

*Access to Substance Abuse Treatment  
Results of a Family Survey*



**MOMSTELL Inc.**

*...because no family should face the disease of addiction alone*

# **Access to Substance Abuse Treatment, Results of a Family Survey Conducted by MOMSTELL Inc.**

## **Executive Summary**

In 2007/2008, MOMSTELL Inc. conducted a survey of Pennsylvania families with at least one member who themselves sought treatment for an alcohol or drug problem or did so on behalf of a family member. The survey was designed to elicit information about barriers to securing treatment, paying for treatment, and extent to which concerned family members, including patients themselves, were supported prior to and during the treatment experience.

Designed and administered by MOMSTELL with input from family members in the Commonwealth, the survey was independently undertaken and not commissioned by any governmental agency. Data was collected from 815 survey respondents and analyzed by the Treatment Research Institute in Philadelphia, PA.

Major findings from the survey are as follows:

### **1. Much treatment is initiated through, and paid for by, the court system.**

The data collected proves the individual's substance abuse use has escalated to the point of involvement with the court system. 506 of the individuals surveyed, 90.9% of the justice system sample, were adults having treatment initiated through the court system. Juveniles who were involved with the justice system comprised the additional 9.1% of the justice system sample. These numbers constitute a need for earlier intervention to eliminate escalation into the court system.

### **2. Lack of general – even basic information.**

The data provides evidence that seeking and finding treatment is a difficult task. 30.8% of the respondents did not know how to pay for services followed closely by 29.6% who were financially unable to pay. Individuals who did not know who to call to access treatment equaled 29.4%. 28.2% did not know where to go for treatment services and 27.5% did not know how to access the treatment system. For those who were able to access treatment services 27.1% did not know what questions to ask. 41.4% of the respondents seeking treatment were not aware of their county services. For those who were able to maneuver the system it took an average of 24 days to find treatment.

### **3. Lack of family support services/counseling provided during the course of treatment.**

The data proves a lack of family support services. 53% of the respondents did not receive support services. Of the 43% who did receive services, the average numbers of service hours were four. 45% of the family members of the person seeking treatment were not aware of family support groups. Of the 40% who attended support group meetings 94% found them helpful.

Details of these and other results, along with conclusions and recommendations for policy makers are provided on the following pages.

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# **Access to Substance Abuse Treatment Results of a Family Survey Conducted by MOMSTELL Inc.**

## **Prologue**

### **What was the Driving Force Behind this Survey?**

This project was a grassroots effort by a family driven nonprofit. Pennsylvania families involved with this survey wanted data that truly was from families about families. All questions were developed by families and designed to ask the questions we all asked when dealing with a loved one with addiction. Families when seeking treatment for a loved one come across numerous barriers, this survey was meant to expose those barriers and shed light on the seriousness of the problem. Our hope is that this information will be used as the basis to create change within the treatment system.

This survey was created to expose the barriers every person comes up against when seeking treatment. Every day we lose precious lives to the disease of addiction; families are ripped apart and devastated by this disease. When a family is faced with the possibility that a loved one has an addiction problem we need a friendly system that is as equally welcoming as the medical field. Families are at a great loss as to where to go, who to talk to, what to ask, and who to trust. Lives have been turned upside down and we need a system with open doors that will welcome not only the person with the addiction but the whole family. The disease of addiction should not be segregated from other diseases but treated as the disease it is and families and those in need of treatment should be welcome and comforted and treated with respect.

Over the past eight years families have contacted MOMSTELL on a regular basis seeking help for their loved one's substance abuse addictions. A pattern started to form as each person began sharing parallel stories of the barriers and frustrations they encountered when trying to access substance abuse treatment services in the Commonwealth. These similarities occurred whether they were located in the downtown or suburban areas of large cities or the rural areas of Pennsylvania. Location did not make a dramatic difference, the stories were the same.

