SUD should not affect my job performance"

"I do not share my recovery status with people I work with as I am concerned about the reaction."

"It is profoundly disappointing – the lack of knowledge and stigma displayed by my colleagues, it is a distressing reality."

"I think as a medical professional there is even more of stigma attached to us. We are expected to be the ones helping not being helped. As for me I was in the medical profession for a few months during my recovery. During that time, it was known to my co-workers that I was not allowed to pass narcotics. I found that many of them just assumed that I had gotten a few DUI's and had my license put on probation. I was told I don't look like a druggie by another RN. I asked her what does a druggy look like? I will never understand how that is more acceptable to people. DUI's and drinking and driving are not as big of deal for some reason."

Q2 Are you open about your recovery / lived experience with your colleagues? If so, how well are you accepted / if not what might be the impact if people found out?

"yes – ONLY because I lost my medical license, if I still was a practicing MD, I would NOT share my history due to implications on practice and *License.*"

"my employment involves the recovery environment; so I am comfortable sharing with my colleagues. I just don't believe I would be so forthcoming if I worked in another environment to share my experiences."

"In my job outside of the medical profession I was very open with it (my boss was in recovery). I am not sure if I would be open in a hospital setting or not. For the most part unless someone actually asks me directly about my recovery I don't divulge that information. Also in my personal life I have found out most people who know the truth about what I did respect me for getting help and getting better. The longer I stay sober the more I don't care if people know my story or not. I can see how in a work place the stigma and the fear people have with being open with sobriety. They may be apprehensive to tell people because if people know you are in recovery they may be passed over for a promotion, be judged, or asked to leave. Also in the rooms we are taught, whether it is correct or not, to be anonymous to outside people. It is just a very "hush hush" disease."

"I was not open at first concerning my son's SUD. There were times that colleagues would ask me if there was something wrong. I did not tell many colleagues because of the shame associated with telling others of my circumstances. Some colleagues treated me differently, others shared their own stories of SUD."

"I am open, honest + direct with everyone I deal with. I observed no changes in my acceptance & status at the hospital"

"I am open about my recovery but I am mindful about using labels – never use the term "alcoholic" or "addict"- always use person in recovery language."

Q3 What is working well in your system in respect to getting people help with an SUD problem?

"Great networked 12 step programs in our area (Hsbg), lots of good Tx centers nearby (we need more DA counselors"
"Nothing is working well. I had to tell a patient to say he was suicidal so he could get detox and rehab. I have also heard of this from other RNs, who had to do the same thing."
"I can only help ones who want help"
"PHP and AA meetings"
"Nothing is working well, practically speaking we do not address a person's addiction here, we treat them and street them here"

Q4 Is information about how to access SUDS services widespread within your service system?
"Not at all. It is not available in the large healthcare network where I work"
"no, not really"
"no"
"not really, most audiences I speak with are unaware of high incidence of SUD & availability / types of services"
"nope"
"I found it VERY difficult to find information in the beginning of my son's addiction to heroin. I strive to help other families find help now because it is so daunting"

Q5 How can access to help and understanding about addiction and recovery be improved within your system? What would it take to make things better than they are?

"While not applicable to the medical office I work in, I find that there is a general lack of understanding about addiction within the medical community." "My opinion would be mandatory training regarding addiction and alcoholism. Especially having people in recovery come in and speak to them and show them that we do recover and not everyone is "low life piece of crap". Training also on how this is a disease and should be treated as such. No one would treat a person with diabetes like crap because they forgot to take their insulin. Also have staff on call or somewhere in the hospital where they can respond quickly to someone who needs admitted to a detox, rehab, etc. They should be specially trained."
"It is very hard to improve something that does not exist – it would take someone dying – someone important followed by public exposure of the problem."
"there is no information available in doctors lounges about what to do if you have a problem. No in-services are available as education in advance."
"Implementing new types of therapies such as ACT (acceptance & commitment therapy)"
"this is the question of the hour! I don't know the answer to this question. Changing the stigma of drug as it is defined as a disease vs a character defect. I believe that the more education people receive on addiction, the more stigma would change."
"we need to remain available to anyone needing help and not judge. Have people who are educated and knowledgeable about addiction"