## **Families Began Telling Their Stories:**

- “Addict’s don’t have 90 days to wait they might not have 90 minutes. The court told me I don’t know how the system works and I told them if that is how the system works someone needs to change the system.”
- “My son is 17 he is addicted to coke and pot; no one will take him into rehab because he is an adolescent. Can you help?”
- “We don’t know where to turn we live in a rural community and there isn’t much help available.”
- “My son is addicted and I am really scared and ignorant of this drug and the addiction. Sometimes I just need to talk to other people who have dealt with it. I need to find out if there are any local programs. I need help.”
- “Please God help me to save my child’s life because our government and insurance companies aren’t.”
- “It should not be so hard to get treatment for kids with addiction problems. I am just blown away by the hoops that have to be jumped through to get help. After a good year of fighting and not taking “no” for an answer we are finally getting help for our 17 year old son.”
- “This last year was a nightmare, his drug use increased considerably and I found my newest obstacle, my son was 14 years old.”
- “By the time I found a qualified facility, and I emphasis qualified, we had dealt with other places and other counselors. If there is suspected drug use all of us agree that we have to have counselors specially trained in the field.”
- “I have been told I am responsible for my son’s actions; after all I have physical custody.”
- “Drug and alcohol abuse is a disease just like cancer. Insurances only pay for a one time treatment, what if we told someone battling leukemia, sorry you used your once in a lifetime chemo allowance?”

After hearing stories like these over and over again throughout the years, we knew we must find a way to document the problems families face when trying to access substance abuse treatment. Families are in desperate need of a treatment system that is family friendly and family focused. Families languish while waiting to encounter a substance abuse system that truly focuses on the needs of not only the addicted loved one, but the needs of the entire family.

## **The Survey Process**

MOMSTELL leadership brought together family members who had sought treatment for a loved one and dealt with numerous system barriers. This group of people discussed the barriers they experienced while accessing treatment for their loved one and from this the survey was developed. The participating family members wanted to create a family friendly survey that would be easily understood, only take a few minutes to answer, and provide critical information concerning the barriers to accessing substance abuse treatment services in Pennsylvania. All questions were done in a multiple choice – yes/no answer.

The survey was distributed by family members across Pennsylvania to individual family members, parent support groups, recovery groups, local churches, drug courts, treatment facilities and rehabilitation centers. Pennsylvania Families Incorporated, a statewide family network also disseminated the survey through their list serve.

Individuals were told the surveys were being done in order to gather information on the barriers to accessing treatment services. Once the individual agreed to participate, they were given the survey and asked to return it once it was completed. After the surveys were completed and collected they were delivered to the Treatment Research Institute in Philadelphia where arrangements had been made by MOMSTELL to have the data analyzed by Dr. Thomas McLellan, former CEO of TRI. A total of 815 surveys were returned, collected and analyzed.

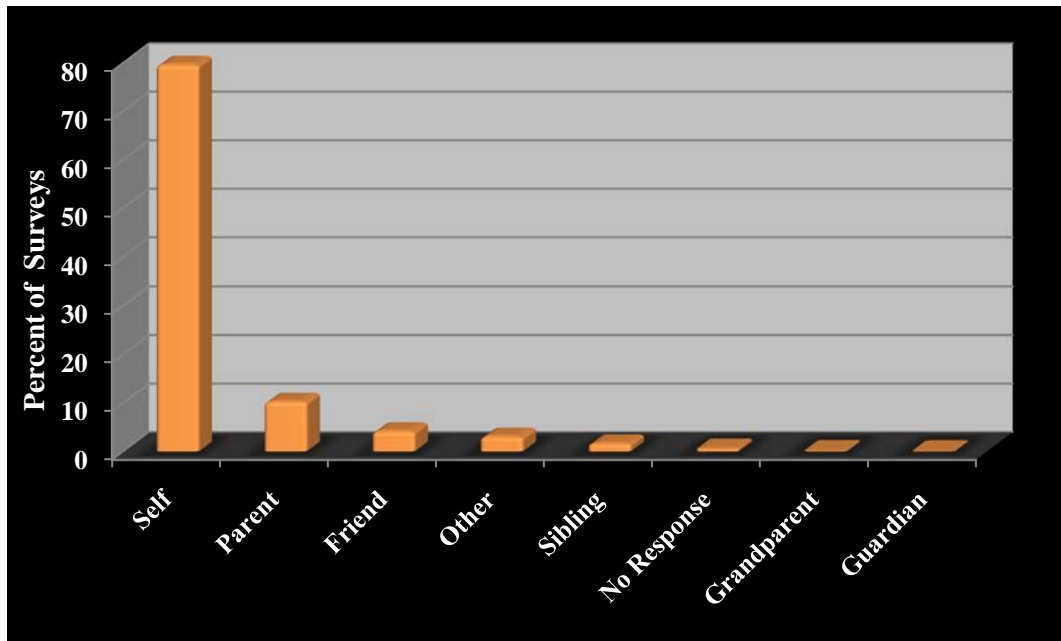
This report and the following recommendations were prepared using the complete TRI analysis report of the MOMSTELL Survey Data.

# Access to Substance Abuse Treatment Results of a Family Survey Conducted by MOMSTELL Inc.

## Results

### Survey Data

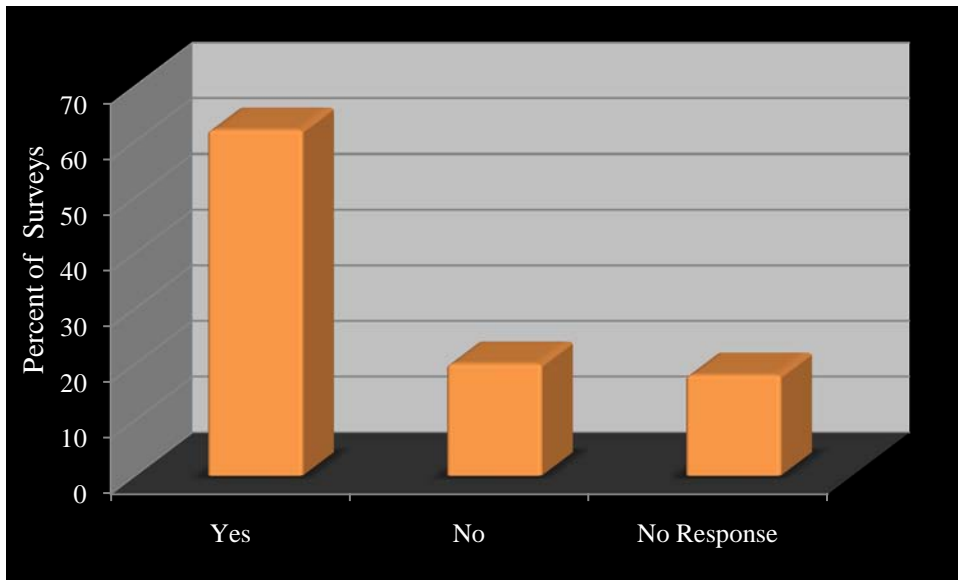
The following graphs and respondent answers come directly from the data analysis. The relationship of the respondent to the person seeking treatment is as follows (“self” meaning the individual seeking treatment for themselves and not for a family member):



## Top Three Identified Barriers

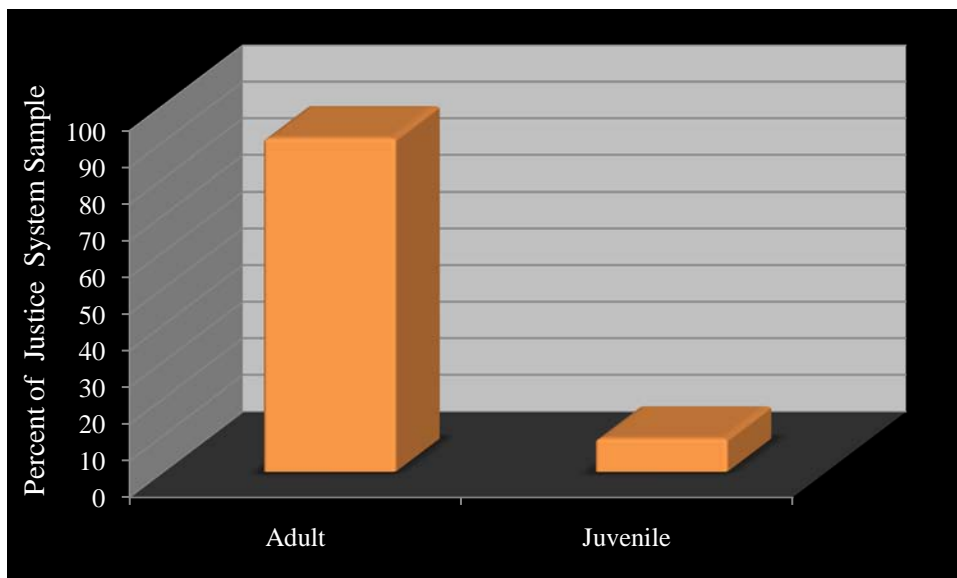
### 1. Treatment initiated through (and paid for by) the court system.