"consolidated statewide website of treatment centers that can be searched by county / region"
"I feel as a professional, I would like to talk to new nurses and physicians. Tell them what the impact on their profession is if they chose to drink or use"

Q6 Do you think that stigma and discrimination against persons with Substance Use Disorders is a significant problem within our medical care system in Pennsylvania?

"ABSOLUTELY – It is the NUMBER ONE STIGMATIZED DISEASE in all of medicine"
"Yes, the problem is terrible. Even when I an active user I looked down upon these people. This stigma may have even kept me for seeking help earlier for fear I would be judged."
"Yes – just another addict / junkie or GOMER (**G**et **O**ut of **M**y **ER**)"
"YES"
"Yes – there are some healthcare / medical staff that don't fully understand substance use disorder. Some even prescribe medications that can lead to substance use disorder. Is it that they don't care or are just plain ignorant?"
"It is an enormous problem – a travesty – a lack of human rights issue – I am ashamed"
"YES! My supervisor treated me so poorly when she found out my son overdosed on Heroin. I feel that if my son had cancer or another disease the public recognizes (as not someone doing it to themselves), I would have been granted a leave of absence and not lost my job"
"I have not experienced that"
"YES- I Have seen it improve to only swing back to too much stigma"

Q7 What would you recommend to eliminate SUD stigma and improve access to SUD services within our medical care system in Pennsylvania?

"Awareness is key to solving this problem. People are afraid of things they don't understand. 30 years ago people thought you could get AIDS from a hand shake. Now it is common knowledge that AIDS is only spread through blood. Teach kids early about addiction. Not "just say no". Spend more time in college courses, med school, nursing school, etc on what addition is. I spoke at least 5 times to a bunch of 8th graders about addiction and what it looks like what it does to families etc. More TV commercials. The more people see it the more it becomes familiar."
"Mandatory education – a requirement for CEUs specifically on SUDs"
"Better training around addiction and recovery"
"Promote the services of the PMP"
"I find people tend to dwell on my problem and not what I have accomplished as a nurse"
"Insurance coverage for wrap-around & on-going long term therapy"
"I believe as a nurse we receive so much training on important needs for good quality safe patient care. Unfortunately, we do not have the same "compassion" for our own. I believe as a CRS I could go into the workplace and educate professionals on the "new" face of addicts. I believe if professionals could see the scientific research behind the chemical changes in the brain, maybe there could be more understanding of SUD"
"Improve (change) the dialogue and terminology being used even with the field of addiction medicine – please refer to the works of John F. Kelly, PhD and William L. White"

Attachment #3

Medical service system / recovery survey

For persons with lived experience with addiction and recovery who work within our medical care systems. Lived Experience can include own addiction / recovery or experiencing addiction / recovery from a family perspective. The intent of this process is to understand how addiction is perceived / managed within our medical systems in Pennsylvania and how it may be improved.
Position: _____

1. What is your recovery / lived experience as a family member of a person with a Substance Use Disorder (SUD) like for you as a medical professional?

2. Are you open about your recovery / lived experience with your colleagues? If so, how well are you accepted / if not what might be the impact if people found out?

3. What is working well in your system in respect to getting people help with an SUD problem?

4. Is information about how to access SUDS services widespread within your service system?

5. How can access to help and understanding about addiction and recovery be improved within your system? What would it take to make things better than they are?

6. Do you think that stigma and discrimination against persons with Substance Use Disorders is a significant problem within our medical care system in Pennsylvania?

7. What would you recommend to eliminate SUD stigma and improve access to SUD services within our medical care system in Pennsylvania?