The data confirms that a significant number of respondents ended up in the court system, which in turn initiated the treatment process.



### Percent of adults and juveniles having treatment initiated through the court system.

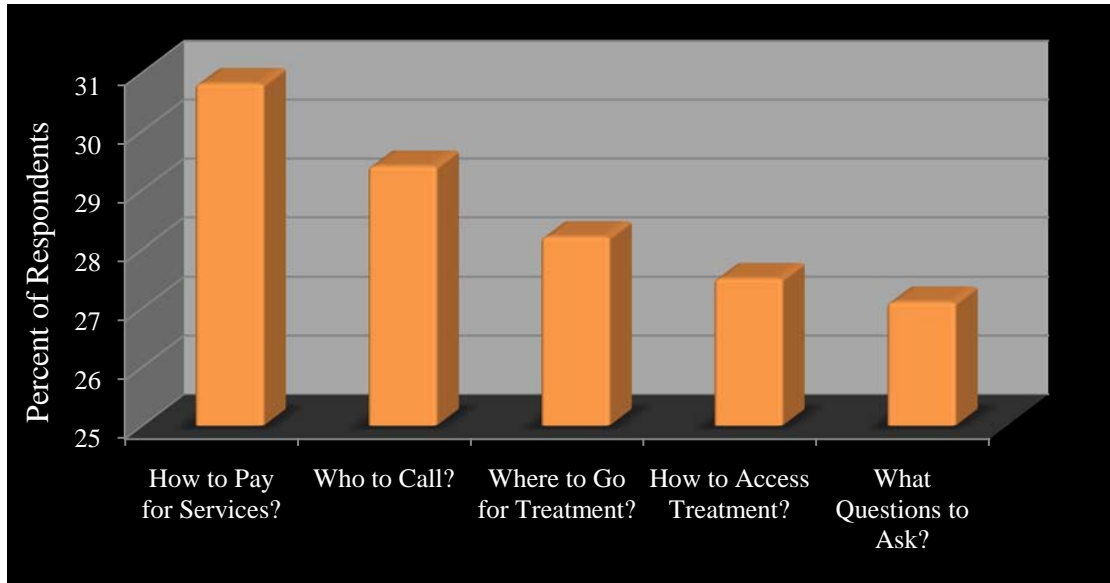
Of the total sample, 506 or 62%, reported treatment initiated through the court system. Of that total amount 90.9% were adults and 9.1% were juveniles.



\*These individuals also had their treatment paid for by the courts

**2. Lack of general – even basic information.**

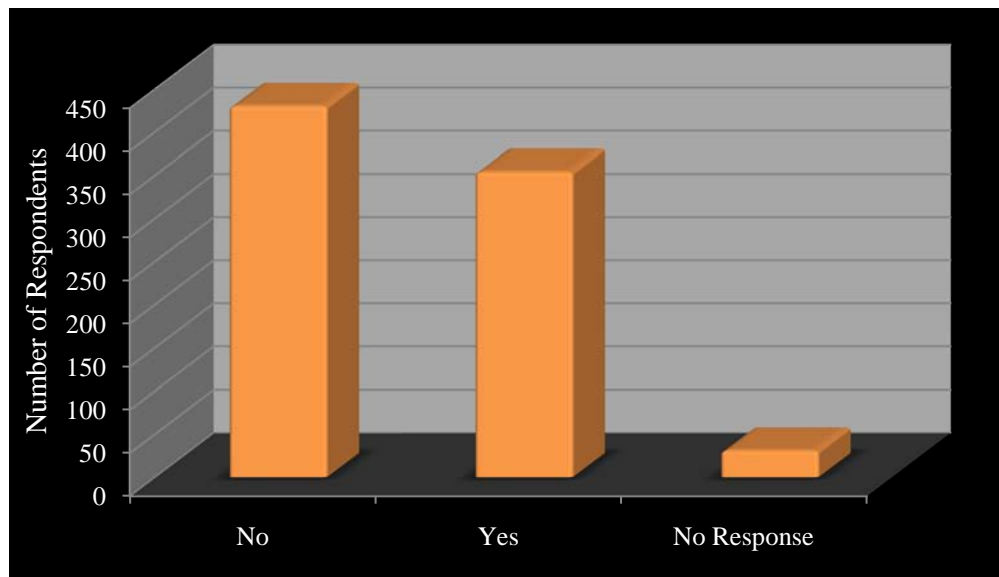
A lack of general, basic information on whom to call, what to ask for, how to pay was an obvious problem faced by a significant proportion of respondents. This data provides evidence that even basic information is not readily available within communities for families seeking help with substance abuse treatment.



\*The average length of time it took to find treatment was 24 days.

**3. Were family support services/counseling provided during the course of treatment?**

The data confirms the need for increased support services for families. Even for those who did receive support services, the average length of time was only four hours.

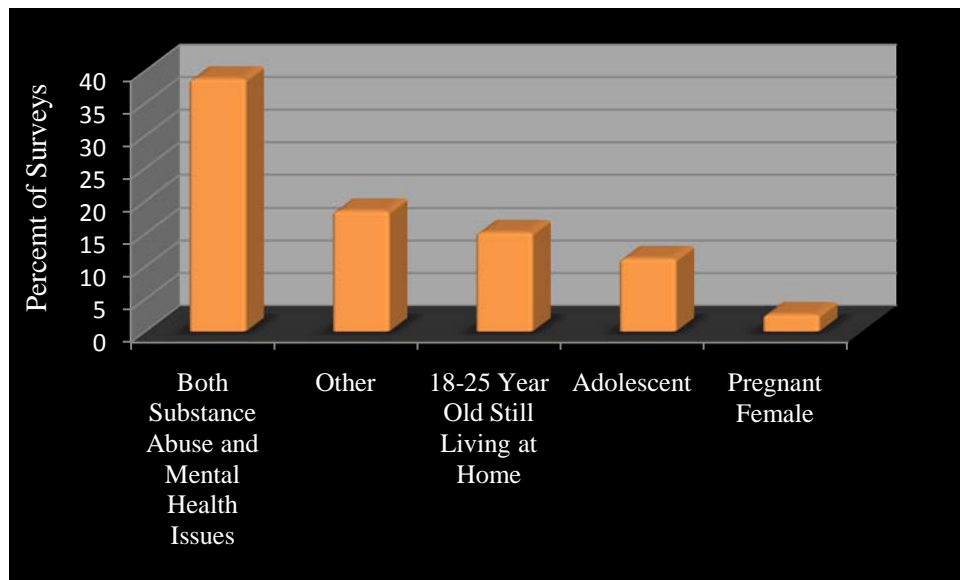


\*Of those who attended family support group meetings 94% said they were helpful.

## Additional Information

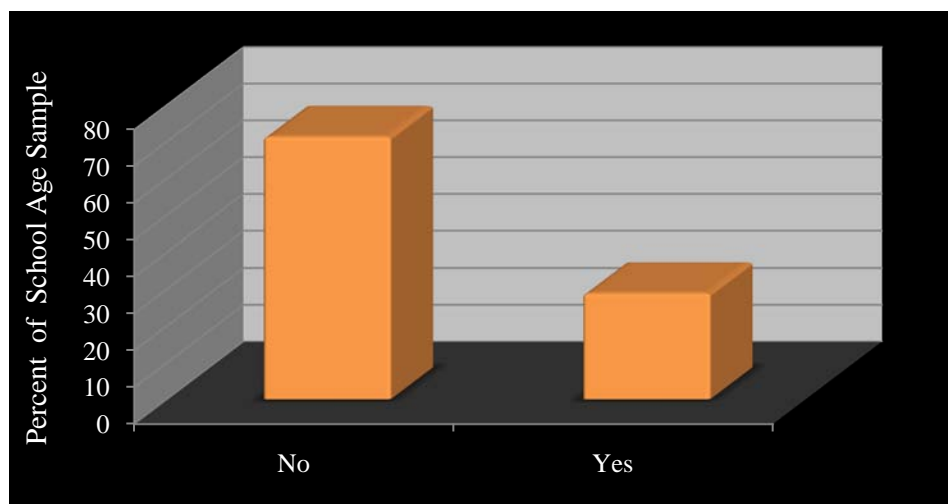
### 1. Special circumstances concerning the person seeking treatment.

The data confirms that the highest level of those seeking treatment had both a substance abuse and mental health issue.



### 2. Was the school helpful in getting the school age youth treatment?

12% of total sample responses concerned school age youth. 71.2% said they received no help from schools and 21.8% said the school was helpful. The data confirms the need for increased school assistance when addressing a student's need for substance abuse treatment.



## **Evidence from the Survey**

The MOMSTELL Inc., Access to Treatment Barriers Survey (ATBS) was created by families to identify the barriers experienced while trying to access treatment services. This survey provided critical information concerning the substance abuse treatment process in Pennsylvania. Our goal is that the data collected will be used to eliminate the barriers, create easier access to quality services and provide appropriate treatment, in order to save lives.

This survey is not your typical scientific survey; it was taken by 815 individuals who have tried to access the treatment system. The top three barriers that were proven by the survey are as follows:

**1. Much treatment is initiated through, and paid for by, the court system.**

The data collected proves the individual's substance abuse use has escalated to the point of involvement with the court system. 506 of the individuals surveyed, 90.9% of the justice system sample, were adults having treatment initiated through the court system. Juveniles who were involved with the justice system comprised the additional 9.1% of the justice system sample. These numbers constitute a need for earlier intervention to eliminate escalation into the court system.

**2. Lack of general – even basic information.**

The data provides evidence that seeking and finding treatment is a difficult task. 30.8% of the respondents did not know how to pay for services followed closely by 29.6% who were financially unable to pay. Individuals who did not know who to call to access treatment equaled 29.4%. 28.2% did not know where to go for treatment services and 27.5% did not know how to access the treatment system. For those who were able to access treatment services 27.1% did not know what questions to ask. 41.4% of the respondents seeking treatment were not aware of their county services. For those who were able to maneuver the system it took an average of 24 days to find treatment.

**3. Lack of family support services/counseling provided during the course of treatment.**

The data proves a lack of family support services. 53% of the respondents did not receive support services. Of the 43% who did receive services the average number of hours were only 4. 45% of the family members of the person seeking treatment were not aware of family support groups. Of the 40% who attended support group meetings 94% found them helpful.

## **Discussion**

### **What do survey respondents want and need?**

- Immediate help/up-to-date available information
- An easily accessible system
- Early intervention with quality treatment
- Family support services/counseling
- Services during off business hours
- Successful school based intervention
- Adolescent facilities
- Recovery support services
- Funding sources/dollars for treatment

### **Immediate help/up-to-date available information**

Lack of immediate help can result in deadly consequences. When a person seeking treatment makes the decision to get help, the window of opportunity is small. If they are met with any resistance, the opportunity could pass quickly, resulting in continued use. Information needs to be as handy as your phone book, with up to date information available to the general public. When seeking help, being able to make one call, having one person to direct you to the appropriate services and help you need, is essential.

### **An easily accessible system**

When a person is in need of treatment services they do not know who to call, where to go or what to ask. Having a system that is people friendly and family focused will eliminate frustration and encourage the person to continue forward in seeking the services they need. When you hit a barrier it's easy to "just give up," lose hope, and go back to using and in some cases the family unit continues to fall apart.

### **Early intervention with quality treatment**

Services are needed at the beginning stages of the disease so it does not escalate into an intervention by the criminal justice system. Appropriate quality treatment is necessary to provide the greatest chance of recovery. There are many special circumstances that occur with a person who is seeking services. Quality treatment would include a complete assessment of the individual seeking treatment. The survey concludes that 38.7% of respondents stated the presence of both substance abuse and mental health issues (co-occurring disorders) while seeking services. 15.2% of 18-24 year old (transition age youth) respondents were still living at home when seeking treatment services. Additional special circumstances can include but are not limited to adolescents and pregnant females.

### **Family support services/counseling**

Addiction is a disease that affects the entire family. Families need to understand the disease, how to cope with their loved ones addiction, how to take care of themselves and other family members, and move forward with their lives. Support services and counseling are needed in order to create a healthy family environment.

### **Services during off business hours**

When seeking help it doesn't always happen from 8 to 5 during the business week days. Calling a help number and getting a recording that the office is closed until Monday morning is devastating. An immediate crisis demands an immediate response. An 800 number that is answered 24/7 by a "live" person and would direct the person in need to immediate available services would eliminate the frustration many experience when trying to access services during off hours.

### **Successful school based intervention**

71.2% of the school age sample said the school was NOT helpful in getting them treatment. Children spend many hours a day within the school system, identifying a problem and getting the child the appropriate intervention, assessment, and services, is a necessity. Parents want to call the school and talk to someone who knows what to do, who to call, and how to access the services their child might need. Parents need compassion and not accusations that "they" caused their child's addiction. The school system needs to partner with the parent so the child can receive appropriate treatment.

### **Adolescent facilities**

Due to a lack of adolescent facilities children are sometimes placed with adults within the treatment population. The family needs to know their child is in a safe appropriate environment. Children's needs are different and require services designed for the adolescents.

### **Recovery support services**

Recovery is never ending, it is a lifelong process. Having accessible recovery support services for those seeking sobriety would help eliminate recidivism.

### **Funding sources/dollars for treatment**

Those seeking treatment are met with waiting lists and limited funding. Many times they are told funding is depleted and they must wait for the new budget year. Increased dollars are needed to create additional resources to eliminate waiting lists. When a person is told there is no money for their treatment often times they will continue to use, end up in the criminal justice system or overdose and die.

## **Our Recommendations**

- Focus on addiction as a family disease; provide education and assistance to the entire family unit in a timely fashion.
- Create a treatment system that is family focused, easily accessible, provides quality treatment, supports recovery for the individual as well as his/her family, and ensures a level of accountability.
- When addressing substance abuse/mental health (co-occurring disorder) having a system that would address both issues at the same time.
- Create a unified plan for all school systems in Pennsylvania to provide information and assistance to families who have children in need of assessment, intervention, and substance abuse treatment.
- Provide early intervention and accessible services to prevent the escalation of drug use to the point of involving the court system.
- Create a recovery support system in every community, which includes recovery programs for the addicted love one and a recovery support system designed to focus on families and their needs.
- How to maneuver the system handbook, which would include phone numbers, agencies, treatment facilities, recovery resources, and payment sources.

## **Our Conclusions**

The substance abuse treatment system that is in place in Pennsylvania is not meeting the needs of the citizens of the Commonwealth. Families and individuals seeking help are met with frustration, desperation, and hopelessness; are often turned away and excluded from the treatment process. These barriers increase anxiety, further isolates the family, the individual, and diminishes the recovery process. As stated from the data enclosed families are forced to seek alternative ways to get their loved one treatment and the majority of the time it involves the criminal justice system.

## **Questions that Need Answered**

- How does an individual or family receive the help they need for a substance abuse issue when they do not know who to call, where to go, or what to ask?
- How is reducing recidivism possible when even basic information and access to quality treatment is unattainable for most?
- How can we expect our loved one in recovery to return to the family, when the family has not been supported, not been educated about the disease of addiction, nor have the changes been made in order to create a healthy environment within the family unit?

## **APPENDICES**



11. When seeking treatment, were you made aware of your rights under Act 106? <input type="checkbox"/> Yes <input type="checkbox"/> No
12. Did the person seeking treatment receive recovery support services? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Outpatient counseling <input type="checkbox"/> Access to prescribed medications <input type="checkbox"/> A list of available support groups <input type="checkbox"/> Peer to peer support <input type="checkbox"/> Other Please explain:
13. If the person seeking treatment was of school age, was the school instrumental in helping them get treatment? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
14. Was the person seeking treatment involved with the justice system? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Juvenile <input type="checkbox"/> Adult
15. Was the person seeking treatment involved with Children and Youth? <input type="checkbox"/> Yes <input type="checkbox"/> No
16. Were family members of the person seeking treatment aware of any family support groups in the area? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, which ones? _____ Were group meetings attended? <input type="checkbox"/> Yes <input type="checkbox"/> No      If yes, was this helpful? <input type="checkbox"/> Yes <input type="checkbox"/> No Comments:
17. What if any problems occurred while trying to access treatment? Check "ALL" that apply. <input type="checkbox"/> Did not know who to call <input type="checkbox"/> Difficult to find quality treatment <input type="checkbox"/> Did not know where to go <input type="checkbox"/> Lack of transportation to treatment <input type="checkbox"/> Did not know how to access the system <input type="checkbox"/> Didn't know what would be appropriate treatment <input type="checkbox"/> Did not know what questions to ask <input type="checkbox"/> Lack of facilities for adolescents <input type="checkbox"/> Did not know how to pay for services <input type="checkbox"/> Financially unable to pay for services <input type="checkbox"/> No facilities near the person seeking treatment <input type="checkbox"/> County funding already ran out for services <input type="checkbox"/> No aftercare facilities <input type="checkbox"/> Did not receive immediate help <input type="checkbox"/> No support groups for families <input type="checkbox"/> Received outdated information/phone numbers <input type="checkbox"/> Didn't know my rights <input type="checkbox"/> Long wait list for treatment <input type="checkbox"/> Lack of placement during off business hours <input type="checkbox"/> Lack of access to information during off business hours Comments:

## **ABOUT MOMSTELL Inc.**

MOMSTELL Inc. is a nonprofit 501(c) (3) parent driven organization. The mission of MOMSTELL is to promote awareness and eliminate the stigma of drug and alcohol abuse through improving drug treatment, education, legislation, policy and prevention. Our vision is to create a networking system of parents and family members throughout the United States to advocate for positive change within the substance abuse treatment system.

MOMSTELL provides assistance to those families throughout Pennsylvania who are seeking access to treatment services and provides emotional support for loved ones of the addicted. Over the years MOMSTELL has helped thousands of families through education, support, and guidance. Reaching out and helping those in need during a crisis situation is one of the crucial components of the organization. Policy issues that affect all Pennsylvanians impacted by the disease of addiction are a focus of MOMSTELL. Supporting legislation that directly affects those with the disease of addiction is a component of the organization. MOMSTELL is driven to create change across Pennsylvania and the country concerning substance abuse treatment issues.

MOMSTELL Inc. developed this survey to provide critical information concerning the substance abuse treatment process in Pennsylvania. Using the data collected by this grassroots effort, this report contains our recommendations to the state regarding the barriers to substance abuse treatment. Our goal is to have this survey used to eliminate these barriers to create easier access to appropriate treatment and quality services for each individual and family impacted by the disease of addiction.

Data was collected from 815 survey respondents, and analyzed by the Treatment Research Institute in Philadelphia, PA. MOMSTELL was provided a full analysis report, which was used in the preparation of these recommendations.

This survey was done independently by and for Pennsylvania families. This survey was not commissioned by any government agency.

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